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Autonomy of the Child in the South African Context

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Abstract

Access to healthcare for all members of society is a right enshrined in the South African Constitution. Worldwide policy makers are beginning to lower the age of consent to medical treatment in response to the changes within society as well as to fulfil international obligations. The age of full legal capacity in South Africa is 18, when section 129 of the Children's Act of 2005 came into effect it empowered children over the age of 12 with the capacity to consent to medical treatment, if they are deemed to possess "sufficient maturity". This article examines the legal and philosophical approaches to the consent of children, with a focus on the South African context. Furthermore, it looks at the development of the adolescent brain to see if functional neuroimaging has presented us with an answer to the question of adolescent's functional capacity for consent.

Keywords: Autonomy; Children; Medical treatment

The Unfortunate Realities of the South African Minor

Section 129 of the Children's Act of 2005 [1] takes into account the emerging autonomy of the adolescent within the South African context, and aims to remove certain barriers from the access to medical treatment for this age group. The previous laws governing the consent of minors to medical treatment required the consent of a biological parent or a legal guardian. This was simply not practical in South Africa and it resulted in an unconstitutional barrier to the access of medical treatment, as minors who have lost their parents often live in a household headed by another adult who is not their legal guardian [2]. In South Africa, UNICEF estimated that, in 2008 there were 3.7 million orphans, 98000 child-headed households and that only 32% of children lived with their biological parents [2]. This was especially problematic considering that orphans and vulnerable children without legal guardians are at an elevated risk of contracting HIV and becoming pregnant [2]. Because of the unique South African context the health care act was revised to be more representative of the needs of the people it serves. Medical intervention and information has been shown to actively decrease the likelihood of these conditions [3]. The new act makes provision for these unique, however distressing, realities of the South African child in the 21st century.

Sufficient Maturity

Neuro-anatomical development of the human brain and its functional implications

The changes in neuroanatomy are reflected in the progression from a care giver dependent child to a fully autonomous adult. The major difference found in brain development and maturation during adolescence is the volume of white matter [4]. The brain begins forming new synapses and there is a linear increase in white matter during adolescence with a resultant higher volume of white matter in both the frontal as well as the parietal lobe [5]. This reflects the increased axonal myelination in both the parietal and frontal cortices during adolescence. It is a reasonable deduction that cognitive abilities specifically relying on the functioning of these regions as well as their ubiquitous interconnectivity will reflect these neuroanatomical changes. In addition, adolescence is a period characterised by an increased vulnerability due to disjunctions between the developing brain and cognitive and behavioural systems [6]. These tend to develop at different rates, and are controlled by often unrelated processes. Adolescents are faced with the newly acquired need to regulate their behaviour and their affect [6] in terms of long terms goals and the consequences of their decisions. It can be deduced that the normative

development during adolescence is a combination of emotional, intellectual, behavioural and physiological tendencies with varying capabilities. Evidence shows that during adolescence the brain changes significantly in terms of structure and associated function. Early adolescence is therefore characterised by a marked improvement in reasoning ability. Particularly adolescents develop the capacity for abstract, planned and hypothetical deduction as they progress towards middle adolescence. Especially relevant to consent to medical treatment is the development of the brain regions associated with the calibration of risk and reward and regulation of emotions, fMRI studies have shown the left dorsolateral and ventromedial prefrontal cortex are especially involved in the comparison of the costs and benefits of outcomes [7]. Relevant to the question of informed consent is the capacity for executive function. This includes long-term planning, selfevaluation and the ability to coordinate their cognition. The prefrontal cortex is especially involved in executive function and it is also one of the last regions to show a loss of grey matter during the latter stages of adolescence [8]. This translates to it being one of the last regions of the brain to mature^{1.2}. This immaturity of the child brain accounts for poorer and less efficient frontal lobe activation, which is why, on fMRI, adults possess faster and more efficient transfers of information within frontocortical circuits [4]. Long term planning may be affected in children as children have been shown to be generally more risk prone than adults [9]. Certain studies have reflected a positive relationship between the volume of the anterior cingulate gyrus and the avoidance of harm in adults [4]. It has been suggested that the low recruitment of motivational brain circuitry in adolescents due to differences in activation of the mesolimbic [5] circuitry leads them to compensate by engaging in more incentive-driven, risky behaviour than adults, despite knowing and understanding the risks involved. Adolescents simply weigh the potential benefits of a decision greater than the potential costs [10].

However, the way adolescents think in the real world is not simply based on cognitive processes, but is a combination of social and

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emotional aspects. Their reasoning with regards to real life situations is not as developed as an adult's. Adolescents do not, and perhaps are not able to, rationally weigh the benefits and consequences of their decisions, but are swayed by social influences and so called gut feelings which appear to be products of the affective systems of the brain [6], outside of conscious awareness.

Piaget, Locke, Kant vs the new evidence based theories of psychosocial development

The issues inherent in either allowing or preventing minors from consenting may burden them with decisions that they do not have the intellectual capacity [11] to make or prevent them from making decisions for which they are fully capable. One of the fundamental principles upon which minors are treated differently within the criminal justice system, for example, is their perceived diminished capability for mature judgement. This immaturity is suspected to be due to the cognitive and psychosocial differences between a child and an adult [10]. The process of decision making changes with the development and maturation of a child. In terms of criminal, antisocial behaviour by minors, the question asked of competence is not whether their antisocial decisions were inherently bad, but whether their coming to these decisions arose from factors that put adolescents at an inherent disadvantage for rational thought in certain situations [10]. Age differences in decision making are postulated to stem more from differences in concerns, than competencies in children as opposed to adults. The factors inherent in psychosocial maturity can be broken down to responsibility (selfreliance and a personal identity), perspective (considering viewpoints from multiple perspectives and placing them within broader contexts) and temperance (an ability to limit impulsivity) [10]. It is impossible to measure maturity of judgement directly. According to Piaget, the stages of cognitive development between 11 and 13 may exclude minors from being able to provide meaningful consent [12], in addition the tendency of children at this stage of development to deference is so normative that their ability to actually provide voluntary consent may be tenuous up to age 14 [11]. The ability of a person to "know" must either be recalled or be characterised by a behaviour that reflects the person's knowledge [11], both are related to intellectual functions and inherently to maturity. The capacity for "knowing" can be defined as semantic knowledge provided by the professional or defined operationally as a paraphrasing of the information given by the health professional. It is important to account for the minor's familiarity with the content that is being discussed as well as the minor's linguistic background. A person's capacity to understand legal as well as ethical terms has been shown to follow a predictable sequence of psychosocial development as they develop in their maturity [11]. Intelligent consent seems to require the capacity to delay a response sufficiently to reflect upon information given and to employ all available cognitive resources. A person's perception of whether or not they have control over their own fate will affect their ability to sufficiently engage their cognitive processes to deal with the myriad of decisions resulting in informed consent. Children below the age of 13 are significantly more prone to perceive that their locus of control is external as opposed to adults [11]. This leads to a more passive acceptance of their fate and of the external influences upon their lives. A person needs to be able to entertain cognitive dissonance especially in terms of medical treatment and alternatives. This involves entertaining their personal views as well as other alternatives as potentially valid. This also involves the ability to role-play as well as the ability to comprehend the emotions, intentions, opinions and beliefs of other people. This is argued as not being possible in children of this age group due to Piaget's "egocentrism" and has been declared a cognitive and moral weakness in this age group. However, in practice many children between 12 and 14 have been found to be adept at role-playing skills [11]. Piaget also suggested that the movement from concrete to formal intellectual operations occurs between 10 and 13. Some adults who have full legal capacity never reach this stage of formal intellectual operation[11]. Therefore at 12 most minors have attained a stage of cognitive development that predominates in the adult population. There is no clear evidence that a random sample of adolescents would be less adept at formal complex thinking than a similarly random sample of adults. Consent is often implied with the patient's compliance [1], which may present a problem with children, as they are inherently more compliant, or inherently less compliant with adults and authority figures. The consent given by a minor should not simply be acquiescing or a deferred response to the authority of the medical professional. Children of this age have a heightened concern for social expectations and conformity and this might impact their ability to consent [11]. Piagetian theories of child development have certainly overemphasised the perceived ignorance, inexperience and absolute lack of the ability to make informed and autonomous decisions in children. Immanuel Kant and John Locke believed children to be alike to animals or machines in being prerational and premoral [13], and that their views could not be informed nor trustworthy and therefore their decisions are usually compliant or resistant with no due cause. Children have also been argued to lack the Kantian autonomy or will require for making voluntary decisions.

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Age is a significant predictor of decision making only when psychosocial maturity is not taken into context, however, when it is taken into consideration the effect of age becomes insignificant [10]. Psychosocial maturity has been shown to significantly predict mature decision making. Significant numbers of adolescents are able to show a higher level of mature judgement compared to less mature adults. The specific regions within psychosocial maturity wherein an adolescent scores below an adult are on self-reliance and personal responsibility, as well as being able to view things in a long-term perspective [10]. The average adolescent can be justifiably stereotyped as more myopic, less responsible and less temperate than the average adult; but not as premoral, prerational or unable to employ rational formal operational skills. Therefore the argument should perhaps not be of whether a child of 12 should be allowed to consent, but whether a child who could be objectively shown to be competent enough to consent, should be given the right to.

Consent

The problem of consent in adolescence

Children being seen as a separate entity to adults can be argued to only have arisen at the end of the *Ancien Regime*, with widespread recognition only beginning during industrialisation and legislative distinctions developing during the twentieth century [14].

A child's consent and the law thereon only become practically relevant when they are deemed to be in contrast with the wishes of the child's parents, guardians or medical practitioners [12] and when no biological parent or legal guardian is in the picture. In a scenario such as this the new laws require the medical practitioner to ascertain whether the child over the age of 12 is of sufficient maturity to actively consent to the treatment being discussed.

Active consent can take two forms, one being the more traditional written consent where a legally binding document is signed, or through verbal assent in cases of, for example, illiteracy or urgency. The requirements for consent are the following: the person giving the consent must be legally capable, the consent must be informed,

the consent must be given clearly, and it must be comprehensive [15]. Medical treatment is undeniably an invasion of physical privacy and bodily autonomy and thus needs to be actively consented to [15]. Minors by law are considered unable to consent to agreements or contracts as they are not believed to be sufficiently mature to understand the consequences of the decisions they make and the agreements they enter in to. The law steps in to protect children from their naivety and lack of experience. Parliaments throughout the world employ age-thresholds for this exact reason [15]. Informed consent usually can be described as requiring the person giving the consent to: understand the information given, the consequences of the actions they take upon that information, and to be able to assess and comprehend the costs and benefits of a proposed action [15]. Parental consent was built into the pre-existing laws with the aim of involving the parents or guardians in the medical care of children. Children are indeed vulnerable actors but they are also autonomous beings and they can be argued to have a greater understanding of their social circumstances than other role players outside of their biological parents. Health care practitioners ought to be adequately trained to interpret and determine the maturity of the involved child. The revised health act legislates that the health care user must be knowledgeable of the full range of concerns pertaining to their health status and proposed range of treatment options, as well as their associated risks and costs. A definition of sufficient maturity usually fulfils these criteria.

Competence, however, is not an isolated state; it is better understood in relation to the child's social context [12]. Competence includes having a plan for their future, and an understanding of their best interests. The argument is that children are not truly capable of what is termed 'cognitive complexity' as they have transient values, no legitimate concept of the moral good, of their own death, or their future and their likely future values [12]. Competence is, however, far more than an intellectual skill; instead it can be understood as a way of relating, wherein each child's inner qualities are seen within a network of relationships and cultural influences. This falls in line with Bronfenbrenner's ecological model which states that early human development takes place within progressively more complicated interactions between "an active, evolving bio psychological human organism and the persons, objects and symbols in its immediate environment". Thus to simply dismiss a person as not developed enough to consent by measure of age is uninformed and incorrect [16]. Involving children in intermediary decisions pertaining to their treatment respects their competence and helps develop their capacity for consent.

It is important to consider the developments in international legislation in light of the international conventions and agreements that spurred them, such as the announcement of the 'International Year of the Child in 1979' and the development of the 'United Nations Convention on the Rights of the Child in 1989' [14]. The latter conveyed principles of provision (equal share of resources within society), protection (adequate care and protection from harm) and participation (both in decision making and within society). The Declaration of Helsinki states that informed consent must be based on an adequate understanding of the nature, purpose and probable effects of an intervention as well as the available alternatives; combined with sufficient comprehension so as to be able to make and signify an enlightened decision [12]. The Nuremberg code speaks of voluntary consent, which is to be understood as the free power of choice (autonomy) including therein the courage and resolve to remain with the decision disregarding the outcome, as well as the legal capacity to give that consent [12]. Apart from the intellectual competence inherently required with informed consent, voluntary consent requires moral maturity as well. Competence can be discerned either on the outcome of the decision: whether the person who assesses the decision agrees with it; or by process: whether the methods employed in coming to the decision are rational and justifiable [13]. The latter is how competence is generally assessed with medical treatment. The former falls in line with the practitioner's belief of whether or not the patient's decision falls in line with their best interests. This, however, cannot be considered true consent as it does not acknowledge or respect the autonomy and rights of self-determination of the patient. Furthermore, it is inherently circular to argue that a rational, competent person will make a wise decision and that a person who makes wise decisions is inherently rational or competent. The capacity to consent is act or decision not person specific and therefore the process of giving consent cannot be a single act but rather an ongoing process [17].

The old laws governing consent

Prior to section 129 of the Children's Act of 2005 coming into effect, a person could only consent to medical treatment independently at age 14 and operations at age 18 [15]. This was based on Hippocratic paternalism [12] which believes that children should, in an ideal world, be protected from the burdens of decision making with the guilt and inherent blame associated with a negative outcome of a decision they may have made, even if they were competent to make that decision [13]. Minors were also thought to need to be protected from the harsh realities of their illnesses. Consent by a biological parent or legal guardian had to be sought, and when this was impossible or impractical new applications to the courts or to the Minister of Health had to be made on each occasion to bypass this. To have to implement these applications each time a child required medical testing (such as for HIV testing) and for treatment was immensely costly and impractical [13]. This approach also did not take into account the emerging, evolving autonomy of the adolescent within the South African context and resulted in inadequate or a failure in distribution of adequate health care services to these people [2]. Active parental consent has also been shown to be an inadequate indicator of the adult's understanding of the procedure proposed. Furthermore, adolescents who gain consent are more likely to be female, white, from intact homes and have parents who are increasingly likely to have had an education [2]. Thus adolescents who are most at a historical risk of economic disadvantage and poor health in South Africa are more likely to be excluded from the medical treatment they need. If a child seeks access to sexual or reproductive information without their parents' consent their parents could take this as an indication of sexual activity and result in increased parental supervision and less access to the valuable treatment and information the doctor may provide [2], as well as damage the family dynamic. Children are not merely an extension of their parents' rights or beliefs and should not be portrayed as so. They are the bearers of their own. Children ought to be able to decide what happens to their bodies and if they are mature enough to understand and give informed consent they should to be allowed to. Strict age restrictions which prevent or increase the difficulty in access to health care may be argued to breach the fundamental human and constitutional rights of these children [15]. Minors are reasoned to have enough maturity to consent to other life defining choices, such as choosing their adoptive parents at age 10 or consenting to the termination of their pregnancy at any age for a female [15]. Some countries, such as Scotland, do not have any barriers to health care due to age. Instead they base the access to health care on the maturity of the child and their ability to understand the costs and benefits of the proposed treatments or interventions [15]. An approach that lessens the barriers to consent could reasonably be deduced to increase the access to health care. Protecting children from

the worst effects of their chronic diseases can only be adequately done when they are involved in their treatment as much as possible, so that they may take responsibility for their treatment and be able to make daily decisions that are necessary for their wellbeing [13]. A child with a disease such as diabetes must make daily decisions pertaining to their diet, injections and blood tests which form a significant part of their treatment. Their ability to make these decisions when faced with the social contexts they find themselves in on a daily basis indicates their predilection for rationality when experienced in their treatment. There has been qualitative research that has shown that children with these chronic diseases have larger levels of knowledge as well as competence when it came to their diagnosis [13]. Children have been found to have a heightened level of understanding of the costs and benefits of a treatment if they were severely ill before the diagnosis. Experience has been found to be the most important factor when determining whether or not a child is intellectually or morally competent. A child suffering from cancer is sometimes seen to be of great maturity due to how they handle their disease. But it is rather the situation than the age that leads to that maturity. This is another indication that age ought not to be the most important factor in consideration here.

The old law was inconsistent in its approach to the problem of child rights, in that physical integrity was protected under laws prohibiting the use of corporal punishment [14], but the same right was not defended when it came to medical intervention.

The new laws governing consent

With respect to Socratic ethics the child may be in the best position to determine what is their concept of a good life and their capacity to foresee a process whereby they may attain that life [13]. Under the new laws children can consent to medical treatment from the age of 12 if they are deemed to have sufficient maturity, consent with parental assent to surgery at the age of 12, consent to HIV testing from the age of 12 if it is in their best interests [2]. Unchanged in the new law is that any person older than 12 years old may not be restricted from access to contraceptives and contraceptive advice. However it is still against the law to have sex below the age of 16, even when this sex is consensual [18]. This indicates that the approach to the emerging autonomy of the child in the South African context has remained inconsistent. Legal capacity traditionally has two components: age and decisional capacity [1]. The changes to the law can be interpreted under these components. The latter is interpreted as maturity, which can be defined as understanding the relevant information, appreciating the consequences of the situation and effectively reasoning about their treatment. The most prevalent interventions in this age group that the new act allows for are often treatments for drug dependence, abuse within the family setting, venereal diseases, abortions, contraception and to access sexual information [11]. The parents, however, who could be argued to have had their prior rights over their children removed, will still be held financially liable for the decisions of their children [11]. Furthermore, with the capacity to consent comes with it the capacity to dissent to decisions or the allowance to decide to opt for no intervention at all. The ability of the minor to dissent is especially important when the treatment which is proposed is of a nonessential type or where the benefits are not immediately obvious.

Implications for the Child

The HPCSA indicates that "a child's best interests are paramount in every matter concerning a child [1]". Due to this the rights of the child ought to be the primary consideration in any medical consultation involving them.

Children in the work-force and child-headed households

Child-headed households are a distressing reality within the South African context. A child often needs to become the primary breadwinner to support their family. These working children are at a heightened risk of malnutrition, anaemia, fatigue and inadequate sleep which makes them more susceptible to infectious diseases [19] such as Tuberculosis. Time for play and recreation in childhood is absolutely essential for this development and this combined with the limited socialisation and increased responsibilities of these children cripples their emotional development [19]. These children support their families at the cost of their education, psychosocial development and integration as a functional member of society. A person with a deprived childhood and unstable home life is more likely to suffer from problems with the function of their prefrontal cortex [20]. This translates to problems with planning and organising behaviour in comparison to someone with a more stable home life. In contrast African, Asian and South American research has shown that children who live independently in the face of adversity have developed higher competencies [13]. Further allowances under the new act include that minors over the age of 12 with parental responsibilities for a child, in accordance with section 129 of the Children's act of 2005, if they are of sufficient maturity, may consent to medical or surgical treatment on behalf of their child. This falls in line with the idea that a biological mother automatically has full responsibility and rights over their child [1].

The requirement of a child to provide informed consent would need the medical practitioner to fully disclose all information regarding their condition to the child under the Patients Health Charter. This has the potential to cause distress to the child. Minors' consent may still be suspended to ensure they do not make decisions that limit their capacity as fully autonomous future individuals. This can be considered under *parens patriae* within the law [17]. However, if the child is given the impression that not consenting will result in their decision being overturned by a court their decision will not be consensual and will merely be acquiescent. If children are afforded the right to consent, they must be reasonably afforded the right to dissent as well, and this right needs to be respected equally, even in cases where they may choose to forego their future autonomy for their present autonomy [17].

In terms of section 12 of the Children's act, "every child has the right to not be subjected to social, cultural or religious practices which are detrimental to his or her wellbeing", this act enables the child to access healthcare on their own terms and thus aids in decreasing the incidence of this [21].

Implications for the family unit

There are multiple philosophical approaches to the problem of the comparison between the dwindling powers of parental protection in light of the increasing independence of the child. Parentalists [12] believe that the person in the best position to determine the best interests of the child would be the psychological parent (i.e.: the adult who is closest to the child) and that they should have full control until the child gains full legal maturity at the age of 18 years. The traditional view of the family as an inner sphere wherein children were a reflection of adult authority has, however, been replaced by a more egalitarian idea that believes children are vessels of their own rights and thus had led to greater state control over the family unit [14]. This shift of the balance of power from the family unit to the state can be interpreted as a challenge to traditional family roles [14]. It is feared that laws which favour the paradigm shift towards children being independent bearers of unalienable rights such as these may hinder the capacity for parents to raise their children within their own framework and belief systems.

It is important for medical practitioners to aim towards a partnership with the parents [21], even with the increasing autonomy of the child. It is important to understand that the right of the child to consent does not remove the ability of the parents to be involved in or contributing to the decision making process.

A Practical Way Forward

The determination of sufficient maturity is an indirect one and needs to consider the minor's responsibility, perspective and temperance. This change in legislation indicates that the capacity for competent decision making in minors needs to be actively encouraged by the medical profession and the involvement of minors in intermediary decision making regarding their treatment from a young age works towards this aim. The implementation of objective criteria for determining psychosocial maturity is a challenge which the profession will be facing in the coming years. A practical way of determining whether a certain minor is sufficiently mature is to demonstrate sufficient knowledge, or sufficient capacity to acquire knowledge. This can be tested by the medical practitioner providing semantic medical information to the minor and then gauging their comprehension of this material, ensuring that the minor is not disadvantaged due to unfamiliarity with the concepts or due to their linguistic background. This capacity for knowledge can also be tested operationally by requiring the minor to paraphrase the information given by the practitioner. These two practices fall in line with the established norms within the profession and when considered in light of the minor's ability to make a decision that reflects their best interests, as well as a demonstrated non-transient value system, they can be understood as being sufficiently mature to consent. The thresholds for this understanding will necessarily increase as the severity of a minor's condition and the danger of the treatments proposed increase so as to minimise the risk to the minor in consenting or dissenting.

Is a 12 year old of sufficient maturity to consent to medical treatment?

The salient point is that children may end up suffering without access to conventional medical treatment. It is important to develop specific programmes with the health care needs of the minors in mind. This is more accessible under a situation wherein minors can access healthcare without their parents' consent, especially in situations where parents would opt to deny their children this treatment on moralistic or religious grounds [2]. Our legal agendas to respect a minor's rights to self-determination are a lot more studied and evidenced than our knowledge of their capacity to assume the psychosocial roles that accessing these self-determining rights require [13]. It is a wasted attempt to solve the problem if children are not involved in their decision making as they may then opt not to comply with whatever is decided on their behalf. Decisional capacity is not an all or nothing concept-a person's capacity to make a decision depends on the nature of the decision [1]. The research indicates that children may not be biologically advanced enough on average to engage adequately with the challenge of consent, or be necessarily psychosocially adept enough to engage with the associated issues and considerations. Although this indicates that there may be philosophical and biological reasons why a child approaches the problem of consent in an inherently different manner to an adult, there is not sufficient evidence to correlate this with an inherently decreased capacity for playing an active role in their medical treatment. A child, when all is said is done, is still but only a child. If society can rob them of their innocence and youth, surely society can empower them to survive the world they are forced into. As the reality of the South African context has robbed some of our children of their childhood, and trusted the responsibility of adulthood upon them, the new health care act is a decent attempt to correlate those responsibilities with equitable rights and is undoubtedly morally defensible.

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