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Truth and trust in consent to surgery

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Researching Parents' and Children's Consent to Heart Surgery
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Truth and trust – the centre of valid consent to surgery

Exchange: honestly shared accounts of symptoms, needs, diagnoses, planned agreed treatment and prognoses by patients and surgeons

Emphasis on surgeons explaining
nature and purpose of treatment, methods and means, risks, hoped-for benefits, alternatives (Nuremberg 1947)

Yet patients also active: understand, question,
weigh risks and benefits,
give voluntary (willing un-coerced) consent,
become committed to undergo surgery
and follow up care

Truth and trust –the centre of valid consent to surgery

Truth: Intense critical international research.

Around 30 congenital heart anomalies identified in 1980s. Now c2,500.(Elliott) Constant revision and updating.

10% mortality rate in 1980s, now well under 1%.

Cardiac surgeons' records published. EPIC system.

All non-emergency pre-surgery cases reviewed by team, >20 consultants. Constant experiment and research on outcomes, risks, what parents want to know.

Trust: multi-disciplinary paediatric cardiac teams all inform and support families through extended consent process, all share information and trust.

Trust can only be mutual, not one-way?

Doctors have to trust adult patients - their reported needs, understanding, consent

Trust in parents – veracity, responsibility, valid representatives of child

Trust children - their self-reported needs, understanding, consent?

Mistrust

Much law and ethics literature: children cannot consent until aged 16, 14, sometimes 12, but they cannot refuse until 18.

US anaesthetic papers on how to suppress children's anxiety with premedication and distraction (clowns, magic tricks)

Deception, covert coercion (Alderson et al)

Social science's uneasy relations to truth

Positivist truth claims rest on the findings being precisely replicable. Impossible with unpredictable free agents, complex social contexts.

Some interpretivist, social constructionist, postmodern views of contingent truths are relativist.

'Each truth only has meaning and validity in specific contexts.'

(This statement is a contradiction.)

Or 'there is no truth or reality' only perceptions and constructions.

(Prevents serious study of bodies and surgery.)

Ethnographies may involve researchers' deceptions.

Positivist surveys include 'trick' questions to test truth of replies.

Ethnomethodology. Examine moral accounts not validity of spoken interactions and relations.

Critical realism helps to resolve these problems

Combines strengths of different research paradigms in a larger framework.

Critical realists agree with:

positivists, there is true reality, independent of our fallible thinking about it;

interpretivists, there can be countless interpretations of reality, but these don't alter or construct reality itself.

Critical realism understands everything at three levels, all reinforcing one another.

Empirical	experiencing, thinking, talking about reality, describing, measuring, perceptions, memories, accounts, facts, statistics
Actual	existing things, people, events, relations, structures - stronger grounds for establishing truths, yet appearances can be deceptive.
Real	causal mechanisms, usually unseen by normal vision and only known in their effects: virus behind a pandemic, genes, cardiovascular system social class, inequality, power, justice, policy personal motives, hopes, intentions

Truth	At three levels
Empirical	We misunderstand, misrepresent, can only ever partly know truth. We are fallible and may be dishonest.
Actual	We break promises, mislead others. Business betray their clients and staff, politicians renege on manifestos. Does this mean truth doesn't exist?
Real	Truth like gravity is an infinite unseen power we rely on for everything – walk down stairs of wood/stone not of treacle, drink tap water not acid… Truth is never fully known, it's a guide and compass point

Consent, in two London children's heart surgery centres

Empirical truth: Families and practitioners all held differing viewpoints related to

Actual truth: children's heart lesions, their effects, planned surgery (the actual positivist level).

Real truth: valid consent is informed and voluntary
involving unseen willingness, courage and trust (the real causal motivating level).

The three interacting levels are central to consent to surgery, and to social research.

Trust in children's consent respects them as persons.

Interviews with 44 healthcare professionals and related experts on the ages when they would begin to respect children's consent or refusal before non-emergency heart surgery.

Many replied they needed consent of children aged about six years before heart transplantation.

If a child aged four years firmly refused anaesthesia, they would cancel the operation, and work with psychologists and play therapists until the child felt informed and willing to have surgery.

Social science: vital to honour empirical, actual and real truth as far as we are able. To produce valid reliable findings to inform policy and practice. Critical realism has many other concepts to assist analyses.

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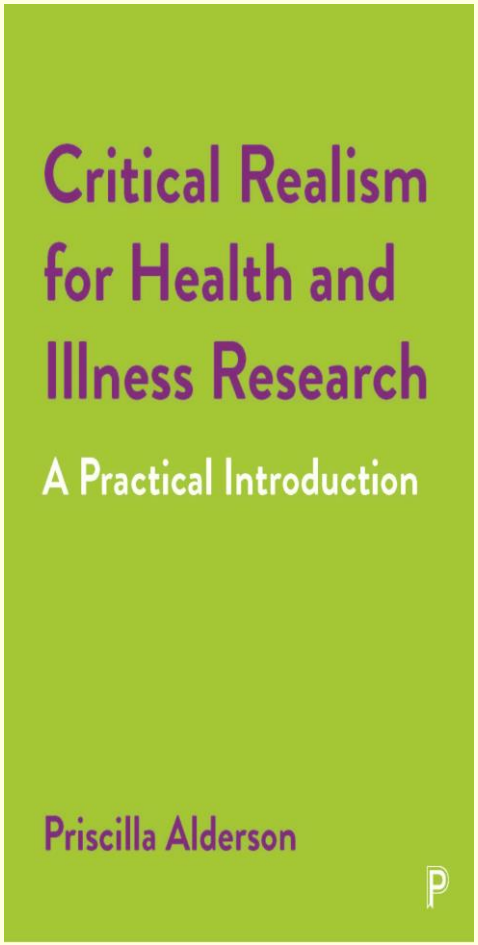

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- By Priscilla Alderson

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- **Ebenezer Durojaye**, University of the Western Cape

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