Children's informed, signified and voluntary consent to heart surgery

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Heart surgery

High risk of mortality and morbidity, brain injury, stroke
complex decisions
distressing, painful, frightening
blood tests, >1 hour echocardiograms, MRI scans
mask or cannula for anaesthetic
intensive care unit, sore throat, pain
Alternative –
mortality and morbidity risks
longing ‘to be like my friends’

Many parents do not want their child to be informed

Competence? At what age can children begin to be informed,
to give consent to surgery, and to refuse surgery?
Methods  November 2018 to May 2021 part time

Funding by British Heart Foundation (applied 2016→)
November 2018 to October 2019 wait for RECs approval
Literature reviews
October 2019 to February 2020
Observe two London children’s heart surgery centres
Interview staff and 16 families (plan 45 staff and 60 families of children aged 6 to 15 years) after non-urgent heart surgery
March 2020 to April 2021: Continue interviews by ‘phone,
Online survey and group discussions with children and parents
Writing and resubmitting papers
Opposition from funders, peer reviewers, journal editors

The law on ages of consent?

South Africa  The Children’s Act 2005
Section 129

Children aged 12 or more - Provided they have the maturity “to understand the benefits, risks, social and other implications of the treatment”...may consent to medical treatment on their own behalf...[and to surgery] a sufficiently mature child may still consent, if he or she is “duly assisted by his or her parent or guardian”.

Children under 12 or over 12 but lacking the maturity to make an informed decision - A parent, guardian or care-giver of the child may consent on behalf of the child to medical treatment.
English and Commonwealth case law
53 countries <2 billion people, Gillick case 1985
US mature minors

No lower age specified
But usually assumed to be >12 years

Reflected in law reports and ethics
and health research literature
– most reported research on consent to children’s treatment
is about parents’ consent
a few reports on young people’s consent
children may make minor decisions
– which arm to have the injection in
Adult right to consent includes right to be informed, right not to be coerced or deceived.

Problems discussed during interviews:
Non-competent children do not have these rights.
Competent children may consent to treatment, but not refuse it, so treatment can be enforced.
Children may be confused, afraid, ‘terrified’, resistant and lose trust.
Those who need life-long cardiac care may not cooperate or become responsible for their healthcare.
Struggles over anaesthesia.
Non-compliance with heart transplant follow up care.
45 interviewees: doctors, nurses, play specialists, psychologists, chaplains, social worker and experts in law and ethics

<table>
<thead>
<tr>
<th>Children’s ages</th>
<th>Begin to inform children</th>
<th>Begin to respect children’s consent</th>
<th>Begin to respect children’s refusal</th>
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<tr>
<td>0-4 years</td>
<td>25</td>
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<td>5-7 years</td>
<td>11</td>
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<td>8-10 years</td>
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<td>11-13 years</td>
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<td>14-16 years</td>
<td>0</td>
<td>3</td>
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<tr>
<td>No reply/Uncertain</td>
<td>5</td>
<td>8</td>
<td>18</td>
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Interviewer: So what would you do about the operation if a 4-year-old very firmly resisted and struggled against the anaesthetic mask or cannula?
Surgeon: Cancel it.
(Followed by multidisciplinary team work)

Several interviewees said that if, after weeks when every effort is made to inform and prepare them, children still refuse a heart transplant, “Of course, there's no point in doing it because they'll destroy it by not taking their medication...it [consent] is vital” (cardiologist).

Participatory research: Co-authored papers with interviewees – five anaesthetists co-authored with us the paper on anaesthetists and children’s consent to heart surgery and their zero-coercion policy. Paper rejected.

Why do the law and literature differ so much from hospital practice?
Law and literature theories

Informed consent – Law, Helsinki 1974/2013

Voluntary consent – unpressured – Nuremberg 1947

Signified consent – legally valid person’s signature

OR Ontology of consent, actual practice

Informed consent – inner understanding, weigh values, motives, risks,

Signified consent – actual active cooperation or resistance

Voluntary consent – free choice, willing consent, trust, hope, real emotions, motivations
Ontology of consent

Informed consent
Voluntary consent
– feel unpressured – *Nuremberg* 1947
Signified consent
– legally valid person’s signature

OR

Informed consent
– understanding, weigh values, motives
Voluntary consent
– free power of choice, willing consent
Signified consent
– active cooperation or resistance

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<th>Actual</th>
<th>Real</th>
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**Epistemic fallacy** do not inform children – as if the word for them is worse than the deed

**Semiotic triangle** remember the referent, the actual experience of surgery, scar and the reality consented to

**Internal conversations** children are meaning makers, unless adults explain their motives children risk assuming they are being punished

**Four planes of social being** overcome mind/body, individual/social, adult/child splits

**MELD** See children’s competence and consent as relational processes not as fixed, static, atomised

**Social positioning theory** children’s present and future interests, rights and obligations
Critical Realism for Health and Illness Research

By Priscilla Alderson

“No doubt, students, researchers and others interested in critical realism and health will find the insightful discussion of this difficult, yet important, topic very useful.” Ebenezer Durojaye, University of the Western Cape

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References


Details of research reports: https://www.ucl.ac.uk/ioe/departments-and-centres/centres/social-science-research-unit/consent-and-shared-decision-making-healthcare/childrens-and-parents-consent-heart-surgery