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**A critical realist analysis of consent to surgery for children,
human nature and dialectic: the pulse of freedom**

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Abstract

Consent can only be voluntary, freely given and uncoerced. Can this legal adult standard also apply to children? High-risk surgery is seldom a wanted choice, but compared with the dangers of the untreated problem, surgery can become the least unwanted option. Critical realism helps to reveal explicit and hidden levels of informed and voluntary consent at empirical, actual and real levels, on the four planes of social being and through the four-stage dialectic. Instead of starting with the rational-legal adult patient standard of consent, and assessing how young children fail this, understanding of consent could start at the other end of life. What does innate physical-social-moral-intuitive human nature in the emotional embodied person tell us about the meaning and purpose of consent/refusal for self-preservation, for avoiding suffering and promoting wellbeing? This discussion paper considers examples of life-giving treatment for children, and ethical dilemmas including one of conjoined twins, when only one child could survive separation.

Introduction

The ‘pulse’ in the title *Dialectic: the Pulse of Freedom* (Bhaskar 2008) suggests a beating heart, and consent is at the heart of freedom. Its absence is at the heart of coercion. We discuss these ideas using examples of shared decision-making and consent to surgery and other major medical treatment for children. The examples are of clearly planned, informed, negotiated and documented consent (Alderson 1990, 1993; Alderson et al. 2005, 2006; Sutcliffe 2010; Mendizabal 2017; Sutcliffe et al. 2019). We consider how critical realism can help to deepen analysis of why consent is so important, when it expresses powerfully held values central to our human nature and its social, moral and embodied origins. While preparing for our current research, we have reflected on how it can be informed by critical realism (CR), and on how CR could have illuminated our earlier studies. (We are conducting observations in two hospitals and interviews with 60 children aged 6- to 15-years, their parents, and 40 hospital staff about consent to heart surgery Sutcliffe et al. (2019).

Consent is paradoxical. Doctors respect patients when they give them information, time and attention, listen to their views, request their consent and, if it arises, accept their dissent. Yet doctors often talk of ‘doing the consents’, meaning that they collect the signed forms from patients before surgery sessions. The phrase appears to overlook how consent reverses the usual model of the active doctor and passive patient, because consent is a major rational, moral, decisive act by the patient. However, consent is also a choice to give away freedom. It is a legal device to transfer responsibility for risk from the doctor to the informed consenting patient, who weighs the harms and hoped-for benefits of proposed surgery. By consenting to undertake the risks for the sake of the hoped-for benefits, the patient can become a hostage to events, losing the right to protest or sue if harms occur, provided these were clearly noted in the contract, and were ‘willingly’ undertaken by the patient (Kennedy, 1988; Brazier and Cave 2016; re *A minors* 2000). ‘Willingly’ here has a complex meaning. Consent can only be voluntary, freely given and not deliberately coerced. Yet high-risk surgery is seldom a wanted choice and there are unavoidable pressures of illness, and perhaps pain and immobility. However, in comparison with the dangers of the untreated problem, surgery can become the least unwanted and much needed option. Can children understand these decisions and give informed voluntary consent?

The following sections show how CR helps to reveal the explicit and hidden, ineffable and largely unseen levels of consent at empirical, actual and real levels (Bhaskar 1998), on the four planes of social being, and through dialectic (Bhaskar 2008). Over millennia, dialectic (interaction and the search for truth) has involved three stages: thesis, antithesis and synthesis. CR extends dialectic into four parts that involve thinking (epistemology) and also being (ontology), absence and presence, and transformative change over time. These CR levels and frameworks are here treated as useful aids for identifying distinct aspects of consent, and for organising and analysing research data from interviews and observations. The levels and frameworks overlap and interact, and are not seen as fixed or final domains.

Enablers and inhibitors of consent at the empirical, actual and real levels

Enabling and inhibiting aspects of the three levels, empirical, actual and real, will be briefly defined and considered in turn. The first empirical level is of our sensed experiences and perceptions, and our thinking, talking, measuring, recalling, interpreting and reporting experiences. Consent is enabled at this level when doctors have accurate knowledge, make clear diagnoses and prognoses, prescribe appropriate treatment, and can skilfully explain and discuss proposed surgery. Informed consent involves knowing ‘the nature, duration, purpose,

method, means...all inconveniences and hazards...effects on health or person' (*Nuremberg Code 1947*). To give valid consent, patients and/or parents need to have sufficient understanding, to be competent to weigh risks with hoped-for benefits, and to form and express their decision, and they are enabled by emotions of trust, hope and courage. The clinical team of doctors, nurses, radiographers, psychologists, social workers, interpreters, phlebotomists, chaplains, bioethicists and many others may share in informing and supporting the family.

Inhibitions on consent at the empirical level include doctors' knowledge and skill being limited. Consent involves the partly unknown future, often presented in terms of the percentage risks of the heart surgery being unsuccessful or even fatal. Although the surgeon's own success rate with the specific operation may be '70 per cent survival', families tend to see this as '50-50'; the child might survive, or might not. Patients may misunderstand the clinical technical details and the risks and benefits, leading to uncertainty, confusion and indecision, with emotions of mistrust, doubt and fear. Families tend to experience a mixture of enablers and inhibitors, with skilful clinical teams helping to reduce the inhibitors and promote the enablers.

The second level involves the actual people and events, the formal legal procedures, when doctors check what patients actually recall of the detailed information, answer their questions and ensure the consent form is signed by both doctor and patient or parent. Given the high risks of heart surgery, children need to be informed and involved as far as they are able or willing to be. Some wish to state their consent formally. Many prefer their parents to sign for them. The need to protect and partly exclude children, or to respect and involve them in the consent process, is much debated (Alderson 1993, 2012, 2018; Wiesemann 2016; Dyer 2008). Actual enablers include caring, respectful activities by the staff when they inform and support families, parents or children voluntarily signing the consent form, and the agreed surgery being performed successfully.

Actual inhibitors, in anticipated or unpredicted harms, involve maladministration, lack of dialogue, patients' inability to understand or recall vital information, incomplete paperwork, lack of needed support from the clinical team, cancelled operations, terms agreed in the consent form not being fulfilled, unsuccessful surgery and unsightly scarring, one of the young people's greatest fears (Harris, 2016).

Most research about consent remains at the empirical and actual levels, concerned with how patients recall and recount the medical information, and is about information rather than consent. The CR third level is of the real, unseen causal mechanisms mainly seen in their effects (moving forces like gravity, or genes or social class). The enabling real level opens valuable insights into meanings and underlying mechanisms of consent. Doctors and families are originally brought together by natural structures, the aetiology of children's innate heart defects (unlike 'adult' cardiology's concern with diseases of the ageing normal heart). Previously unseen morphology is increasingly revealed by new imaging technologies. Anderson and colleagues (2002) identified a group of about 32 innate heart lesions, whereas today around 3,600 are known, with around 2,400 known clinical interventions (Elliott 2016). Through the political-economic-social structures (in Britain) of the tertiary National Health Service (NHS), children are referred from their local hospital (secondary tier) to the few supra-regional tertiary children's heart centres. Other enabling social mechanisms include: the research, training and support that prepare the paediatric cardiac teams; their motives to benefit patients, and to increase medical and nursing skill and knowledge in order to promote health and improve services. There are real-level types of doctor-patient relationships; in enabling ones children and parents are treated as informed partners with the healthcare team, and as experts in how the illness, treatment, risks and hoped-for benefits may affect the child. Patients' enabling emotions of trust, hope and courage inform and motivate them. Whereas at

the empirical level, paediatric cardiac information given to families is partial and fallible knowledge, its validity depends on how nearly it approaches the true reality of the heart condition and treatments, which will never fully be known, as considered later. The *Nuremberg Code* (1948) recognised the real heart of consent: ‘1. The voluntary consent of the human subject is absolutely essential... free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion’ in the unseen volition of the thinking-feeling, choosing, deciding process of consent (Alderson 1990). US law has lower standards of respect for children’s consent partly because their parents have to pay the hospital or insurance company. The free NHS respects every child as an individual patient from the moment of birth.

Inhibiting factors at the real level of causal mechanisms that produce effects involve the dangerous and sometimes intractable nature of the innate heart problems. Concerning the political and economic context, the NHS is rapidly being privatised (El-Gingihy 2018). Before the NHS opened in 1948, few families could afford to pay for healthcare but paediatric services, resources, staff training and research greatly developed from the 1950s onwards. On the personal level of real causal mechanisms, some doctors are influenced by the profit motive and career enhancement; reports from the USA show how this can increase unnecessary and expensive treatments (El-Gingihy 2018). Disabling actual processes can also work as unseen causal mechanisms if practitioners subtly bias information or exert: ‘force, fraud, deceit, duress, or over-reaching or other ulterior form of constraint or coercion’ (*Nuremberg Code* 1948; Lukes 2005). If healthcare is regarded as a commodity, patients may be treated as work objects or sources of profit. Instead of being informed, respected partners, they may be confused, fearful, helpless and mistrustful.

The three levels (actual, empirical and real) can aid analysis of the different levels of consent but, besides being distinct, they overlap and interact in complex ways, so that elements of consent can be understood on every level. For example, trust can be understood through: 1) empirical ways in which people feel, think and talk about it; 2) the actual nature of trusting or mistrustful relationships, interactions, discussions and rituals in practitioner-family encounters; 3) the real, powerful unseen forces, social, cultural, political and economic, which influence people’s beliefs and behaviours related to trust, and trust itself. Trust can also be understood in its absence, in acts of manipulation, deception or abuse of power. The ideals of voluntary consent and perfect trust are seldom if ever fully achieved at empirical and actual levels. They might seem to be unrealistic ideals, partly emotional illusions, perhaps better dispensed with in modern scientific medicine. Yet, like gravity, the underlying enduring ineffable reality of consent, trust and the absence of coercion or deceit work like a compass. They point towards the magnetic power of the ideal, which is unreachable but guides, defines and evaluates all our interactions in how nearly we approach it or how far we deviate from it. Truth, the freedom of voluntariness, and consent are vital for practical useful reasons. They also matter at deep levels of our inalienable, authentic human nature. These three levels were partly explored in our earlier research on involving children, and now, with the benefit of CR, we look forward to analysing in more formal, organised and productive ways the stratified reality in our current research.

Why consent matters

The three levels of reality can increase awareness of why consent matters. The *Nuremberg Code* (1947) was internationally agreed in reaction to Nazi medical experiments during the Holocaust, which treated certain social groups as subhuman: Jews, disabled people and gypsies. They were assumed not to meet the Kantian standard of rational persons (MacIntyre

2002), which includes respect for their competence to consent. The *Code* was accompanied by *Universal Declaration of Human Rights* (UDHR, UN 1948). The Preamble states:

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people...

The Preamble is clear on the need to respect rights and consent and the dangers of not doing so. Consent is the personal-political right, reality and symbol at the heart of free, just and equal societies. Respect for consent is necessary: to prevent cruelty, injustice, force, fear, oppression, exploitation, conflict and suffering; to promote rational and just relations; to recognise the dialectic of individual and collective rights and interests; and to promote flourishing human relations, which express our fulfilled human nature (Freeman 2017; Gearty 2011). Yet consent tends to be seen as an adult capacity, exercised after 'the age of consent'. Can children and young people give valid consent and, even if they can, should they be expected to do so, and should their decisions be respected? Instead of assuming that competence to consent is acquired by adulthood, another approach is to search for its origins in infancy.

Consent and human nature

How is consent framed and informed by actual human nature and by concepts of human nature, morality and child development? A dominant current version of human nature is of self-interested 'economic man' (Robbins 1932) whose calculations involve making maximum profit through agreed contracts in the supposedly free market. This selfish individualism is seen by many as incompatible with just communities (Sen 1977) and with human rights and freedoms (Bhaskar 2008; Gearty 2011). The economic model is also incompatible with the above enabling model of patients as partners with doctors. Instead, it endorses views of healthcare and patients as commodities and profit opportunities, though patients are also risk liabilities if they complain or sue health authorities. Consent is then primarily a legal safeguard for healthcare providers and researchers rather than a process of respect for patients' integrity, rights or freedom. Hägglund (2019) considers the setting aside of freedom, which like CR he defines partly by absences, 'a fatal mistake...only in light of a commitment to freedom can we render anything intelligible as oppression, exploitation, or alienation.'

Many psychologists and sociologists overlook 'essential' human nature as mainly biological and, in young children, pre-social. They are concerned with how the malleable, contingent, social and moral self is constructed and acquired through language, education and culture. To Durkheim (1911/1979: 150) for years the child as an 'individual, in both the physical and moral sense, does not yet exist, [during] the period in which he is made, develops and is formed'. In that tradition, the psychologist Rom Harré (1983: 77) contended that 'all human beings are members of moral orders as persons', but contingent upon their being taught a theory of self. The child develops from being an empirical person to becoming a theoretical self by being taught a culturally acquired theory of self, only then being able to realise an organised private-individual sense of self. In later childhood, individuals can become reflexive, according to strong local conventions about acceptable rules and roles (*Ibid*: 277)

when their minds have been formed by accepted local language, grammar and structure, and by publicly agreed reasons, intentions, emotions. The conscience internalises accepted morals. The journey from biology to culture: 'from the dark foundations of the private-individual area, to be clothed in the civilising garb of acceptable interpretations' (*Ibid*: 284). This tradition prompted a founding member of the subspecialty the philosophy of education to ponder how to get young children to 'overcome their passions and self-love' so that they respect others. How, he wondered, could teachers 'sustain and cultivate a crust of civilisation over the volcanic core of atavistic emotions' until children begin to become educable when aged about 7-years (Peters 1972: 87). This view positions morality as a set of impersonal, often hard and unrewarding, unnatural and somewhat alien lessons, despite morality being a highly civilised and valued human duty. Yet the origins of this seemingly arbitrary, synthetic morality, and why it should matter, are not explained.

Hannah Arendt (1951/1973) and Zygmunt Bauman (2003) saw great dangers in teaching children unquestioning moral obedience. They believed that critical moral reasoning, personal choices and decisions (all features of consent) are crucial. They considered that the Holocaust revealed three main human groups, who show the extent of human good and evil: the cruel perpetrators, the majority of bystanders or compliers, and the few brave protestors. Ordinary good people commit evil when they obey orders, transfer responsibility up the hierarchy, and fail to see victims as persons. Morality is then the rare courage to resist and protest against unjust and cruel majority views, in compassion and solidarity with oppressed people. Consent involves dissent and the courage to resist and protest and to refuse to comply unwillingly. Such protests are at the heart and origin of all civil rights movements. Young people's active concerns are shown in the US students who started the 1960s civil rights protests, Soweto school students who started the anti-apartheid campaigns, and the school strikes on climate change that bring new urgency to politics.

Instead of favouring obedience that assumes actions are evil if they are against the rules, which would override individuals' free thinking and consent, Arendt (1951/1962) and Bauman (2003) believed that rules should only be made if they prohibit actions that are evil. This view respects public needs, consensus and consent. It potentially transforms beliefs about good and evil, right and wrong, from the edicts of remote, possibly divine, authorities and unquestioned traditions, into our everyday challenging, questioning, living realities, our human nature, conscience, actions, relationships and consent.

Alvin Gouldner (1977) considered that sociologists' attempts to seem objective and value-free simply remap and reorder the world towards other moralities of prudence or profit, utility or rule-keeping, or appearance (Goffman 1959). The usual human assumption is to equate power with goodness. When 'value-free' utilitarianism frequently pronounces that things of power (such as finance) lack morality, and things of value (such as rights and justice) lack power, this seems incongruous (Gouldner 1977:84f). Older moralities (arising from human nature), Gouldner believed, include attachment and shared need, the virtues of 'kindness, courage, civility, loyalty, love, generosity and gratitude'. Yet these have been replaced, he contended, by calculated rational self-interest, which dismisses virtue as sentiment, 'thinly disguises avarice', and resolves personal worth into exchange value (Gouldner 1971: 74).

What kind of beings would we be if we did not instinctively (rather than calculatingly) want to do good and enjoy doing so? To reduce human nature to amoral biology denies our intensely embodied social and spiritual qualities, our continuous practical activity in the material world, and physical-emotional suffering, passion and compassion. The morality of compassionate solidarity can be seen as part of human nature and matters to us well beyond the level of talk (Marx 1844: 118; Seidler 1986; Midgley 2002; Sayer 2011, 2019; Smith 2010). Bauman questioned where concepts of morality come from if they are all somehow socially imagined, constructed and taught. Who invents them, how and why? He questioned

Durkheim's view of wholly cultural morality imposed on young children, as if it is alien to human nature. Bauman wondered if there might be 'pre-social grounds of moral behaviour'. If so, he thought, we would need radical revision of ideas about 'the origins of the sources of moral norms and the obligatory power' (Bauman 2003: 177). He did not pursue these ideas, which raise the questions: What does it mean to be human and when does human moral life begin?

The four planes of social being

The framework of the four planes of social being (Bhaskar 2008: 153f) aids social analysis by drawing attention to the four distinct planes and their constant interactions. The planes will be considered in turn: physical bodies in relation to nature, interpersonal relations, social structures and inner being. Some examples of babies show how the later more formal capacity to consent develops from babies' early intuitions and responses. And consent matters so much because it relates to our innate human integrity and identity.

Plane 1. Bodies in relation to nature

Margaret Archer's (2000, 2003) analysis can be applied to explain, first, why consent to surgery matters so deeply, when it is connected to ultimate concerns of personal survival and, second, why the views and consent of young children are worthy of respect. Archer (2000: 105f) reverses Harré's theory, to show how our learning does not begin when we acquire language and are taught formally, but it emerges through our biological body-brain and experience in the natural world. Archer contrasts our *sense* (felt experience) of our embodied human selfhood gained through practical activity versus our later acquired *theory* of self conferred by society (Ibid: 125). We know and sense ourselves to be the same being over our life-time through our two dominant forms of memory: sensed recognitions (a face, a scent) and countless physical habits and skills (walking upstairs, clapping hands). Crucially, both these kinds of embodied memories are non-verbal (Ibid: 138). They begin before birth when even premature babies remember and turn towards their parents' voices preferring them to other voices (Als 1999; Mendizabal 2017). Appreciating social animals' highly complex lives (Midgley 2002; de Waal 2013) increases understanding of babies' complex thinking, which micro-recordings of their gaze and heartbeat rate reveal (Bloom 2014; Gopnik 2010). Over millennia, natural selection appears to favour sociable caring human parents and babies, who enjoy higher rates of survival, so that empathy appears to have evolved into an innate human capacity (Broad et al. 2006; de Waal 2013; Bloom 2014). Consciousness in all living species is constantly concerned with physical survival. In humans, this ontology involves promoting wellbeing and reducing suffering (Turner 2008; Bhaskar 2016), amplified by the powerful subconscious (Pilgrim 2017) and intuition (Haidt 2008). Babies' protests, if they are left in a strange place with strangers, can then be seen as logical and necessary.

Plane 2. Interpersonal relations

On this second social plane, babies' protests may be seen not simply as an irritation, which adults ignore so that childcare systems function smoothly. In well-intentioned systems, most babies adapt to being left. Yet one logical reason why babies need to be with a main person whom they trust is that they keep checking the reactions on that person's face to each new experience. Is it safe or harmful, threatening or amusing? From birth, babies engage in the micro-interactions of speech, nodding in time, waiting for a pause before responding, and by

three months they initiate as well as respond to playful and loving interactions (Stern 1977). Babies' constant fascination with other people challenges the views of Jean Piaget (1924) and Melanie Klein's version of psychoanalysis (1987), which still influence critical realism (for example, Archer (2000) on Piaget, and Wilson (2019) on Klein and therefore they will briefly be considered.

Young children's competencies are greatly underestimated. Piaget's (1924) theory that children aged under-six-years cannot understand conservation of mass was refuted by three-year-olds (Donaldson 1978), yet continues to be more widely accepted than the newer evidence. Feminists are gradually unravelling the centuries of patriarchy's silencing and misinterpreting of women, but patriarchy's greater effects on children, still promoted through child development theory as a slow biological unfolding, have scarcely been challenged so far, despite the 'new' sociology of childhood (for example, James and Prout 1990/1997; Alderson 2013, 2016). Many developmental psychologists still assume that language must be their research medium, and test children's understanding through children's own verbal explanations, unlike newer preverbal approaches (Stern 1977; Murray and Andrews 2005; Gopnik 2010; Bloom 2014). A psychology professor mentioned a child aged 5-years knowing about heat and cold. One of the authors observed a 15-month-old child help to lay small logs in a wood-burner. He watched the fire being lit, helped to replace the fireguard, then turned to warn her, shaking his head and saying, 'Hhh, hhh,' (it's hot, don't touch), showing his preverbal understanding of social and moral values associated with fire.

Klein (1924) explored babies' aggressive fantasies of hate, envy and greed and traced their development from the initial paranoid-schizoid position, with fear of invasive malevolence projected out of the death instinct, to the depressive position. Extraordinarily, babies' relationships were perceived as object-relations rather than as interpersonal relations, in their supposed destructive defence against the pain of loss, and 'megalomaniac' denial of vulnerable dependence. The depressive position of gradually realising both good and bad in others is believed to enable older children to develop sympathy and love. While people of all ages feel these negative emotions, besides many positive ones, why does Kleinian psychoanalysis see babies' emotions so negatively? The newer psychological research cited earlier (and the authors' daily experiences of living with babies) are far more positive about babies' early capacities for joy, love, sympathy, generosity, trust and being actively helpful.

Possible reasons for Klein's emphasis on the distressed angry baby include: Klein's own clinical pre- and post-natal depression and time away from her children while having treatment; the trauma for Klein's family and friends of lethal anti-semitism, repeated asylum-seeking during two world wars and the Holocaust; her clinical work with very disturbed children; the harsh era of Truby-King 1907-1970s, when white mothers of the British Empire (later Commonwealth) were told that to safeguard their babies' health they must feed them only at four-hourly intervals and avoid touching them (Bradley 1989); the pain for children of pre-1940s upper-middle-class distancing of parents from children who were largely consigned to the care of servants and boarding schools (Proust 1913/2001; Bowlby 1953); and Klein's scientific concern to identify and heal pathology. She 'made the death instinct the centerpiece of her work with children...the child as a being interminably at war with itself [*sic*].' As international political reparations faltered through the decades, Klein's 'ethical aspiration to reparations' and restitution struggled 'to realize an individualized form of socio-political justice' (Laubender 2017: 107-8). There are also the preceding centuries of belief in innate original sin and mistrust of nature (including in the biologised pre-social child) that are central to patriarchy, and of men requiring devoted care from wives modelled on the prototype of the needy baby and the mother-figure (Merchant 1982; Bradley 1989). The constant current comparison of badly behaved politicians with angry babies is another instance of fallacious splitting and projection. Adults reserve all good qualities for

themselves, and project their failings onto the assumedly wholly volatile, irrational child. Freudian-Kleinian psychoanalysis needed to deny that actual child abuse was widespread (Miller, 1983), so posited a hierarchy of health/pathology, truth/falsehood (Pilgrim 2017: 477): the scientific, healing analyst; the analyst and recalling deceptive memories not actual events; and (we suggest) the pathological baby. Before children's consent and dissent can be respected as reasonable, outdated views about childhood have to change.

Plane 3. Social contexts and structures

The third plane of social being ranges from social, political and economic structures to abstract, cultural structures such as childhood, which involves beliefs that vary greatly across time and place about what children are like and what adult-child relations ought to be like (James and Prout 1990/1997). The development of paediatric services, noted earlier, is the structural context for children's surgery and medical treatment. These are life-enhancing and life-saving in many countries but are still denied to millions of children.

Social, cultural and natural structures complement and compete with one another while agents reproduce or resist them. For example, for children with type I diabetes, their consent, meaning their informed willing commitment to their diabetes care, is vital. They need daily finger-prick blood tests, insulin injections, and careful control over their diet. Unless these are understood, accepted, and often administered by young children themselves, then the child may fearfully resist and have to be coerced, endangering physical and mental wellbeing (Sutcliffe 2010; Alderson et al. 2006). Children are meaning-makers and need to know the explanation or 'story'. A 4-year-old explained, 'insulin is the key that turns sugar into energy', knowing from her low blood sugar episodes how severely lack of energy could affect her. Older children feel increasing pressures from healthcare staff who advise strict compliance with structured daily medical routines. Yet they also feel social pressures to be 'normal' and 'just like my friends'. Their medical 'non-compliance' can seem foolish unless their difficulties with competing clinical and social structures are appreciated.

Consent exists within ethical and legal structures. International law identifies four levels of contributing to decision-making: 1) to be informed; 2) to form and express views; 3) to influence a decision (UNCRC 1989, Article 12); and 4) to be the main decider about proposed treatment or care (*Gillick* [1985] recognised in English and Commonwealth law; Alderson and Montgomery 1996). Babies prefer 1) to be informed in being warned and prepared. Blind babies startle and cry if they are suddenly picked up and need adults to talk to them while they approach. Babies certainly 2) form plans and preferences and express strong views and 3) they inform and influence adults' decisions about their daily care (Als 1999; Alderson et al. 2005; Mendizabal 2017, Mendizabal & Warren 2019). Although lacking the reasoned, verbally informed, formally negotiated capacities to consent, nevertheless from their early days, babies 4) begin to express a rudimentary consent/refusal in their interactions with others, in their willing cooperation, passive compliance, or active resistance. English/Commonwealth law exceeds the UNCRC, in that minors aged under-16-years with no specified lower age limit can give valid consent to treatment, provided the child is 'able 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]). The US concept of 'assent' by legal minors is spreading internationally, and its meaning varies from informed decision-making to practitioners leaving parents to decide when, how, and even whether to inform and listen to their children (Biggs 2009; Alderson 2012).

Age is not a clear criterion for assessing children's competence to consent. More salient criteria are children's experience of the illness and the treatments, of sharing information and

decisions with adults, and their courage and confidence (Alderson 1993, 2018; Alderson et al., 2006). This relates to the fourth plane.

Plane 4. Inner being, the fourth plane of social being

Years before children are *Gillick* competent and able to give legally valid, informed, voluntary and wise consent, we suggest that they show early capacities. If innate, the capacities are more than synthetic, acquired skills or tastes; they are authentic, profound, integral and inalienable to human nature. The capacities include sensitive awareness of risk and trust, safety and danger, fear and pleasure, cooperation and coercion, compliance and resistance, and morality. Beyond words, morality inheres in babies' emotions, relationships and interactions from birth (Murray and Andrews 2005; Gopnik 2010). They soon show strong preferences, joy when a beloved person appears and grief when the person leaves. If harmed, even premature babies show strong memories of fear and mistrust (Als 1999; Mendizabal 2017). By six months, babies express concern and empathy for others (Darwin 1877). When babies aged from 3-months were shown puppets that acted well or badly in hindering or helping one another, micro-second-videos of their gaze and responses of attention and surprise showed their interest in the goodness and badness of others' actions (Bloom 2014). Their rudimentary sense of justice seems to develop long before concepts can be explained to them in words. When they do begin talk, before they are 2-years they often claim, 'it's not fair'. Archer (2000) analyses how our 'sense of self' could seem wholly epistemic, but it is also grounded in ontology, in the primacy of practice rather than language, and the human power of self-consciousness. This determines what we care about. Far from compromising our rationality, our emotions inform how we care consistently, actively and enduringly about certain people, objects and actions (Wiesemann 2016).

Christian Smith (2010: 340) identified 30 human capacities. They include being a conscious, reflexive, embodied, self-transcending centre of subjective experience, with a durable identity, moral commitment, in social and emotional communication and loving relationships with other personal selves and with the non-personal world. However, Smith sees personhood as an emergent property of human nature, developing gradually through four stages towards adult 'higher capacities' such as interpersonal communion and love. Yet research, mainly by women and often with their own children (Gopnik 2010), suggests that all 30 capacities are arguably present from birth, in rudimentary potential ways as innate and essential parts of human nature (Alderson 2013: 156-171; Alderson and Yoshida, 2019). Babies are especially good at interpersonal communion and love, loyalty and trust. Smith (2010: 400) sees humans as each having a telos in 'the essential nature of their true human personhood' which provides 'a broad but definite vision of what an excellent version of one's life looks like'. One way to see excellence is not at some adult mid-life high point, but at each stage, living life fully as a baby or as a very old person. There is lifelong developing emergence of the originally innate reason, imagination and compassion, but there is no clear correlation of age with virtue. 'Sociology needs to overcome its bizarre indifference to the early years of life, and give more attention to the question of how we contingently become persons. This would require the mutual contempt and competition between sociology and psychology to be replaced by a dialogue in which both are prepared to change' (Sayer 2011; see also Pilgrim 2017).

The four planes of social being help to show why consent matters, for physical and mental self-preservation. To overlook a child's consent or refusal then becomes more than a technical or legal problem when it could seriously wrong the person, violate respect for her integrity, and arouse potentially justified fear and distress. Morality moves on from being cultural norms into being necessary protections and guidance with direct, urgent meaning

when it protects the self and others, is rooted in vulnerable, needy human nature, our interdependence and long, dependent childhood, and when it promotes human flourishing and reduces suffering. This will be illustrated by an example in the next section.

Consent as emergence and process: the benign dialectic

Whereas the four planes of social being are partly spatial, sited in the body and surrounding contexts, the four stages of the critical realist dialectic are partly temporal, progressing forward and interacting back and forth over time. (For clarity and brevity, we avoid the rather confusing acronym MELD and other important CR terms and details, see Bhaskar 2008, 2016: 112-143).

The main theme in this paper is life-long respect beginning with young children's views, needs and rights. Ontology (their being and doing) can matter more than epistemology (explicit verbal discussion). '[O]ur embodied and practical knowledge develop in direct interplay with nature and material culture...many of the things that humans know have not been filtered through meanings belonging to the discursive order'(Archer 2000: 189).

The four-stage benign dialectic helps to reveal consent as a positive process and journey, not an event. Later, a malign dialectic will reveal problems. Benign stage 1 involves absence and non-identity when researchers do not impose their assumed identities and explanations, but stand back to examine absences. Like anthropologists, they search for hidden inner meanings held by the people they observe. Similarly, when patients have unidentified illnesses, doctors do not stop at the visible symptoms and offer palliatives. Instead they search for often unseen causes, in order to understand how to cure or prevent illness. We have researched the often ignored perspectives of children aged 3- to 15-years. How much were they informed? At what age do they, and the caring adults, believe they are able to give informed and willing consent to major surgery 'as well as their parents can', or to understand and share in managing their daily diabetes care? (Alderson 1993; Alderson et al. 2006; Sutcliffe 2010). How do sick and premature babies inform adults about the kinds of care they need? (Alderson et al., 2005; Mendizabal 2017; Mendizabal and Warren 2019). The research shows the importance of understanding and working with children, not against them, and respecting their informal tacit consent in moral though not necessarily legal terms. Compared with almost infinite absence (all that was, or will be, or might be, or is elsewhere), the present is only a ripple on the ocean of absence (Bhaskar: 1998: 5). For example, current limited medical skill and knowledge exist within almost infinite possibilities, so that treatment decisions, prognoses and consent can only be partly informed.

Stage 2 involves interventions to negate problems and overcome coercion (termed negative 'power2' in CR), transforming it through creative freedom ('power1'). Doctors and patients discuss options, and decide on diagnoses and treatments intended to negate the negations of illness in its causes and effects. Consent is the catalyst, when experiences, options and reflections gather to the point of signifying consent, and are channelled and transformed into decision and action. The person chooses to act, or feels forced by others into compliance or other coercion. This interaction between individuals and their social and cultural contexts epitomises morphogenesis (Archer 2000, 2003) and the transformational model of social activity (Bhaskar 1998). Judges speak of minors' confused overwhelming feelings, and their need for adults to decide for them. When a 15½-year-old refused a heart transplant, an emergency legal hearing, without consulting her, authorised the transplant, which was performed (Dyer 1999). In 2008, Hannah Jones aged 13 refused a heart transplant, after her heart was damaged by ten years of leukaemia treatment, and she thanked her parents for respecting her views (Jones 2008). Her mother was an intensive care nurse who has worked

in transplant units. Hannah consented to a transplant the following year, and recorded her joy that she has survived. However, when facing the need for high-risk surgery on their child, adults too feel overwhelmed by emotions at first. They need time to journey from fear and rejection, sadness, shock and perhaps horror at the prospect of surgery, towards doubt, growing trust and confidence in the clinical team, belief that the untreated condition can be worse than the treatment, and then courage and resolve to consent. Respect for consent involves allowing the time needed for this journey whenever possible (Alderson 1990).

Stage 3 of totality and synthesis draws together assumed opposites, body/mind, doctor/patient, fear/hope. Each element is understood to be distinct and partly independent, not conflated, so that their interplay or dialectic may then be traced (Archer 2000: 306; Bhaskar 1998). Gradually, absences are filled (all being well) and negations negated, when trusting partnerships develop, information is shared, surgery actually heals impaired bodies, and patients expect a new healthier life. For researchers, stage 3 offers space to combine micro and macro reports in their social, political, economic and global contexts of worldwide research, training of healthcare staff and development of technical resources.

Stage 4 examines transformative emancipatory power¹, both within all the agents concerned, and in collective movements towards freedom, justice and health. NHS staff, for example, are often praised for their patience and kindness as well as their skill. There is constant learning from experience, successes and mistakes, in a continual reworking of the dialectic, which returns to stage 1 with new insights to repeat the virtuous cycle.

The search for the origins of human values, motives and hopes, which are more than simply learned or acquired, reveals dimensions of consent relating to inalienable aspects of evolved human nature. The United Nations' (UN 1948 1989) concern with 'the inherent dignity and of the equal and inalienable rights of all members of the human family' was mentioned earlier. Dignity has been dismissed as 'a useless concept' (Macklin 2003). Yet adults and children immediately know when their dignity is disrespected. Dignity, like inalienable rights, is most apparent when it seems to be absent if children are neglected or abused, coerced, exploited or ridiculed. Without that respect, bioethics review of patients' cases can risk turning into a mechanical exercise without motive or real meaning. It may be a self-interested legal-economic precaution, without concern for the other person's capacities and vulnerabilities. Macklin claimed that dignity is shown to be useless in its irrelevance to how a corpse is treated, because a corpse 'is no longer a person but a cadaver' (Ibid). Yet this denies the importance in most societies of respect for deceased people and their remains, celebrated in Sophocles's 5th Century BCE *Antigone*. 'To treat a child with dignity' might seem a vague concept, which can confusingly transfer dignity from a quality inherent in the child to a description of the (adult's) act. Yet dignity is emergent, when persons can realise their telos, and it is 'an inherent worth of immeasurable value that is deserving of certain morally appropriate responses' (Smith 2010: 400, 435).

Ineffable dignity can be understood through ontological realism (accepting the referent of the child's humanity, and of appropriate relations between members of the same species), through epistemological relativism (accepting that dignity is understood and experienced in many different ways), and through judgemental rationality (accepting reasonable defences of this reality). Dignity, one's own and others', is empirically and subjectively experienced, yet also objectively and actually recognised, respected or disrespected. Like truth, at actual and empirical levels, dignity may be seen as ephemeral and even imaginary. They therefore also need to be understood at the unseen real level of causal mechanisms at the default centre of human identity and relationships (Bhaskar, 2016: 170).

Besides benign processes, the four-stage dialectic can trace unhelpful or malign processes. Vital stages 1, 3 and 4 may be neglected or omitted, and intervention stage 2 is therefore ineffective. Yet stage 2 may then be repeated or reinforced. (An example is President

Trump's policy simply to build a wall to keep out immigrants.) The following example reveals a dialectic of missing processes.

Surgery for conjoined twins?¹

Stage 1, investigation. When Marieme and Ndeye were born as conjoined twins in Senegal in 2016, their father Ibrahim Ndiaye contacted hospitals around the world, and a surgeon at Great Ormond Street Hospital (GOSH) London offered to help. Ndiaye left his wife and four older children in Senegal and now lives in the UK. The surgeon had separated more than 30 sets of conjoined twins, but always when both children could survive independently. Marieme and Ndeye have separate heads and chests, and one arm each. They share a common abdomen, two legs and a central arm with two hands, which they use together skilfully. In a film (BBC 2019), when they were nearly 3-years-old, they smiled and played, perfectly coordinated when they sat and shuffled along on the floor.

Ndiaya said that before he arrived in London he was sure 'they will find a solution'. But then, he said, 'Paolo [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' (Sherwood 2019). In the sole precedent of twins being separated in Britain when only one could survive, they were aged 3-months and the parents withheld their consent (Brazier and Cave 2016: 440-442). Critical, searching questions about the twins' actual needs and interests, their anatomy, the social and moral dilemmas raised, the differing contexts in Senegal and in Britain, and the kind of 'help' offered seem to have been missing at stage 1 before the twins were moved to London.

Stage 2, intervention. Ndiaya was advised to consent to the twins being separated before Marieme became so weak and dependent on Ndeye's circulatory system that Ndeye would also die. He could not bear to give consent. 'In this situation, you don't use your brain, you follow your heart. Any decision is heartbreaking, so much turmoil, so many consequences' (Sherwood 2019). The BBC film showed the GOSH advisory Clinical Ethics Committee (CEC) holding long discussions, trying to resolve the dilemma. The CEC had advised on the highly publicised Charlie Gard case (Dyer 2017; Linney et al. 2019), when doctors and parents disputed through the law courts whether life-support should be withdrawn from a terminally ill baby. CEC members considered referring the twins' case to the courts in order compassionately to relieve from the father having to decide, 'in a way that would make it easier for him because it's not his decision' (BBC 2019), as if parents' painful moral responsibility can be delegated.

The CEC members shown were mainly doctors, and the philosopher member stated support for the medical view: in 'disagreements between doctors and patients [about] factual matters (will this treatment work, for instance)...it is unclear why medical expertise should not be decisive' (Archard 2019, 145). Yet information alone cannot be decisive. It is often contested, may be mistaken, and effective treatment may be not wanted. However, the philosopher criticised some doctors who also work as bioethicists when, he said, they fail the basic task of bioethics 'to evaluate the normative framework within which such disagreements are to be understood and also to [avoid] their degeneration into open conflict' (Archard 2019, 146). During the film (BBC 2019) he asked, 'What's a life that's worth living?' No discussion was shown either of this question, or of the only serious comment about the girls' views.

This comment came from a paediatrician who said of 'dad', Ibrahim Ndiaye: 'He's the one who will have to live with the consequences. He will even potentially have to live 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.’ No one in the film questioned the assumption that Ndeye would not ask sooner than ‘a few years time’, or questioned how the twins would be informed and prepared, how their views might be sought, or how Ndeye could be supported after surgery. Young children need explanations, or they assume events such as surgery are a punishment for some wrong they have done, and suffer guilt (Miller 1983). Some children seem to choose to die after unwanted surgery. ‘Their life is in their hands’, a senior transplant nurse warned (Alderson 1993: 162-3). Lack of explanations would increase Ndeye’s loss and loneliness. Individualist bioethics complicates efforts to imagine the 3-year-old twins’ symbiotic life and identities, each an individual, a twin, and a part of the greater whole of conjoined twins. To be conjoined with another in love, friendship and intimacy has been imagined as a blissful state of never feeling incomplete or lonely (Plato, 2003). How could Ndeye form a new life as a sole, severed survivor? Was her dignified father, sustained by his Sufi Muslim faith, hinting at this when he said: ‘They are together. They are equal...I will never let them walk alone’ (Sherwood 2019). The CEC members aimed to ‘offer different perspectives from everyone who’s involved’ but they excluded the children’s views, apart from reports that they ‘clearly love each other’ and ‘are happy’. The CEC evaded moral debate, first with medical discussions and second with euphemisms. Apart from the ‘sacrifice’ mentioned above, Marieme’s certain death was usually evaded with talk of ‘risk’, ‘harm’, ‘the separation’, ‘existentially letting one [twin] down’, ‘succumb’ and, from a surgeon, it ‘will almost inevitably lead to the end of her life’. The ‘girls’ interests’ were discussed as if they were united, and remained unidentified in the film apart from talk of ‘survival’ and vague ‘quality of life’. Everyone seemed to find words inadequate, and this summary cannot convey the intense and empathic though, at least in the film, adult-centric meetings. Surgeons hoped to operate in time to save Ndeye and warned the father that they knew that Marieme was almost too weak for the surgery to be feasible. He repeatedly replied that he needed clearer evidence before he could decide, until eventually the surgeons agreed it was too late to attempt the operation.

Stage 3. The case raises questions about: the limits of modern medicine; the god-like decisions; whether medically-dominated CECs are the best means of scrutiny and support; the absence of skilled, experienced advocates for the children (Als 1999; Winter 2011); how the twins’ healthcare was financed, and in whose interests; the reliability of the BBC film, influenced by GOSH’s large public relations and fund-raising departments; the economics of children’s healthcare globally, when scarce practitioners and resources are so unequally distributed, and low-cost, low-risk, effective care is denied to so many children. There is the growth of litigation when numerous formerly private decisions now go through the courts (Sumption 2019), and through US-style CECs (Doyle 2001), depriving ‘parents of their normal moral and legal right and responsibility to decide on their child’s best interests’ (Gillon 2018). The global spread of streamlined US models of parental consent (Larcher et al. 2015; McDougal et al. 2016; Nuffield Council, 2019; Wilkinson and Savulescu 2019) overrides children’s views, rights, values, trust and voluntary consent (Biggs, 2009; Alderson 2012, 2018; Wiesemann 2016).

Conclusion

Stage 4 of the CR dialectic includes drawing conclusions and is the basis of this conclusion. In the dilemma of the twins, stage 4 draws together, stage 1 inadequate analysis of absences and unknowns, stage 2 unproductive attempts at interventions to negate negations, and stage 3’s greater concerns and totalities, which pervade, shape and help to explain individual cases. Stage 4 examines personal and political self-transformative agency and emancipating power in the benign dialectic that is the pulse of freedom. It cannot offer a solution to the dilemma,

but perhaps can offer ways to enlarge analysis and insight. It is vital to prepare and support children as much as possible, to listen to their unique and essential views before and during all healthcare treatments, and to give these ‘due weight’ (UNCRC 1989: Articles 12 and 13, and authors’ research).

Archer (2000: 306) calls for ‘the re-emergence of humanity [when] due acknowledgement is given to the properties and powers of real people forged in the real world’. The paediatrician-bioethicist CEC chair said, ‘We always put the child at the centre of everything’. Yet ‘the child’ here seemed to be a cipher, not the two, conjoined, real, physical-social-moral people. CEC members do not work closely with the families whose cases they are supposed to review objectively. The CEC philosopher remarked that, if they were adults the twins’ consent would be respected, but that is not possible for children, as if that excuses no discussion at all with them. Alderson and Montgomery (1996) question this all or nothing assumption based on adult legal standards of consent. Instead of assessing how far a child falls short of that ideal standard (which many adults fail), it is worth examining the meaning and purpose of voluntary consent, and the knowledge that informs it, in its self-preserving, self-fulfilling, embodied, partly instinctive innate origins. Emotions, far from detracting from rationality, are vital commentaries on human concerns (Alderson 1990; Archer 2000; Haidt 2008). The validity of CECs with no immediate contact with these human processes is questionable. CECs risk displacing child patients and parents, and treating children as malfunctioning machines to be repaired, not as persons.

A moral approach would include attempting to listen to the twins, and viewing the dilemma, as far as possible, from their two uniquely individual and shared perspectives. If they were adults, it is possible that Ndeye could only manage to create and live her new single identity if she believed that was what Marieme wanted for her. As a moral meaning-maker, would Ndeye need some childlike version of that belief for her 3-year-old self? If so, is there any way to nurture it? If not, could a separate life possibly be tolerable for her? This approach could seem unacceptable. Yet though talking (epistemology) may seem too cruel, the actual separation (ontology) is far worse for the children, involving realities the CEC seems unable to face.

Critical realism can help to analyse these and other possibilities that respect children’s early, partial versions of informed and voluntary consent, not in order to meet legal standards but to help to inform adults’ decisions, to reduce children’s fear and suffering, and to support their trust and flourishing.

Note

1. This section is based on a BBC film of the actual case, and an interview with a journalist, not on detailed direct research. There may be errors, however the film was made with the hospital authorities and is likely to have been carefully checked for accuracy and for presenting an account the hospital would wish to promote.

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