

# The Voices and Rooms of European Bioethics

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## Chapter 10

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**‘You don’t need proof when you’ve got instinct!’:  
Gut feelings and some limits to parental authority**

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# 10 ‘You don’t need proof when you’ve got instinct!’: gut feelings and some limits to parental authority

*Giles Birchley*

## 10.1 Introduction

While, in Europe and beyond, decisions about children who lack competence to contribute to their treatment decisions are based upon their best interests, both the European Court of Human Rights and bioethical theorists consider that there must be substantial involvement of parents in these decisions. In the United Kingdom (UK), legal and clinical guidelines say that critically ill children’s best interests must be agreed by their parents and doctors, or the courts, in a process of shared decision-making. There is widespread acceptance that there should be limitations on parental authority in shared decisions, yet parental authority is ill-defined, and without some agreement on the source of parental authority it is difficult to limit it either cogently or consistently.

This chapter presents results from an empirical ethics investigation into shared decision-making in the paediatric intensive care unit, a study that focused on critical decisions in which an infant child’s treatment or non-treatment would be decided. While many of the parents involved expressed their views about their child’s best interests as an intuition, this intuition was generally based on their knowledge, emotional intimacy and close proximity to their child. However, in some circumstances such intuition appeared to have no basis in fact or experience, and this was notably the case for the intuitions parents said they would rely upon to make critical decisions about treatment at the end of life. A combination of knowledge, emotional connection, intimacy and intuition also saw many parents actively contribute to decision-making and frequently request treatments for their child. I use intuition here to characterise an instinctive sense that something is the case – what is sometimes termed a ‘gut instinct’.<sup>1</sup> Normative accounts of intuition, which I will discuss in this chapter, are divided about the basis and the value of intuitions, but not the definition; as McMahan puts it, moral intuition is a ‘spontaneous moral judgement’ (2000: 93).

The study results allow us to glimpse a rich picture of the sources of parental authority, and thus offer the cogent reasons we need in order to place consistent limits on the scope of parental authority in shared decisions.

I contend that parental authority can have a basis in intuition, which should be based upon tangible, intimate knowledge of their child, their child's therapy and their child's medical history; however I suggest that, without this basis, parental intuition alone should not be authoritative. I accept that requests for treatment may communicate such knowledge and thus be useful for raising the quality of care. However, I observe that such requests may also have a deleterious effect on other children within the clinical setting because of the physical limitations of resources and the varying abilities of parents as advocates. For these reasons, while I argue there are strong reasons to involve in decisions about their children parents who are (in ways I explore) close to their offspring, I suggest there are defensible, definable and consistent limits to the exercise of parental authority in shared decisions.

## 10.2 Parental authority in practice

Parents are widely considered to share decision-making authority with clinicians (Sullivan, Monagle and Gillam, 2014), all the more so in decisions about infants who are unable to express their own wishes. In the UK, clinical guidelines, including those from the General Medical Council (2010), the Nuffield Council on Bioethics (2007) and the Royal College of Paediatrics and Child Health (2004), suggest a parent-clinician partnership to serve the child's best interests. This clinical partnership is also recognised in common law in the leading case of *Re J (a minor) (wardship: medical treatment)* [1991] Fam 33, in which Lord Donaldson MR (at 41) characterised a parent's ability to refuse or consent to their child's treatment as part of a system of checks and balances on doctors or the courts.

There is, however, widespread agreement that there should be some limits to parental authority. For instance, parents have no authority to demand treatment under English law (Munby, 2013). Yet even this relatively clear legal boundary to parental authority relies on the best interests principle, which has been widely argued to be vague and indefinable (Bellieni and Buonocore, 2009; Baines, 2010). Clinical guidelines limit clinicians' authority to objective medical knowledge: for instance, the General Medical Council (2010: 47) says: 'You must not rely on your personal values when making best interests decisions [or] make judgements based on poorly informed or unfounded assumptions about the impact of a disability on a child'. However, guidelines suggest no similar boundaries to parental authority. Bioethicists like Schoeman have advocated for increased parental authority while limiting that authority by reference to somewhat platitudinous criteria, such as cases in which the child will come to 'extreme, irremediable and obvious harm' (Schoeman, 1985: 52). Others, such as Bailey (2001), have suggested that families' input ought to be based on subjective values because they act as a proxy for the subjective preferences of their relative. However, even if accepted without argument, such a criterion provides no scope for differentiating acceptable from unacceptable values. Moreover, by suggesting that, in

the case of newborn babies, parents ‘are often best placed to know what is in the interests of their child because of their closeness to him or her and the special bond that they enjoy’, guidelines from the Nuffield Council on Bioethics (2007: 23) arguably suggest that parents’ knowledge of their infant is intrinsic and intuitive – exceptionally difficult criteria on which to offer limits.

What all of the preceding criteria share is a failure to articulate clearly consistent boundaries to parental authority which can be applied in practice. The results from empirical ethics research into this issue, which I now present, suggest that to conceive parental knowledge as intrinsic or innately subjective fails to capture the rich and informative nature of this knowledge. While parents do claim intuitive knowledge of their infant’s interests in critical medical situations, this is often based upon tangible factors. These factors, while not being entirely determinative, offer a platform from which to more clearly reflect on both the scope of parental authority and the limits we should place on our expectations of it in shared decision-making.

### **10.3 The BIPIC study**

While European empirical studies have contributed to knowledge of a wide range of issues salient to the current topic, including the degree to which parental authority is determinative of children’s treatment (Hagen et al., 2012) and the effect on parental wellbeing of sharing decisions (Caeymaex et al., 2013), the content of parental contributions to shared decisions is rarely examined (a rare example is a single case study from de Vos et al., 2015). Judging Best Interests in Paediatric Intensive Care (BIPIC) is a qualitative empirical ethics study funded by a Wellcome Trust Fellowship in Society and Ethics (grant number WT097725FR), which investigates the values and experiences of decision-makers in the paediatric intensive care unit, and thus examines parental contributions to decisions in detail.

#### **10.3.1 Methodology**

The study used a qualitative empirical ethics methodology<sup>2</sup> consisting of an empirical component followed by a process of reflective equilibrium, in which the empirical data was reconciled with ethical theory. The method of reflective equilibrium broadly followed that postulated by Daniels (1979). The empirical research drew participants from the four decision-making groups identified in guidelines from the Nuffield Council on Bioethics (2007), namely doctors, nurses, members of clinical ethics committees and parents. Only parent interviews are considered in this chapter, although their observations are corroborated by other groups. Parents were recruited through three paediatric intensive care units (PICU) and took part in in-depth face-to-face interviews about their experiences. Not all parents had direct experience of making a critical, life-or-death decision, although all had vivid memories of their child’s critical illness and their own experiences relating to this.

Participants continued to be recruited and interviews conducted until no new themes emerged.

### 10.3.2 Recruitment method

The study was reviewed and approved by a local research ethics committee. To ensure the researcher had no access to confidential data, a senior clinician in each intensive care unit identified potential parent participants from clinical records. Parents were eligible to take part if their child had been a critically ill inpatient between one and two years prior to recruitment. Their child had to conform to the following criteria at the time of their admission: Paediatric Intensive Care Society critical illness level two or above (i.e. one or more organs supported); less than four years old or otherwise unable to contribute to decisions about their care; and a PICU stay of more than four days. Eligible parents were contacted by a letter from the senior clinician, and responded directly to the researcher if they were interested in participating. Parents were purposively recruited to reflect the range of outcomes expected nationally from a PICU admission, thus about 10 per cent had experienced a bereavement and another 30 per cent had children with ongoing morbidity.

### 10.3.3 Recruitment results

A total of 131 parents were approached by letter, of whom 17 responded and 14 subsequently took part in an interview (Table 10.1).

Parents were interviewed alone or in couples at a private location of their choosing, depending on their preference. Two parents brought friends or relatives to the interview for support, rather than a spouse. Parents provided written consent and were assigned code numbers to preserve their anonymity. Details of participant characteristics are given in Table 10.2.

### 10.3.4 Data collection

Interviews were semi-structured and followed a topic guide that was formulated from a literature review at the beginning of the project. Questions were modified as the study progressed in order to iteratively explore themes that emerged in prior interviews. Open questions encouraged participants to tell their story, and follow-up questions explored the experiences, values and

Table 10.1 Parent recruitment

<i>Study Site</i>	<i>Approached</i>	<i>Responded</i>	<i>Consented</i>	<i>Interviewed</i>	<i>Total</i>
Site 1	71	11	8	8	14
Site 2	40	3	3	3	
Site 3	20	3	3	3	

Table 10.2 Characteristics of BIPIC parent participants

<i>Interview</i>	<i>Present at interview</i>	<i>Length of admission</i>	<i>Outcome of admission<sup>a</sup></i>
40	Both parents	210 days <sup>b</sup>	Ongoing morbidity
41	Both parents	61 days <sup>b</sup>	Death
42	Mother and relative	4 days	Death
45	Both parents	16 days	Ongoing morbidity
55	Mother	14 days <sup>c</sup>	Recovery
56	Both parents	5 days	Recovery
58	Mother	10 days	Ongoing morbidity
59	Both parents	4 days	Ongoing morbidity
60	Mother	12 days	Recovery
61	Mother	9 days	Ongoing morbidity
62	Mother	10 days	Recovery
63	Mother and friend	7 days	Recovery
64	Mother	5 days	Recovery
65	Both parents	10 days	Recovery

a *Recovery* is where child leaves PICU with an improvement in their admission baseline health, *Ongoing morbidity* is where the child leaves PICU with a deficit to their pre-admission baseline health.

b Includes time on ward due to multiple readmissions to PICU during hospital stay.

c Duration of ward plus PICU stay as times were unclear in the interview.

beliefs that underlay the participant's interpretations of children's best interests. Interviews lasted between 73 and 180 minutes. All participants agreed to have their interviews audio recorded.

### 10.3.5 Analysis

Interview recordings were transcribed by a professional transcriber. The transcripts were anonymised to remove identifying names and locations before being analysed, using thematic analysis (Braun and Clarke, 2006). This method was selected because it was iterative and did not require parents to participate in repeated interviews about a sensitive and potentially distressing topic. The analysis involved coding the interview data to identify key words, phrases and topics that participants used to express their experiences and beliefs. By analysing codes across all parent interviews, key themes emerged that offered insights into the parental role in decision-making.

## 10.4 Key findings

Parent participants (hereafter referred to simply as 'parents') felt they had a special understanding of their child's physiological and behavioural norms, as well as substantial clinical knowledge and expertise in their child's clinical history

and clinical condition. Such understanding often took the form of an intuitive sense of the child's wellbeing, which apparently rested on this expertise and proximity. Where critical end-of-life decisions needed to be taken, most parents also thought that they would intuitively know what the right thing to do would be. Parents' knowledge and intuition also provided a platform from which to request treatments and advocate for their child; these requests included changing treatments, ensuring interventions were undertaken as planned and otherwise attempting to improve the quality of their child's care.

#### **10.4.1 Parents' knowledge of their child**

Parents recalled intuitive feelings of unease at the onset of their child's acute illness or if their child's clinical condition deteriorated. These feelings were driven by their knowledge of their child's normal appearance and behaviours, which resulted from a constant close proximity to their child. In a typical example, P41 describes becoming aware of her baby's sudden deterioration following an initial discharge from PICU:

P41 (MOTHER): And I had not been apart from my baby ever, and I knew him, and I knew every colour on his face and every look that he gave me and every movement that he made, I knew it. So the minute that something changed, I knew it.

Parents also felt that their close proximity to their child throughout the hospital admission gave them a firm narrative of their child's medical history, and that this was sometimes more accurate than that of their doctors and nurses. For instance, one parent, by being present at shift changes, was both able to learn the clinical details and to correct mistakes or omissions in the clinical history. Others were familiar with earlier treatments or procedures and queried the accuracy of documentation:

P40 (MOTHER): You've been in hospital with your child for several months, and you've seen like day in, day – 24 hours a day, you know what they've done. Like sometimes things might get written down, abbreviated to like what actually happened and you'll be like, 'Hang on a minute, that's not exactly what happened. This is what happened.'

This ability to keep an accurate narrative history was noted particularly where there were gaps in the medical narrative, such as when care was shared between more than one institution or where, as in the case of P59, the child had a long-term condition that was rarely seen by medical trainees:

P59 (FATHER): . . . not so much the regular nurses, but doctors that we don't see before, they're always asking us, because at the end of the day we

know more about her and her diagnosis than most of the doctors up there. It's only really the specialist for her that knows more than us.

Parents also brought a very particular perceptual knowledge of their child as an individual. While this sentiment was more often implied than expressed, P45, whose child had a relatively common congenital disability, was concerned this depersonalised her child to some clinicians:

P45 (MOTHER): . . . because she's got [congenital condition] um she's treated in the same sort of way [as other infants with that condition]. So like well [certain symptoms] can be explained away because she's got [congenital condition], and you don't want that: you want them still to assess her as her and make sure that they don't make excuses or let things happen just because of that.

Parents were therefore able to bring a wide range of knowledge and connection with their child to discussions with healthcare professionals. Moreover, parents also related the ways they used this knowledge to advocate for particular directions to be taken in their child's treatment.

#### **10.4.2 Parents' requests for treatment**

Parents' knowledge of their child's medical norms and history meant they were able to interact with healthcare professionals to broaden and improve the medical narrative. Moreover, parents frequently intervened in their child's care and made requests for treatment. Examples included requesting extra laboratory tests on blood samples to match tests taken on prior occasions, challenging the method of a proposed surgery or, in this example, requesting that staff combine x-rays in order to reduce x-ray exposure:

P65 (MOTHER): He was having some x-rays and they wanted to do two x-rays. I did question them and said, 'Why do you need to do two? Can you not just do one?' In the end, they just did one. But a bigger one. Because they wanted to take one of one area and one of another area. I said, 'Surely, he's only little, you can fit it into one,' and they did. I didn't want him to have more than he really needed.

Very often, these interjections were to remind staff of an intervention the parent had expected them to initiate, such as commencing their child's feed or complying with infection control measures. An example of this is P55's request that a central venous catheter be removed in line with local infection control policy, which she had discovered on the hospital's public website:

P55 (MOTHER): A femoral line, he still had that in, and they came to take that out. 'Cos I complained, I said, 'He's not meant to have that in

there is he, after a certain amount of time?’ And they said, ‘Oh OK, we’ll take that out,’ you know, ’cos I knew you’re not meant to have that in [from looking at the internet].

This data gives insights into tangible contributions parents made to the care of their child, and moreover shows these parents’ requests for treatment could be based on competent assessments of technical criteria. However, there was one further strong driver of decision-making: intuition.

### **10.4.3 Intuitive knowledge**

Some parents suggested their knowledge of what was best for their child was intuitive, and found it hard to believe that they would be able to act in a way that was contrary to their intuition. P61 talked of a ‘gut feeling’ that had played a role in her recognition that her child was becoming seriously ill, and because of this she felt parents would instinctively know when treatment was no longer in their child’s best interests:

P61 (MOTHER): I had that gut feeling, I knew [my child] wasn’t right. It wasn’t just a bug. It wasn’t just give him [paracetamol] and [ibuprofen] and lots of fluid, and see how he was. That [. . .] morning was – he was lying on my bed – you knew there was something wrong. I suppose, maybe, as a parent, when you get to that point, again, you know that, yes, this is the end of the line. There’s nothing more that can be done. No matter how hard it is, maybe you do that, that does kick in.

This projection of intuitive knowledge of their child from a situation they had experienced to an instance they had not was repeated by other parents; for example, P59, the mother of a life-limited child, said:

P59 (MOTHER): I just think parents know the child’s best interests. I don’t think it even needs to take a doctor to say that. What kind of parent would put their child through something they didn’t feel that they had to be put? No parent would. I think you just know.

Thus, while intuition was often underwritten by experiential knowledge of the child, this foundation caused parents to give credence to intuitions about more suppositional situations.

## **10.5 Discussion**

Emergent themes from parent interviews suggest that parents’ day-to-day intimacy with their child furnishes them with a practical knowledge of their child’s wellbeing, which can be employed in a variety of clinical and

non-clinical situations. This knowledge can be applied in clinical scenarios and at times can compete with clinicians' specialist knowledge. Practical knowledge gives parents a sense of intuition about their child's wellbeing, and this intuition can extend beyond familiar situations, for instance engendering the conviction that they will know the best interests of their child in a critical decision about treatment or non-treatment. Knowledge of their child as an individual may also provide a heightened degree of emotional sympathy, and, further, drive parents to request treatments that they consider to be in the child's interests. The interviews thus offer significant insights into the complex role of parents in the shared decision-making process, and allow some conclusions to be drawn. These conclusions focus particularly upon infants whose wishes and values, should they exist, we have no way of knowing.

The way parental knowledge is gathered suggests that a parent's intimacy with their child is profoundly important to their ability to contribute to a shared decision, an idea which has formed the mainstay of a number of influential theories of family authority. In the remainder of this chapter I shall use this information to set out some limits to parental authority. I will argue that it is parents' intimacy with their child which gives them familiarity with their child's medical course and this offers a credible basis for their role in the decision-making process. Such a basis, however, also implies a limitation where intimacy and familiarity are absent. While parents may form strong intuitions about their child's wellbeing, which, when driven by experience, are likely to be well-founded, intuitions that are not driven by experience (such as, often, decisions about whether treatment or non-treatment is in the child's interests) are of less practical value and must be viewed more cautiously in the decision-making process. While this implies a restriction, parental involvement in critical decisions may also be important because of the focus parents bring upon the child as an individual. Where a child suffers a common condition that may lead clinicians to depersonalise the child, parents' emotional sympathy may bring the focus back on to the individual and combat this depersonalisation. Finally, parents are strong advocates for their child and often request treatments. This phenomenon is particularly interesting, because it both highlights a reason for involving parents in shared decisions and a reason for limiting their authority, perhaps highlighting the difference between a 'request' and a 'demand'. This is because even valid requests for treatment may be a mechanism for raising the quality of care for their child, while conversely reducing equitability for those with less powerful advocates. Let us consider these conclusions in more detail.

### ***10.5.1 Intimacy and knowledge***

A parent's intimacy with, and proximity to, their child throughout their lives may lead to a detailed knowledge of their child's development and clinical history. Close proximity may also mean that parents develop a grasp of clinical

facts about their child that is comparable to (or potentially greater than) that of attending clinicians. Constant presence at the child's bedside provides parents with a narrative that can be more coherent than a clinician who sees the child episodically due to the provision of their speciality, the fragmented nature of shift systems and so on. These observations suggest that intimacy is a key component in a parent's ability to contribute to decisions.

The importance of intimacy in parental decisions resonates with Hegel's theory that families are a unique and intimate community characterised by love (Hegel, 1851/1976: 110). Hegel argued that parents have a duty to imbue in their children a sense of individuality and self-worth, since this sense of individuality will lay the foundation for moral autonomy (Blustein, 1982: 90–95). In a similar position, Ross (1998: 20–38) and others (Schoeman, 1985; Downie and Randall, 1997; Erickson, 2010) have argued that parental authority in decision-making is drawn from the intimate nature of families. This intimacy distinguishes them from other collections of individuals since they know each other best, share each other's goals, their wellbeing is intertwined and the boundary between the interests of their members is blurred. For Ross, these interconnected interests mean that families should make unfettered decisions about their members, and controversial decisions such as those based on the quality of a child's life should remain within the family's ambit. Other thinkers argue that parental authority in medical decisions rests upon parents' exposure to grief (McHaffie, 2001:393–415) or the burden of care they will carry if their child has a disability (Harrison, 2008). While they may have merit, because these arguments rest on reducing burdens for the parents rather than the child, they are inherently controversial.

Other theorists are wary of involving parents in decisions. For instance, Dare (2009) contends that parental perceptions of best interests may be mistaken, and that mere possession of a beneficent motivation does not single parents out from doctors or other well-motivated carers; indeed, as Archard (2004: 137–149) observes, it is dangerous to assume parental beneficence. Dare also suggests that parental knowledge may be plausible in some circumstances, but that the family has no intrinsic knowledge of the needs or motivations of an infant, nor does the burden of care which falls upon families reasonably entitle them to disregard medical facts and likely prognoses.

Responses from BIPIC give us a lens through which to consider these theoretical contributions. It seems that Ross is correct to identify the importance of intimacy to parental decision-making, however, this is not because parents share the child's interests, but because intimacy is a source of knowledge about (and, as I will consider later, emotional connection with) children's best interests. The value of this claim rests on important presumptions. The first is that the parent is actually an intimate with their child; clearly a parent who has had little contact with their child (such as an absent father) will have no intimate knowledge. Secondly, the parent must be competent to both remember and report the clinical narrative. This will often be the case but, as parents have a range of abilities, there will be instances where parents will

not be able to meet the intellectual or emotional demands that this involves. However, assuming these caveats are met, intimacy, and especially intimate knowledge, is a credible criterion on which to found parental authority in shared decision-making.

### **10.5.2 Intuition**

In BIPIC, intimacy also gave parents a strong sense of intuition about their child's best interests, and the contributions to shared decisions that parents reported relied strongly upon their intuitions. In many cases these intuitions were derived from their intimacy with their children, and the knowledge that this gave rise to. Thus parents were used to the way their child looked and behaved when they were well, and this drove their intuitions that their child was becoming sick. Crediting this type of 'gut feeling' with authority seems reasonable, since it is based on the knowledge that will be gained from close association. But parental intuitions were not limited to areas about which they had intimate knowledge. Intuitions about whether treatment or non-treatment was in the best interests of their infant were not based upon parents' past knowledge of their child; and infants could not have communicated their wishes about the length and intensity of efforts to continue their lives, even if they had had such thoughts.

In these circumstances it is helpful to consider how intuitions have been perceived in moral philosophy. In metaethics, the study of the nature of right and wrong, intuition has been considered at length. G.E. Moore (1903) regarded intuition as the only way of *directly* appreciating what is fundamentally morally right (in other words, we could not find secondary reasons for moral approval without also possessing an intuition); a century later, Audi (1998) wrote that intuition was epistemically equal to inference in detecting fundamental moral principles. Yet, in the realm of clinical ethics, since we are uncertain about what is fundamentally morally right, moral intuitions are given less status than in metaethics, being seen instead as playing a part in moral behaviour, without alone being regarded as sufficient to make moral decisions. Such a view is espoused by McMahan (2000), who does not disregard intuitions (since he believes they may harbour deeply important beliefs that are essential to humanity), yet he rejects the idea that intuitions alone can provide moral answers. McMahan instead argues that moral intuitions are important because they offer us somewhere to start our moral inquiries. Our intuitions let us take a guess at the correct answer, from which we can try to reason using the knowledge, observations and arguments at our disposal. I therefore contend that parental intuitions about critical treatment decisions may lead to the discovery of important, hitherto unarticulated, reasons that may influence the final decision. Such intuitions should prompt further inquiry. Yet these intuitions cannot form the sole basis on which to continue or discontinue treatment. Knowledge, rather than intuition, must be the bedrock of parental authority.

Intuition does, however, have a further role to play. As I noted above, parents are not just a source of knowledge about their infant, but also a source of intuitive emotional connection. A parent who appreciates their child as an individual is expressing a fundamental tenet of parenthood. While this may have no bearing on the validity of their opinions, it may nevertheless be an important reason for involving families in decision-making. In the emotivist ethical framework of David Hume (1998/1751), emotional sympathies, rather than rationality and argumentation, are the *source* of moral feeling. Hume argued that, while rationality can provide us with moral answers, it is emotional sympathy that gives us the moral questions – for example, it is because we emotionally value human life that bioethics debates how to promote this value.<sup>3</sup> In practice this means a parent's intimate emotional connection to their infant may make them emotional catalysts who can ensure that 'rational' clinicians focus on what is valuable about the infant. For instance, parents may draw attention to the value of their child when clinicians have submerged that concern in a multitude of others, or have written off a child as a 'futile' case. Thus parents may offer an antidote to prejudice, emotional fatigue or overwork amongst staff. Because this emotional sympathy does not need to be informed, while a powerful reason for considering parents' views about the child's treatment, it should not represent grounds for parental authority on its own.

### **10.5.3 Requests for treatment**

Parental intimacy, knowledge, intuition and emotional connection come together when parents request treatments in the belief that they will improve the quality of their child's care. Parents may fight for what they perceive as the interests of their child with stamina that exceeds any other party. A parent, as a child's advocate, can literally demand the attention of doctors and nurses, and such behaviour may advance their child's care in a way that will be effective in a large, busy hospital. For instance, a clinician may be encouraged to give extra pain relief, to expedite an important test result or to seek a second opinion, where these steps may otherwise not be undertaken. This is an important consideration, for if we wish to do what is best for children, a strong advocate is an important asset. Thus, while English law tells us parental *demands* are not determinative, some, perhaps many, parent *requests* for treatment actively improve the quality of their child's care, an undeniably important role.

The benefits of these requests must be tempered with a recognition that advocacy is a two-edged sword. Parents may also request treatments that work *against* the benefit of the child and are at best a distraction, and at worst impede clinicians from doing their best for the child. Even if we assume such instances are rare and the usual outcome of a treatment request is to do good to the child concerned, parental inclination is to maximise their own child's opportunity, which may clash with another important clinical motive, that of

treating patients equitably. This equitability is based on inherent limitations of resources, such as the finite time clinicians have to spend at the patient's bedside. Parents who demand a larger share of these resources for their child deprive others whose parents are quieter or less effective at making their case, not to mention those children who have no parent to advocate for them. Although this phenomenon has not been studied in a hospital setting, a recent review offers compelling evidence that articulate, middle-class public service users are adept at vocalising and advancing their needs (Matthews and Hastings, 2013).<sup>4</sup> This underlines international evidence from primary care settings indicating that patients from wealthier, more articulate social groups receive longer consultations (Deveugele et al., 2002; Furler et al., 2002; Mercer and Watt, 2007). Although not directly analogous to the sort of micro-allocation that takes place between patients at the ward level, there are clear parallels.

There is thus a mixed picture of the effects of parental requests for treatment which adds more nuance to the legal position, and helps us tease out the difference between a *demand* and a *request* for treatment. Some additional perspective can be gained by considering phenomena related to the family more generally. Rawls (1971/1999) argued that, since families vary in wealth and ability and are motivated to use what resources they possess to benefit their children, they are basic drivers against social equality. Such observations go back at least as far as Plato's *Republic* and have led to utopian experiments with collectivised child-rearing in various modern societies, such as Maoist China, Israel and Soviet Russia (Archard, 2004: 213–215). Because of this patchy history, Blustein (1982: 212–214 and *passim*) concludes that we must respond to Rawls' critique, yet we have no convincing model that improves upon the family itself as a nurturing environment for children. Instead, if we wish to benefit children at large, individual families must be restrained in their ability to advantage their members. These observations are important because they clarify the basic conflict between a parental desire to benefit their child and the clinician's desire to offer care fairly and equitably. Parental requests for treatment as a means of achieving a good quality of care must therefore be divided from a presumptive right of families to benefit their child at disproportionate cost to others, and the latter, which we could label treatment *demands*, should be beyond the limits of family authority.

## 10.6 Conclusion

Throughout Europe, decisions about children, and in particular children who lack the capacity to express their wishes, are made in their best interests. These are broadly conceived as arising from a shared decision between doctors and parents, but, while clinical roles in a shared decision are clearly defined, the scope of parental authority in shared decision-making is ill-defined. This is equally true of bioethical accounts and, in the UK at least, clinical guidelines and the law. Clinical guidance in some cases appears to consider parental

input to be based on intrinsic knowledge of the child's best interests, while bioethical accounts lack detailed or consistent criteria for placing limitations on parental authority. Even the lack of authority to demand treatment within the law lacks clarity since it relies on the vagaries of the best interest test.

Interviews with parents about their own contributions to shared decisions reveal contributions in several related areas. Parents' intimacy with their child may make them sensitive to their child's health and behavioural norms. Their close proximity to their child throughout their clinical stay may give them access to an unbroken clinical narrative, and their emotional intimacy may lead them to communicate the unique value of their child to others. This intimacy may be felt as an intuition, although parents may also have strong intuitions in areas where they have no underlying experience. Proximity, intimacy and intuition may also make parents powerful advocates for their child's cause, requesting treatments to improve the quality of their child's care and making sure their interests are heard by clinicians amongst the demands of others.

Such contributions provide powerful reasons to include parents in shared decisions, but they also give us criteria to demarcate some consistent limits to parental authority: Parents must have intimate contact with their child and the capacity to use this knowledge. Parental intuitions that are grounded in intimacy and knowledge appear more authoritative than those ungrounded intuitions that are more suppositional. We must be wary of giving both types of intuition the same status, and when parents are in new and unfamiliar situations their intuitions may represent the beginning rather than the end of a moral inquiry. Parental requests for treatment are in many cases reasonable and likely to benefit their child, yet the authority of these requests must be bound by reference to the needs of others. Articulate parents must not be afforded benefits for their children to the detriment of others with less effective advocates.

While offering robust theoretical criteria, the scope of parental authority offered here is intended to help guide consistency and transparency in practical cases. While shared decision-making between doctors and parents represents a significant area of consensus, we risk inconsistency if we share decisions without inquiring into why parental views may be authoritative. By analysing the contributions that parents make to shared decisions in practice, we can bring clarity to an area where authority is too often assumed to be self-evident.

## Notes

- 1 The quotation in the title is from the character Joe Cabot in the 1992 film *Reservoir Dogs* (dir. Tarantino).
- 2 The degree to which empirical data should cause the re-evaluation of normative theory is a controversial topic in bioethics. Although I, along with many others, suggest empirical data makes a valid contribution to these problems, I shall leave it to others, such as de Vries and van Leeuwen (2010), to make these arguments.

- 3 Such arguments are gaining renewed traction through social intuitionist explanations of the psychological sources of moral thinking (Haidt, 2001), which suggests our thought processes produce intuitive moral judgements before we embark on rational moral reasoning.
- 4 It is notable that this review suggests there is no evidence that articulate parents and families create broader uplift of standards from which there is a more general benefit, as is sometimes claimed.

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