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PAPER

Overriding parents' medical decisions for their children: a systematic review of normative literature

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ABSTRACT

This paper reviews the ethical literature on conflicts between health professionals and parents about medical decision-making for children. We present the results of a systematic review which addressed the question 'when health professionals and parents disagree about the appropriate course of medical treatment for a child, under what circumstances is the health professional ethically justified in overriding the parents' wishes?' We identified nine different ethical frameworks that were put forward by their authors as applicable across various ages and clinical scenarios. Each of these frameworks centred on a different key moral concept including harm, constrained parental autonomy, best interests, medically reasonable alternatives, responsible thinking and rationality.

In the vast majority of cases, medical treatment decisions are made for children without conflict between families and health professionals. However, in an important minority of cases, conflict arises to varying degrees. Ethicists have made a range of attempts to analyse such conflicts and to articulate the kinds of parental decisions that ought to be overridden. This paper reviews the ethical literature on conflicts between health professionals and parents about medical decision-making for children, focusing specifically on circumstances in which parents' decisions ought to be overridden by health professionals.

We conducted a systematic review of literature in this area. Several models of systematic review in bioethics have been proposed, each suited to different questions, types of literature and audiences. We considered the model of systematic review proposed by McCullough and colleagues to be the most appropriate for this review, given our focus on normative literature, our intended audience and the time available.¹ Our review addressed the question 'when health professionals and parents disagree about the appropriate course of medical treatment for a child, under what circumstances is the health professional ethically justified in overriding the parents' wishes?'

SEARCH METHOD

An electronic literature search of the Web of Science, Scopus, EBSCO (Academic Search Complete, CINAHL and MEDLINE) and Philosopher's Index databases was performed using combinations and spelling variations of the following key words: paediatric*, child*, adolescen*, teenage*, young person, young people, healthcare professional, doctor,

physician, clinician, nurs*, ethic*, morality, role, parent*, disagree*, conflict*, dispute, decision-making, refus*, object* and authority (for the exact search terms and combinations used, refer to figure 1). The electronic database search was supplemented by manually searching three recent key anthologies on paediatric bioethics for relevant chapters.²⁻⁴ We also searched the reference lists and footnotes of all included articles and book chapters to identify additional relevant publications.

Given that we are particularly interested in the Australian paediatric hospital setting, we included only publications that met the following criteria:

1. The author(s) describe an ethical framework that specifies the circumstances under which a health professional is justified in overriding a parent's wishes about a child's medical treatment
2. The proposed framework focuses on hospital-based healthcare professionals (rather than, eg, general practitioners or school nurses)
3. The article is written in and about a developed country setting
4. The article has a publication date between 1982 and 2012
5. The article is written in English.

Publications were excluded if they focused on conflicts about issues other than medical treatment (eg, participation in research, truth-telling about prognosis or other aspects of a child's medical condition, presymptomatic or carrier testing for genetic conditions, vaccination) or disagreement between parents and children or adolescents about appropriate medical treatment. We also decided to exclude publications involving children who are victims of parental abuse as these situations are so far removed from the norm in which parents care deeply about the well-being of their children.

To align our understandings of the inclusion criteria, both of us reviewed the titles and abstracts for all search records generated from the first database search (Web of Science). We compared our results and discussed the discrepancies until we reached a shared understanding of the criteria. For the subsequent databases, the second author reviewed titles, followed by abstracts for articles deemed potentially relevant from title review. Following this, the first author reviewed the full text of publications deemed potentially relevant from their abstracts.

Some articles that were excluded on the basis of their title or abstract were then reconsidered as whole papers, when they were referenced in other articles. If an article was referenced in a way that

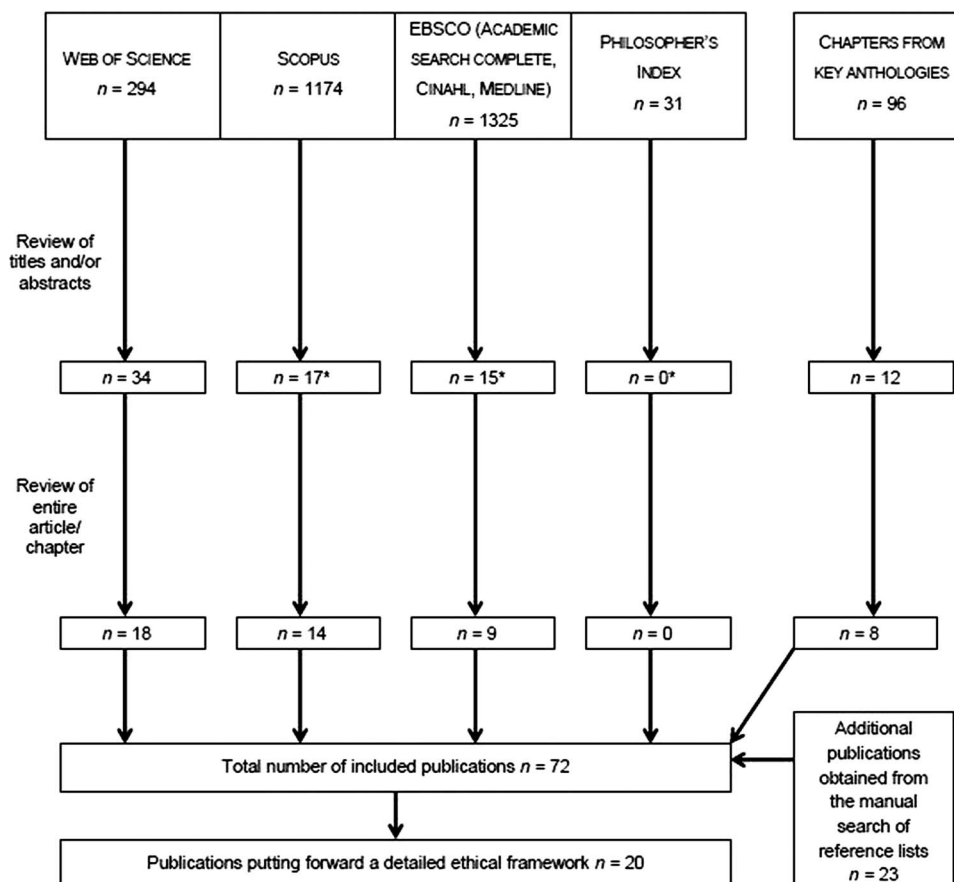


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One search was conducted in each database:

- Web of Science and Scopus:** (paediatric OR pediatric OR child* OR adolescen* OR teenage* OR "young person" OR "young people") AND ("health professional" OR "health care professional" OR "healthcare professional" OR doctor OR physician OR paediatrician OR pediatrician OR clinician OR "general practitioner" OR nurse) AND (ethic* OR morality OR role) AND (parent) AND (disagree* OR conflict OR dispute OR decision-making OR refus*)
- EBSCO (Academic Search Complete, CINAHL, MEDLINE) and Philosopher's Index:** (paediatric OR pediatric OR child* OR adolescen* OR teenage* OR "young person" OR "young people") AND ("health professional" OR "health care professional" OR "healthcare professional" OR doctor OR physician OR paediatrician OR pediatrician OR clinician OR nurs*) AND (ethic* OR morality OR role) AND (parent*) AND (disagree* OR conflict* OR dispute OR decision-making OR "decision making" OR refus* OR object* OR authority)



* These numbers reflect articles not retrieved from the previous database search (for example, the 17 articles retrieved from the Scopus database search and deemed potentially relevant from their titles and abstracts were not retrieved from the Web of Science search). This allowed for the early removal of duplicates throughout the database searching process.

Figure 1 Literature search process.

suggested that it may warrant inclusion, we looked at the whole article regardless of whether it had previously been excluded in the title assessment or abstract assessment phases.

RESULTS

From the database and anthology searching, 49 publications met our inclusion criteria: 41 journal articles and eight anthology chapters. The manual search of the reference lists of these articles and anthology chapters identified 23 additional publications, bringing the total number of included publications to 72.

The publications fell into two broad types. Twenty of the publications were primarily dedicated to putting forward a detailed framework, supported by substantial ethical argument, describing circumstances under which health professionals would be justified in overriding parents' medical decisions. The remainder, in contrast, included a brief section explaining or invoking a particular ethical framework in the context of a particular issue

or a specific type of clinical situation (eg, withdrawing and withholding life-sustaining treatment, responding to parents' desire to use complementary and alternative medicine, refusal of blood transfusion for a Jehovah's Witness child). We chose to focus on the publications that put forward detailed frameworks, as these were the articles providing a substantial answer to the review question.

A summary of the literature search process can be found in figure 1.

An assessment of the quality of the publication is a feature of the systematic review process that is challenging in the bioethics context. The criteria for quality are far less concrete and codifiable than in the biomedical sciences. We chose to take a satisfying approach to quality assessment, based on the academic peer review process. If an article appeared in an international peer-reviewed journal or a book chapter had been published by a prominent academic publisher, that publication was considered

to be of sufficiently high quality to be included in the review. All 20 of the publications putting forward detailed ethical frameworks met this threshold. No further assessment of quality was made within that group.

NINE ETHICAL FRAMEWORKS

Our review identified nine different ethical frameworks outlining circumstances in which a health professional is justified in overriding parents' medical decision-making for children. Each framework was centred on a different moral concept, such as harm or best interests. Frameworks tended to focus either on the child, particularly his or her well-being, or on the parents, usually their adequacy as decision-makers.

Harm principle

Concerned about the prominence of the concept of best interests, Diekema puts forward the harm principle as a more robust alternative.⁵⁻⁷ He argues that best interests can be difficult to define, conceived differently by parents and health professionals, and do not represent the standard applied in practice (p. 247).⁵ He suggests that harm is in fact the central moral concept in this area. According to Diekema's harm principle, a health professional is ethically justified in seeking state intervention when the parents' decision 'significantly increase[s] the likelihood of serious harm as compared to other options' (p. 252).⁵ Although Diekema does not explicitly define 'harm', his discussions suggest that relevant harms go beyond the physical, including the domain of the child's future autonomy (p. 251;⁵ pp. 15-16;⁶ p. 132⁷). He proposes a series of eight conditions that 'must [all] be met before considering the use of state intervention to require medical treatment of children over parental objections' (p. 252);⁵ the harm principle is thus put forward specifically in the context of conflicts about parental *refusals* of treatment (in contrast to the best interests standard which is also posited in the context of disagreements about parental requests). The eight criteria are

- ▶ The refusal puts the child at 'significant risk of serious harm'
- ▶ The harm is imminent
- ▶ The refused intervention is necessary to prevent the harm
- ▶ The refused intervention is 'of proven efficacy'
- ▶ The projected benefit to burden ratio of the refused intervention is 'significantly more favourable' than that associated with the parents' preferred option
- ▶ No other option would prevent serious harm to the child in a way that is more acceptable to the parents
- ▶ The state would intervene in 'all other similar situations', regardless of the nature of the parents' reasons
- ▶ Most parents would agree that the state intervention was reasonable (p. 252).⁵

Constrained parental autonomy

A second prominent framework centres around the concept of a child's basic needs and is referred to by its author as 'constrained parental autonomy'.⁸ Ross argues that '[p]arents should have a presumptive right to non-interference, a right that is restricted only if they fail to provide for their child's basic needs' (p. 24).⁸ She argues for the inadequacy of the best interests standard as a guidance principle on the basis that families have group goals, distinct from the self-regarding goals and interests of each member, and that parents may 'compromise the interests of the child [for the sake of a group goal or another family member's interests], provided that they do not sacrifice the child's basic needs' (pp. 44, 51).⁸ She endorses

three specific criteria that need to be fulfilled in order for state intervention in parental decision-making to be justified:

- ▶ 'medical experts agree that the treatment is non-experimental and appropriate for the child
- ▶ denial of that treatment (which is of proven efficacy and has a high probability of success) would result in the deprivation of the child's basic needs
- ▶ the anticipated result of treatment gives the child a chance for normal healthy growth or a life worth living as evaluated from the child's own perspective' (p. 140).⁸

Miller similarly invokes constrained parental autonomy and children's basic needs as fundamental concepts in relation to conflict situations. He writes that 'the right of family privacy is not absolute; it is contingent on whether parents or guardians respect their child's fundamental needs' (p. 5).⁹

Best interests

Acting in an individual's best interests is widely understood as 'acting so as to promote maximally the good of the individual' (p. 88).¹⁰ Kopelman is a leading advocate of the best interests standard in the paediatric context, arguing in a number of papers that best interests is the fundamental concept guiding intervention in parents' medical decision-making.¹¹⁻¹⁴ However, it is important to note the particular understanding of best interests that Kopelman advocates and the specific role that the concept plays in her framework. Her ideas echo Buchanan and Brock's stipulation that the best interests principle 'is to serve only as a regulative ideal, not as a strict and literal requirement' and that 'a mere failure on the part of the parents to *optimise* the child's interest is not sufficient to trigger justified intervention'; parents are entitled to take into account their own self-interests and their obligations to their other children (pp. 235-6)¹⁰ (italics in original).

According to Kopelman, parents' failure to choose the treatment option that is in the child's best interests is *not* the appropriate threshold for state intervention. Rather, the parents' choice of a harmful or unreasonable option plays this role. Best interests are then used, in a separate second step, to guide the state's decision about the appropriate treatment to require. Kopelman writes that:

[t]o override parental authority, the state must prove...that the child has suffered or is in danger of suffering serious harm... Once the threshold has been met...the courts apply a second test that can be couched in terms of the child's best interest to determine what to do with the child. (p. 272)¹¹

Alongside harm, the notion of reasonableness is also invoked to define the circumstances that require state intervention by writers advocating this framework. Pope, for example, writes that '[i]nterference is justified only when parents make a decision that no reasonable parent would make under the same or similar circumstances' (p. 134;¹⁵ see also pp. 25-6¹⁴).

Departing from the everyday understanding of best interests, Kopelman emphasises that the best interests standard does not require the state to 'seek what is absolutely best for the child', but rather to focus on the child in seeking 'some fair balance between many people's needs, rights, and interests' (pp. 280-2).¹¹ Pursuing the option that maximises benefits and minimises burdens to the child is a *prima facie* duty (p. 188)¹² or 'ideal'¹⁶ but the actual option chosen ought to reflect resource limitations and the needs of others within the child's network of relationships. Such an option is still described as 'in the child's best interests'; this is a potential source of confusion in relation to this

framework. Macklin¹⁷, Nelson and Nelson¹⁸, and Fleischman *et al*¹⁹ also describe the best interests framework.

Choice within the range of medically reasonable alternatives

In their advocacy of the best interests principle, Buchanan and Brock further stipulate that the treatment that parents choose for their child must be 'within the range of medically sound alternatives, as determined by appropriate medical community standards' (p. 143).¹⁰ McCullough takes this idea as central to ethical justifications for overriding parental decisions. He argues that 'the paediatrician and parents are co-fiduciaries of the child who is a patient' and thus that the paediatrician has the obligation to present all of the 'medically reasonable alternatives' to parents (p. 18).²⁰ He defines medically reasonable alternatives as all the 'technically possible and physically available clinical management plans that have a reliable evidence base of expected net clinical benefit' (p. 18).²⁰ According to McCullough, parents are 'not ethically free to reject all medically reasonable alternatives, because doing so is not consistent with protecting and promoting the child's health-related interests' (p. 18).²⁰ Paediatricians' professional integrity entitles them to attempt to convince parents to choose from among the medically reasonable alternatives and, where necessary, to involve the institution's ethics committee or state agencies.

Responsible mode of thinking

Schoeman argues that the child's best interests is an appropriate concept to structure the relationship between a child and the state, but that the intimate nature of the parent-child relationship justifies a different standard, one that is lower with respect to the child's individual well-being.²¹ Like Ross, Schoeman sees the family unit as 'an organic and enduring entity' with its own welfare and ideals, separate from those of the individual members of the family (pp. 54, 56-7).²¹ He claims that a family has its own goals and purposes, and that 'parents are permitted to compromise the child's interests for ends related to these familial goals' (p. 45).²¹ In Schoeman's view, parents' medical decisions should be overridden 'only if it can be shown that no responsible mode of thinking warrants such treatment of a child' (p. 45).²¹ The implication is that a mode of thinking is sufficiently responsible 'unless the parental decision would seem from most perspectives as shockingly reckless or negligent' (p. 58).²¹ He cites 'imminent and serious harm' to the child as a result of a parental decision that 'reflect[s] gross ineptitude in moral resolution' as threshold conditions for state intervention (p. 60).²¹

Reasons that other reasonable people could refuse

Another of the less prominent frameworks is 'the not unreasonable standard', put forward by Rhodes and Holzman.²² They frame their argument in terms of physicians and all surrogate decision-making. They argue that, in the paediatric context, health professionals need to assess first the appropriateness of the parents as decision-makers for the child and second the appropriateness of the parents' actual decision. According to these authors, parents are entitled to be decision-makers only when they have 'a commitment to the patient's well-being and [at least] a minimally appropriate level of concern [for the child]' (p. 378).²² Where parents fail to meet these criteria, the healthcare team should seek state involvement to appoint an appropriate surrogate decision-maker for the child. In terms of assessing the actual decision, Rhodes and Holzman argue that '[i]t is critical to recognize the moral difference between a patient's decisions and a surrogate's; patients' are entitled to

make treatment decisions based on 'idiosyncratic' personal reasons, whereas surrogates including parents are not (p. 383).²² They argue that there are different types of reasons, and identify a 'domain of judgments that are idiosyncratic or shared only by some particular social or cultural group' (pp. 372-3).²² They call these 'reasons that other reasonable people could refuse' (p. 372).²² They argue that parental refusals of treatment based on such reasons ought to be overridden in cases when treatment is likely to bring significant benefit to the child. Their position is that '[o]nly decisions based on universal reasons are acceptable for surrogate refusal of highly beneficial treatment' (p. 383).²²

Rational parent

Cooper and Koch put forward a different standard based on the concept of rational decision-making:

a rational parent standard would require that a parent demonstrate the ability to prioritize options for her child within the context of her own value system. The absence of a definable value system, and the absence of demonstrated and consistent decision-making ability, would bring the parent's capacity to make decisions for her child into question. (p. 156)²³

This allows parents a wide scope of discretion. As the authors highlight, the rational parent standard does not require parents to decide in line with the child's best interests and enables parents to make treatment choices that increase risk of harm (pp. 156, 160).²³ The limit relates to inevitable harm: parents 'should not be permitted to choose so low a level of care that it not only increases risk of harm but also guarantees that harm will occur' (p. 160).²³

Balance of costs and benefits

DeMarco and colleagues present a theory based on economic concepts:²⁴ the cost of treatment to the patient, the benefit of treatment to the patient and the costs borne by others (externalities) as a result of the patient's treatment. Their framework dictates that 'the best interest of the patient be...overridden if marginal costs...are greater than marginal treatment benefits when the costs to third parties are considered' (p. 297).²⁴ They claim that, unlike Diekema's harm threshold, their approach 'consistently takes into consideration both the interests of the parents and of the child' (p. 297).²⁴

Decisional capacity of the minor

Kipnis, in his discussion of religiously-based parental refusals of medical care, puts forward the 'decisional capacity of the minor' as a crucial factor in determining whether a parental refusal ought to be overridden (pp. 272-3).²⁵ He argues that when a child agrees with the parental refusal and there is 'grounded confidence that the child will still own the decision later on in life', this should be given 'great weight in medical decision-making' (p. 272).²⁵ He suggests that if the child's refusal 'made sense against a background of what appeared to be reasonably stable personal values', health professionals are not justified in overriding a parental refusal of treatment (pp. 273-4).²⁵

CONCLUSIONS

The work of Diekema highlighted to us an important ambiguity in the way that we had constructed the review question. What exactly constitutes 'overriding' in this context? Questioning parents' decisions? Attempting to persuade parents to change their minds? Involving a state agency? By formulating the question in terms of health professionals 'overriding' parents'

decisions, we had conflated various actions on the part of health professionals. This lack of clarity reflects the nature of the literature in this area, much of which fails to distinguish between parental decision-making that is somehow suboptimal from an ethical perspective, and parental decision-making that justifies state involvement to remove parental authority over the decision in question. Diekema emphasises the limitations on health professionals' capacity to actually override parents' decisions: '[a] clinician's authority to interfere with parental decision-making is limited...Only the *state* can order a parent to comply with medical recommendations' (p. 15,⁶ our italics). When discussing the ethics of overriding parental decision-making, it is crucial to clarify exactly what type of overriding is being proposed.

There is a substantial consensus among ethicists that harm is the central moral concept when judging the appropriate threshold for state intervention in parents' medical decision-making. The focus of Ross⁸ on deprivation of basic needs can be interpreted as a concern about harm and, as Pope highlights, 'the best interests standard includes a contemplation of harm' (p. 136).¹⁵ The much more controversial area seems to be responding to disagreements that fall below that threshold. How should health professionals respond when they think that a parent is making a decision that is significantly suboptimal from the child's perspective, but does not involve the serious imminent harm that justifies state intervention? In such cases, is it always ethically appropriate for health professionals to question parental decisions? When should a health professional attempt to persuade a parent? What degree of persuasion is justified? These questions remain open and point to the importance of continuing ethics research in this area.

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Contributors RM designed the review, analysed data and drafted the article (excluding the method section). LN formulated the search terms, performed the searches, analysed data and drafted the method section.

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