

# Work of a paediatric bioethics centre during the COVID-19 pandemic first phase

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## ABSTRACT

**Objectives** Decisions with an ethical component have been controversial during the COVID-19 pandemic, whether leaked intensive care unit (ICU)-rationing documents, transfer of people to care-homes to 'protect the National Health Service' or the duty to treat patients despite inadequate personal protective equipment. To counter criticism of ethics per se, and to help those planning ethics support we describe the practical work of a children's hospital bioethics team in supporting children, families and clinicians during this unprecedented period.

**Design/setting** Three phases of activity: (i) preparation: we composed several documents to support/guide hospital teams and, together with colleagues, provided them to regional inpatient, community and hospice settings. We adapted existing mechanisms to combat workforce moral injury; (ii) activity (March–June 2020): was highest in our rapid response service where children/families consider difficult treatment decisions with medical teams. Education provided 'pandemic webcasts' on decision-making and broader child-health concerns. Staff support was essential, especially for those deployed to overwhelmed local adult ICUs. Research ascertained young people's views on the pandemic; (iii) reflection: focussed on (a) research about future re-deployment to adult services and minimisation of moral distress/injury, (b) remote video-conferencing—parents'/participants' experience/ability to consider complex ethical issues and (c) role of faith/non-faith in society's recovery and children's views.

**Main outcome/conclusions** Our bioethics team's role during the pandemic included: case reviews via video-conferencing, many involving innovative therapy for severely unwell children with COVID-19/Paediatric-Inflammatory-Multisystem Syndrome-Temporally associated with SARS-CoV-2 together with their parents; processes to protect healthcare staff from moral harm and research/educational activity focused on paediatric-specific ethical arising during the pandemic.

## INTRODUCTION

The UK bioethical environment has received criticism during the COVID-19 pandemic,<sup>1</sup> including lack of ethical input in national decision-making,<sup>2</sup> and failure to adequately prepare medical teams, people and society for the moral challenges faced.<sup>3</sup> We wish to provide at least a partial rebuttal by reinforcing the practical bioethics role at the bedside and within the hospital corridors. The bioethicist should be rapidly available to those with urgent need, offering education and support for those

## What is already known on this topic?

- ▶ Criticism of the UK bioethical environment during COVID-19 is justified, but best answered by the practical support provided at the bedside to professionals and patients.
- ▶ Bioethics support is crucial for children's hospital staff and families when rare and complex, diseases or novel treatments mean rapid challenging ethical decisions are necessary.
- ▶ Face-to-face meetings are the usual mechanism of bioethics support; most UK ethics teams do not include patients in their meetings, we do where possible.

## What this study adds?

- ▶ Bioethics support in our children's hospital increased markedly during COVID-19 including rapid case reviews surrounding use of innovative treatments for both COVID-19 infection and Paediatric-Inflammatory-Multisystem Syndrome-Temporally associated with SARS-CoV-2.
- ▶ Reviews were adapted with the use of video-conferencing, often with parents as well as clinicians and the ethics team which worked surprisingly well.
- ▶ Moral injury prevention processes can be made compliant with social-distancing constraints, and we consider were crucial for paediatric staff deployed to adult units.

involved in challenging decisions—whether clinicians or patients.

In this retrospective descriptive study, we report the work of a Paediatric Bioethics Centre (PBC) team in a specialist children's hospital during the largest healthcare crisis of our generation.

Considering the likely ethical implications of COVID-19 for children, families and clinical teams at the outset, our main fear was the potential need for tough rationing decisions involving life-sustaining therapy. This was based on comparatively low UK intensive care unit (ICU) bed numbers, and changes in the paediatric population since previous pandemic planning.<sup>4</sup> Because of this, as many others did, we initially produced suitable ethical guidance. Thankfully, it became apparent that overt rationing would not, at least in the first wave, be necessary for children.<sup>5 6</sup>



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The PBC team is a multidisciplinary group of professional, (eg, healthcare, legal, ethics, psychologists and social workers) and lay members. (eg, chaplains and parents of former patients).<sup>7</sup> Four basic PBC-*working groups* operate, each with a dedicated lead: rapid case reviews group (RCR), ethical staff support, research and education; supported by a crucial part-time administrator.

Before COVID-19, RCR met with children, their families and referring teams to review ethical issues in challenging situations for around 30 cases annually. Ethical staff support was provided to bedside nurses/teams, usually in areas of particular need such as ICUs or during crises via ethics sessions to protect against moral injury. The research group has five to six peer-reviewed publications a year and the education group supervises both higher and taught degrees (PhD, iBSc and Masters) and provides education on ethical and legal issues both internally and externally.

PBC, operating with hospital-board designated authority and is accountable to both medical director and institutional Quality and Safety committee, receiving regular feedback and providing counsel to both. These links provide institutional oversight and support, as well as being an occasional source of referral.

Given that our children's hospital predominantly has patients with complex or rare disorders, the effect of the COVID-19 pandemic was unpredictable. Many such treatments stopped, and several nearby secondary paediatric services moved into the children's hospital to allow site—focus on the unprecedented number of adult patients. While this facilitated acute paediatric care, most elective specialist and non-specialist work stopped, as elsewhere.

There was concern that the complex, rare disease and frail paediatric population might be particularly vulnerable to COVID-19, particularly children with ongoing palliative care, technological dependence/chronic organ failure or the immunosuppressed. We recently argued that contemporary child-health services, especially for this group, were poorly prepared for a pandemic affecting children.<sup>4</sup> This included an ongoing need for education about ethical issues related to pandemics for clinicians, children and families and the public.

At the end of March, the government-directed lockdown proscribed routine face-to-face activities. The bioethics team had previously engaged in remote video-conferencing for shared care children with distant teams, but had to develop new processes to provide timely and effective ethics support in several forms with parents as part of video-conferences. We describe the preparation phase, the activity during the acute pandemic phase and, although early, our initial reflections and plans.

### PREPARATION PHASE (JANUARY–MARCH)

Four main areas were addressed:

1. A regional bioethics support group was formed with input from major paediatric centres, neurorehabilitation centres and hospices. The group was approved and endorsed by the regional paediatric and paediatric critical care networks,<sup>8</sup> offering a forum for any sector of child health to consider ethical issues. In reality, this was only used occasionally due to the nature of the first phase.
2. Documents regarding personal and institutional pandemic ethical practice, detailing bespoke bioethics support were prepared, accepted by hospital command and disseminated as part of institutional COVID-19 resources. Support was also provided to the Royal College of Paediatrics and Child Health Ethics and Law Advisory Committee as it established pandemic support documents.

3. Weekly bioethics leads teleconference meetings were established to facilitate communication, and timely address of internal and external ethical support needs.
4. Support was provided to the infectious disease (ID) team as they planned therapeutic options for children with severe COVID-19 infection. This process evolved with the PBC and ID team joining Drugs and Therapeutics Committee review of likely effective agents, with inbuilt rapid second opinions from another tertiary centre and parent involvement by video-link.

### ACTIVITY (MARCH–JUNE)

During the pandemic, each working group addressed relevant ethics support needs and challenges:

*RCR:* following social distancing recommendations, remote video-conferences continued this service. If both parents attended one joined from the child's bedside another from home, or both from home if social distancing.

A substantial increase in RCR work occurred during the 4 months from the previous average of two to three cases monthly.

1. *Innovative treatment* was, as anticipated, a large part of RCR work.

ID/PIC teams referred six children with respiratory disease and proven COVID-19 for rapid consideration of innovative treatment: two ex-preterm infants, one with pre-existing lung disease; one child with morbid obesity; one immunosuppressed due to cancer/chemotherapy and one with critical congenital heart disease needing urgent bypass surgery. Five were undergoing mechanical ventilation, and four were also on inotropes at referral.

Reviews were carried out as per published guidance,<sup>9</sup> but by telemedicine, with parent involvement where possible (4/6) or telephone (2/6). In all cases, the eight Great Ormond Street Hospital (GOSH)-innovative treatment criteria were fulfilled, and treatment proceeded in five, one parent declined treatment after ethical discussion. The situation presented a significant challenge due to the (i) speed of RCR required, in often critically ill children (four occurred the day of referral) and (ii) the need to ensure all those providing consent fully understood quite complex information in a rapid timeframe. The last was challenging due to the single parent hospital policy, with other family members at home. Teleconferencing-facilitated processes allowed PBC members to join the initial (ID and paediatric intensive care unit (PICU)) meeting before the ethics discussion, so they were aware of emerging information about novel COVID-19 management. After the meeting the chair of the ethics review met/video-conference the parents and treating clinicians to facilitate informed consent.

As Paediatric-Inflammatory-Multisystem Syndrome-Temporally associated with SARS-CoV-2, emerged, the treating teams (ID, cardiology and PICU) engaged with the PBC team to develop a treatment approach. Four children were initially discussed, within hours of presentation, before a standard protocol was established. One child later had a formal ethical consultation due to severity and atypical symptoms.<sup>10</sup>

All children survived and have been discharged from the hospital.

2. *Prioritisation and rationing with the COVID-19 pandemic* Seven infants with severe combined immunodeficiency from overseas planned for specialist treatment (one of two international centres to provide this) were referred to consider

if such therapies should proceed given direction of national and local resources to the pandemic. Deliberation involved consideration of each child's best interests, discussion of how hospital resources might be optimally used to minimise admission time and reflection of the international duty of care of a centre providing such highly specialised lifesaving treatment.

Two patients with immune deficiency on 'compassionate use' antiviral treatment were referred to consider how to allocate remaining limited drug supplies. Both required the drug for ongoing treatment, but supply had ceased as the drug been redirected in the country of origin for trial use in COVID-19.

3. Six non-COVID-19 children reviewed (four about treatment limitation; one high-risk surgery and one bone marrow donation from non-competent sibling). These cases highlight the need for routine ethics reviews/support to continue despite the demands related to the pandemic.
4. *Other work*
  - i. PBC as 'duty of candour' resource considered non-use of organs for transplant due to resource restrictions (team availability not COVID-related)
  - ii. Web conference advice to established ethics team in another city about management of paediatric referrals; advice to several regional and national hospital managers about establishing ethics support.
  - iii. Reassurance to 'children with disabilities' support groups that no change in the law or PICU-admission criteria was envisaged due to the pandemic (capacity maintained by transfer of PICU capacity to regional children's hospitals, while collocated PICUs provided adult care). Although this does remain a live question for any future pandemic that predominantly affects children, therefore we recommended the groups to adopt a proactive approach to ensure representation and continued advocacy.<sup>4</sup>

### Education

Presented webcasts about pandemic ethical issues for the European Academy of Paediatrics, together with colleagues from Italy and for the International Collaborative Bioethics group (Boston Children's Hospital). We also ran training sessions on pandemic ethical aspects for local and European Intensive Care teams. Finally, a hospital Grand round shared the bioethics team's work during the pandemic.

A video-conference on the role of faith/humanism in the recovery from the pandemic, organised together with the UK Paediatric Chaplaincy Group and Mission and Public Affairs Department of the Church of England explored this crucial aspect in societal recovery.

### Staff well-being

Recognition that institutional/other constraints limiting a practitioner's morally preferred choice may lead to distress is well established,<sup>11</sup> yet little was considered during pandemic planning.<sup>12</sup> Moral injury to professionals that experience rapid and frequent existential decision-making exacerbated by operating in an area outside one's usual expertise was of concern.<sup>13</sup>

PBC processes to address this issue were adapted to provide socially distanced support. Usual 'at the coalface' ethics drop-in sessions were replaced by (a) individual informal (socially distanced) face-to-face support (1–3 per day Monday–Friday March–June) and (b) weekly group video-link sessions (1–8 people per week; mean 4.6).

### Box 1 Challenges children's hospital staff faced during the pandemic

- ▶ Challenges meeting personal obligations to safeguard family at home and continue to meet professional obligations to continue to work.
- ▶ Risk of exposure through working with inadequate personal protective equipment.
- ▶ Inequalities of risk for those who continued to come to work, as opposed to those working from home.
- ▶ Redeployment and working outside the zone of personal expertise, especially those redeployed to adult services.
- ▶ Providing ongoing complex care with limited resource.
- ▶ Inability to perform the usual daily job, for example, "I cannot do cardiac surgery".
- ▶ Providing a reduced standard of what is considered best care in some adult units.
- ▶ Being involved in end-of-life care in isolation from family.
- ▶ Lack of personalisation in the patient's bed space.
- ▶ Repeatedly witnessing pain, suffering and death on an unprecedented scale.

Clearly healthcare personnel's experiences should be taken into account to inform the recovery phase and to prepare for future surges. Many challenges were linked to staff deployment to overwhelmed adult ICUs or transport teams under severe pressure, but these staff experienced notable benefits too: a strong sense of camaraderie, doing something useful during a time of unprecedented national crisis and feeling valued by colleagues.

A Moral Distress Card was adapted (with permission), for the hospital *well-being hub*, which provides resources and triage services to signpost staff to specific support. It includes information about the causes, symptoms, signs and potential consequences of moral distress.

The specific ability of a bioethics team to review the complex ethical challenges faced by staff during a pandemic in the lens of nuanced moral deliberation provides the rudiments of protection against moral injury. Informal feedback suggests these sessions were crucial in helping staff cope with the challenges faced. Formal research in this area is planned. Challenges raised by staff are highlighted [box 1](#).

PBC contributed to creation of an international framework describing moral distress shared by the UK Clinical Ethics Network. Comparison with other centres' well-being activity is challenging with little to date in the public domain; but deployed staff informed us that they were aware of only one adult unit with similar support at the time.

### Research

A paper concerning how poorly prepared the UK and other countries were for any pandemic severely affecting children was published early in the pandemic.<sup>4</sup>

A paper and blog about children's role in pandemic recovery<sup>14</sup> led to a video-conference with the GOSH-Young People's Forum regarding the pandemic and their role in recovery with analysis published, together with the young people (see below under Reflection and the future).<sup>15</sup> PBC members authored a BMJ Blog about the function of ethics committees and chaplaincy support during the pandemic,<sup>16</sup> and an article on the adult ICU legal situation.<sup>17</sup>

### Clinical ethics committee

Clinical ethics committee meetings were held via video-conference at the beginning and towards the end of the pandemic period to update/inform members who could not participate in activities during the period.

### REFLECTION AND THE FUTURE

The PBC team have reflected on the pandemic's effects on children, which have not been limited to direct viral infection. Sadly, the consequences of lockdown include morbidity and even death in children due to delayed presentation, an increase in non-accidental injury and other child abuse/domestic violence. There are as yet, undetermined effects on the well-being of children with school/education closures and limited social/sporting contact; and likely longstanding effects in terms of child mental health, child abuse and poverty.

The process we have developed to help children and families consider, together with clinicians and scientists, the compassionate use of innovative and experimental treatments outside formal trials proved of significant use. As previously reported,<sup>18</sup> this process provides an ethical, holistic and supportive framework for complex deliberation about the use of unproven therapies—often in rare disease, 'n=1' cases and often where the prognosis is poor.<sup>19</sup>

Somewhat surprisingly, video-conferencing worked well in this context, but was the only option rather than a choice. Arranging meetings was far easier in terms of ready availability, and only once was there a potential issue around confidentiality, with a clinician clearly needing to move to prevent being inappropriately overheard.

Further work is needed to compare video-conferencing for ethics meetings with usual face-to-face meetings. Anecdotal feedback from parents, clinicians and bioethics team members was excellent. No one reported their ability to contribute to be either reduced or restricted.

Intersurge and recovery phases provide an opportunity for supported reflection and the building of resilience in healthcare teams. Key to this will be identifying the challenges that all staff groups faced, acknowledging that experience and creating a narrative that allows us to build resilience for managing future surges.

Video-conferences with faith/non-faith leaders about the role of religion and non-faith support in the pandemic and with young people on the subject of the pandemic enabled the PBC to start to consider the ethical issues surrounding the broader social problems crucial to health outcomes. As ethicists, we were depressed but not surprised that our young people's group did not consider that they had any voice early in this pandemic on the broader national stage. They felt little more than passive recipients in recovery planning towards the end of the first lockdown.<sup>15</sup>

### SUMMARY

We offer this novel description of a Children's Hospital Bioethics team's work during this unprecedented pandemic to both illustrate the utility of bioethics to the modern hospital, and to serve as a roadmap for new bioethics services being established, to support institutions.

Clearly video-conferencing is a new paradigm for our group, and not reported in the literature for this purpose to our knowledge. It seemed to work remarkably well, but formal research is underway. Other elements of our work such as prevention of

moral injury in teams, education and research accelerated during the pandemic, but required significant input from the team.

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**Collaborators** Linthicum James.

**Contributors** All authors worked together to redesign the bioethics team approach to COVID-19. JB led the team, wrote the major on documents and led education. SA led the rapid review service. AM did the staff support element. MD organised and facilitated all components. JB/MD composed the study and analysed the data and then wrote the paper with respective contributions from SA and AM of their areas. All authors contributed to the final documents.

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