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Responding Proportionately to the COVID-19 Pandemic in UK Long-Stay Inpatient Pediatric Wards

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Context: The COVID-19 Pandemic in the United Kingdom in Autumn 2020

Across Europe, countries responded differently to the COVID-19 pandemic, according to sometimes regional but usually national political judgments and the infection rates at any given time. The United Kingdom was among the most seriously affected countries in Europe. The United Kingdom comprises four countries: England, Wales, Scotland, and Northern Ireland. The last three have devolved responsibilities for public health, and the measures taken across the four countries did, therefore, differ at times. Having some understanding of how the pandemic affected England is relevant to this chapter. Rather than focusing on the proportionality of measures that affect the whole population, we will explore how the broader policies affected staff, patients, and their families at the micro level by looking at the typical restrictions placed on non-COVID-19 pediatric inpatient services in England in late autumn 2020. To give some context to this case study, we will briefly outline the progress of the virus and the measures taken in response to the pandemic from January 2020 to July 2021.

In the United Kingdom, the first COVID-19 wave struck rapidly, with reported cases rising from forty new cases on March 2, 2020, to 2,339 by March 23, 2020,[1] when a UK-wide lockdown was announced (Institute for Government 2022). New daily cases peaked at around 5,151 a month later.[2] Mass testing was not available at this time, so the case incident rate was probably much higher. Although it was clear in January that a pandemic was imminent, the World

[1] https://github.com/CSSEGISandData/COVID-19.
[2] https://github.com/CSSEGISandData/COVID-19.

Health Organization did not declare it as underway until March 11, 2020.[3] At this time, little was known about the SARS-CoV-2 virus. The National Health Service (NHS), along with the UK public, had little time to respond and little information upon which to base its response. In the 2009 H1N1 (swine flu) pandemic, pregnant women, children, and young adults, especially those with underlying health conditions, were found to be particularly vulnerable.[4] Understandably, therefore, these groups initially attracted greater concern, including, in some cases (e.g., those in the third trimester of pregnancy), additionally stringent measures designed to protect them from COVID-19 until more information about the virus was available. Included in these measures were others who were considered most vulnerable. This included, for example, those known to be severely immunocompromised (NHS n.d.). These measures included complete shielding: confining people to their home, except to receive urgent medical treatment. Those sharing a home with shielded patients were advised to remain as isolated as possible. These restrictions, or variations of them, remained in place in England until April 2022.[5]

In England, hospitals and other care settings moved rapidly to introduce infection control measures based on radically reducing person-to-person contact. This included minimizing footfall by limiting access to sites to patients only and asking staff whose roles could be performed from home not to come into work. Social distancing measures were initially introduced in hospitals, and more broadly within the community, against a background of limited and erratic supplies of personal protective equipment (PPE). Visiting was initially strictly prohibited, with some very limited exceptions eventually made for those who were dying. Visiting restrictions remained in place for over a year but were variously softened and hardened again in response to infection waves and were only finally lifted in June 2022. In addition, in March 2020 as many inpatients as possible were discharged to be cared for in the community. This was both to increase capacity for treating COVID-19 patients and to limit the spread of infection within hospitals. For those who could not be discharged, life on the ward was radically changed by the infection control measures. These measures were put in place not just to protect patients and the staff caring for them but also to curb the spread of COVID-19 *within* hospitals and *from* hospitals back

[3] WHO. 2020. "WHO Director-General's Opening Remarks at the Media Briefing on COVID-19." Media briefing, March 11. https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19—11-march-2020.

[4] NHS Health A–Z (2020), January 1. https://webarchive.nationalarchives.gov.uk/ukgwa/20230127142206/https://www.nhs.uk/conditions/swine-flu/ (available via webarchive.org, accessed February 19, 2024).

[5] UK Government Department of Health and Social Care and UK Health Security Agency, Guidance for people previously considered extremely vulnerable from COVID-19, https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19 (accessed February 19, 2024).

out into the community. The response mirrored the wider public health measures being enacted in other nonhealthcare settings. In April 2020, all nonurgent, nonessential, non-COVID-19 related services were suspended for three months. A COVID-19 NHS Test and Trace service became operational in England in May 2020, with polymerase chain reaction tests available to individuals with a raised temperature, a continual cough, or altered taste/smell.

Most parts of the United Kingdom[6] had enjoyed a brief summer with relatively few restrictions. Conforming to mask wearing in public became something of a political statement. Measures to enforce mask wearing came into force in July 2020.[7] The NHS recovery plan commenced in July 2020 with the reintroduction of normal services.

New variant strains of the virus began to cause concern in the United Kingdom in September and October 2020, however, and cases once again began to soar, reaching a peak of around 33,487 per day in mid-November. This second wave, which incorporated the emergence of the highly infectious Alpha variant in December 2020 and another peak in January 2021, continued until April 2021 (Office for National Statistics 2021). Regional, tiered restrictions were instigated in England in mid-October 2020, and a further month-long, England-wide lockdown was announced on October 31 to start on November 5, 2020. Many areas were in the highest tier, which had four measures, by December 26, 2020; some restrictions were lifted for twenty-four hours over Christmas. By January 6, 2021, England was once again in lockdown. The vaccine rollout started on December 8, 2020, with priority being given to those over eighty years old and healthcare workers; lower-risk groups were called for vaccination from April 2021 (Mounier-Jack et al. 2023). A three-step plan to remove restrictions started in March 2021 with the reopening of schools, and universally available lateral flow testing made available in April 2021. It was mid-July 2021, however, before the majority of the legal restrictions were lifted in England (Institute for Government 2022).

Background

In this chapter, we explore the ethical and legal dimensions of the effect of hospital infection control measures on patients, families, and staff in long-stay pediatric wards. Our insights were gained from a research project titled

[6] In addition to the devolved governments making decisions for Scotland, Wales, and Northern Ireland, more local regional measures meant that some areas, such as Leicester and parts of Leicestershire, remained heavily restricted from July 2020 to spring 2021. The first lockdown was for the entire United Kingdom.

[7] Health Protection (Coronavirus, Wearing of Face Coverings in a Relevant Place) (England) Regulations 2020 (SI 2020/791).

When Pandemic and Everyday Ethics Collide: Supporting Ethical Decision-Making in Maternity Care and Pediatrics During the COVID-19 Pandemic.[8] Our research took place in England between July 2020 and September 2021 over five geographically diverse NHS sites and concentrated on pediatric and maternity services that did not treat COVID-19 patients. We explored how ethical considerations underpinned healthcare decision-making during the period immediately following the first wave in the United Kingdom as nonurgent, non-COVID-19 services were being reinstated in an environment that was still being ravaged by the pandemic as the second wave hit. We received Health Research Authority approval and approval for study participation from each NHS Trust. Our methods and results have been published elsewhere (Chiumento et al. 2020). To protect site/participant confidentiality, the following case description is based on composite data drawn from all sites.

Case Description

The setting we devised as our case study for this chapter draws on composite data from all our sites to describe a fairly typical surgical ward in a specialist pediatric inner-city hospital in England in late autumn 2020. It was the designated regional center for complex orthopedic surgery, including trauma (e.g., from road traffic accidents). It was a "green" (non-COVID-19) ward with tight infection control measures. Pre-COVID-19, the ward had ten beds, but capacity was reduced to six to ensure the required two-meter distance between the beds. Children undergoing complex surgery could be expected to be in the ward for several weeks at least, sometimes many months.

Staff wore light PPE (e.g., masks, gloves, disposable aprons, and sometimes visors for specific procedures). Most children were bedbound, but when they were not, they were encouraged to remain within their bed space. This area was marked out on the floor with thick adhesive tape. The children were not required to wear masks but were tested regularly for COVID-19. Only one designated visitor per child was permitted on hospital premises at a time. This person was required to be from the child's usual household. Ideally, there was a single designated person; in most cases, this was a parent. If that person tested positive for COVID-19, became ill, or was self-isolating, another person could be designated. If the child normally lived across two households, a designated person

[8] **Frith, L. (PI)** (2020–2021). *When Pandemic and Everyday Ethics Collide: Supporting Ethical Decision-Making in Maternity Care and Paediatrics* (UKRI project AH/V00820X/1). University of Liverpool (lead), with collaborators at University of Central Lancashire, Royal College of Physicians of London, University of Exeter, Liverpool Health Partners, Liverpool Women's Hospital, UK Clinical Ethics Network, Birmingham Women's & Children's NHS FT, Alder Hey Children's NHS Foundation Trust.

from each household was permitted to visit but not at the same time. Both parents were allowed to visit together in exceptional circumstances—for example, immediately before (one hour) and after (thirty minutes) surgery or if a child was dying. Visitors were required to remain within their child's bed space and to wear a mask at all times. The parents/family common room was closed, and parents were no longer permitted to use the ward kitchen. Staff policed compliance with these requirements, and parents were encouraged to move on if they stopped to chat with other parents.

Discussion

Providing a case study is a useful way of considering how proportionate the response to the pandemic was in a specific clinical context and point in time. The focus of our discussion is the impact of the infection prevention and control measures. Clearly, these were proposed with good reason; it is worth reflecting now, however, on whether these measures were proportionate because, as our data illustrate, they were not without cost.

The infection prevention and control policies served at least four purposes. First, they were intended to prevent pediatric patients from being infected with COVID-19. By this time, children were generally known to only experience relatively mild illness if infected unless they had other medical conditions. Nonetheless, the patients in our case study would have experienced illness on top of the effects of their surgery or the conditions for which surgery was needed. Even if COVID-19 was not ultimately life-threatening, a persistent cough, for instance, could exacerbate wound pain, and respiratory viruses may predispose patients who have had recent surgery with a general anesthetic to developing a chest infection, which would be unpleasant even if treatable with antibiotics. Moreover, any patient who developed COVID-19 in a green ward would be moved to a "red" (COVID-19) ward to minimize the risk of infection for other patients and staff in the ward. Such relocations might represent unwelcome upheaval for the child and mean that specialist staff were less able to respond to a patient's underlying surgical condition, potentially resulting in setbacks to their recovery.

Second, infection control minimized the risk that staff would be infected and be off sick or need to self-isolate because of close contact with an infected person and, therefore, be absent from work until testing could demonstrate that they were not infectious. Staff absences, whether as a direct result of COVID-19 infection or because of self-isolation owing to close contact with an infected person, meant it was often challenging for the NHS to staff services safely.

Staffing problems clearly affected patients in terms of service delivery and staff well-being by putting working staff under even greater pressure.

Third, preventing transmission to parents was important in maintaining the limited visits that were allowed for patients in the ward. Isolation arrangements meant that if a parent or other family member living with the parents became infected, the patient would have no visitors (unless their parents were living in separate households).

Finally, in addition to seeking to prevent spread within the ward, the infection measures also sought to limit spread *between* wards and *from* the hospital to the community and from the community to the hospital. In this respect, the ward restrictions were often not that different to the restrictions pertaining outside the hospital (Institute for Government 2022). In England, a circuit-breaker lockdown was imposed in November 2020, though local lockdowns had started as early as July. Most areas of England emerged from the November lockdown into tiered restrictions that amounted to much of the same in terms of limiting social interactions between different households. By early January 2021, England was once again in lockdown, with all parts of the country being placed into tier 4, "stay at home" restrictions. These restrictions were, however, particularly significant in their effects on patients whose rehabilitation would ordinarily have included incremental challenges, such as moving from the ward to another space within the hospital, visiting a playground or a shopping center, or having weekend home leave.

Whether these measures were *proportionate* requires a consideration of the effects on those concerned. The effects of the measures, which included inconvenience, frustration, loneliness, fear, were arguably more significant for these patients (and their families) *because* they were children than they were for non-COVID-19 adult inpatients. At the least, the effects were highly significant, given children's general dependence on their parents. We draw on the insights from our participants to highlight some of the impacts of infection control measures in this context that are potentially less often discussed.

Effects of Broken Communities on the Wards

Infection prevention and control measures resulted in the loss of a benefit that is fairly specific to long-stay pediatric wards—the community of parents providing peer support to each other during their children's inpatient stay. In common with the staff, some parents and patients had direct experience of big changes that the arrival of COVID-19 to the United Kingdom brought to the ward environment. They had a shared experience of "before" and "now" as the infection prevention and control measures were rolled out. These parents lost peer support—a benefit

that was abruptly removed/changed. For others, the measures put in place to control infection were all they had known.

> But obviously once you restarted the services, you went in your bed space, you stayed in your bed space, they couldn't you know, they can't go and sit next to [a patient's] mum in bed eight because she's upset because he's going to theater. It's a very different feel. And we policed that quite strongly . . . . And that's not, you know, we've grew up on a ward that's very sociable: The kids will often play, the physios will get the two children throwing balls to each other across the bed spaces, and you know, it's quite a friendly ward . . . . [It] is quite a community feel, especially amongst the parents, and the staff will often look after the same patients for weeks so that there's quite a relationship built up there . . . . Well obviously, . . . the more community side of the ward had to stop. (Nurse, ward manager)

Peer support is known to be a valuable resource for parents of children being treated for long-term conditions or being treated over an extended period (see, e.g., Pilona et al. 2021). Complex, specialist surgery often requires considerable inpatient recovery time and may be accompanied by setbacks that require further surgery and readmission for further reconstruction. There are different routes into a ward such as the one we described: Some children will need surgery for conditions they were born with, others as a result of accidents or recently diagnosed conditions. There will, however, often be significant elements of shared experience, such as periods of acute anxiety and uncertainty, dashed and rebuilt hopes, and long periods of time away from the home environment, which necessitate juggling work commitments and/or care for other children and trying to maintain other relationships, such as with a partner or spouse, under strained and constrained circumstances.

During the pandemic, parents were also dealing with a multitude of other problems, including COVID-19 infection and self-isolation, the illness of family members (some of whom were also dependents, others of whom were providing much-needed support at home), the loss of paid employment or reduction of income, and homeschooling during lockdown periods.

> And what it turns out to be was her fridge had broken the day before, something else had broken and then she . . . had had a parking ticket. And it just was what finished it off and then I walked onto the ward and I was just the person to talk to! . . . And I certainly have noticed in more recent months that everything seems to be sharpened and heightened, you know, so people are less resilient[,] . . . less flexible, more kind of set, more kind of irritable, almost. And I think it's to do with the fact that, you know, we haven't been able to go

> anywhere; we, some of us, haven't seen our families in a year, you know, children, . . . elderly family members. Can't even go down the pub! You know, you can't go and watch a movie in the cinema . . . . And I suppose having people at home that would normally go out to work, that can, that could be stressful. So I could see how it flares quite easily at times. (NHS senior manager)

Hence, parents whose children were admitted to hospital had a lot to cope with and were isolated from familiar means of support and isolated from each other during this phase of the COVID-19 pandemic. On top of this, they faced the strain of presenting a calm and comforting exterior to their child.

Staff told us about how, prior to the pandemic, they strove to generate a community feeling on wards like those outlined in our case study. We were told, for instance, about how staff organized film and takeout nights and about how the parents themselves formed mutual support groups and shared their experiences with others who had a good understanding of what they were going through.

> So quite often the parents become each other's support . . . . You know, [Name] in bed six and [Name] in bed eight is going to meet me for coffee at nine o'clock after ward round. And you know, we'll go for a bit of breakfast, and we'll have a chat and . . . they'll form those support groups. Well, we see that that's good for the families. But obviously at the moment, it's not . . . . It can't be the priority because none of our children would do well from being COVID positive. (Nurse, ward manager)

The forging of informal supportive networks or communities on wards may provide a benefit to some parents—though not all will benefit equally. This benefit could be regarded from the perspective of proportionality as a superlative or bonus to good care. While clearly beneficial to those participating in these networks and communities, it is not obvious that any of those helping create this benefit are *obliged* to do so. Given this, because the benefits are in addition to what could be reasonably expected and the harms prevented by the restrictions are serious, such restrictions may seem proportional and justified. We will now look at each of the parties involved in these communities to determine what their obligations to each other are and whether this affects the calculation of whether loss of peer support weighs more lightly than do the harms prevented.

Parents, as people forced together by circumstance, have some obligations to each other of the kind that could be described as common decency, such as contributing to preserving the general orderliness of communal areas, not making undue noise or being a nuisance to others, and being respectful of privacy and others' possessions. What is less clear is what is required of them in terms of offering friendship or expressing empathy. There may be some obligation to

offer a fellow in distress some immediate comfort, other things being equal, or to be willing to reciprocate such comfort willingly received. In this respect, a supportive community of parents in a ward can arise organically as a result of some individual kindness that results in that kindness being reciprocated or in behaviors to others that emulate the kindnesses an individual has received. But the creation of such a mutually beneficial community seems to be supererogatory rather than obligatory, though it is easy to see how duties of reciprocity might enable it to be(come) self-sustaining. In fact, parents were still able to form limited communities by using electronic devices to engage in chat via groups hosted on social media. While this was a much-scaled-down means of support, it enabled something of a community to emerge that did not contravene social distancing measures.

Ward staff have a clear and obvious professional duty to protect and promote the best interests of their patients, not least because of the patients' legal status as minors. As most hospitalized children benefit from having the company of their parents during their stay, bolstering the parents' capabilities to support their children will, in turn, benefit the child. Pediatric healthcare professionals have long recognized that because children invariably exist—and thrive—in families, pediatric services should be family centered where possible. Moreover, parents (or those with parental responsibility) are legal proxies for their children and must, therefore, be closely involved in decision-making and understand the ramifications of treatment decisions.

At the same time, there is a limit to the support that staff are obliged to offer to family members. Harsh as it may seem, responding to a parent's distress is an expression of *personal* compassion by the staff but is, perhaps, not *professionally* required. This assumes that a parent's emotional or psychological strain is not affecting their child and that the obligation to family may be part of promoting the best interests of the patients. Time and effort are resources that are, like all other resources in the NHS, thinly spread. Across the NHS and social care, family members who are perceived to be coping may be regarded as less in need than those who are floundering and so are unable to contribute meaningfully to the ongoing care of the patient. Against this background, investing time in enabling a supportive ward community—in which parents thrive as opposed to survive—could be regarded as supererogatory in a pandemic context, and its loss could be seen as a sacrifice less costly than it may first appear, compared to infection control.

Having said that, the NHS Trust responsible for the ward has no reason to prevent initiatives that improve the experiences of everyone, provided that the costs (which in this case appeared to be minimal) do not disproportionately affect

services elsewhere. It is also arguable that, from the staff perspective, there is a cost in *not* helping parents do more than survive.

> But we're very much the type of people that if . . . they come back sobbing, we'd give them a cuddle . . . . It's very difficult to see somebody crying and not give them a little bit of comfort. (Nurse, ward manager)

At the same time, under the circumstances it seems clear that restoring the community—or even implementing measures to grow it in other ways, such as through electronic means of communication—might be a low priority.

Inhibited Right to Family Life and Loss of Right to Parent

In late autumn 2020, all areas of the hospital would have been similarly affected by restrictions, and pediatric visiting arrangements were actually less restrictive than were those for adult patients, whereby, at times, no routine visiting was permitted.[9] That an exception was made for pediatric wards is a compromise between infection control imperatives, on the one hand, and the best interests of children and the rights of parents on the other. Given the speed at which infection control policies were implemented in March 2020, and given that they had changed very little by November 2020, these policies were unlikely to have been driven solely by scientific evidence. They were also possibly influenced by the expediency (at the level of hospitals) of keeping the rules for the public simple, clear, and consistent across the entire organization. Moreover, it is probably not possible for any given hospital to be able to quantify precisely what the infection risks might be of changing visiting arrangements in different ways on different wards for different categories of patient and at different points in the pandemic. Even when more was known about the COVID-19 virus, there were just too many variables. This meant that members of the public had to trust that advertised visiting arrangements were the best that could be provided under the circumstances. However, policies should always adhere to ethical standards and be fair and evenly applied. Fairness does not necessarily mean identical treatment, but it does imply that like cases should be treated alike when they are similar in morally relevant ways or differently if their differences are morally relevant.

[9] This extended to maternity care, where the nonbirthing partner was not permitted to re-enter the hospital once they had left following the birth. This led to prolonged loss of opportunities for early bonding with a new baby when either the birthing partner or baby had to remain in hospital.

The first morally relevant difference to note is that between child and adult patients. Tight visiting restrictions in the case of adults who had capacity at the time of admission remained in place. An exception was sometimes made for dying patients. Some wards permitted one person who was free of symptoms or had tested negative for COVID-19 or both to be with a noninfectious adult patient as they died, but many adult patients—especially those with COVID-19 and/or in nursing homes—died without loved ones physically present.[10] The visiting policy regarding children was, therefore, already an exception to this general rule. Equity needs to be maintained between arrangements for children and for other patients and between children. Making an exception for children is likely to be acceptable to the general population, although there was, in fact, no public consultation about any of the measures imposed in March 2020. While our public focus group participants understood that meaningful dialogue with parents of hospitalized children would have been difficult (if not impossible) under the circumstances, there was a clear sense that better preparation should be made for any future public health emergencies.

> My child's hospitals battened down the hatches effectively and started to prepare, because we didn't know how children were going to be affected by COVID-19 at all. And it could have been—it could have been awful. It could have been, especially for the very, very sick children. And they had to tackle it in a way that was immediate. And talking to us about that would have been really, really hard for them to do, but before, they could have actually done it and could have caused more problems than it was worth. So although I do think that we should have strategies for public engagement and all the time, there are circumstances like this last year that it would have probably been dangerous for them to do it. Now, as it happens, of course, we're being told that children are barely affected by this. They're not even—they don't even seem to be spreading it very much. . . . So we planned for something awful, and then it didn't turn out to be awful, from a child's point of view. I wonder whether we just need to put these strategies in in order to prepare for future events like this, now that we've been through one, and they probably should have been in beforehand to have very quick decisions being made, but it [was] unprecedented. (Participant, public focus group)

This included both imposing infection control measures and lifting them.

[10] Families were sometimes able to say their goodbyes using videoconferencing or telephones. It should also be noted that family members often caught COVID-19 from each other and were, therefore, ill or infected themselves as patients died. Very overstretched staff also needed to recognize when patients were near to death and to have enough time to alert a family member to come to the hospital. Restrictions in care homes were even more stringent.

> I agree that unprecedented time at the beginning where there was a lot, a lot of unknowns. And hospitals did have to go into sort of a, I suppose, like an emergency mode—like, it was completely understandable. But then what then seemed to subsequently happen long after having a good, empirical understanding that the actual virus itself was not a significant risk to children was there was inadequate consultation with regards to the sort of the management of coming out of that emergency phase. And it felt like a lot of decisions. Well, it felt, in our experience, it was that we had zero involvement in any of the decision . . . . The onus was on me to find out what the process was . . . . I just think that there should have—as soon as, sort of, it was clear that there was not a significant risk to children—I think that children's hospital services should have tried to well involve us with at least communication as to how they're trying to recover from it. A lot more. (Participant, public focus group)

In the United Kingdom, pediatric patients are those from birth to fifteen, with young people (those aged sixteen and seventeen) often—but not always—treated on adult wards. It would have been distressing for younger children to be physically separated from their parents for long periods, and unlike adults, they may not be capable of understanding why this was necessary. Extended separation may also have damaged the parent-child relationship. Allowing one parent to remain with the child is a compromise, since it is in the interests of all patients and staff for the risk of infection on the ward to remain as low as possible. Allowing this in the case of all minors—even those with greater capacity—could be justified on pragmatic grounds (it is difficult for hospitals to accurately assess and enforce age- and capacity-specific criteria) or because of the relative emotional immaturity of children compared to adults.

One morally relevant disparity between children is family circumstances. As reflected in our case description, children whose parents had separated could be visited by both parents, whereas parents living in the same household had to designate a single parent to visit their child. Arrangements for children whose parents live in different homes were in line with the government's approach to social distancing in the wider population. Even during the UK-wide first and tightest lockdown, no restrictions were placed on the movement of children between the homes of separated parents, even though this considerably increased the social contacts of both households. The view that the welfare interests of children are furthered by maintaining a relationship with both parents, unless proved otherwise, is stated in legislation.[11] By November 2020, the COVID-19 risks of this arrangement were generally thought not to be borne

[11] Children Act 1989 section 1 (2A)–(2B). See also the Explanatory Notes to the Children and Families Act 2014, Pt. 2, Sec. 11.

by the children, as evidence had emerged that younger children who were fit and well when infected were generally asymptomatic or only experienced mild symptoms. Instead, the risks were to the adults in both households, particularly those with specific COVID-19-related vulnerabilities.

The arrangements for separated parents were observed by our pediatric staff participants to have created some tensions on the ward. They were perceived as unfair by some parents who were not separated and who were forced to choose whom to designate as the visitor. The arrangement seemed to them to privilege parents who were separated, as both were able to visit, whereas in their case one parent (the nondesignated visitor parent) was effectively prevented from maintaining an ongoing relationship with their child.[12] Recognizing the importance of interactions with their family, the guidance around phone and tablet use in hospital settings was considerably relaxed, and many wards, such as the one in our case study, encouraged their patients to speak to and see other family members on video calls.

> So we were doing baby's cares on FaceTime for parents to be involved and to help them choose an outfit and things like that, you know, . . . which was lovely . . . . So it was just trying to do what we would normally do for our families . . . [to] find different ways . . . to try and reduce that, that the impact of things, really. (Pediatric high-dependency ward nurse)

> So we can set up Zoom calls, and we can set up WhatsApp calls, and we can help like that. But I would imagine [there'd] still be a portion of the parents that have been in that would very much say their views, and [their] wishes to have family with them haven't been adhered to. But I don't know how you get around that. (Pediatric nurse)

To the best of our knowledge, visiting policies on pediatric wards were not subject to court challenge. The Children Act 1989 stipulates that the welfare interests of the child should be the paramount consideration of all public bodies, which includes hospitals. It is possible that if parents could have demonstrated that their child's welfare was being damaged by the visiting arrangements, a court might have made an order on the basis of their child's best interests, particularly if they could also demonstrate how they could manage visiting without increasing the risk that the infection control measures were designed to mitigate (including the risks to their own child). Most parents, given the reduction of visitor facilities (canteen, family areas, the staff kitchen, showers, etc.) needed to return home periodically and were then mixing with the other parents and family members in their household. This made it even harder for staff to explain and for parents

[12] Later, visiting policies did change to permit both parents to visit separately.

to understand, how, nevertheless, the overall infection risk increased if those household members came into the hospital, particularly when both parents from separated families were allowed to visit.

> But during [July and August 2020], we could go to the pub with five different friends. And we were being encouraged to eat out to help out—there was all these schemes, and . . . the transmission rates were very low. But there was no movement. And there was no visiting at our trust . . . . And in September, guidance was issued . . . to say . . . trusts should review their risk assessments. And my local trust didn't do that until Christmastime, just before Christmas, and only began implementing changes then in February, and that I cannot understand. (Participant, public focus group)

Going forward, evidence and ethical rationales for these kinds of restrictions should be more clearly articulated to staff and the public alike.

Parents could also have considered a challenge under the Human Rights Act 1998. This act incorporated the European Convention on Human Rights (ECHR) into domestic law and protects UK citizens and residents against breaches of their rights by public authorities, including NHS hospitals. Article 8 of the ECHR protects the right to respect for private and family life and often underpins challenges to healthcare decision-making. But the protected rights in this article are not absolute. Accordingly, if, for example, interfering with someone's right to respect for their private and family life can be shown to be in accordance with the law, meet a legitimate aim (e.g., protecting public health in the context of a pandemic), and address a pressing social need proportionately, then it is likely to be considered justifiable.[13]

The law in England recognizes the difficult nature of some of the decisions that must be made; the key is that, in making them, human rights must be respected and promoted.[14] In the case of COVID-19 restrictions on the ward in our case study, visiting restrictions were relaxed in the most challenging of circumstances. So, for example, both parents were permitted to be present together with their child for the hour before surgery and for thirty minutes in the recovery unit[15] or

[13] See, for example, respective discussions in *Evans v. United Kingdom*, App. 6339/05, 46 EHRR 34 (2007) (Eur. Ct. H.R.); *Pretty v. United Kingdom*, App. 2346/02, 2 FCR 97 (2002) (Eur. Ct. H.R.); and *Enhorn v. Sweden*, App. 56529/00, 41 EHRR 30 (2005) (Eur. Ct. H.R.).

[14] See, for example, *R v. Secretary of State for Education* (2020), EWCA (Civ.) 1577 (Eng.), in which the secretary of state for education was found to have acted unlawfully in failing to consult the Children's Commissioner for England and other children's rights organizations before making "substantial and wide-ranging" changes to legal protections for England's seventy-eight thousand children in care.

[15] Recovery units in the UK NHS are where patients go immediately from theaters to be stabilized prior to transfer. Time spent in recovery can vary according to, for example, the depth and duration

if a child was approaching the end of life.[16] These exceptions recognized that a preoccupation with infection risks may be disproportionate in circumstances in which the harms of keeping loved ones apart were very great, such as in the last moments of life, when there would be no possibility of postponing significant family contact to some future point, thereby creating a lasting and irreversible harm.

Our participants reported not only that parents appreciated this small relaxation for surgery but also that, on occasions, the nondesignated visitor parent would become hostile when their thirty minutes were up, or when the child was moved from recovery back to the ward, or when a child thought to be dying rallied.

> We've let two people [in] because their child's been extremely sick or might die, and then actually you come to the point where they actually they don't look like they're going to die anymore. And you have to sort of go back to normal rules. And they find that quite challenging. (Advanced Nurse Practitioner [ANP], pediatric intensive care)

The above considerations are pertinent to our third theme, the effect on the ward staff who were responsible for enforcing the visiting restrictions.

The Negative Effects of Using Healthcare Staff to Police Infection Measures

Many of the staff who were required to police compliance with infection prevention and control measures had, pre-COVID-19, been actively involved in *cultivating* family friendly and supportive communities in children's wards. After the pandemic was declared, they found themselves *actively disrupting* conversations between parents on the ward, thus actively impeding the development of mutually beneficial or reciprocally supportive relationships, and they struggled with this. They also had to manage conflict situations—for example, a nondesignated parent refusing to leave or designated parents trying to smuggle

of anesthetic and patient factors such as blood pressure, pain levels, respiration rates, pulse, and temperature.

[16] This was not initially the case early in the pandemic. The first child to die as a result of COVID-19 in the United Kingdom was thirteen-year-old Ismail Mohamed Abdulwahab, whose family was not permitted to be with him when he died on March 30, 2020. On April 15, 2020, the government announced, citing the death of Ismail Mohamed Abdulwahab, that whenever possible, arrangements would be made for family to be with patients as they died, though commentary at the time said that the change had already been made as early as April 2, 2020 (BBC 2020).

nondesignated parents into the ward to visit their child by opening fire escape doors or by opening the main ward door when no one was watching.

> They're just not coping very well, and they're cross . . . so you just get that more passive-aggressiveness from them in the bed space really, or they're . . . constantly testing the rules. So they will just bring another person in—they'll sort of sneak somebody in . . . and they're like, "Oh, such and such let us [in]." And so that [is] constant, almost testing the rules. (Nurse)

Because of social distancing, it was not always possible to conduct these difficult enforcement conversations and dispute resolutions in private—and all were conducted with the additional barrier of PPE. Equally, on the rare occasion when an exception was made because of extreme circumstances, other parents would challenge staff for an explanation.

> I felt, we all felt, it was the right decision to let both parents be with this child pre-op. And then they had half an hour when he came back and then Dad checked into a hotel. And it caused an awful lot of bad feeling with the other parents. . . . It literally got to the stage where people wouldn't say good morning to this family. And it had only happened for a couple of hours. But all the surrounding parents were saying to the staff, "That's not fair, that's a choice, that's not fair." And we felt awful for allowing that to happen. (Nurse, ward manager)

Rightly evoking patient confidentiality could be perceived as evasion, leading to further tensions with staff and between parents.

> But . . . it's very difficult to explain a situation when you can't breach confidentiality, because obviously, we didn't want to say, "D'you know they just found yesterday he's got cancer, you need to lay off the family." Obviously, can't say anything. . . . And . . . it was quite difficult at the time, because [it] seems like a silly issue out of the context, [but] when you've had a mum [who's] had no other adult company [for four weeks], it's huge. . . . It's just massive. . . . And it was quite upsetting for the [other staff] . . . because that's an awful thing to have happened. (Nurse, ward manager)

Yet staff are accustomed to monitoring visitors' behavior (we include parents here) in hospital wards. Indeed, the use of infection control measures, such as washing hands or wearing gloves before performing any kind of procedure or examination with patients, was widely enforced prior to the coronavirus pandemic, with some NHS Trusts displaying posters encouraging everyone—including patients and visitors—to ensure that this was adhered to by all.

The perception of enforcing COVID-19 infection mitigation measures as policing per se may, therefore, be something of a misperception. Staff are expected to enforce a variety of organizational policies, including respectful behavior while visiting. It may be hard, but it is not unreasonable to ask them to do this.

However, staff members have the right to respectful interactions with patients and visitors, even in a pandemic, and hospitals have the responsibility and the right to protect patients from harm. Accordingly, when parents push back against policies, it may be reasonable to have additional but proportionate policies in place that support staff efforts. In the United Kingdom, NHS hospitals now promote zero tolerance for the verbal or physical abuse of staff. In the case of *adult* patients, repeated transgressions can result in the withdrawal of care. When children pose a threat to staff, additional staffing or other measures are deployed as part of the duty to act in the best interests of the child. Responses such as red carding (whereby visiting rights are completely withdrawn and visitors banned from hospital premises) are more controversial in the case of parents of child patients than visitors to adult patients, because of the potentially negative effect on children. But presumably, such measures and those that fall short of these should be imposed when necessary to protect staff. It seems important, therefore, to enact additional measures alongside visiting restrictions for de-escalating the inevitable tensions that will result. This may go some way to limiting the harms to all. It is important that policies be evenly enforced in order for them to be perceived as fair and proportionate by those most affected.

The policing of social distancing measures was, however, perceived a little differently from other interpersonal disagreements. Staff were sympathetic to the needs of parents to see their children, and they were responsive to the problems that the strict visiting restrictions created, both for parents and for their children. Such restrictions not only ran completely counter to the considerable efforts those same staff had, over many years, invested in creating family-centric, supportive ward communities, the restrictions but also added yet another barrier to the demonstration of care that was already perceived by staff as having been disrupted by wearing PPE and maintaining two meters distance.

> And I think something that I've noticed very much . . . was the number of parents that feel it's very wrong. It's wrong. They blame us . . . . We have no right to prevent them being with their child and visiting their child. . . . I had one mum who said to me, "This is not negotiable. I will be present here with my husband and the father of my child. And it is totally unethical, inappropriate, and against all of my rights as a parent, for you to say that both parents cannot be at the bedside." . . . [But] she actually was very receptive when I [told] her about my experience in adult services . . . to keep COVID out of the hospital.

Staff exhibited tremendous resilience in the face of the ethical challenges of delivering care during the pandemic. This includes those maintaining non-COVID-19 treatment services. We have discussed elsewhere (Chiumento et al. 2024) the damaging effect on staff of having their ability to demonstrate compassionate care limited by infection prevention and control measures and the need to consider the longer-term damage of fracturing compassionate care in any future pandemic. Accordingly, in the context of this chapter, we are inclined to interpret the responses of staff to policing infection control measures as further reflection on how their ability to demonstrate compassionate delivery of care was compromised. It is true that healthcare staff are accustomed to enforcing hospital policies (e.g., about infection control and visiting). During the pandemic, however, they were also enforcing policies that many regarded as undermining or compromising their professional identity as compassionate carers. Although these may have been policies that they broadly agreed were necessary for public health reasons, defending them to individuals—particularly when the costs of doing so were evident—may have felt like a betrayal of deep-seated values of clinical ethics such as "make your patient your first concern" (General Medical Council 2024).[17] Such values reflect the quality of individual patient-carer relationships to which healthcare professionals should aspire but which may be difficult to achieve in pandemic circumstances when public health considerations comes to the fore (Baines et al. 2020).

Conclusion

In this chapter, we have used a case study to describe and discuss some of the day-to-day effects of the COVID-19 infection prevention restrictions for patients, their family, and staff in non-COVID-19 long-stay pediatric hospital wards. Our wider study has clearly influenced our sense of the costs to all concerned, and, in particular, our findings related to the fracturing of compassionate care. During the worst parts of the pandemic in England, those living as patients in care environments experienced greater isolation. The dual imperatives for health organizations of protecting vulnerable patients and staff (as both employees and a precious social resource) meant that even during times when restrictions in the wider community were somewhat lifted, tighter restrictions were maintained within those organizations. As we now begin to reflect on whether the restrictions on the wider community were proportionate, it is important to remember that these dual imperatives for health organizations could have been used to justify more significant restrictions than those imposed outside these settings.

[17] The Nursing and Midwifery Council's *Code* similarly states, "Put the interests of people using or needing nursing and midwifery services first. Make their care and safety your main concern."

Infection control measures did impose considerable burdens on patients, their families, and staff—some of which may not have been obvious at the time, like the fracturing of care relationships. As we have discussed, they were probably on balance proportionate, given the dangers infection posed to patients and the broader consequences of infection spreading within the hospital and from the hospital to other parts of the community. These measures did reflect those in place elsewhere in the community and in adult NHS services, and that comparison adds weight to the argument that they were proportionate—at least in the context in which they were imposed. It is, however, important to remember that permitting limited parental visiting represented a departure from restrictions elsewhere, and further compassionate exceptions were made in addition to this. The exception made for some limited parental visiting is one that can be justified with reference to the status, rights, and needs of children. Although there were still costs, making this exception went some way to lessening the burdens experienced by everyone concerned.

Finally, as we start to reflect on what measures might be justified and proportionate in hospital settings (and beyond) in a future pandemic, we should also consider how best to utilize stakeholder engagement in this process. The COVID-19 pandemic left little time in the United Kingdom for consultation beyond core groups of experts. It is easy to forget how little was known about the virus at the start of the pandemic, when it seems patterns for how states ought to respond were set early on by the responses of those who were hit hardest first. When planning for the next pandemic of a novel pathogen, it may be difficult to re-create the sense of dealing with something completely unknown when stakeholders of all kinds will be influenced by their own memories of COVID-19 and the benefit of hindsight. Nonetheless, planning measures should include mechanisms for rapid, inclusive, and effective stakeholder involvement to help inform judgments about the acceptability of the potential range of measures being considered in response.

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Competing Interests

There are no competing interests to declare.

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