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Title:
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Date:
2015-09-01

Citation:
McDougall, R., Notini, L. & Phillips, J. (2015). Conflicts Between Parents and Health Professionals About a Child’s Medical Treatment: Using Clinical Ethics Records to Find Gaps in the Bioethics Literature. Journal of Bioethical Inquiry, 12 (3), pp.429-436. https://doi.org/10.1007/s11673-015-9643-7.

Persistent Link:
https://hdl.handle.net/11343/216686

[issue] **12(3)**
[category] **Original Research**

[title] **Conflicts Between Parents and Health Professionals About a Child's Medical Treatment: Using Clinical Ethics Records to Find Gaps in the Bioethics Literature**

[subtitle]

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Abstract Clinical ethics records offer bioethics researchers a rich source of cases that clinicians have identified as ethically complex. In this paper, we suggest that clinical ethics records can be used to point to types of cases that lack attention in the current bioethics literature, identifying new areas in need of more detailed bioethical work. We conducted an analysis of the clinical ethics records of one paediatric hospital in Australia, focusing specifically on conflicts between parents and health professionals about a child's medical treatment. We identified, analysed, and compared cases of this type from the clinical ethics records with cases of this type discussed in bioethics journals. While the cases from journals tended to describe situations involving imminent risk to the child's life, a significant proportion of the clinical ethics records cases involved different stakes for the child involved. These included distress, poorer functional outcome, poorer psychosocial outcome, or increased risk of surgical complications. Our analysis suggests that one type of case that warrants more detailed ethics research is parental refusal of recommended treatment, where the refusal does not endanger the child's life but rather some other aspect of the child's well-being.

Keywords Paediatrics; Clinical ethics; Parents; Conflict

Bioethicists have previously stressed the importance of analysing the everyday challenges of clinical practice, alongside the dramatic technology-driven issues that often dominate bioethics scholarship (e.g., Guillemin and Gillam 2006; Komesaroff 1995; Worthley 1997). One way in which such day-to-day challenges can be identified is through the case records of the clinical ethics services that are an increasingly common presence in hospitals. Such records represent a repository of cases that clinicians have identified as ethically difficult. The present study is part of a broader research project investigating conflicts between parents and hospital-based health professionals about a child's medical treatment. The broader project aims to generate ethical guidance for hospital-based paediatric health professionals facing this type of conflict. In the context of this aim, it is important to understand the full range of types of conflict situations about medical treatment that arise between parents and health professionals in paediatric hospitals. We investigated whether the clinical ethics records at one Australian paediatric hospital reveal additional types of conflict cases that diverge from the types of cases described and analysed in the existing bioethics literature.

At the Royal Children's Hospital, Melbourne (RCH), the clinical ethics service has kept a database of cases referred to the service since the first case referral in June 2005. Any doctor, nurse, or allied health worker in the hospital can refer a case to the clinical ethics group. Cases usually relate to current patients or, more rarely, to a recent situation that caused clinicians concern. A multidisciplinary discussion with the ethics group and the treating team is then convened. A written summary of the discussion and the ethics group's advice is provided to the referring clinician; the advice is not binding and decisions remain with the clinicians (for greater detail, see Gold, Hall, and Gillam 2011; McDougall et al. 2014). Over the last five years (2010–2014), the RCH clinical ethics service has conducted an average of twenty-eight case consultations per year (McDougall and Notini unpublished data).

Approximately one in five of the cases referred to the RCH clinical ethics service involves a conflict between parents and the treating team (McDougall and Notini unpublished data). This aligns with the proportion reported in another study of ethics consultations at a paediatric hospital (Yen and Schneiderman 1999, 375). Almost all of these conflicts are about the appropriate medical treatment for a child. (Another type of disagreement that arises is around truth-telling to paediatric patients. Truth-telling disagreements may relate to disclosing prognosis or a traumatic event such as the death of a family member; the RCH clinical ethics service offered advice on two such cases in the period June 2005 to Feb 2013. A further type of disagreement involves parents seeking genetic testing for carrier status in a child; the RCH clinical ethics service offered advice on one such case in the same period.) This study focuses specifically on conflicts about medical treatment. We define a conflict case as one in which health professionals and parents explicitly disagree about the appropriate medical treatment for the child. We include cases in which the health professionals ultimately act in accordance with the parents' decision as well as cases that reach an impasse and are subsequently referred to the courts.

This paper reports the results of an analysis that aimed to answer three questions:

1. What are the features of the cases involving conflict between parents and health professionals about medical treatment that have been referred to the clinical ethics service at the Royal Children's Hospital, Melbourne (for example: age of child, condition, key point of contention)?
2. How do these clinical ethics cases compare with the group of conflict cases discussed in the existing bioethics literature?
3. Do the clinical ethics records point to types of conflict cases that lack attention in the current bioethics literature, suggesting new foci for detailed ethical analysis?

We addressed these questions by first searching key bioethics journals and then searching the case database of the RCH clinical ethics service for cases involving conflict between parents and health professionals about a child's medical treatment. We identified, analysed, and compared cases from these two sources and, on this basis, suggest that there is (at least) one type of conflict case that warrants more detailed attention and analysis by bioethicists.

Conflict Cases in Existing Bioethics Literature

The Search

To identify conflict cases discussed in the existing bioethics literature, we conducted a search of fourteen bioethics journals. The highest-impact journals were included, as well as less prominent journals that have particular relevance to the topic (e.g., *Clinical Ethics*). In alphabetical order, the journals searched were *The American Journal of Bioethics, Bioethics, Cambridge Quarterly of Healthcare Ethics, Clinical Ethics, The Hastings Center Report, International Journal of Feminist Approaches to Bioethics, Journal of Bioethical Inquiry,* *Journal of Clinical Ethics*, *The Journal of Law, Medicine & Ethics*, *Journal of Medical Ethics*, *The Journal of Medicine and Philosophy*, *Kennedy Institute of Ethics Journal*, *Nursing Ethics*, and *Theoretical Medicine and Bioethics*.

For ten of the journals, an advanced electronic search of the individual journal was conducted using various spellings and combinations of the following keywords and phrases: paediatric*, child*, teenage*, adolescen*, young people, health professional*, health care professional*, doctor*, physician*, nurs*, clinic*, hospital, surgery, ethic*, moral*, parent*, mother*, father*, guardian*, disagree*, conflict*, dispute, refus*, object*, case, case study, and report. Four of the journals did not have an advanced electronic search function available. For these journals, the indexes and titles of each issue published between and including January 2002 and June 2013 were manually reviewed. If the title of the paper was not indicative of its content, the abstract and/or the entire paper was reviewed.

Papers were read and assessed against the following inclusion criteria. Only papers that met all criteria were included in the next stage of analysis.

- The paper describes a case in terms of conflict between the child's parent(s) and at least one of the health professionals directly involved in the child's care.
- The conflict is about a child's medical treatment in a hospital setting.
- The health professionals involved are based at a hospital (rather than school nurses or general practitioners, for example).
- The child was being cared for in a developed country setting.
- The paper is written in English.
- The paper was published between and including January 2002 and June 2013.

Where a case was reported in more than one paper, all papers were included. Both identified and de-identified cases were included. When a paper was structured as a case followed by multiple commentaries by different authors, this was counted as one paper. Similarly, when an article appeared with simultaneously published responses, this was counted as one paper. Papers were excluded if they only discussed a hypothetical case or cases. Papers were also excluded if the reported conflict did not relate to the child's *medical treatment* (for example, disagreements about whether to tell the child the truth about his or her diagnosis and/or prognosis and disagreements regarding genetic testing and participation in research) or if the proposed medical intervention was not hospital based (e.g., vaccination). Papers were excluded if the parents in the reported case were accused of abusing their child, as this situation does not reflect the standard paediatric health care situation in which parents care deeply about their child’s well-being.

Some articles described one case, and others described multiple cases. For each conflict case in each paper that met the above inclusion criteria, features of the case were manually entered into an Excel spreadsheet under the following headings:

- Country in which the conflict occurred
- Age of child
- Child’s health condition
- Key point(s) of contention
- Parents seeking or refusing treatment
- Reasons for conflict
- Outcome at stake (e.g., child’s death, quality of life)
- Whether the case was taken to court
- Legal and/or clinical outcome of the case

Results

The search identified fifty-one relevant papers. (The full list of papers is available from the authors on request.) As some articles described multiple cases, there were a total of eighty-five case descriptions in the fifty-one papers. Some prominent cases were described in multiple papers. For example, the case of Charlotte Wyatt was discussed extensively (e.g., Brazier 2004; Glover 2006; McPhee and Stewart 2005a, 2005b, 2005c; Stewart 2007) as was the case of conjoined twins Mary and Jodie (e.g., Appel 2009; Cowley 2003; Glover 2006; Harris 2003; Kaveny 2002; Nobbs 2007). Once case descriptions that were clearly describing the same child were grouped together, there were seventy-one separate cases described.

In the seventy-one cases overall, there were approximately equal numbers of cases involving parents refusing a recommended treatment path (e.g., Austin et al. 2009; Boyle, Salter, and Arnander 2004; Kipnis 2007; Kopelman and Kopelman 2007; Rhodes and Holzman 2004) and cases involving parents seeking treatment against the doctors’ recommendations (e.g., Carnevale 2005; Goldworth 2010; Jecker 2011; Jonas 2007; Opel and Wilfond 2009).

There were several striking features of the cases. The first of these relates to the ages of the children involved. Although cases involving school-aged children and teenagers were reported (e.g., Freysteinson 2009; Hui 2008; Savell 2011; Skene 2004; Unsworth-Webb 2006), the majority (53 out of 71) of the conflict cases reported in the bioethics literature involve newborns and infants less than a year old. A second feature of this group of cases is that almost all involve a child with multiple complex life-threatening conditions. A third notable feature of cases reported in the existing bioethics literature was the frequency of court involvement. Of the seventy-one cases, forty-one specified court involvement, with a further six cases in which the question of court involvement was unclear from the description. Obviously, this feature relates to the previous feature: the very high stakes involved in the treatment decision at issue. It is interesting to note that almost all court cases were unsuccessful from the parents' perspective, with the judiciary overwhelmingly tending to support doctors' views in this group of conflict cases (e.g., Austin et al. 2009; Boyle, Salter, and Arnander 2004; McPhee and Stewart 2005a, 2005b; Savell 2011). As discussed in the following section, these three features—very young age, complex life-threatening medical issue, court involvement—were far less common in the cases recorded in the clinical ethics service database.

Conflict Cases in the Clinical Ethics Records of One Australian Paediatric Hospital

The Search

The clinical ethics service database of the Royal Children's Hospital commenced in June 2005 when the first clinical ethics case referral was received. All cases in the period June 2005 to February 2013 were reviewed for potential inclusion in this analysis. Two of the researchers read through all of the cases individually to select those involving conflict between parents and clinicians about a child's medical treatment. There was a very high level of consensus as to which cases ought to be included. In the few cases of non-concordant decisions, we erred on the side of inclusion. When a case was identified as appropriate for inclusion, the information present in the database about that case was analysed in detail. The database includes information fields headed "de-identified case summary," "ethical issue," and "Clinical Ethics Response Group recommendations" (as well as other fields). The information in these three fields was analysed to extract data under the same headings as for the cases from the existing bioethics literature (age of child, child's health condition, key point[s] of contention, parents seeking or refusing treatment, reasons for conflict, outcome at stake, taken to court, outcome of case). "Country" was not included as all cases were from a single location. Because of the nature of the clinical ethics service and its records, whether the case went to court and the final outcome were not always known. In line with the inclusion criteria for the search of the bioethics literature, we excluded cases where the conflict did not relate to the appropriate *medical treatment* for the child.

The project was approved by the Royal Children's Hospital Human Research Ethics Committee.

Results

Twenty-two relevant cases were identified from the clinical ethics service database. Again, there were approximately equal numbers of cases involving parents refusing a recommended treatment path (12 cases) and cases involving parents seeking treatment against the doctors' recommendations (10 cases). The types of cases are summarized in Figure 1.

This group of cases is much more difficult to characterize than the set of cases from the bioethics journals, due to the greater degree of overall diversity. There was a large range of different medical conditions involved in this group of cases. All were serious, but they were not necessarily immediately life-threatening nor in such complex combinations as in the set of cases derived from the bioethics journals. The clinical ethics cases represented a much more even spread of patient ages. There were six cases relating to children less than a year of age (two neonates, three infants, and one baby whose age was not recorded in the clinical ethics notes), but this age group did not dominate the set of cases, unlike the conflict cases reported in the bioethics literature. This reflects the fact that babies born prematurely are usually cared for in the nearby women's hospital. These patients generally only come to the Royal Children's Hospital for surgery, and thus the issues around life-sustaining interventions for these children are primarily dealt with elsewhere.

There were ten cases involving parents seeking treatment for their child that differed from the care that doctors were recommending. Nine of these focused on continuing or instigating life-sustaining interventions. The life-sustaining interventions that parents were seeking included intubation, ventilation, intensive care unit admission, dialysis, and heart surgery. These cases involved patients aged between ten days and fifteen years. In the majority of cases, the child in question was acutely unwell with a very poor prognosis. A common theme in these conflicts was staff concerns about the futility of life-sustaining interventions and the burden to the child associated with these interventions. The final case was unique compared to the other clinical ethics service cases: it involved parents seeking an operation for a child's craniofacial condition, with the aim of reducing social stigma. The doctors involved held the view that the operation was inappropriate because they believed the potential benefits of the surgery did not outweigh the risks and that the child would still be subject to social stigmatization as she had other visible differences.

When analysing the twelve cases in which parents refused the treatment recommended for their child, a clear subgroup emerged. This subgroup of five cases involved parents refusing the medically optimal treatment that doctors were recommending and opting instead for a form of active treatment with an outcome that was known to be suboptimal from a medical perspective. These were not parents rejecting biomedicine in favour of alternative treatments. Rather, these were parents who were choosing a biomedical hospital-based treatment path that was not the most beneficial from a medical perspective. These cases included several families refusing surgery-related blood transfusions for faith-based reasons; the parents preferred treatment options that involved no blood transfusion but a riskier process of surgery or the possibility of a poorer functional outcome for the child. Other cases in this subgroup involved the refusal of a Port-a-Cath insertion in favour of distressing weekly peripheral intravenous cannulation for a young child and ongoing oral steroid use with its associated long-term growth attenuation side effects for the treatment of anaemia in place of blood transfusion. In some of these cases, the clinical ethics group had advised supporting the parents' decision, while in others it was suggested that the parents' preferred treatment ought not to be provided.

There was great diversity in the remaining seven cases involving parental refusals of treatment. In two cases, alternative medicine was being sought or used in place of conventional biomedicine. In two other cases, clinicians were uncomfortable with the parents' decision to move to a palliative care pathway for the children involved. These were significantly different from the subgroup of five cases discussed in the previous paragraph, as these cases involved parents refusing *any* form of curative treatment (rather than refusing the form of treatment that the doctors advocated in favour of a different form). In a further two cases, parents refused medications for their children for reasons that were unclear from the information available in the database. In one situation, the refusal of medication was shortening the child's lifespan (although death was not imminent). In the other, the refusal of medication was causing seizures that were likely resulting in neurological damage and associated developmental delay. The remaining case involved parents who expressed disbelief and denial about their child's condition and, as a result, refused the therapy being advocated by the treating team. This case involved the refusal of hearing aids and alternative communication modes (e.g., signing) for a profoundly hearing-impaired child.

Discussion

Many of the clinical ethics conflict cases did not involve a life-or-death treatment decision. There were different things at stake for the child in these cases, such as distress, disability, or increased risk of surgical complications. For example, several of the refusal cases involved parents rejecting the recommended type of surgery in favour of multiple surgeries that would decrease the chance of a blood transfusion being necessary. Here the parental refusal did not directly endanger the child's life but rather increased the risk of surgical complications or precipitated a poorer functional outcome for the child. There were also cases in which the parents' or clinicians' concerns related to the child's psychosocial outcome, for example lack of language development for the child whose parents were in denial of her hearing impairment or social stigma for the child whose parents were seeking surgery for her craniofacial condition. In many cases, the outcome of complying with the parents' decision was uncertain, and the disvalue of the outcome for the child was subjective and contested. This analysis highlights that parents and health professionals often come into conflict about medical treatment decisions that do not involve a life-or-death decision; other very serious consequences for children may be what is at stake.

This analysis also highlights a particular type of conflict case that warrants greater ethical attention and research: parents refusing optimal treatment where the situation is not life-threatening. Such cases involve parents refusing the recommended treatment and instead wanting a different course of treatment within the hospital setting. These cases could perhaps be understood as challenging the seeking/refusing dichotomy that is standardly invoked in ethical discussions of conflicts between parents and health professionals. In these cases, parents were both refusing the recommended treatment and seeking a treatment that clinicians considered suboptimal. In these cases, it is a poorer health outcome or exposure to greater risk of a poorer health outcome or perhaps simply distress that is at stake for the child. Examples such as Case A (see box) describe this type of situation. This case is based on features of several cases in the clinical ethics service database, altered and amalgamated to protect the confidentiality of the families and clinicians involved. The prevalence of this type of case in the clinical ethics records (5 out of 22) suggests that such situations are a key source of ethical concern, at least for clinicians at the hospital studied.

We suggest that this type of case warrants greater bioethical attention. Among the seventy-one conflict cases identified from bioethics journals, only two were cases of this type. One situation involved parents choosing for their child to remain on dialysis rather than seek a kidney transplant, because of the blood transfusion that would be associated with the transplant surgery (Richards and Stewart 2013). The second case focused on the parents' refusal to send their newborn to a neonatal intensive care unit, opting instead for transfer to a less intensive special care nursery (DeMarco, Powell, and Stewart 2011). The first paper is a straightforward report of a legal case. The second paper, in contrast, offers a detailed proposal for ethical decision-making in this context, based on the economic concept of externalities. DeMarco, Powell, and Stewart's (2011) proposal has not, however, been widely discussed in the literature and leaves open many fundamental questions about how costs and benefits ought to be assessed, calculated, and compared in these situations. A further instance of this type of work in a nursing journal relies on the four principles as the mode of analysis (Rossiter and Diehl 1997). Given the lack of detailed bioethics work in this area, there is clearly a need for further discussion and ethical reflection on this type of case, in order to guide clinicians and clinical ethics committees in their work with families in the paediatric hospital setting.

This study indicates that clinical ethics records represent an important additional source of cases for bioethics research. Many of the conflict cases discussed in the bioethics literature involved the courts, suggesting that court records and media coverage of court cases is one prevailing way in which ethically complex cases come to the attention of the bioethics community. One result of this is that bioethics scholarship has tended to focus on cases in which the child's life is in imminent danger, as state intervention is accepted as necessary in such cases (Diekema 2004; McDougall and Notini 2013). Clinical ethics records thus represent a key avenue for accessing other types of ethically difficult cases. Not only do such records capture rich detail about cases that clinicians have found troubling and the deliberations of clinical ethics committees in these cases, they also enable insights into a far wider range of cases than those that are covered in court records or the media, as they are not limited to situations in which a child's life is at stake. The ethical issues associated with these cases are important ones for bioethicists to analyse. Clinical ethics records therefore have the capacity to play a useful agenda-setting role for ethics research by ensuring that ethical attention is focused on the full range of challenges facing hospital-based health professionals.

SPRINGER: PLEASE PLACE IN BOX

Case A: Parental Refusal Leading to Disability

Child A is a four-year-old girl. Her parents are Jehovah's Witnesses. She presents to the emergency department with a severe injury to her left leg. The main blood vessels to her leg and the nerves that control movement were severed in a traffic accident. Doctors recommend blood transfusion and a complete surgical repair that would

> *require a further blood transfusion. A's blood loss is not life-threatening, but the doctors' view is that if A does not receive blood, then she may lose function in the leg or require amputation. A's parents refuse the blood transfusion and the complete surgical repair. They opt instead for incomplete surgical repair of A's leg, which does not require a blood transfusion but has a lower probability of restoring full mobility and will mean further surgeries for A in the future. An incomplete but better-than-expected surgical repair of the leg is performed at the hospital, without transfusion.*

Acknowledgements The authors thank Alison Brookes for her research assistance. This project was funded by an Australian Research Council Discovery Early Career Researcher Award (grant number DE120100488).

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Parents seeking treatment (10 cases)	Continuing or instigating life-sustaining interventions (9 cases)
	Craniofacial operation to reduce social stigma (1 case)
Parents refusing treatment (12 cases)	Refusing optimal treatment, prefer different course of hospital-based active treatment; refusal not life-threatening (5 cases)
	Prefer alternative medicine (2 cases)
	Prefer palliative care (2 cases)
	Refusing medications – reasons not well specified (2 cases)
	Denying child's condition (1 case)

Figure 1. Types of conflict cases in the clinical ethics records