

Children's ages of consent to non-urgent heart surgery: The views of two paediatric cardiology teams

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Abstract

Paediatric cardiology practitioners and related experts report unusually young ages when they begin to inform children about their non-urgent heart surgery and begin to respect children's consent or refusal. Research methods included observations in two paediatric cardiology units, audio-recorded interviews with 45 experts, and qualitative data analysis. Significantly younger ages were cited than are usually recommended in the clinical and legal literature. Interviewed practitioners took seriously children's consent to or refusal of a heart transplant from around 6 years, and a child's firm refusal of induction of anaesthesia from around 4 years, when surgery might be postponed.

KEYWORDS

assent, capacity, competence, informed consent, resistance

INTRODUCTION

This introduction summarises age-related standards generally reported in the medical, legal and nursing literature. Later sections will compare these standards with age-based standards that were observed and reported in two paediatric cardiology centres.

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Medical literature

Official guidelines and a growing literature emphasise the benefits of respecting young patients and informing them honestly (British Medical Association, 2020; General Medical Council, 2018; National Health Service, 2019; Stein et al., 2019). There are long held respectful views of child patients. In 1994, UK doctors emphasised:

In all but the most life-threatening circumstances it amounts to an abuse of a child's rights as a member of society to disregard a refusal to consent to treatment if the child seems to have made a fully informed and considered decision. This is especially true in the 1990s—for with the classic family unit having so often disintegrated the child may have a more stable and balanced viewpoint than either parent (Shield & Baum, 1994).

This review by Shield and Baum (1994) of a book about 120 children aged 8–15 having major orthopaedic surgery noted, “One of the many themes running through Alderson's [1993] book is the dismay and anger expressed by children who felt cheated by the explanations or lack of them, from parents and clinicians.”

In 1995, the American Association of Paediatrics emphasised that parents' consent must primarily serve the child's interests not necessarily the parents' preferences, and that children should be respected and involved as fully as possible.

A patient's reluctance or refusal to assent should also carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be deferred without substantial risk. Medical personnel should respect the wishes of patients who withhold or temporarily refuse assent in order to gain a better understanding of their situation or to come to terms with fears or other concerns regarding proposed care. Coercion in diagnosis or treatment is a last resort.

However, there appears to be increasing reluctance in the literature to respect children's consent. Recent systematic reviews report that papers on consent to children's treatment mainly concentrate on adults' and parents' consent and exclude children (Chotai et al., 2017; Katz & Webb, 2016). “Shared decision-making [with children] is rarely implemented in paediatric practice” (Boland et al., 2019). Reviews about participation by Kiili and Moilanen (2019) and by Kennan et al. (2018) stress adults' not children's agency. For example, a paper for a paediatric journal advocating respect for patient autonomy as a medical professional virtue does not mention child patients (Cook et al., 2015). Current authors persist with outdated views.

Most minors are not able to give informed consent to be treated... To ameliorate the ethical problems inherent in deciding for another, both parents and providers should involve the minor patient in health care decisions to the extent possible in an age-appropriate manner. Assent should be sought from adolescents and teenagers with capacity (Teti & Silber, 2022:111).

Wasserman et al. (2019) challenged the view that it is not worthwhile for doctors to ask for a child's assent when the doctor intends to override the child's objection. They advise that moral respect for the child involves requesting assent and apologising if this is overridden. Wijngaarde

et al. (2021:2345) show how formal shared decision-making tools can “increase the children’s knowledge and satisfaction and reduce decisional conflicts”. However, many papers on shared decision-making tend to address pre-decision discussions but not the actual making and signifying of decisions and who made them. Little is said about informing and involving younger children.

Legal complications

The two main purposes of informed consent involve different standards. The clinical aim is to ensure that the child patient is as informed and willing and committed to the treatment as possible. Cautiously concerned to prevent complaints or litigation, legal definitions of consent involve the patient knowing many details about the nature and purpose of surgery, risks, hoped-for benefits and alternatives (Montgomery v Lanarkshire Health Board [2015]). This second legal aim seeks to ensure that the consent meets standards which potentially could be tested and verified in a law court. This higher level relies on parents/guardians’ legal status and detailed adult understanding. Too often, legal consent standards override or displace the clinical aim to respect and involve young patients.

Children’s “assent” is a favoured term, but assent is a vague concept, which needs to be more clearly and philosophically defined (Birchley, 2023). Consent, however, has been clearly defined by decades-old international agreements, which concern healthcare research but are also relevant to treatment (Nuremberg Code, 1947; World Medical Association, 1964, 2013). Assent does not require that children are informed. It can merely mean that the child does not refuse, the opposite of consent when the choice to give or withhold consent is central. Assent contradicts English Gillick case law (Birchley, 2023). The Gillick competent minor aged under-16 years has the legal right to consent, provided the child “achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed [and] has sufficient discretion to enable him or her to make a wise choice in his or her own best interests” (Gillick, 1985). No minimum age is mentioned, though in many countries lawyers advise that children cannot begin to consent or assent to major decisions until they are aged 12 years or older and legal minors cannot refuse recommended major surgery (Griffith & Dowie, 2019; Hein et al., 2015) although some conclude that the law is confused (Brazier & Cave, 2016).

The age of legal capacity varies between countries and in Scotland it is 16. Doctors may respect a younger patient if “in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment” (Age of Legal Capacity (Scotland) Act 1991, 2.4). Some lawyers consider the right to consent also means the right to refuse. “In logic there can be no difference between an ability to consent to treatment and an ability to refuse treatment” (Balcomb, 1992). Yet English law is still dominated by Lord Donaldson’s rulings (In re R, A Minor [1991] and In re W, A Minor [1992]), particularly his view that: parents can overrule children’s refusal up to age 18; the child’s right to consent therefore does not always include the right to refuse; girls aged 15 and 16 are not competent.

The girls in Re R and Re W had psychotic illness, but Donaldson did not apply the Mental Health Act and his views on incompetence are applied generally in court cases involving minors who refuse recommended treatment. Some commentators saw Donaldson’s views as a regressive “backlash against *Gillick*”.

A Scottish judge, Sherriff MacGowen (Medical Law Review, 1997) disagreed with Donaldson and ruled that:

In Scottish law, a 15-year-old boy with a psychotic illness could understand the nature and possible consequences of the treatment and therefore he “enjoyed the legal capacity to consent

to surgical, medical or dental procedures or treatment under s. 2(4) of the Age of Legal Capacity (Scotland) Act 1991”:

Although the existing rights of guardians are expressly preserved by s.5(1) the minor's decision is paramount. It would be illogical to grant a power to consent to medical treatment if this decision can be overridden by a guardian;

Any consent referred to in s.2(4) of the 1991 Act covers both consent or refusal of medical treatment.

MacGowan concluded that in this case, despite the paramountcy of the minor's decision, the young man's psychotic illness was serious, and detention under s.18 was required. However, this case is crucial in upholding the rights of all other young patients who are not severely affected by mental illness.

The lawyer Kay Tisdall (2018:159) concludes that the term “competence” is often used casually,

and judging capacity remains problematic in both law and practice...[B]oth concepts detract from children's participation rights [as if they] are inherent to the child rather than contextual and relational. If the concepts were to be used, they should be subject to more critique and precise definition. However, children's participation rights are more likely to be furthered by alternatives, such as fresh ideas about recognising and supporting people's legal capacity within the UN Convention on the Rights of Persons with Disabilities.

The 1989 Children Act for England and Wales supports adults who inform a child if they believe this is in the child's best interests. However, the *Convention on the Rights of the Child* (UNCRC; United Nations, 1989) enshrines the child's right to be informed and to express views (discussed later). Under the *Vienna Convention on the Law of Treaties*, the UK has to implement the UNCRC. Wales did so in 2011 and Scotland in 2014, but in England the UNCRC is not directly justiciable.

Pösö (2022) considers that research about children's consent to welfare services may have been neglected and overshadowed by concern with children's participation. Consent clarifies how power is held and shared, whereas adults may prefer to attend to participation because it avoids this recognition. Pösö recommends that, instead of approaching children as individualistic rights-holders,

a more relational understanding about consenting is required, both conceptually and in practice, to acknowledge the social, emotional and power relations in which children's consent (or objection) becomes topical in child welfare. Without that recognition, consenting may be far from meaningful participation.

The lawyer Aoife Daly (2018) goes further in showing the harms of overriding children's views “in their best interests” during legal proceedings. She proposes moving away from ideas about competency and instead providing “autonomy support” to help children to consider their options carefully.

Nurses' concerns

Nursing journals tend to publish more papers on nurses' practical reluctance to enforce interventions on children. Nursing researchers report that many practitioners are unhappy about

overriding children's decisions if it involves having to “hold” them during enforced interventions. They recommend a “clinical pause...with the time to consider children's expressed wishes and explore alternative approaches to holding” (Bray et al., 2019).

So far, the nursing literature tends to report children being “generally involved in minor decisions” (about their cancer care) by practitioners whose aims were “gaining their cooperation, making treatment more palatable, giving back a sense of control and building trusting relationships” (Coyne et al., 2014:273). Yet “some adolescents were aware that choices were not ‘real’ decisions since they were not allowed to refuse and expressed feelings of frustration.” Imelda Coyne (2020) acknowledges that young children can be highly knowledgeable about their chronic illness.

This paper is part of a series that has reviewed the background ethics and law on children's consent (Alderson, Bowman, Brierley, Dedieu, et al., 2022; Alderson, Bowman, Brierley, Elliott, et al., 2022), how consent involves feeling and acting as well as thinking and talking (Alderson, Bellsham-Revell, Brierley, Dedieu, et al., 2022), practitioners' responses to children's consent (Alderson, Cohen, Davies, Elliott, et al., 2022) and moral relationships during the consent process (Alderson, Bellsham-Revell, Dedieu, King, et al., 2022).

After a summary of the research methods, the interviewees' views will be reported showing how and why they inform young children and respect their consent or refusal. Their reports are then discussed. The conclusion considers the need to update the general clinical and legal literature.

METHODS

After research ethics approval was obtained, practitioners in two London paediatric cardiology departments were observed in the wards, clinics and medical meetings during October 2019 to February 2020. (Observations ended early because of COVID-19 when all non-urgent surgery was cancelled.) A purposive sample of 45 senior healthcare professionals and related experts was invited to take part and given information leaflets. Twenty different specialties were involved, and many interviewees worked in two or more current or previous specialties. All doctors were consultants, and most interviewees were experienced, influential people. Of the three lawyers, one was a professor of healthcare law, and two were hospital chaplains and former lawyers, one of them had been a professor.

The 45 interviewees were only a small sample of the large staff. In the cardiac department at the bigger hospital, there were 20 consultant cardiologists, 5 consultant surgeons, 10 consultant anaesthetists, 8 physiologists, 7 advanced nurse practitioners, 8 senior nurse managers, 32 specialist nurses besides many other junior doctors and nurses and visiting specialists, and 8 chaplains. Chaplains were selected to represent different faith groups.

We do not know how representative the interviewees were. When they were selected, their views were not known, and Table 2 reports a range of views. They were mainly chosen as experienced senior staff who taught and supported junior colleagues in adopting their values and routines. To avoid putting pressure on anyone, choice of interviewees was led by who was quickly available, replied promptly to email requests, and seemed keen to take part, practicalities which could influence the findings.

Audio-recorded interviews were conducted with participants' informed written consent. They were interviewed once in private face-to-face sessions and, from February 2020 to March 2021, by telephone, for around an hour. Semi-structured question guides, based on previous research

(Alderson, 1993, 2023 [1990]) asked about interviewees' views and experiences concerning children's heart surgery, and about ages of competence. Anonymised research notes were made of observations in the hospitals (parents and children were also observed and interviewed but these findings are not reported in this paper).

Encrypted interview recordings were professionally transcribed and then anonymised. Meetings with an interdisciplinary advisory group guided the research. From January 2020 onward, observation notes and transcripts were repeatedly read and thematically analysed. For example, every reference to age was analysed for this paper. The research plan expected to discover when children begin to be informed and to give consent, but had not expected examples of their refusal being respected. Replies about ages when children begin to be respected were analysed independently by two researchers and disagreements about specific ages were resolved by discussion with a third researcher. Some interviewees shared in co-authoring the papers. Further details about the research methods are shown online (Project webpage, 2023).

Ethics

The research methods followed those used in a 1980s study of parents' consent to heart surgery, and a 1989–1991 study of children's consent to orthopaedic surgery (Alderson, 1993, Alderson, 2023 [1990]). These involved ethnographic observations of staff and families in wards and clinics, and interviews with hospital staff and families. No one raised concerns that interviewing children could be unethical, except that the Health Research Authority took 16 months before deciding to give permission for ethnographic observations in wards and clinics without the prior written consent of all concerned. All the usual standards of ethics for research in healthcare and with children were observed, especially for gaining adults' and children's informed consent as this was the topic of the research. Information leaflets and further details are shown on the project website (2023).

RESULTS

Table 1 shows the professions of the 45 interviewees.

Table 2 shows the ages that interviewees cited when they begin to inform children about elective heart surgery and to respect their consent or refusal. For example, 12 interviewees said they would begin to respect the consent, perhaps of exceptional children, of those aged 6 or 7 years. The final row in Table 2 records interviewees who, after detailed discussion, did not state a specific age. Some of them were ambivalent. "I don't think you can do an age. The ages are arbitrary. It's a sign of maturity, and some very young children can be incredibly mature" (chaplain/lawyer 12) (numbers in brackets after quotes denote interviewee's number). Many believed the child's experiences, background, abilities, or relationship with the parents may be more salient than age. One ambiguity was that some patients "experience inequality or have that lack of privilege versus those that have it, so it's not just about race, it's also about economic and social background and language...[and the] struggle to access services" (paediatric cardiologist 36). A "blanket age" is confusing when "some 14-year-olds are absolutely capable of taking the lead and making decisions, and some...aren't emotionally capable of doing that. So for me the big conundrum is...having a one size fits all in a situation where they're so very different" (children's heart charity youth officer 34). Some interviewees gave an age-range such as 6–8 years, and Table 2 gives the youngest age mentioned.

TABLE 1 Specialties of the 45 interviewees.

Specialty	Total number
Anaesthetists	5
Cardiologists	10
Chaplains	4
Children's heart charities support and information services	5
Ethics committee members	8
Intensivists	2
Lawyers	3
Mediator	1
Members of hospital directorate	5
Nurses	6
Paediatricians (not cardiologists or anaesthetists)	6
Palliative care (paediatric)	2
Patient care coordinator	1
Play specialists	2
Psychologists	4
Psychiatrist and psychoanalyst	1
Senior lecturer in nursing	1
Senior operating department practitioner	1
Social worker for heart transplant families	1
Surgeons	3

TABLE 2 Numbers of interviewees who stated the ages when they begin to inform children and to respect their consent or refusal.

Children's ages	Begin to inform children, <i>n</i> = 45	Begin to respect children's consent, <i>n</i> = 45	Begin to respect children's refusal, <i>n</i> = 45
0–3 years	20	1	4
4–5 years	7	4	4
6–7 years	9	12	5
8–10 years	2	11	7
11–13 years	2	6	4
14–16 years	0	3	3
No reply/uncertain	5	8	18

Interviewees were asked the youngest age when they might check for the perhaps rare possibility of early capacity, and start to work with that, instead of dismissing it. A few considered they were not qualified to assess capacity and that only doctors should do so, such as the play specialist (2) who helps many very young children to understand and cooperate with their treatment. “Respect” was generally defined as “take seriously” or “respond positively without deception or coercion” though not always to accept the child’s refusal fully, as shown later. Most interviewees cited much younger ages than those assumed in the consent law and literature. The following

sections on informing children, respecting consent, and respecting refusal, explain why these ages were cited.

Informing children

Most interviewees inform young children. In Table 2, “0” denotes children’s first year, with replies such as “always”, “when would you not inform them?” or “from the beginning” (lawyer/ethics committee member 44). Some interviewees valued partly nonverbal communication. “If I’m managing nonverbal babies, I’m explaining to them what I’m doing and why and I chatter to them all the time” (paediatrician 6). Some interviewees consider that 1-year-olds can begin to understand the crucial insight that interventions they find upsetting can be intended to help them, not hurt them. Interviewees reported that many parents believe pre-surgery information would only upset their child who should be protected from hearing it. However, many interviewees consider that informing children reduces their fear and anxiety, and increases their trust and cooperation, which are so important throughout their life-long cardiac care. A paediatric cardiologist (17) said, “I don’t think there’s an age limit. I think you should always talk to the children and tell them that something is going to happen. You just need to adjust [to] what they’re capable of understanding and...what the parents are allowing you to say”. She added that parents need to know that it is vital to inform children and she recalled an uninformed 6-year-old after surgery.

He was so scared and so angry with his [parents]...the people who you rely on the most and you trust the most in your life and, basically, they were not honest with you. Psychologically, I think this is terrible for the child...[I say] ‘You will be put to sleep and the doctor is going to fix your heart...and when you wake up in intensive care, mummy and daddy will be there’.

Children who need a heart transplant usually spend several days in hospital being investigated and informed, to see if their name should be added to the waiting list. Their embodied experience of prolonged severe illness increases their understanding. A psychologist (5) recalled a 3-year-old who knew he was.

going to have a new heart and [his body’s] going to be the same outside, a bit like when a car gets a new engine...It helped him understand why he had to take his medication because that was like putting the fuel in and if he didn’t put his petrol in then his engine would stop...He didn’t know that the engine could stop altogether or the new one might not work and he never asked that question. [If he had] we would have told him that the engine might not start but we wouldn’t have volunteered that information to him. [If we had told him] I think he’d have been quite matter of fact about it because I think he just was. So he was very aware that this engine that he already had wasn’t working very well and that this engine might stop.

Doctors, nurses, play specialists, psychologists, social workers, chaplains, interpreters, and others provide different kinds of information through talking, images, models, illustrated books, play and role play, dolls with masks and lines, videos, counselling, and pre-surgery visits to operating and intensive care departments. They help children to understand as much as they seem able, willing and needing to know.

If a 5-year-old looks as though they're going to be smart enough, I'm happy to talk to them as normal...and if you then ask, 'What am I going to do?' you're always surprised how much they recall. [A celebrity was shown round the hospital, and replying to her questions] these children gave the most magnificent descriptions of what was wrong with them, almost from 4 or 5 upwards throughout the hospital. I felt...these kids actually understand. [They knew what drugs they were on and said they had looked up information on the internet] and they produced that on their iPad for her...I think that you have to trust children to be able to learn, that's what they do all the time...Informing children is a moral responsibility because they've got this [heart condition] for the rest of their lives [and need to keep learning how to cope with it]. You can't leave them out... it's much nicer when the children are involved [although extra care is needed] if you've got something really bad to say...and you have talked to the family first about what they want (surgeon/ethics committee member 19).

We will always encourage families and healthcare professionals to involve children as much as possible in discussions and decision-making on the basis that actually children invariably know a lot more than any of us realise, and often not communicating with them generates greater fear...I meet some incredibly savvy kids who are, I'm sure are much savvier than I was at their age. And as long as a child can understand or start to understand then they should be part of that process (palliative care consultant/ethics committee member 45).

Interviewees' explanations emphasised the purpose of surgery and of pre- and post-operative procedures. Families bring questions, some raised through their internet searches and contact with informative children's heart charities. Practitioners stressed that children need answers to their questions and fears, and explanations about details they may have overheard or misunderstood.

Lower average ages for informed understanding tended to be cited by practitioners who worked most directly with young children, drawing on their experience. Much time is spent persuading parents that their child needs to be informed.

We have had 6- and 7-year-olds who have...said, 'Will I wake up?' That's been a real shock to parents. [Some parents become grateful when shown how to share information, and one] said, 'It allowed us to be able to have conversations that I felt really uncomfortable having but did not realise that my 7-year-old was feeling like this because I wanted to protect him' (play specialist 25).

Families' understanding may be affected by practitioners' communication skills. A paediatric cardiologist (14) spoke of his difficulties in giving information. He thought that, to a 7-year-old, the techniques of single ventricle surgery are

probably overwhelming but saying... 'We are going to make you feel so much less breathless, you are going to have so much more energy...to play football' is more relevant... Maybe when someone is 12, I think you can start more discussing with them, more in detail about what's wrong with their heart, but...we don't really do a huge amount of explanation in children of 6-years of age...[Some] parents are in their forties and fifties and you explain the same thing 15, 20 times to them and they

still have no understanding of what the heart problem was and what was done, they are completely clueless.

However, a surgeon (15) believed,

The simpler you think, the better your communication is. [I avoid] jargon, actually medical babble, that never helps anybody...I'm a very simple person, I'm a plumber [and aim] in a non-patronising way [to] try and explain the principles of what an operation might entail. And until they [parents] understand that, I won't be actually satisfied.

Respecting children's consent

Interviewees tended to give young ages for when they begin to respect children's profound though not necessarily technically detailed understanding that informs their consent. This enables children to agree and "want" to undergo surgery. "0" in Table 2 central column denotes interviewees who believe some form of consent should "always" be respected, through sensitive interactions that encourage children's confidence, patiently helping them through their fears and hesitations, and avoiding forced interventions. A surgeon/ethics committee member (26) said that during procedures before surgery, "we try to have the same [standard] really, that the small child has in a sense consented in just the same way as an adult might to have a blood pressure check, ECG..." to prevent children being psychologically disturbed if they are coerced.

Although young children cannot understand technical details of heart surgery, a psychologist (32) described how a 2-year-old can know when "something's poorly and it needs some medicine or it needs to be fixed". This helps children to understand the essential meaning of consent, when they can trust and cooperate with adults' intention to help them not harm them during frightening distressing procedures, such as blood tests.

By around 8-years, some children were thought to be able to understand complex procedures and risks. One example is children with heart failure who agree to go on ventricular assistance in cardiac critical care while they wait for a heart transplant. A surgeon (15) described teamwork:

There's lots of medical counselling before I even get involved...We make massive efforts with the psychology team, with the anxiety management. [The life-sustaining pump can cause] a devastating stroke for example which is a very real possibility [when life-support would have to be withdrawn]. So I always have those conversations very upfront before I do any operating on them...It's not legally enforceable but actually it just helps I think to explain everything. And that usually takes two or three conversations... so anything from about 8 [years] upwards. And I have quite sort of decent conversations with them about that.

Interviewees caring for children who need a heart transplant generally rely on the informed consent of children aged from 6-years. This is to ensure they will actively cooperate with their essential life-long follow-up care.

Interviewees respected children's consent in its own right, alongside parents' consent. A mediator/former paediatrician (35) said, "For me it [consent] has to be 100% from all the research we know around human behaviour, around psychology, around placebo effect. You have to be bought into the intervention for it to be effective...it's about knowing that you matter."

An anaesthetist/ethics committee member (18) considered that children vary, but some.

7-, 8-year-olds can be very involved...I don't think you would be looking to them as a sole decision maker, but you certainly can be involving them in the decision...We've designed our [consent form] to make it clear...[if] it's the [older] child's decision then the parents can sign in a specified place saying they support the kid's decision... There's only one decision maker basically. And the parents are either making that decision or supporting, and that's clear.

Respecting children's refusal

Of the 27 interviewees who cited an age when they begin to respect a child's refusal, only two who worked with older children said 16-years, 13 gave ages under 8-years and eight were uncertain (Table 2). Interviewees who said refusal by the youngest children should be respected were: "always" a surgeon/member of hospital directorate/ethics committee member; "from 2-years" another surgeon/ethics committee member; "from 3-years" an anaesthetist and a law professor/member of hospital directorate/ethics committee member; "from 4-years" a surgeon; and "from 5-years" a paediatric cardiologist, a psychology professor/member of hospital directorate, and the chief executive of a children's heart charity.

Young children's resistance and refusal could be decisive. Practitioners generally said they negotiate with children and avoid coercion. If children from around 4-years cannot be calmed, non-urgent surgery is postponed (interviewees 1, 15, 18, 19, 26, 35). A mediator/former paediatrician (35) believed that if "children got to the anaesthetic room kicking and screaming saying, 'No, no, don't do it!'" there has been lack of preparation. Children need to feel their "best interests were...being considered...and you're not a car that somebody's just fixing, you're a person that matters."

At every stage we're trying to eliminate the sort of traumatic experience which may have a permanent psychological effect...and for procedures that are likely to end up as a fight we just back off. Unless children are relaxed, an echocardiogram, for example, is not really going to tell you what the normal situation's like. So you'll get bad results by a bad practice, physiologically and psychologically (surgeon/ethics committee member 26).

Several interviewees expressed concern that trust, which could take years to establish, could quickly be lost so that children would resist and even later opt out of the lifelong cardiac care they need.

A psychologist/hospital directorate member (5) questioned "What are they saying 'no' to?... Sometimes...they're more frightened about...the needles or the anaesthetic...not necessarily the operation." The anaesthetists' policy is to wait, negotiate, try moderate sedation or distraction with toys or, if these fail, refer children for carefully designed support such as POEMS (2023), play sessions and discussions. "You'd have to look at the root cause...Have they had a terrible experience with surgery before? Did they nearly pass [die] from an experience before? 'Is there a reason that they are so adamant and negative towards this treatment?' or is it 'teenage rebellion?'" (children's heart charity youth officer 34). Children with learning difficulties can form firm views. "Some, girls, more than boys, are very, very eloquent...from the age of 8, 9, 10" (Children's heart charity information officer 28). A palliative care consultant/ethics committee member (45) said,

There's quite clear legal guidance that in essence children cannot refuse surgery that their parents' consent for them. But obviously in practice you don't want to do anything which is in essence an assault because a child absolutely doesn't want it. So I don't think it's a question of age, I think it's a much more complex situation than that and it involves really exploring with psychologists, with the healthcare professionals, with their family, obviously with the child, why they're refusing, what their fears are and are they justified. And I don't think you can make a blanket decision on age. But again, I think if you feel that a child is old enough and has capacity to make decisions about consent, let's say 7 or 8...then equally I think that they should be able to be involved in decisions about why they wouldn't. But understanding that they cannot refuse treatment if everybody else feels it is in their best interests, I think they can be involved in the decision-making...[or] you just end up with scared children.

Nurses, play therapists, and psychologists help young patients to become able to consent through understanding their need for surgery, wanting the benefits, coping with specific anxieties, and gaining trust and confidence. This can take several sessions over weeks.

Occasionally, a child's refusal is final. If, after every effort to inform and prepare them, children aged from 6-years still refuse a heart transplantation, "Of course, there's no point in doing it because they'll destroy it by not taking their medication...it [consent] is vital" (cardiologist 40).

DISCUSSION

This section considers why our findings differ so much from most published work on children's consent and how they are supported in some psychology research. Our paper is unusual, first, in reporting that young children make healthcare decisions. Second, some practitioners respect not only young children's consent but also their refusal. Third, decisions that can seem "minor", such as refusing an anaesthetic mask, become "major" and decisive in their effects if the operation is postponed. Fourth, some practitioners report that they respect the most complex, serious and major decision of all, when certain very ill young children refuse a life-saving heart transplant.

This is in marked contrast to the medical, legal and nursing literature. There, the general belief that competence to consent begins around 12-years echoes Piaget's development theory that, around 12-years, adolescents begin to make probability judgements. Piaget assumed that children do not understand until they can verbally explain their thoughts. However, psychologists now accept that most young children know and intuit much more than they can say; their probability intuitions are highly structured, they can distinguish determining events from chance, and connect outcomes to causes (Schlottmann & Wilkening, 2012).

"0" in Table 2 might seem too early to start informing children, but research with babies shows they are calmed and soothed when gently held and spoken to (Gopnik, 2009). They become agitated, cry and resist if they are suddenly handled by silent strangers and their anxiety is ignored. Premature babies quickly learn to flinch when their foot is held, anticipating the heel prick (Als, 1999). From their first months, babies are meaning makers, connecting cause to effect, and intuiting adults' intentions.

In many countries, the law respects older minors' consent but sets the much higher age of legal majority before allowing refusal. The sample of 45 interviewees is too small to support generalisations. However, in Table 2, in contrast to the literature, eight interviewees including all three surgeons said they respected the refusal given by children aged 5-years or younger, whereas a smaller number, five, said they respected the youngest children's consent.

Interviewees who cited ages from 6-years upwards were more likely to respect consent at a younger age than refusal. Since consent involves the option to refuse, the ages cited for either response might be expected to be the same. In practice, these interviewees seemed to find it easier to trust and “respect” young children who concur with the adults’ decision, but they set a higher standard and age for when they would take on the inconvenience and risks of accepting a child’s refusal.

The main reasons interviewees gave for respecting children relate to therapy and effective care: to sustain trust and mutual respect between children and staff; to ease unpleasant procedures and avoid mental and physical conflicts; to reduce fear; to promote the placebo effects when children believe in the therapeutic value of their care; to prevent the serious dangers that children might lose faith in the life-saving, life-supporting cardiac services and might leave when they are young adults.

In ethical analysis, these reasons serve utilitarian aims for maximum benefits and minimum harms. Yet they also serve the ethics of values and principles (deontology): honesty, mutual respect, keeping promises. Principles relate to rights, such as those enshrined in the UNCRC (United Nations, 1989). Education, the other main service for children, involves group care, whereas cardiac care is one-to-one. Cardiologists respond to their patients individually, knowing them and their families very well by meeting them regularly in clinics throughout their childhood, and caring for them during the crises of hospital admissions. It is unusual for children to have such an intimate relationship with adults outside their family. Their physical and mental cardiac healthcare can illuminate the profound meanings of children’s rights in exceptional ways. The following UNCRC rights are especially relevant to children having cardiac care:

‘Recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family’, not just adults, and including babies;
Faith in ‘the dignity and worth of the human person...to promote social progress and better standards of life’;
Respectful childcare in ‘the spirit of peace, dignity, tolerance, freedom, equality and solidarity’ between generations and without any discrimination (UNCRC Preamble).
Working with children to promote their ‘best interests’ (Article 3);
Giving ‘due weight’ to children’s views (Article 12) while recognising that young children with serious illness can be unusually mature in some ways;
Honouring children’s ‘right to freedom of expression...[and] information’, ‘through any other media of the child’s choice’ such as play therapy (Article 13);
Respecting children’s ‘freedom of thought [and] conscience’ and working with parents ‘to provide direction to the child’ (Article 14);
Protecting each child ‘from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment’ (Article 19), when balancing a child’s refusal with the child’s need for interventions;
Helping disabled children ‘to enjoy a full and decent life with active participation in the community’ (Article 23), through promoting their health and confidence;
Recognising ‘the right of the child to the enjoyment of the highest attainable standard of health’ and healthcare (Article 24).

In these practical ways, children’s rights may be deeply honoured even if rights are not explicitly referred to. The families’ intense gratitude was recorded, for example, in thank you cards displayed in the wards, and in their online notes about a recently deceased cardiologist (Brompton Awareness, 2021).

Adults' consent is valued partly to avoid the oppression of the patient having to live with unwanted effects of a decision that other people have made. Risks are clearly explained in order that the patient may weight them and personally decide if the hoped-for benefits justify undertaking the risks. Explanations also prepare adult patients to cope with and feel responsible for harmful outcomes if these emerge. It is usually assumed in the literature that children cannot take on this responsibility or know their best interests (for example, Archard & Skivenes, 2009; Conti et al., 2018). Examples such as young Jehovah's Witnesses refusing life-saving blood transfusions are used to claim that children generally are pre-rational. The interviewees understood the heart surgery children very differently. Their views were not seen as irrational or unscientific beliefs, but as informed by wanting the ends of surgery (better health) but fearing painful means. The adults therefore appeal to children's reasoning with rational arguments and reassurance to help them to manage their reasonable hopes and fears.

The burden of having to live with unwanted consequences of a decision made by others breaches human rights and personal autonomy. With adult patients, informed consent is intended to prevent this burden, whereas children are expected to accept adults' decisions and to bear any unwanted consequences "in their best interests". The interviewees did not relate this burden directly to children's rights, but instead gave practical examples of how children resist the unwanted decision and its adverse effects ranging from loss of trust, to potentially life-threatening non-cooperation or even later opting out of essential cardiac care. They had learned from former patients that it was vital to sustain mutual trust and respect. Their comments affirmed our findings on how consent involves practical and emotional cooperation to avoid active refusal and resistance (Alderson, Bellsham-Revell, Brierley, Dedieu, et al., 2022; Alderson, Cohen, Davies, Elliott, et al., 2022).

LIMITATIONS

The research was limited to elective surgery in two paediatric cardiology departments. It remains unclear how widely shared the respectful views and practices reported here are in many other hospitals. Yet practitioners usually train and work in different hospitals, so standards are likely to be shared across the UK.

The 45 interviewees are a very small and possibly unusual sample from numerous paediatric professionals. To verify how widely shared their views are among other paediatric specialties, it would be useful to conduct a questionnaire survey with a much larger sample. The purpose of this paper is not to generalise about all healthcare professionals' views, but to report that at least some leading practitioners do respect young children in policy and practice, and believe that this is the correct ethical and therapeutic standard.

The two hospitals are unusually well staffed and funded to support services to help children who refuse. These resources are not available everywhere. However, by working to develop new skills and higher standards, these hospitals can help less well-resourced ones to copy their work.

Heart surgery involves unusually complex, high risk, challenging decisions. Yet this means the research findings may be relevant to all other clinical specialities, including lower risk ones.

CONCLUSION

When recommended heart surgery effectively addresses serious fatal illness, consent might seem to be the only option. Yet as shown, young children's resistance and refusal could cause operations to be postponed or occasionally cancelled. Respect for children's consent depends partly on how consent is defined. The law and ethics literature is mainly concerned with consent as

intellectual weighing of detailed risks and benefits. This may exclude many children as incompetent. This research shows that when consent is seen as a personal relationship of mutual trust, practitioners aim to ensure that the child understands the basic principles: treatment is needed to relieve a problem; the adults intend to help and not harm the child; recommended treatment results from the best possible expert judgement; and the child's views are valued. Very young children, for some interviewees even babies, were seen as able to begin intuitively to understand and respond to some of these principles, which are the essence of consent.

Competence to consent is often aligned with an age: around 12-years for Gillick or mature minors, 18-years for legal majority. In line with the uncertainties, listed earlier, held by many interviewees about a definite age, it may be more realistic to see a continuum of competence to consent and refuse. This begins in the first years and increases through years of experience. Crucially, this approach can respect and protect every child as shown in the practical examples in this paper. The law literature rightly addresses the legal validity of informed consent, necessary to prevent complaints and litigation. Yet the literature should be updated, to attend also to current high standards of clinical care when young children's decisions are respected, as reported in the two paediatric cardiac centres of excellence.

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

In agreement with the ethics reviewers, interview transcripts and observation notes will not be shared publicly, to protect participants' anonymity.

ETHICS STATEMENT

The authors assert that all procedures contributing to this work comply with the ethical standards on human experimentation of the British Sociological Association Statement of Ethical Practice, revised in 2017, and with the Helsinki Declaration of 1975, as revised in 2013, and has been approved by the institutional committees: NHS HRA (19/LO/0073), Hampstead Research Ethics Committee (ID 248332), Institute of Education UCL (REC1188), and HRA-Confidentiality Advisory Group (19/CAG/0148).

PATIENT CONSENT

No patients are named or quoted.

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