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RESEARCH ARTICLE

Ethical challenges faced by healthcare workers in pediatric oncology care during the COVID-19 pandemic in Australia

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Abstract

Objective: This qualitative study examined ethical challenges reported by healthcare professionals (HCPs) working in a large Australian pediatric oncology center during a period of strict COVID-19 restrictions.

Methods: We conducted semi-structured interviews with 21 HCPs who provided pediatric cancer care during the pandemic in 2020, during strict lockdown periods. Interviews examined the difficulties they faced, as well as their own ethical evaluation of the impact of COVID-19 policies on oncology care. Data were analyzed using inductive content analysis and thematic analysis.

Results: HCPs faced several challenges, primarily originating from hospital restrictions, which led to changes in usual clinical practices. These challenges included delivering care with personal protective equipment (PPE), the impact of a one-parent visitation policy, changes in psychosocial and allied health services, and COVID-19 swabbing policies. Overall, there was consensus from participants that hospital restrictions were justified and, while difficult, HCPs simply had to provide the best care possible given the circumstances. However, participants described decreased capacity to deliver holistic patient care and, in some instances, a tendency to avoid ethical reflection. Lastly, there was a consistent theme of shame and sense of responsibility underlying some participants' anxiety around inadvertently transmitting COVID-19 to immunocompromised patients.

Conclusion: Our findings show that many staff felt unease at the disruptions in patient care due to COVID-19 restrictions. Some HCPs indicated a degree of moral distress, with a possibility of moral injury among some HCPs. A focus on ethical recovery could assist in preventing any ongoing difficulties among HCPs because of their experiences.

KEYWORDS
COVID-19, ethics, moral distress, moral injury, oncology, pediatric

Abbreviations: HCP, healthcare professional; PPE, personal protective equipment.

1 | INTRODUCTION

The oncology care setting has endured widespread impacts related to the COVID-19 pandemic.[1–4] One such impact is that healthcare professionals (HCPs) have faced new ethical challenges resulting from the pandemic and its associated restrictions.[3,5,6] The nature of these challenges in the pediatric oncology context specifically is yet to be thoroughly explored. The existing literature on pandemic-related ethical challenges in healthcare has primarily focused on policy-level perspectives, identifying issues including staff workforce shortages[6] and resource scarcity.[3,5–8] In contrast, there is limited research investigating the personal ethical (or values-based) challenges arising from the pandemic as experienced by HCPs,[9,10] and no such studies in pediatric oncology. There is a small but growing number of studies investigating pandemic-related moral distress,[11–14] but these impose a particular framing that does not necessarily explicate the nature of the values at stake and the ethical concerns that might give rise to distress.

In this qualitative study, we investigated HCP-reported challenges related to ethics and values (referred to hereafter "ethical challenges") in a large pediatric oncology center in Melbourne, Australia. During the study period, rates of COVID-19 infections, hospital admissions, and deaths in Australia were very low compared to other nations, with measures including national and international travel restrictions, high levels of testing and contact tracing, and strict "stay-at-home" or lockdown orders. Metropolitan Melbourne experienced a total of 23 weeks of strict lockdown between March and October 2020, with the highest number of cases (average 491 cases daily) peaking in July–August. Similar to worldwide responses, hospital restrictions at the time included mandated personal protective equipment (PPE) for all staff, visitor restrictions (including allowing only one parent caregiver and no sibling visits), mandatory asymptomatic COVID-19 nasopharyngeal swabs for patients before every surgical procedure, and strict patient (and parent) isolation while awaiting results. Many outpatient appointments were converted to telehealth, and staff worked from home when not directly providing inpatient care.

Within this context, the delivery of pediatric oncology care, which is characterized by family-centered and developmentally guided care, has been identified as particularly challenging.[15,16] Accepted holistic models of healthcare delivery mean that oncology HCPs are not only concerned with providing good medical care, but also providing quality psychosocial care, which enhances the child and family's overall health, wellbeing, and ability to cope with illness.[17] The restrictions placed on the oncology center during 2020 resulted in separation of families and a reduction of available psychosocial and allied health supports, representing a significant deviation from usual care practices. Such changes may well present ethical challenges and dilemmas for HCPs, who consider their standard care practices as the appropriate way to fulfil their ethical obligations to promote the best interests of children and their families.

Addressing these challenges from the individual perspectives of pediatric oncology HCPs is central to assessing any damage to their sense of moral integrity resulting from the pandemic, as well as formulating possible solutions to achieve moral recovery. Ethical dilemmas have the potential to cause distress among HCPs who must make and/or carry difficult decisions, and thus feel moral responsibility for these decisions.[18,19] If these ethical dilemmas and challenges remain unresolved, this can lead to moral distress, which is "the distress experienced when you believe you know what the morally 'right' thing to do is but something or someone prevents you from acting accordingly."[20] Moral distress has the potential to leave behind "moral residues" that, if accumulated, could ultimately cause a moral injury.[18] A moral injury describes impaired functioning resulting from living with moral distress,[21] which can manifest in numerous ways including disengagement from work, self-care practices or spirituality, or even maladaptive behaviors including substance use or self-harm.[21] This study aimed to understand the experiences of HCPs during the pandemic by identifying ethical challenges as a means of eventually directing moral recovery efforts, without assuming that all ethical challenges lead to moral distress.

2 | METHODS

This study was one of the several studies conducted within our center to examine the impacts of the COVID-19 pandemic upon families and HCPs.[22,23] Ethics approval was granted by the institutional Human Research Ethics Committee on September 24, 2020 (HREC 68429).

2.1 | Participants and recruitment

Study participants were clinical oncology staff (medical, nursing, and allied health) who directly delivered patient care in a large Australian pediatric oncology center during the pandemic period (commencing March 16, 2020). Potential participants were invited via departmental email distribution lists and provided written consent for participation. Recruitment occurred over a 12-week period.

2.2 | Data collection

Individual semi-structured interviews were conducted by Jenny O'Neill, a study team member who has no professional relationship with study participants. Interviews were conducted by telephone or videoconferencing, using an interview schedule, which included questions about changes participants noticed in patient care during the pandemic, and any difficulties they faced (see Table S1). Interviews were conducted between October 2020 and January 2021, audio-recorded and transcribed verbatim by a professional transcriber.

2.3 | Data analysis

De-identified interview transcripts were imported into NVivo 12 software for coding. Analysis was conducted in two rounds, the first using inductive content analysis,[20] and the second using thematic analysis.[24]

The aim of the inductive content analysis was to identify the domains of challenges experienced by HCPs that were common across the dataset. Initial coding of a subset of the transcripts was conducted by India R. Marks and Maria C. McCarthy, and then discussed by the full research team (India R. Marks, Maria C. McCarthy, Jenny O'Neill, Lynn Gillam). Challenges identified in this coding round were not necessarily explicitly named by the participants as ethical; however, were included if they could reasonably be interpreted as having ethical significance, in order to not exclude relevant data. A final coding schema for challenges was developed and all transcripts were re-coded by India R. Marks.

The aim of the thematic analysis was to identify ethical aspects or interpretations of these challenges by examining underlying patterns of meaning within and across the content categories. All transcripts were re-read and re-coded for thematic analysis by India R. Marks, focusing upon units of analysis that indicated ethical, moral, or values-based evaluation expressed by participants. The full research team discussed the initial coding at length, agreed on a coding scheme, and coding was again finalized by India R. Marks.

3 | RESULTS

3.1 | Sample characteristics

Twenty-three HCPs indicated interest in participating in the study and 21 completed interviews (91.3%; two HCPs were unavailable during the study period). Nineteen (90.5%) participants were female; 10 (47.6%) nurses, seven (33.3%) allied health/psychosocial, and three (14.3%) medical. Years of oncology experience ranged from under 2 years ($n = 4$; 19.0%) to 15+ years ($n = 6$; 28.6%). Pseudonyms have been used for confidentiality purposes.

3.2 | Domains of challenges experienced by HCPs

Six main challenges faced by HCPs were identified: (a) Treatment changes resulting from the pandemic; (b) PPE; (c) one-parent policy; (d) COVID-19 swabbing policies; (e) impact on staff wellbeing; and (f) anxiety about COVID-19 transmission. Table S2 shows sample quotations to demonstrate the basis for these categories. All categories were mentioned by at least three participants. The most common categories were the one-parent and swabbing policies. HCPs who worked primarily from home throughout the period cited fewer challenges than those who worked in the hospital. Some participants also indicated positive outcomes, including increased support in the workplace culture and increased ease with which parents of immunosuppressed children could justify to others their need to take extra hygiene measures.

3.3 | Ethical valence of challenges

Participants felt, and articulated to varying extents, an ethical valence or undercurrent in the challenges they experienced. Four main themes were identified, based on evaluative language, which suggested implicit value-based appraisal, and often ethical or moral unease. These themes (ethical concerns) were: (i) best care given under the circumstances, (ii) lack of agency, (iii) avoiding ethical reflection, and (iv) shame and sense of responsibility.

The first three ethical concerns were associated with several categories of challenges, specifically treatment changes resulting from the pandemic, PPE, the one-parent policy, and COVID-19 swabbing policies (challenge categories a–d). The final ethical concern, shame, and sense of responsibility, related particularly to anxiety about transmitting COVID-19 (challenge category f). Challenge category (e) (impact on staff wellbeing) was not identified as having ethical valence by participants, and therefore was not categorized under our ethical themes. This category likely reflected more of an organizational challenge and, as such, is discussed in terms of the clinical implications of the study.

3.3.1 | Best care given in the circumstances

Most ethical concern arose from the impact of the policies on patients and families aimed at providing a more COVID-safe environment (challenge categories a–d). Nevertheless, very few participants criticized the rules as excessive or unnecessary: there was a consensus that, while difficult, the rules were justified. For instance, Amira (nurse) stated that she felt discomfort "more because it's distressing, not because it's wrong. We have to be safe." Likewise, Kendall (doctor) described the restrictions as "not wrong because I think that's what we need to do but this bug is just making life difficult." Others commented that it "has to be done" (Ella, nurse manager), "needed to happen" (Helena, psychosocial), and "don't think we really had a choice" (Amira, nurse). Rebecca (nurse) described the hospital as being caught between a "rock and a hard place," showing recognition of the bind the hospital was in due to competing ethical considerations.

The role of staff was seen by several participants as providing the "best [care] you possibly can in the circumstances" (Eliza, psychosocial). However, many participants reported that this was difficult in varying ways. Amelia (nurse) noted that "I think that we've had to adjust to [changes in practice] and that has been uncomfortable…to not be able to provide the appropriate social care to families." Bonnie (nurse) referred to the one-parent rule as "counterintuitive," but also acknowledged the underlying belief that "the right thing to do is to separate" from each other. Other HCPs described varying levels of emotional unease around their inability to provide the usual level of family-centered psychosocial cancer care due to various restrictive policies. When referring to disruptions to psychosocial care (challenge category a), one-parent policy (challenge category c), and COVID-19 swabbing policies (challenge category d), participants expressed negative appraisals or emotions ranging from "challenging" (Kendall, doctor), "uncomfortable" (Helena, psychosocial), and "difficult" (Nora, nurse), to feeling "torn" (Ella, nurse) or "distressed" (Amelia, nurse). These reactions were particularly expressed in relation to the one-parent policy: "The psychosocial impact on the family and then their distress

to us was really distressing" (Amelia, nurse). Participants' distress was especially evident in relation to children in palliative care who could not have family visitors. Farah (doctor) commented, "It breaks my heart they cannot have the visitors. They cannot enjoy this last time that they have with - I think it's terrible." Nora (nurse) stated that "It will stay with me for the rest of my career that you've had families that have not been able to be together during that time." Sometimes the emotion was not named, but strongly implied: "They can't see your face [through PPE], they can't see your facial expressions, and you just wonder, *can they [patients and families] feel your compassion*?" (Amira, nurse).

3.3.2 | Lack of agency

Many participants conveyed the sense they lacked agency related to the changes in practice. Comments evoked a sense that the policies and rules were immovable and "out of our hands"; the changes were "hospital policy and we have to do it" (Galina, nurse). Sandy (nurse) noted that staff "can't say anything" to explain the disruptions in care to patients, other than reminding families of patients they are "doing their best." Her use of the common adage between a "rock and a hard place" can be interpreted as alluding to the powerlessness of hospital policy-makers given the equally compelling but competing considerations at play. Amelia (nurse) emphasized that it felt "upsetting because we can't change the rules," expressing her regret around the inability of individual HCPs to carry out optimal family-centered care. Georgia (nurse) reiterated this limited sense of agency as she described her concerns about the changes to psychosocial care available to patients: "There was a couple of kids I was worried about and just sitting with that, I hope they're okay *'cause I can only do what I can do'*."

3.3.3 | Avoiding ethical reflection

The language of some interviewees indicated a degree of avoidance of explicit ethical reflection. For instance, Francesca (psychosocial) described how she had "just gotten on with the situation" without reflecting on the ethical elements of the COVID-19 restrictions:

"I guess *I'm just resigned to the fact* that it's the way it is. I probably haven't gone there. I don't have much to offer to this question because *I don't think I've gone there in my head* to think about the ethics of that situation."

Likewise, Teri (allied health) gave a similar comment about the tendency to accept the PPE rules (challenge category b) without ethical appraisal: "I guess I'm the type of person to just accept advice and I never felt like an expert *so it's just best to not question it too much*." Helena (psychosocial) described a similar concept of avoiding ethical reflection in reference to the COVID-19 swabbing policies (challenge category d). She commented on the growing "culture of let's just get this done" leading to holding children down as a means of hastening the potentially distressing procedure, as best practice "seemed to go out the window" in this scenario.

3.3.4 | Shame and sense of responsibility

Many staff expressed a common anxiety around COVID-19 transmission (challenge category 6), underpinned by a sense of shame at potentially being the staff member who exposes immunocompromised patients to the virus. These concerns were more pronounced in relation to bringing COVID-19 into the hospital ward rather than bringing it home. For instance, Amelia (nurse) described the idea of transmitting the virus as "scary," Anya (allied health) noted it was her "biggest fear," and Eliza (psychosocial) remarked it caused her an "overwhelming sense of anxiety." Likewise, Helena (psychosocial) noted that these worries were "always at the back of our minds" during this period.

A common thread of shame was consistent across multiple interviews: Eliza (psychosocial) directly referred to her "shame," and Teri (allied health) to a sense of "guilt," as underscoring their fear of transmitting the virus. Comments such as "You don't want to be that one" (Farah, doctor) and "You never want to be the nurse" (Nora, nurse) implied it would be shameful to be the one HCP who, even inadvertently, spreads COVID-19. Helena (psychosocial) noted that she felt "responsible" for the wellbeing of her immunocompromised patients and equated transmitting COVID-19 to "harming people." Farah (doctor) described that the "stigma" around spreading COVID-19 works mainly against oneself as the transmitter of the virus: "If I were to have the COVID and contaminated people I would feel super, super-bad…I know that it's no-one's fault, it's a very contagious disease… *[but] it's always different when it's yourself*."

4 | DISCUSSION

To date few studies have focused on individual HCP perceptions of COVID-19-related ethical concerns in delivering clinical care. This qualitative study elicited Australian HCPs' perspectives on providing pediatric oncology care during the 2020 phase of the pandemic. Even though participants required little prompting to discuss COVID-19-related challenges, they did not always explicitly identify these as ethical concerns. Thematic analysis identified latent ethical themes even where participants did not make explicit comments. Like Wiener et al.,[12] we found that most ethical challenges arose from restrictions on the provision of usual care to all patients and families, rather than from experiences of caring for COVID-19-positive patients specifically, which was the focus of studies by Abu-El-Noor and Abu-El-Noor and Jia et al.[9,25] The central ethical challenge faced by staff in our study can be summarized as follows: to what degree is it ethically acceptable for holistic pediatric oncology care to be compromised in order to reduce COVID-19-related risks?

The unease felt by HCPs when pondering this dilemma can be better appreciated by considering the background culture of the healthcare workforce, including ways in which HCPs perceive their roles and responsibilities toward their patients. The role of a healthcare worker is commonly understood as that of a carer, healer, or protector. Moreover, both "patient-centered care" and "family-centered care" are commonly regarded as accepted practice. Therefore, a hospital service

that suddenly restricts available contact with family supports and open access to HCPs, including psychosocial and allied health care, seems incongruent with this. It is tenable that COVID-19 policies enforced within a pediatric oncology center could cause moral distress in HCPs who endeavor to achieve the highest level of care possible.

It is through this lens that some participants' responses to ethical challenges in this study can be understood. For instance, our analysis identified a common discourse around shame at the concept of transmitting COVID-19 to a vulnerable patient group. This finding is similar to that of Simonovich et al. who identified that nurses felt guilt around letting their patients down during the pandemic, but less specifically around the idea of viral transmission itself.[26] Importantly, our data were collected when COVID-19 vaccination was not yet widely available in Australia, and the experience of COVID-19 infection among children with cancer was less well characterized, which likely contributed to clinicians' fearful response regarding COVID-19 transmission. A common thread was that being responsible for bringing the virus to the ward would contradict HCPs' deep sense of obligation to heal and help while simultaneously "doing no harm."

Participants framed their discomfort with the changes to patient care in a variety of ways. Some addressed ethical challenges with a cognitive framing suggesting moral regret rather than moral distress. Despite involving less emotional turmoil, this moral regret still displayed a recognition that while public health measures were justified, individual patient care mattered morally and therefore something important was being lost. Other staff used language indicative of moral distress, particularly in relation to issues of the one-parent policy and changes to psychosocial support. This is consistent with existing literature, which suggests that moral distress among HCPs is a possible by-product of the COVID-19 pandemic.[27,28] Importantly, this distress has the potential to become morally injurious. The concept of moral injury originates from a military context but has been expanded to describe the same phenomenon within other contexts, including the healthcare setting.[21,29] While related to moral distress, moral injury describes the ongoing impaired functioning that results from morally distressing experiences.[21]

Moral injury has the potential to result in not only lingering psychological distress due to a sense of failing to uphold ethical values and standards, but also the appraisal that one's sense of self has been irreparably damaged, leading to poor self-esteem and a lost sense of identity.[30] These impacts could affect functioning in both personal and professional domains. Additionally, some might suppress their moral instincts as a way of coping. This "damage done to [one's] moral fiber" could ultimately cause a lasting shift in their moral compass, potentially making it difficult for affected individuals to return to their baseline moral instincts.[30] Importantly, our analysis did identify that some participants indicated avoidance of ethical reflection, either to cope with some level of moral distress, or due to feeling overwhelmed by competing ethical considerations and unable to come to a considered view. Regardless of the underlying impetus, avoiding ethical reflection could have consequences. For example, Suhonen and Scott describe possible consequences of "ethically blind" decision-making: HCPs not recognizing or pondering the ethical elements of their decision-making can result in undesirable outcomes such as discrimination, injustices, and ultimately negligence.[31] Furthermore, there are possible negative impacts on integrity and moral sense of self from deciding not to notice or engage with ethical aspects of one's work.[32] Therefore, in addition to the potentially harmful sequelae of moral injury, the propensity to avoid ethical reflection could also lead to unwanted personal and professional outcomes.

This research has highlighted the possibility that working within the pediatric oncology setting during the pandemic period has generated varying levels of moral distress, bringing with it the possibility of longer term moral injury. Even if these outcomes only occur for a small percentage of HCPs, they constitute a significant workforce issue. Unfortunately, moral distress can linger after the events that initially caused it. For this reason, we argue that attention must be given to the concept of moral recovery. Currently, there is no uniform definition of moral recovery. We suggest that moral recovery is a process that enables restoration of moral wellbeing in the aftermath of a moral injury. Formulating a moral recovery plan could aid individual staff but also ensure optimal clinical care is restored as the world emerges into a "COVID-normal" era.

There is, however, little understanding of the ways to achieve moral recovery in the healthcare setting. Strategies for achieving moral recovery are an important area of research as the world emerges from the COVID-19 pandemic. We suggest that standard staff wellbeing activities, such as free exercise sessions or team bonding opportunities, while important, are not sufficient to address moral distress. Ultimately, moral distress is a threat to moral wellbeing, and therefore structured moral recovery is the appropriate intervention. This would likely begin with raising the collective conscious level around awareness of the possible impacts of the pandemic and the potential for ongoing moral injury, encouraging staff to actively reflect on the ethical elements of their practice during the pandemic.[28,33–35] Further empirical research is needed, however, to identify effective strategies for promoting moral recovery among HCPs who worked through the pandemic. While there is research on strategies to address moral distress in other contexts, most commonly in the setting of end-of-life decisions in neonatal intensive care,[36,37] this work may have limited relevance to COVID-19 due the different nature of the ethical concerns. We owe this special attention to COVID-19 moral recovery both to HCPs and to the patients and families for whom they provide care.

A limitation of this study is that it was conducted in a single center. Patterns of COVID-19 transmission and public health restrictions have varied between countries and health systems, and it is important to note that the ethical issues discussed in this study emerged in the context of relatively low levels of COVID-19, and primarily arose due to COVID-19 restrictions rather than due to direct disease burden. Staff were not required to ration care, as was required in other countries with dramatically higher COVID-19 case numbers. Thoughtful extrapolation to other contexts should be considered with the possibility of greater moral distress in other contexts or changes in distress patterns over the evolution of the pandemic.

5 | CONCLUSION

This research identified that working within the pediatric oncology setting during 2020 could potentially have given rise to varying levels of HCP moral distress, with the possibility of moral injury among some HCPs. As a result, it is highly important that we shift our collective focus to the concept of ethical recovery, in particular what interventions can be put in place to facilitate the rekindling of ethical resilience.

AUTHOR CONTRIBUTIONS

Maria C. McCarthy, Lynn Gillam, and Jenny O'Neill conceptualized and implemented the study. Analyses were undertaken by all authors and finalized by India R. Marks. Drafting of the manuscript was undertaken by India R. Marks. Review and editing were completed by all authors.

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CONFLICT OF INTEREST

The authors have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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