

# *Epistemic injustice and children who have major surgery*

**Addressing Epistemic Injustice:  
Perspectives from Health Law and Bioethics  
Symposium, 15 September 2023, City University London**

**Priscilla Alderson**

Professor Emerita of Childhood Studies

Social Research Institute, University College London, UK

## Epistemic contradictions about children's best interests

Parents' 'visiting' their child in hospital very limited until 1980-90s. Parents banned from most baby units.

'Parents increase infection risks'

'Parents only upset their children when they visit'

Scientific clinical knowledge, objective, impersonal, rational, detached, patriarchal, rules taught by experts

Parents' national campaign to be able to stay with and care for their child in hospital - 1950s-1990s (1974-1986)

Family knowledge – subjective, personal, rational-emotional, engaged, feminine ethic of care, experiential, embodied, evolved over millennia.

Bowlby 1953, Platt 1959, Kennel & Klaus 1976, psychology, biology, nursing, child abuse, evolutionary anthropology, nutrition, etc.



J & J Robertson, *A 2-year old goes to hospital*, 1952, film

## Consent to research: law and bioethics → epistemic justice

Dangers of unregulated research:

Nuremberg 1947; Beecher 1966; Pappworth 1967.

**Reform** Bioethics to protect and emancipate research subjects and patients  
To promote respect for informed consent.

US -National Commission for the Protection of Human Subjects of Bioemical and Behavioral Research. *Research Involving Children* 1977; *Belmont Report* 1979. Beauchamp & Childress 1979.

UK- *Medical Research with Children: ethics, law and practice* 1985.

CERES, Consumers for Ethics in Research 1989 – 2006

BPA/RCPCH Revised *Guidelines* 1992/2000. Promote the 'lay' view of research.

# Parents' consent to treatment

1984-1987 Parents' consent to paediatric cardiac surgery in two London hospitals.

Observing and talking with 100s of parents and staff in wards, clinics and medical meetings.

The research question:

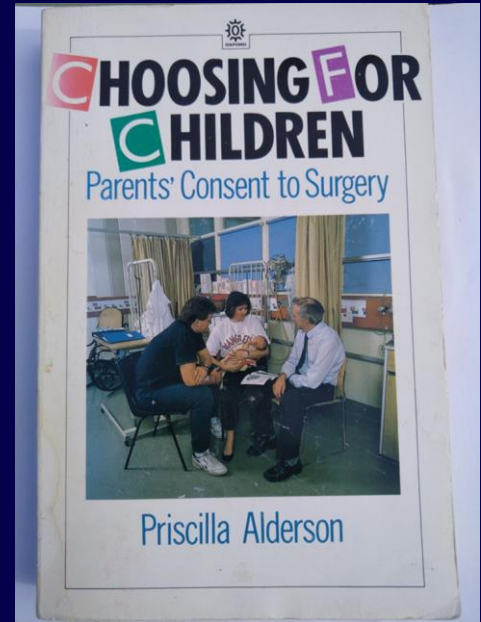
When children need life-saving heart surgery,

Is it worth spending time requesting consent from extremely stressed anxious parents?

Does that just distress and confuse them? Is parents' consent a mere formality?

Medical and legal benign epistemologies vs parents' negative emotions?

Alderson, *Choosing for Children*. Oxford University Press, 1990.



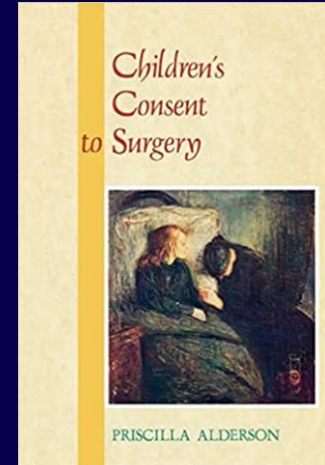
## Value of the epistemic journey of informed and voluntary consent

Moral emotions inform rational understanding

Parents' empathic journey for their child.

Fear of mutilating surgery, rejection, doubt, uncertainty,  
growing trust, confidence, courage,  
commitment, willing voluntary consent.

Surgery as the least unwanted option.



Children also make this journey (1989-1991).

120 children aged 8-15 years having orthopaedic surgery and their parents  
in 4 hospitals. Pain, mobility, appearance. Child as expert.

13 parents and children said child was 'main decider' from 8 years+

Alderson, *Children's Consent to Surgery*. Open University Press, 1993.

## Ages of consent

Children are meaning makers. If they are not informed they tend to assume surgery is a punishment, and endure fear, guilt and confusion.

Diabetes study (2004-2006)

Vital to gain children's informed consent to daily blood tests and injections.

'Insulin is the key that turns sugar into energy'

Harriet aged 4-years.

(Alderson et al. Children's consent to medical treatment. *Hastings Centre Report*, 2006)

## Children's and parents' consent to elective heart surgery, 2018-2021

45 interviewees: surgeons, anaesthetists, physicians, nurses, psychologists, play specialists, chaplains, social worker, experts in law and ethics

Children's ages	Begin to inform children	Begin to respect children's consent	Begin to respect children's refusal
0-4 years	25	4	5
5-7 years	11	13	8
8-10 years	2	11	7
11-13 years	2	6	4
14-16 years	0	3	3
No reply/Uncertain	5	8	18

Alderson, et al. 2023, Children's ages of consent to non-urgent heart surgery, *Children & Society*,

# Children's refusal

Interviewer: So what would you do about the [non-urgent heart] operation, if a 4-year-old very firmly resisted and struggled against the anaesthetic mask or cannula?

Surgeon: Cancel it. (Followed by multidisciplinary teamwork)

Several interviewees said that if, after weeks when every effort is made to inform and prepare them, children aged from 6-years still refuse a heart transplant:

Cardiologist: Of course, there's no point in doing it because they'll destroy it by not taking their medication...it [consent] is vital.\*

'Their life is in their hands'\*\*

\* Interviews during 2018-2021 research, children's and parents' consent to heart surgery

\*\* Alderson P, Goodwin M (1993) Contradictions within concepts of children's competence. *International Journal of Children's Rights* 1: 303-313.



# Great difference between actual clinical practice and main theories in law and bioethics journals

- ‘Non-competent’ child cannot consent to treatment
- No one aged <18-years can refuse recommended major treatment\*
- How to ‘hypothesise values’ of ‘a capacitous person who has not yet existed’\*\* - Young child as non-person

(5 slides on reasons and processes for respect in clinical practice and general disrespect in law and bioethics)

\* Goold I. 2021 Children and Consent to Medical Treatment. Gresham College.

\*\* Pugh J. The child’s right to bodily integrity and autonomy: A conceptual analysis. *Clinical Ethics*. 2023;0(0). doi:[10.1177/14777509231188817](https://doi.org/10.1177/14777509231188817))

# Children's consent to surgery

Hermeneutical injustice: how we interpret, construct and reconstruct the other as inadequate in self-fulfilling, reinforcing interactions\*  
Barriers of unjust prejudice.

Robin aged 13: 'I would like to see the age limits completely scrapped and maturity brought in. As you grow up your age has a stereotype. I'm trying to escape from that stereotype.'



Child as incompetent?  
Or a competent partner?

\* Fricker, M. 2007 *Epistemic Injustice: Power and the Ethics of Knowing*.  
Oxford University Press.

# Children's consent to surgery

Testimonial injustice\*

Prejudices against speakers' identity, understanding, status and therefore knowledge; unfairly exclude, silence, distort, misrepresent, undervalue and distrust their accounts.

Children are not informed or involved in decisions. Their ignorance and inexperience are then used as reasons to exclude them.

\* Fricker, M. 2007 *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press.

# Clinical ethics committees and epistemic injustice

BBC film 2019 of best CEC practice\*

Ibrahima Ndiaye with his daughters Marieme (left) and Ndeye Twins share a liver, bladder and digestive system. Travel from Senegal. Ibrahima: Then the surgeon 'told me we can't do [the separation] without losing Marieme' the twin with a weak heart. 'The light, the hope, the expectation – all of a sudden, this vanished' \*\*



Epistemic hierarchy in CEC - profession, gender, dress, phones.

'Primary objective of CECs is to provide support to healthcare professionals'.

Advised surgery to enable Ndeye to survive.

\* <https://www.bbc.co.uk/programmes/m0007f81>

\*\* Sherwood, "They are together, they are equal' Observer, 4 August 2019.

<https://people.com/health/meet-single-dad-raising-6-year-old-conjoined-twins-doctors-said-couldnt-survive/>

2023 Photo: Lauren Joy Fleishman

## Engaged or disengaged ethics

Father: 'You don't use your brain, you follow your heart...They are together. They are equal...I will never let them walk alone'.\*

No mention on film of twins' views, of informing or listening to them, except a paediatrician: 'Dad... will have to live with the consequences...even potentially ...with a child who may ask questions in a few years' time if she survives that she's the one who survived but because her sister was sacrificed.'

Refer to courts to relieve Ibrahima of moral responsibility to decide?  
Individualist bioethics and medical hubris vs  
twins' symbiotic life and conjoined identities. A blissful state? (Plato)  
How could Ndeye form a new life as a sole, severed survivor?

\* Sherwood, 2019, Observer, 4 August.

# Towards epistemic justice?

## 1. Expand bioethics?

Enlarge understanding and sympathy with excluded groups

Thereby increase expertise and authority

Gain a higher perspective and pedestal.

Yet clash of paradigms: cerebral detached bioethics vs emotional embodied lay morality and engaged moral relationships.

## 2. Critical learning?

Climb down to examine cracks in the pedestal

Socratic ignorance and Locke's under-labouring

Start again from a new base.



## Children's consent to heart surgery – reasons for respect in clinical practice

- Deeply experienced, severely ill children.
- Their own paediatric cardiologist knows them very well through continuing life-long personal care.
- If interventions enforced – moral distress for staff and patients
- counterproductive risk of loss of child's trust and cooperation.
- Follow up - risk of long-term PTSD,
- costly efforts and delays trying to regain trust and cooperation in later treatment,
- risk of opting out of later adult care.

Alderson P, Goodwin M (1993) Contradictions within concepts of children's competence. *International Journal of Children's Rights* 1: 303-313.

# Bioethics: reasons and processes for epistemic injustice 1

Clinical evidence ignored

Outdated refuted Piagetian child development theory relied on

Generalisations from unusual court cases

Hospital lawyers and pharmaceutical trialists require

highly legalised defensive adult-based consent

to protect practitioners/hospitals/companies rather than patients

Barriers set by journal editors and reviewers loathe to admit

they may be dangerously mistaken

Risks ignored of enforcing treatment on confused, terrified, resisting children.

Yet child's fear expresses values and meaning-making,

not a mindless zombie state.

Abstract thinking, detached from actual patients



## Bioethics: reasons and processes for epistemic injustice 2

As an expert academic specialty like medicine and law, bioethics  
risks downgrading and dismissing lay morality

Procedural justice applies rules, laws and cost-effective calculations  
not the justice of equal access to knowledge and power  
or to healthcare – apolitical about suffering and injustice?

UN human rights - world justice, equality and peace \*\*

Bioethics - libertarian adult-centric autonomy, divisive rights of

\*\* Preambles, UDHR 1948, UNCRC 1989

# Bioethics: reasons and processes for epistemic injustice 3

Ethic of justice, missing ethic of care

Mexican example shows epistemic injustice can involve class,  
gender, race, religion, age

It increases practitioners' power and control over  
decisions and resources

UK: 'Primary objective of CECs is to provide support  
to healthcare professionals'

Increases medical/lay imbalance

Detaches ethics away from being central  
to doctor-patient relationship?

# Human rights: epistemic injustice

The central adult right

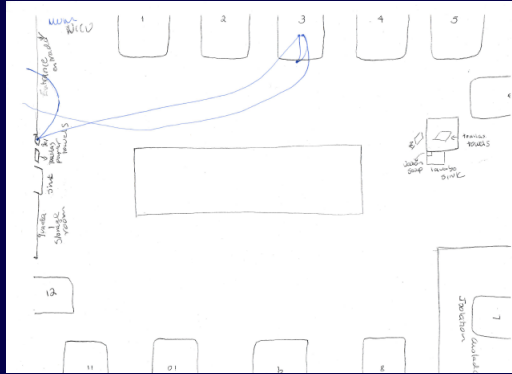
- to respect for autonomy and bodily integrity
- rights to be informed, and not be coerced or deceived

Extraordinary this is denied to children\*

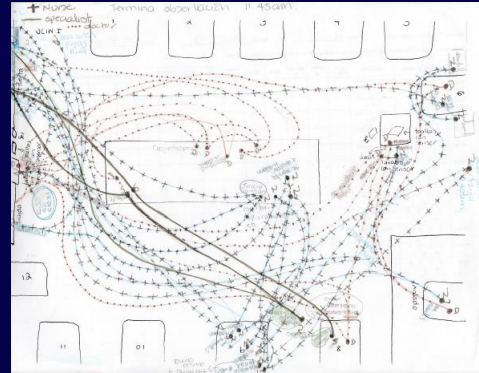
\*Daly A. 2018 *Children, Autonomy and the Courts: Beyond the Right to be Heard*. BRILL,189-90.

Clinicians' privileged knowledge can be dangerous:  
Parents' and children's emotion-based knowledge can be wise

1.



2.



1. One mother, parents allowed to visit twice a day.
  2. One nurse, one neonatologist and one paediatric cardiologist.
- 25% mortality rate in this Mexican SCBU 2017.

Mendizabal-Espinosa RM, Warren I. Non-evidence-based beliefs increase inequalities in the provision of infant- and family-centred neonatal care. *Acta Paediatr.* 2020;109(2):314-320. doi: 10.1111/apa.14972.