

Title: Operationalising the notion of sufficient maturity
to provide informed consent when minors present for
treatment.

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Declaration

Unless specifically indicated to the contrary, this research report is the result of my own work

Name_____

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Date_____

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Abstract

Laws in South Africa, such as the *Children's Amendment Act 41 of 2007* (Government Gazette, Act 38 of 2005), is developed with good intentions of promoting prevention and intervention on various health-related issues. Laws also dictate, based on developmental and evolving capabilities, chronological ages at which children and adolescents may access certain healthcare services without parental consent, whilst limiting them in other areas such as decision-making for research participation. Of interest to this study is how specialists in health care, conceptualise, understand and apply "sufficient maturity" in their encounters with minors presenting for treatment, in order to identify key concepts of sufficient maturity. From the interviews conducted, themes were identified that were relevant to the construct of "sufficient maturity." Results indicated that there were two primary perspectives participants used to assess "sufficient maturity" when minors presented for treatment. Health care practitioners, depending on the health care context, assess minors' sufficient maturity in relation to, either a competency based or a deficiency model.

1. Introduction

Globally, health laws have been put into practice with the intention of improving the quality of living and healthcare for its communities. Even though laws in South Africa, such as the *Children's Act* (Government Gazette, Act 38 of 2005) and more recently the *Children's Amendment Act 41 of 2007* were developed with good intentions of prevention and intervention on various health-related issues such as the HIV/AIDS epidemic, many contradictions and challenges may arise regarding the ethico-legal underpinnings, hence limiting independent decision-making. The *Children's Amendment Act*, implemented on 1 April 2010, is aimed at giving children the right to decision-making pertaining to treatment (Mahery, Proudlock & Jamieson, 2010). Furthermore, laws also dictate, based on developmental and evolving capabilities, chronological ages at which children and adolescents have access to certain healthcare services without the need for parental consent whilst limiting them in other areas such as decision-making for research participation and treatment. Some of these laws appear inconsistent. Considering the importance of parental consent for some procedures and research, it remains questionable on what grounds these age restrictions have been implemented and what effect this might have on future generations' treatment and prevention of diseases.

1.1) The development of children's rights in South Africa

In 2003, the *Children's Bill* was drafted and tabled in Parliament. The Bill adopted an approach that drew on various services, some of which were filled by national government, and others by provincial governments. As a result, the Bill was separated into two Bills. In 2005 the first Bill (*Children's Act 38 of 2005*) was passed concerning national government's role. "The president then published a proclamation in the Government Gazette

for 44 sections of the *Children's Act* to come into force on 1 July 2007” (Mahery et al., 2010, p. 4). Many of these sections concentrated on the notion of child consent to treatment.

The second Bill, the *Children's Amendment Act* was passed by Parliament in 2007. Later these two Acts were synthesised as a regulatory guide to the rights of children as based on the Constitution of South African law (Mahery et al., 2010; see also Government Gazette, *Act 38 of 2005*).

1.2) Premise on which laws are based

Historically, The *Children's Act of 1983* stated that children above the age of 14 could consent to medical treatment and at 18 years of age, to surgical operations. Children under the age of 14 required consent from parents or legal guardians. When the child did not have a parent or legal guardian to give consent, a social worker with the authority to give consent was given the responsibility (Mahery et al., 2010).

This Act presented some practical problems with the increasing rates of the HIV pandemic and the inability of a neighbour or caregiver to give consent to treatment if not regarded as a legal guardian (Mahery et al., 2010). The Act was therefore criticised for not being adaptive to the challenges of its context. Various challenges posed by the HIV epidemic and migration in South Africa resulted in limited services available for children (orphans) without the consent of parents or legal guardians. According to Ford and Hosegood (2005) in 1993, 11 million children in Sub-Saharan Africa alone, had lost one or both parents to AIDS. The numbers of AIDS orphans have become a big concern for policy makers. “By 2007, there were an estimated 1,708,032 maternal orphans in the country, of whom 1,201,675 were orphaned as a result of AIDS” (Budlender, Proudlock & Jamieson, 2008, p. 3). The act did not provide for flexibility in such situations, for example, if the caregiver was not the legal

guardian, consent could not be given for the minor. Furthermore, the Act ignored the ability of the child to be involved in decision-making pertaining to their health(Mahery et al.,2010).

The current *Children's Act* provided more flexibility in terms of“the focus on consent to medical treatment, surgical operations, HIV testing, access to contraceptives and circumcision” (Jamieson, Mahery & Seyisis-Tom, 2009/2010, p.12). It is not clear on what arguments, or foundation current child health laws are constituted. There are however two possible approaches that might have been adopted to establish the current *Children's Act* and health laws concerning minors.

Capabilities of minors:

It can be argued, on the one hand, that age parameters intended to provide support for independent consent are based on research conducted on the cognitive and developmental capabilities of early adolescents. It is based on the assumption that they can and will, as early adolescents, understand. Thereafter, based on the information received, they will reflect on the consequences and then make an informed decision.

Public health perspective:

Alternatively, it could be said that epidemiological research has merely indicated the highest prevalence and incidence rates of diseases (sexually transmitted infections STI's), within which unwanted teenage pregnancy and the HIV/AIDS epidemics occur. According to Jamieson et al. (2009/2010), the current Act provides much more flexibility for the minor to have access to treatment that would otherwise be restricted. Furthermore, it also takes into account the early age of sexual initiation and high rate of sexually transmitted infections (STI's).According to Rehle, Shisana, Pillay, Zuma, Puren & Parker (2007, p. 194) “among youth aged 15 – 24 years, females account for 90% of the recent HIV infections.”Thus, in the

attempt to curb and treat these high rates, laws are required to grant children the right to provide independent consent to certain health care services. Little is known about the effect of the decision the child has to make and live with, but hoping that by implementing the law, the prevalence and incidence rates will decrease. This public health perspective is probably the more realistic approach on which most health laws are based. It therefore can be argued that the former perspective then (capabilities of minors), taking into account their evolving cognitive capabilities, is not the primary basis of government research for drafting laws, but rather a viewpoint of the social issues faced that create potential problems for the growth of the country.

1.3) Overview of current South African law concerning minors

Specific sections have been created in the current *Children's Act* passed by Parliament realising the notion of the child's right to decision-making concerning health-related issues. These sections also take into account multiple role players in the health sector and how they can assist the minor in making decisions. *Section 10 of the Children's Act* states that

Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration (Mahery, Proudlock & Jamieson, 2010, p. 6)

Even though legal capacities of minors are somewhat controversial and limited in South Africa, as they seem to be globally, they can however, by law (*Children's Amendment Act 41 of 2007, Section 129*) from the age of 12 years and being deemed 'sufficiently mature' by a medical practitioner, provide independent consent to medical treatment. Similarly, they are by law (*Children's Act, Section 134*) given the freedom to access contraceptives and receive HIV testing from the age of 12. Termination of pregnancy has no age limitation and therefore

pregnancy can be terminated at any age without any parent supervision or consent (Mahery et al., 2010; Strode, Slack & Essack, 2010).

Act 41 of 2007: Section 129

Among other sections, this section of the *Children's Act* will be emphasised and explained in more detail as support to the argument presented. It outlines the conditions under which the minor can provide independent consent for treatment. *Section 129* states that:

“A child may consent to his or her own medical treatment or to the medical treatment of his or her child if:

“(a) the child is over the age of 12-years; and

(b) the child is of sufficient maturity and has the mental capacity to understand the

benefits, risks, social and other implications of the treatment”(Mahery et al., 2010, p. 6).

If however, the minor is under the age of 12 or assessed as not being sufficiently mature for treatment, then the *Children's Act* states that the consent of the parent or legal guardian must be obtained. According to the *Children's Act (Section 129)*, they define the consent framework of a parent:

When both parents have full parental rights, either parent may consent individually to medical treatment or surgery. However, where a decision could “significantly change, or have an adverse effect on the child’s ... health” the person giving consent must take into consideration “any views and wishes expressed by any co-holder of parental responsibilities and rights”, e.g. the other parent (s31)(Mahery et al., 2010, p. 11).

In the *Children's Act*, parents are defined as the biological mother or father of the minor. If consent cannot be obtained from either of the parents, the Act states that a caregiver must then give consent. What follows are the extensive definitions given by the *Children's Act* for

what constitutes a biological mother or father and caregivers. *Act 41 of 2007: Section 129* provides lengthy explanations regarding the definition of a biological mother, father and caregiver. These definitions are beyond the scope of this study and are therefore presented in Appendix 4.

2. Review of literature

2.1) Legal issues: mature minor/emancipated minor

As discussed above, the law requires minors to be of a certain age in order to access certain types of health care (except for termination of pregnancy). There are however instances in which the law requires a second component in addition to the chronological age of the minor. This requirement, specifically pertaining to treatment, requires evidence of “sufficient maturity.” The notion of sufficient maturity can best be conceptualised as the ability of the child (minor) to “understand the benefits, risks and social implications” of medical treatment (Strode et al., 2010, p. 247). Sufficient maturity draws on concepts such as the abilities and competencies of minors, as determined by a judge’s ruling (High Court or Children’s Court, *Section 129 (9)*). Although the law sets out clear standard procedures, “a well-reasoned, unambiguous, and uniform standard has failed to emerge.” (Slonina, 2007, p.184). Maturity seems somewhat unreliable and subjective, as to date, there is no single specific quantifiable measure or psychometric test that can be undertaken to measure sufficient maturity of minors. Minors (according to *Section 17 of the Children’s Act*) are regarded as children under the age of 18 years. In cases such as medical treatment and HIV testing, South African law allows minors under the specified age to give consent to and access these facilities when they display “sufficient maturity.” When sufficient maturity is granted, it allows minors below the age specified (12), by law, to give consent. There are also many distal (contextual) factors that may influence the maturity level during child development that are not always taken into consideration. The reason for minimising the emphasis of contextual influences on child development is mainly because the emphasis is always on the chronological age of the child.

When the court (South Africa's Children's or High Court) has concluded that the minor displays sufficient maturity, he/she is regarded as a mature minor, which gives the minor the ability to seek treatment without informed consent from parents. When adequate evidence is provided that the minor displays sufficient maturity, then it becomes unconstitutional to withhold independent authorisation to treatment (Maradiegue, 2003). This notion is also known as judicial bypass and was developed to protect the privacy and confidentiality of the minor's actions and healthcare choices. Emancipated minors do also not require parental consent. By statute, they are regarded as financially self-sufficient and no longer living with their parents (Maradiegue, 2003). According to Maradiegue (2003, p. 172) the state statute generally defines that the emancipated minor be "a minimum age, usually 16 years old...married, pregnant or a parent...have the ability to enter into a contract, rent an apartment and consent to medical care."

2.2) Ethical issues: Informed consent, confidentiality and minors' autonomy

When working with minors, as with adults, it is important to consider the ethical implications that are presented in treatment procedures. Beauchamp and Childress' (2009) work on biomedical ethics remains very important here. It outlines influential principles that are followed in the medical, psychiatric and psychological fields. The four main principles inform many of the issues that will be discussed below, as they are relevant and related to each other.

a) Autonomy

The first is respect for autonomy. It is a principle related to and entangled in morality. Furthermore, this principle informs and is related to the decision-making of the minor (patient) and more specifically the ability to make an informed decision regarding treatment.

Beauchamp and Childress (2001 p. 57; also see 2009) however caution against misinterpretation of this principle and clarify that

The principle of respect for autonomy overrides all other moral considerations. This we firmly deny. We aim to construct a conception of respect for autonomy that is not excessively individualistic, not excessively focused on reason and not unduly legalistic.

Historically, the term autonomy referred to a form of governance. Since then it has been extended to include liberty and rights of individual governance. Therefore, an autonomous individual is referred to as “an individual that acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets of policies” (Beauchamp & Childress, 2001, p. 58).

Theories of autonomy, as mentioned by Beauchamp and Childress (2009), focus on two main qualities of an individual, namely liberty and agency. The former refers to the ability or “independence from controlling influences” whereas the latter refers to “the capacity for intentional action” (Beauchamp & Childress, 2001, p. 58). An autonomous person then, according to this definition, should have the ability or capacity of self-governance. This requires a basic capacity of understanding and the ability to reason, resulting in an independent decision (Beauchamp & Childress, 2001). An underlying assumption of some theories of autonomy is that the patient will have and can control their “first order desires or preferences through higher level, second order desires or preferences” (Beauchamp & Childress, 2001, p. 58). This assumption has been brought into question, as “acceptance or repudiation of a desire can be motivated by an overriding desire that is simply stronger, not more rational or autonomous” (Beauchamp & Childress, 2001, p. 59). Beauchamp and Childress address the shortcomings of these frameworks of respect for autonomy and instead argue that autonomy should consist of the following: “normal choosers who act intentionally,

with understanding and without controlling influences that determine their action”

(Beauchamp & Childress, 2001, p. 59).

Ideally, independent behaviour is what most parents eventually would want for their children.

This however is in stark contrast to the way decisions regarding health care are made.

Viewing the minor as incompetent and unable to participate in their own health care decisions has various implications. One of these implications is the notion that “prevention of minors’ participation in the planning of their own care, especially those in the 13- to 18-year age range, defies autonomy rights and stunts developmental progress toward independent behaviour” (Pohlman, Dickey, Kiefner, & Beidler, 2002, p. 179). Thus, not only is excluding a minor from health care decision-making a violation of their rights, but may also negatively affect their development. A study conducted by Taylor et al. (1984, as cited in Mann, Harmoni & Power, 1989) indicated that the perceptions of adolescents regarding autonomous decision-making were in line with those of previous research conducted. Results indicated that “the subjects believed that age for decisions concerning everyday activities (TV viewing, clothes and friends) should be, on average, 12.3 years. The age for major life events (leaving home, marriage), should be, on average, 14.8 years of age, and the age for health related decisions (birth control, discontinuing medication) should be, on average 15.1 years” (Mann et al., 1989, p. 273).

b) Nonmaleficence and beneficence

Nonmaleficence is the principle that requires that no harm be inflicted on the patient. Medical ethics address this principle as *Primum non nocere*, “above all do no harm” (Beauchamp & Childress, 2001, p. 113). In many cases, nonmaleficence and beneficence are discussed together because they complement each other. However, a distinction is drawn between the two concepts. The former is focused on the idea not to harm, whilst the latter emphasises the

maximisation of benefits. Therefore, nonmaleficence focuses more on the responsibility of the practitioner not to inflict harm, whereas the principle of beneficence is focused on maximising benefit.

c) Justice

The last principle, as identified by Beauchamp and Childress, is that of justice. This principle is based on fairness and equality. A number of theories have been discussed by Beauchamp and Childress (2001), specifically addressing controversies regarding this principle. The theories they specifically draw on are utilitarian, libertarian, communitarian and egalitarian. Discussion of these theories is, however, beyond the scope of this study. A detailed account can be found in Beauchamp and Childress (2001). Its original source can be found in Burchell and Milton (1997).

At the core of ethical decision-making, are moral judgments. Morals and values of the health care practitioner are often what guide them to follow ethical regulations. Kitchener (1984, as cited in Cottone & Claus, 2003) provides a very clear ethical framework on which to draw when faced with ethical decision-making dilemmas. Her framework is based on the work of Beauchamp and Childress (1979) and Hare (1981, as cited in Cottone & Claus, 2003). She specifically combined Hare's 'levels of moral thinking' in *The Philosophical Basis of Psychiatric Ethics* (Hare, 1981) with the four well-known principles of biomedical ethics in the *Principles of Biomedical Ethics* (Beauchamp & Childress, 2009). Similarly, Beauchamp and Childress have revised their former editions in order to accommodate recent literature on ethical decision-making. The *Principles of Biomedical Ethics* has been an excellent guide to making judgments regarding patient care. Many authors have however criticised these well-known principles for various reasons. Unlike Kitchener's model, the principles fail to explain processes in-depth regarding decision-making. Instead, they focus on the theoretical

underpinnings of what makes the four principles so important. These theories were based on basic models of Utilitarianism, Kantianism as well as liberal individualism (Cottone & Claus, 2003). As an attempt to settle some criticisms of these theoretical principles, Beauchamp and Walters (1994, as cited in Cottone & Claus, 2003) collaborated on a model to resolve moral disagreements. This model focused on “a) obtaining objective information, b) providing definitional clarity , c) adopting a code and d) using examples and counterexamples” (Cottone & Claus, 2003, p. 275). This attempt to address controversies was once again reductionist and lacked in-depth clarity on processes involved. What follows below are important requirements to meet when a patient (minor) presents for treatment. These requirements are based on the principles of Beauchamp and Childress and are addressed in their book *The Principles of Biomedical ethics* (2009), in detail.

2.3)Applying principles of informed consent to health care of minors

Informed consent remains a critical requirement before health care workers treat patients. It is seen as an indication that the patient understands the risks of the treatment. Furthermore, it requires that the patient understands what the consequences of such treatment might entail. According to McCabe (1995, p. 506) “there are three legal requirements for consent to medical treatment: a) the decisions must be informed, b) voluntary and free of coercion, c) individual must be competent.” Informed consent is based on the principle of autonomy. However, when minors present for treatment, their autonomy becomes limited to the opinions of their parents. Such reasoning is based on the fact that “developing competence for informed consent decisions is associated with cognitive capacity” (Pohlman et al., 2002, p. 179). This assumption implies that competence comes only when reaching a certain level of cognitive capacity and limits the minor’s participation. With consent being free of coercion,

being informed and competent, there are three distinct components of informed consent. These are discussed below.

a) Knowledge component

The first is viewed in the light of “knowing consent.” This concept is defined as “the understanding of the semantic content of the information that is provided by the professional” (Grisso & Vierling, 1978, p. 416). It requires an understanding of the language and phrases used by the professional. What the patient knows is based on the link between what the professional has said and what the patient has understood. The dilemma faced here, then, is the lack of measures to indicate true or adequate understanding on the part of the minor. Conceptualisation of the health related issue and proposed treatment plan becomes somewhat problematic because “what is known, is dependent in part upon the cognitive and intellectual capacities of the minor” (Grisso & Vierling, 1978, p. 418). Knowledge could be tested by simple recall tasks, but is not synonymous with understanding, which is described below.

b) Understanding component

The second type of consent is that of “intelligent consent.” This concept is best defined as “the competence of the patient to arrive at the consent decision rationally, not upon others’ opinions concerning the advisability of the patient’s decision itself” (Grisso & Vierling, 1978, p. 418). This requires the patient to assess the risks, benefits in a logical and rational manner that requires reflexivity. It was found that “reflective as compared to impulsive, children have been found to ask more mature questions in seeking information, to process information more efficiently and to employ inductive reasoning more effectively” (Grisso & Vierling, 1978, p. 418). A study assessing the importance of understanding information was conducted by Lindegger, Milford, Slack, Quayle, Xaba, and Vardas (2006). The aim was to assess the

interaction between memory, understanding and acceptance when information was given when enrolling for HIV vaccination trials. Common methods used to assess understanding included self-report, questionnaires, narrative format and vignettes. Findings from this study revealed that questionnaires overestimate understanding. This study recommended that priority be given to personal implications. Even though questionnaires are economical, checking difficult concepts and personal implications with added assessments (example vignettes) was shown to provide a more realistic estimate of the level of understanding (Lindegger et al., 2006).

c) Voluntariness component

Voluntary consent makes up the final component of informed consent. It is referred to as the announcement “to a person of some prestige and authority one’s decision regarding the proposed treatment or, perhaps more accurately, is requested to comply with a treatment proposal” (Grisso & Vierling, 1978, p. 421). Voluntariness is linked to the minor’s social and developmental capacity regarding conformity. What becomes of increasing importance is the minor’s “conformity or nonconformity, or, the child’s relational style with authority” (McCabe, 1995, p. 509). Conformity is seen to be the highest around early adolescence (10 – 13 years of age), followed by middle adolescence where minors are seen as being able to give informed consent voluntarily. Other factors such as identity development, stability of values and a preoccupation of body image will influence the adolescent’s choices in treatment (McCabe, 1995). Identity development is created through experimentation with various identities during adolescence. The peer group serves as an emotional support network where adolescents are seen to be experiencing the same feelings and frustrations, hence making the individual feel that they belong. Furthermore, level of responsibility, family communication,

religiosity and cultural beliefs are also indicated by literature to have a direct impact on the outcome of decision-making (McCabe, 1995).

Assent

Due to the evolving capacities of minors, it has gradually been argued that adolescents must play a part in the role of decision-making when presenting for treatment (Kuther, 2003).

What underlies this assumption is the fact that minors' (adolescents) autonomy is already compromised and limited and therefore health care practitioners want to involve their patients in their own treatment decisions by empowering them. As children get older, there is an increased need for independence and responsibility. It is argued that by giving the minor some rights in decision-making, ethical guidelines will still be followed and adhered to.

According to Kuther (2003, p. 351), "both the American Medical Association and American Academy of Paediatrics advise that physicians have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities." In order to solve this dilemma it was then agreed that minors be asked for their assent. Assent is

An interactive process between a minor and a physician that involves developmentally appropriate disclosure about the illness, and solicitation of the minor's willingness and preferences regarding treatment. This commonly accepted definition of assent as a minor's agreement to participate sets a lower standard of competence than informed consent because it does not require the depth of understanding or the demonstration of reasoning ability required for informed consent (Kuther, 2003, p. 351).

Being able to provide assent as a minor is an indication of gradually maturing and making decisions based on certain criteria. This in turn prepares them for taking responsibility as well as basing decisions on risks and benefits of facts with the guidance of the health care practitioner as well as the parents. Furthermore, assent provides an open space for communication between these three parties, becoming a facilitator of open communication.

According to literature, assent and open communication also has benefits regarding the minor's social and emotional states. A study conducted with paediatric cancer patients and use of open communication indicated an increase in their ability to cope with treatment procedures (Kuther, 2003). Health care practitioners must however explain the treatment of a condition to a minor at a developmentally appropriate level in order for understanding and decision-making participation to be of any significance.

Dissent

Similar to the notion of assent, a minor's ability to refuse treatment is debatable. Legal cases seem somewhat unreliable. Ultimately, it is most likely the physician who has to make the final recommendations, but still cannot force the minor to accept the treatment. In such cases, health care practitioners must assess the seriousness of the minor's condition and determine the risk-benefit ratio (Kuther, 2003). One of the general guidelines used in such situations is that "physicians should respect the adolescent's decision, regardless of parental insistence. If a treatment is judged to have a low probability of success, it does not need to be initiated, or can be discontinued" (Kuther, 2003, p. 354).

2.4) Competence and cognitive capacity of minors

Taking the legal and ethical issues into account when assessing a minor's maturity, it is important to understand the notion of competence and why it is required. As Pohlman et al. (2002) and McCabe (1995) have pointed out, competency is regarded a prerequisite for assessing sufficient maturity. Embedded in the notion of competency, is the requirement of the necessary cognitive capacity. Competence is required for treatment based on the principle of autonomy. It draws on the underlying assumption that individuals have to be able to make independent decisions. Beauchamp and Childress (2001) emphasise the flexibility inherent in

the term competence. They argue that this is due to the contextual dependence of the term. The context in which competence is applied is varied and therefore no single standard of competence can be applied. It is also for this reason that no test exists to distinguish incompetent people. Therefore, competence is broadly defined as “the ability to perform a task” (Beauchamp & Childress, 2001, p. 70). What is specific to this definition, is the criteria that distinguish incompetent persons from competent ones based on the situation and the context the person is in. Beauchamp and Childress (2001, p. 70) argue that “the competence to decide is therefore relative to the particular decision being made.” What then becomes important is not merely the person’s ability but more importantly, “how that person’s abilities match the particular decision-making task he or she confronts” (Beauchamp & Childress, 2001, p. 70). There is, however, the need for standards or levels of competence. These standards of competence normally assume autonomy and are more specifically based on cognitive abilities. In professions such as law and medicine, these standards are primarily based on “various abilities to comprehend and process information and to reason about the consequences of one’s actions” (Beauchamp & Childress, 2001, p. 72).

Beauchamp and Childress (2001) describe a framework upon which to base competence or incompetence. There are levels at which the person is regarded incompetent. There are seven standards to consider, ranging from one (requiring least ability) to seven. Below, a short outline and discussion of this spectrum is provided (Beauchamp & Childress, 2001, p. 73):

- 1) Inability to express or communicate a preference or choice
- 2) Inability to understand one’s situation and its consequences
- 3) Inability to understand relevant information
- 4) Inability to give a reason
- 5) Inability to give a rational reason

6) Inability to give risk benefit-related reasons

7) Inability to reach a reasonable decision

These standards of incompetence tap into three abilities. Standard one focuses on the ability of the person (patient) to state preferences. Standards 2 and 3 examine the ability of information to be understood as well as to understand the situation. The last three standards (4 – 7) focus on the ability to reason, which requires the skills of rationality and reflection to foresee the consequences.

2.4.1) Drawing on a legal framework to assess competence

Legally, minors can be assessed as competent. According to Kennedy and Grubb (1988, as cited in Parekh, 2006, p. 78) childhood can be divided into three distinct stages. The first stage is called early childhood, the second stage is a Gillick competent child, and the final stage is a child aged 16-18. “Gillick competence” has been used in various ethico-legal cases concerning competence of children. Competence is normally based on the chronological age of the child. However, Thompson (1992) raises an important point when he argues that

Perhaps searching for a minimum threshold age for children’s consent is asking the wrong question. Depending on the context and the complexity of the judgement, children at most ages are capable of making decisions concerning what they want to do, so perhaps the child’s competency...should not be regarded as an inflexible limitation deriving from the child’s age, but rather as an interaction of the child, the context and the nature of the task (Thompson, 1992; as cited in Morrow & Richards, 1996, p. 95).

The babysitter test that was conducted by Nicholson and his team (as cited in Koren, Carmeli, Carmeli & Haslan, 1993) was based on the notion that children had the ability to illustrate competency skills. The test was based on the assumption that crucial skills, such as responsibility and maturity, are required to babysit. Results indicated that “14-year old adolescents demonstrated competence levels comparable to adult study groups. Nine-year old

children were similar to adults in measures of competence, although they scored significantly low in understanding and rationality” (Koren et al., 1993, p. 146). The babysitter test therefore makes a very important point when arguing that adults trust children to have enough knowledge and maturity to look after another child, but are regarded as being too immature to take part in their own treatment decisions based on their knowledge and understanding of the problem. Perhaps then, age is not the determining factor that we should examine when adolescents present for treatment, but instead, the severity and duration of the treatment. According to Parekh (2006, p. 79) “relevant experience of illness or treatment was also found to be more important than age in acquiring competence for the consent to treatment for the relevant illness.”

2.4.2) Developmental psychological framework

The argument of competence and sufficient maturity would not be complete without examining psychological theories explaining cognition and the acquisition of skills. It is argued from a developmental perspective, that children (ages 1 – 11) are unlikely to be granted “sufficient maturity.” In most cases, it is clear that they cannot be regarded as mature minors based on limited social, psychological and cognitive development. In order for minors to be regarded competent, they must have the cognitive abilities of formal operational thought as well as abstract thinking capacity. Below, two theories are explored, suggesting how maturity can be assessed. The first and more common theory focuses on the importance of cognition as a crucial part of maturity. Secondly, Fischer’s hierarchy of skills is also outlined, emphasising the importance of the context in which maturity can be developed.

a) Piaget's theory of cognitive development

i) Child development

Piaget's cognitive theory describes four cognitive developmental stages of childhood. He views childhood development through the achievement of cognitive benchmarks. The first stage is present from the age of 0 – 2 years of age, known as the sensory-motor stage, followed by a second stage from the age 2 – 7 years, where children still lack logical thinking capacity (known as the preoperational stage). During this stage, children still lack much of the cognitive capacity required for basic understanding of certain activities. Middle childhood (7 -11) is the third stage of Piaget's cognitive development theory. This stage is characterized by concrete operational thought where the necessary cognitive skills of reversibility, decentration, conservation and transitivity are learnt (Swartz, De la Rey & Duncan, 2006). These cognitive capacities allow for logical thinking and reasoning which facilitate understanding.

Level four, the last cognitive developmental stage, takes place between ages eleven and fifteen. The child is regarded as a young adolescent. It is at this stage that they can imagine the past, present, and future conditions of a situation and hypothesize how the situation might occur in different conditions. At this stage (known as formal operational thinking), young adolescents can solve problems by applying theories and engaging in pure thought aside from real-world actions. In Piagetian theory, by the age of fifteen, a child's (adolescent's) thinking has evolved into a mature state[,] and adult thought exists within the child's repertoire of mental functions (Silvina, 2007, p. 194).

It is difficult for health care practitioners to communicate treatment and diagnosis with minors aged between 5 – 11. It is suggested that play provides a way to explain the implications that the treatment might have for the minor. According to Piagetian studies (as cited in Swartz, De la Rey & Duncan, 2006, p. 65) “intellectually, play provides a context

for using language to communicate and the mind to fantasise, plan strategies and solve problems. Children often show more advanced intellectual skills during play than they do when performing other activities suggesting that play fosters cognitive development.”

ii) Adolescent development

Adolescents still fall under the legal definition of a minor and therefore still require independent consent from parents or legal guardians. However, adolescence is characterised as a transitional phase that results in increased cognitive capacities. Lewis (1987, as cited in Kuther, 2003, p. 348) argues that “during the adolescent years, minors become better able to consider information and opinions from diverse sources and capable of owning their own judgements.” They have the ability to act responsibly (see babysitter test) as well as weigh up costs and benefits of certain behaviours and social interactions. Although adolescents may have the ability to make decisions, this stage is influenced by their egocentrism (Elkind, 1984) and preoccupation with their bodily changes. This concern with the self during the adolescent developmental phase, is linked to cognitive changes, implying that “adolescent’s reflection extends to a preoccupation with thoughts about the self, which may exacerbate their growing self-consciousness due to physical changes in their bodies” (Swartz, De la Rey & Duncan, 2006, p. 76).

According to Cauffman and Steinberg (2000, p. 744) various studies have been conducted to assess the relationship between adult and adolescent decision-making capacities. They argue that there are two possible explanations. “One line of reasoning, derived from behavioural decision theory, is that adolescents and adults employ the same logical processes when making decisions, but differ in the sorts of information they use and the priorities they hold.” However, a study by Scherer and Repucci (1980) examined this statement by applying varying degrees of parental involvement to hypothetical situations. The aim was to see how

the decision-making abilities of the adolescents would be affected by parental involvement. Results indicated that “adolescents were mindful of and deferential to, parents, but were more likely to resist parental influence when they perceived the consequences of the decision as having serious implications for health” (Kuther, 2003, p. 348). Furthermore, adolescents want to feel independent by making their own decisions. Therefore, it can be hypothesised that adolescents have the ability to be regarded as mature minors and could qualify for independent consent, without the consent of a parent or legal guardian.

b) Fischer’s hierarchy and construction of skill

Even though Piaget’s theory of cognitive development is seen as an interactional theory, the main premises are drawn on from cognition and the organism, with the environment playing a minimal role. Alternatively, learning and behavioural theories (such as Skinner and Bandura) focus more on the environment, minimising the importance of the organism. Fischer’s theory of skills focuses on developmental transformation in the first 20 years of life. It draws on assumptions of intelligence, cognitive development as well as lifelong learning and the development of problem solving. This is mainly based on cognitive development as part of the construction of certain skills. Fischer (1980, p. 477) argues that “skill theory treats cognitive development as the construction of hierarchically ordered collections of specific skills which are defined formally by a means of a set-theory description.” It is a theory that combines other theoretical frameworks of cognitive development, conditioning, learning as well as information-processing perspectives. Furthermore, this theory highlights the importance of organism-environment interaction that facilitates development. It mentions that “even the maturation of a child results from a combination of organism factors and environmental factors” (Fischer, 1980, p. 478). The sets that create the structure of the hierarchy are contingent on the interaction between the organism and its environment. It is

for this reason that the actions of the organism are mainly dependent on the contextual environment it interacts with. Fischer's theory comprises of 10 hierarchies. These hierarchical phases draw on three tiers that are contingent and build on each other. These tiers are sensory-motor skills, representation and abstract skills. In order to achieve a higher level in the hierarchy, the preceding level must be mastered. Like Piaget's theory, the skills theory "is characterized by a reasonably well defined type of structure that indicates the kinds of behaviour that a person (child or adult) can control at that level" (Fischer, 1980, p. 479). Through this, the environment creates a context where development is facilitated. In certain contexts then, certain skills are acquired. It is for this reason, that some skills will be more developed than others. Furthermore, an organism may be presented with some contexts more than in others, strengthening a specific skill relevant to that environment. Uneven development in the capabilities of an organism are what makes it unique.

Levels 1 – 7 are primarily based on the first tier that focuses on cognitive development and sensory-motor skills during the phase on childhood through to adolescence. Unlike most theories that define cognition as "skills of a particular type of content – typically knowledge of the physical world, or knowledge as measured by standard Piagetian tasks", skills theory refers to cognition as "the process by which the organism operates control over sources of variation in its own behaviour" (Fischer, 1980, p. 481).

The sensory motor tier consists of levels 1- 4 primarily focused on perceptions developed of objects, people and events. This tier is very similar to Piaget's cognitive development as the child gets familiar with the world through the five senses and by moving around.

Furthermore, this tier focuses on the skills achieved when the infant "understands how to act on specific things in the world but cannot think of those things independently of acting on them" (Fischer, 1980, 490). Until level 4 of representation is achieved, the infant does not

know that persons and events exist independently with their own characteristics. Fischer refers to the infant responding to the tableau as the understand the tableau, as the infant is not yet aware that her rattle for example makes a noise independently but rather experiences it by acting upon it. Level 2 is present when the infant is able to combine sets learnt in the preceding level. The characteristic structure of this level is mapping sets together. Therefore, one sensory motor set must be mapped with a second sensory motor set. This allows the infant to comprehend that one action brings about another action. Level 3 is “characterised by the sensory motor system, in which two components of one sensory motor set is related to two components of another sensory motor set” (Fischer, 1980, p. 492).

Levels 4 – 7 are referred to as the representational tier. Level 4 builds on the sensory motor system, but combines all the various systems in order to create a representational set which allows the child to “represent simple properties of objects, event and people independently of their own immediate action” (Fischer, 1980, p. 493). During level 4, the child should be able to develop many representational sets. Representation in this context refers to “concordination of two or more sensory motor systems to form a single representational set, not to recall memory or symbolisation per se” (Fischer, 1980, p. 493). The next characteristic structure is argued to be present with representational mapping. This is achieved when a representational set is mapped onto another representational set. Level 6 follows the same pattern, where the various mapped representational subsets are combined to form a representational system. The child is however still limited in its ability to combine and differentiate between systems.

Only in levels 7 – 10 can the child start thinking abstractly. Level 7 is where all representational systems are combined and allows for a single abstract set. “In an abstract set, the person abstracts an intangible attribute that characterises broad categories of events,

people or objects...the person can control the relation between two representational systems” (Fischer, 1980, p. 495). The person is also able to understand political concepts and things that extend beyond their family lives, like society and laws. “At Level 7, single abstract sets, a person can for the first time construct abstract identity skills. These identity concepts result from the coordination of two representational systems about the self” (Fischer, 1980, p. 495). Level 8 is achieved by the ability to map the various abstract subsets. Level 9 is where abstract systems are produced allowing level 10 where systems of abstract systems are created.

2.5) Research on competence of minors to consent for treatment

Minors’ understanding of illness

According to Burbach and Peterson (1986, as cited in Kuther, 2003) young children tend to view illness differently based on their developmental level. Young children tend to view illness in global and nonspecific ways. For example, they do not differentiate between the symptoms and causes of illness and view illness as being transmitted magically. According to Kister and Patterson, (1980, as cited in Kuther, 2003) young children often view illness as punishment for misbehaving. This is because of their association with an unpleasant response to an unpleasant (bad) behaviour. As the child gets older and develops cognitively, they develop a more realistic conceptualisation of illness that extends beyond their close interactions with parents or caregivers. With this development in cognition, minors are then better able to understand what causes illness and recognise their systems and treatment. According to Kuther (2003, p. 346) older children “begin to conceptualise illness in terms of specific symptoms and diseases, to appreciate the psychological, affective and social aspects of physical illness to associate illness with infection and germs.” This section critically explores three research studies conducted specifically in the area of competency of minors

related to treatment. Various studies have been conducted to illustrate that children have the required level of competence to understand a condition or disease and what the appropriate treatment would be, followed by the risks and benefits of each treatment. A good example of such a study was that of Alderson, Sutcliffe and Curtis (2006). This study involved qualitative interview sessions with diabetic (type 1) children aged between 4 and 12. Questions were asked about their illness, how it was treated and what had to be done when blood sugar became too high or too low. Diabetes is a chronic illness where responsibility is placed on the child and parents to control their diet and test their sugar levels. Some of the children even tested their sugar levels without the supervision of an adult, indicating that the child is competent in various areas of keeping the condition under control and understands the implications that the illness has on them and their lives. Alderson et al. (2006, p. 26) therefore make the important point that “daily management of diabetes illuminates exceptionally clearly children’s intellectual, moral and social competencies.” Results of the study indicated that children from the very young age of four (4) “showed that they understood the principles and recommended standards of controlling diabetes” (Alderson et al., 2006, p. 32).

It also becomes important to pay careful attention to the question of whether children are competent enough to understand and comprehend what is required when treatment is necessary for a medical condition and to make an informed decision based on the processing of information received from the medical practitioner. A study by Weithorn and Campbell (1982) aimed to assess whether children between the ages of 9 and 21 were competent enough to make informed decisions about their own health care. “The research was designed to provide an initial empirical analysis of the degree to which legal age standards governing consent for and refusal of treatment are consistent with the chronological development of the

psychological skills required to render competent treatment decisions” (Weithorn& Campbell, 1982, p. 1590). A structured interview was completed using the “Measurement of Competence to Render Informed Treatment Decisions questionnaire” (MOC) (Pohlman et al., 2002, p. 180). Results indicated that 14-year olds did not differ from the opinions held by adults in the study. There was however a significant difference in 9-year olds regarding rationality and understanding of the possible treatment options given. More specifically, results indicated that “minors aged 14 were found to demonstrate a level of competency equivalent to that of adults according to four standards of competency (evidence of choice, reasonable outcome, rational reasons and understanding) and for four hypothetical dilemmas, (diabetes, epilepsy, depression and enuresis). Younger minors aged 9 however appeared less competent than adults according to the standards of competency requiring understanding and a rational reasonable process.” It must however not then be assumed that children aged nine are incompetent. Based on the results of the study, 9-year olds indicated a basic understanding of their own health care and were able to give preference to one type of treatment over another, therefore illustrating the ability to base their decision of treatment on the possible options available.

Pohlman (1992, as cited in Pohlman et al., 2002) extended the study conducted by Weithorn and Campbell (1982). Pohlman et al., questioned the Piagetian assumption on which Weithorn and Campbell’s study was based, requiring formal operational thought in order to be regarded as fully comprehending informed consent. She also used the structured MOC questionnaire, but added the Arlin Test of Formal Reasoning (ATFR) to assess the presence of formal operational thought in the participants aged between 11- 16. Her results were similar to those of Weithorn and Campbell, indicating that “when adolescents of normal or higher intelligence are given all the information to make health care treatment decisions, they

probably make them similarly to adults” (Pohlman et al., 2002, p. 180). Her results also indicated that there was no significant relationship between “reasonable decisions based on abstract thinking and formal operations as described by Piaget (1972, as cited in Pohlman et al., 2002, p. 180).

2.6)Children’s competence and medical treatment

Having examined the multidimensional facets of competence as a way of understanding sufficient maturity, we can now apply this concept to the medical treatment of minors by exploring their decision-making capacities when faced with such a situation. “Competency is one of three components (together with voluntariness and information) necessary for a patient’s treatment decisions to be considered legally valid” (Weithorn & Campbell, 1982, p. 1590). Competency, according to general understanding of the law, is very loosely defined and therefore becomes problematic when being assessed. Masten and Coatsworth (1998, p. 206) define competency operationally when taking into account various factors. They define competency as “a pattern of effective adaptation in the environment, either broadly defined in terms of reasonable success with major developmental tasks expected for a person of a given age and gender in the context of his or her culture, society, and time, or more narrowly defined in terms of specific domains of achievement, such as academics, peer acceptance, or athletics.” (Weithorn & Campbell, 1982, p. 1590). Roth, Meisel and Lidz (1977) as well as Meisel (1979) have operationalised the test of competency with certain concepts being key. These tests of competency include “a) evidence of choice (the simple expression of a preference relative to the treatment alternatives) , b) reasonable outcome of choice (the option selected corresponds to the choice a hypothetically person might make), c) rational reasons (the treatment preference was derived from rational or logical reasoning), d) understanding (comprehension of the risks, benefits and alternatives to the treatment) .”

Literature suggests that evidence of choice displayed by the minor is also influenced by the minor's "internal locus of control and high self-esteem" (Mann, Harmoni & Power, 1989, p. 267). Mann et al. (1989), found that adolescents aged between 15-17 scored higher on internal locus measures (using the Nowicki and Strickland Locus of Control Scale, 1973) as compared to scores of early adolescents. Furthermore, Grisso et al. (1978) found that locus of control was situated in different areas depending on the age of the minor. It was found that children below the ages of 12-13 were significantly more prone to perceive locus of control as being external than older children (Grisso et al., 1978). Similar results regarding self-esteem were also found, where older adolescents scored higher on self-esteem than their younger counterparts. A proposed reason for this is due to "the growth of personal control and responsibility for choices is often delayed by the adolescent's tendency to conform to the peer group. American studies of conformity to group pressures during adolescence reveal a peak in conformity among 12- to 13-year-olds, followed by a decrease among 15- to 17-year-olds" (Mann et al., 1989, p. 267).

a) *Preference and outcomes of choice*

Anticipating the outcomes of choice, also referred to as anticipated consequences, are considered a prerequisite for competency. This is not only thinking of what the consequences of the treatment might have for the minor, but being able to think of how the consequences will affect others. A study conducted by Mann et al. in 1984 (as cited in Mann et al., 1989, p. 269) on a group of 13- and 15-year olds found that "30% of 13-year olds, but 51% of 15-year olds spontaneously referred to consideration of consequences." Similarly, a study conducted by Lewis (1981, as cited in Mann et al., 1989, p. 270) found that "7-8th graders and 10th graders, compared with 12th graders were less competent in their ability to imagine risks and consequences of medical decisions such as cosmetic surgery and acne experimentation."

b) Rational reasoning

Rational and logical decision-making is based on the ability to understand and process information given by the health care practitioner about the relevant treatment options available. This information, after being processed, must be used to examine the possible risks and benefits that it might hold. Therefore, a minor must have the abilities of abstract reasoning that can then be applied to hypothetical scenarios of the treatments.

c) Understanding

Comprehension, also known as understanding, is the last component of competence. It is seen as understanding the possible implications of the decision for the appropriate treatment. Therefore, it is the understanding of the possible risks and benefits of the treatment. This component largely involves a cognitive process. It is argued that comprehension is made up of knowledge: “person knowledge, task knowledge and strategy knowledge” (Mann et al., 1989, p. 268). These three categories were used in a study (Ormand, Mann & Luszcz, 1987; as cited in Mann et al. 1989) of 12 – 15-year olds. Results indicated that 15-year olds scored much higher on all the related knowledge categories as compared to the 13-year olds.

2.7 Challenges for health care practitioners in assessing competence

To understand competence, it is important to understand incompetence. This section is an extension of the argument that children are regarded as incompetent and not mature enough to consent to treatment. Children, historically, had no rights at all. Globally, children were seen as property belonging to their parents (Aries, 1962). This was however changed by the South African Constitution and the development of *Children’s Act*, where children were given some rights (McCabe, 1995). Laws are institutionalised to protect citizens from harm. A government possesses “*parens patriae*” which is the right to protect minors’ health, safety

and welfare (McCabe, 1995, p.171). It is based on the notion that minors are not mature enough to fully comprehend the consequences of their decisions (Maradiegue, 2003). The rights of minors are however very limited in comparison to that of parental (adult) rights over their children. It is argued that “their [children’s] rights are not protected to the same degree as those of an adult. There are three reasons that minors do not have the same constitutional rights as an adult: the vulnerability of children, their limited decision-making capacity and the important role parents play in making decisions for their children” (McCabe, 1995, p. 171). These are outlined below.

a) *Children as vulnerable: lacking cognitive capacity and life experience*

This view originates from earlier theories describing children as inexperienced and incompetent. Weithorn and Campbell (1982, p. 1589) argue the same point when they emphasise how law is used to construct the idea of children being helpless and immature. They emphasise that “the law’s concept of the family rests on a presumption that parents possesses what a child lacks in maturity, experience, and capacity for judgement required for making life’s difficult decisions.” Alderson, Sutcliff and Curtis (2006, p. 25) argue that “bioethics is still dominated, though, by outdated Piagetian age-stage theories of child development that tend to emphasise children’s ignorance, inexperience and inability to make truly informed autonomous decisions as if the mind and conscious grows as slowly as the body.”

As discussed before, ethical guidelines with regard to decision-making are followed when it comes to treatment of children in order to protect the child. The core of this requirement is the assumption that this population group is incompetent, vulnerable and not mature enough to make decisions regarding treatment of a disease or condition. Children are regarded as inexperienced in life and lack physical strength and are therefore seen as incapable of making

their own life choices and decision to treatment. As Landsdown (1994) points out, “there is a tendency to rely too heavily on a presumption of children’s biological and psychological vulnerability in developing our law, policy and practice, and insufficient focus on the extent to which their lack of civil status creates their vulnerability” (as cited in Morrow & Richards, 1996, p. 97).

b) Role of parents

It may also happen that the interests of the parents’ decision for the minor’s treatment are not what the minor wants. Both parties present conflicting treatment plans. This creates a problem, as it is the body of the minor that has to undergo treatment, while it is the decision of the parent for the minor to receive treatment. McCabe (1995, p. 507) argues that “parental discretion is legally challenged when a) parents refuse life-saving treatment, b) treatment would not be of direct benefit for the minor, c) treatment involves rights to privacy of minors, d) situations arise that involve significant loss of liberty for the minor and e) situations that arise about emancipated minors.”

c) Financial dependence

Financial support from parents in various areas of a minor’s life can also be seen as one of the constraints and limitations of minors accessing health care. The assumption is that minors (that are not by law regarded as emancipated or mature) cannot access private health care facilities if they are not earning an income large enough to pay for treatment costs. In most cases, parents are responsible for paying these costs. Similarly, parents might have their adolescent on their medical aid, and therefore can ask health care insurers for statements in which they are able to access some records. This influences the decision-making ability of the minor, as the parent/caregiver feels responsible to make the decision on behalf of the minor.

Diaz, Neil, Nucci, Ludmer, Bitterman & Edwards(2004) propose that there are ways of working around this to accommodate the needs of minors. They argue that “physicians can attempt to minimise this [financial costs] by taking additional precautions to explore the billing procedure of a minor’s insurance company or by providing services for a fee that the adolescent can afford, including free services when necessary” (Diaz et al., 2004, p. 184). Even though this seems to be somewhat feasible, there are still various limitations that would have to be examined. In South Africa, there are constrained and limited resources, and by reducing the costs of treatment for minors, remains questionable. Health care services, more specifically public and governmental hospitals and clinics are under tremendous pressure, providing for more persons that they can due to under-resourced staff. Ensuring that minors are billed a reduced fee adds more requirements to the already limited staff. However, in practice and in countries already struggling with limited resources, it is something that can be worked towards in future.

d) Language barriers

Much research in this area has been conducted on Spanish patients visiting American health care institutions. Similar to language barriers experienced in South Africa, 11% of American patients can only speak Spanish, therefore relying primarily on English as the main language of communication to explain diagnosis and treatment (Bernard, Whitaker, Ray, Rockich, Barton-Baxter, Barnes, Boulanger et al., 2006). Language barriers have far-reaching implications regarding the quality of care as well as the cost thereof. For example Bernard et al. (2006, p. 355) argued that “non-English speakers are also more likely to report problems with care, communication and diagnostic tests than are English speaking patients.” Similarly, it has been reported that there is an increase in cost of treatment. Bernard et al. (2006, p. 355) argue that “increased emergency department visit durations and increased resource utilization

have been reported, including a threefold increase in the use of abdomino pelvic computed tomography scanning in non-English speaking patients in the evaluation of abdominal pain in the emergency department.”

The interaction between language and thought processes are thus vital for assessing sufficient maturity. However, the language in which one is spoken to and the ‘language’ of one’s thinking might be different. Understanding, communication and thought are all linked to the cognitive ability of the child. This becomes somewhat problematic when assessing a child’s ability to relate to health care practitioners in English, when the context the child has matured in and developed in has mainly been a Zulu upbringing based on a Zulu culture.

2.8) Limitations of research conducted on competency of minors

It is important to note that what most, if not all of the above-mentioned research regarding treatment of minors has not taken into account, is the fact that the participants in these studies were healthy. Anxiety and depression about illness would not have affected measures of competence. Emotional factors may influence information processing as well as the ability to make decisions. McCabe argues that “the child’s physical state influences his/her attention span and concentration, particularly factors such as pain, discomfort and a variety of medications. The child’s level of intellectual functioning, including any information processing difficulties, also determines his/her ability to learn and remember medical information” (McCabe, 1995, p. 510).

Summary

This thesis explores the conceptual notion of sufficient maturity when minors present for treatment. This above literature review covered four main areas in the literature i.e., legal and ethical frameworks, psychological theories, and competence in decision-making. Historical

and current South African laws institutionalised to protect children were mentioned. Further, legal and ethical issues were explored in relation to treatment of minors. The last section focused on the concepts of competence, cognitive abilities and how these are understood and applied in treatment and decision-making. In these four main areas, important concepts such as understanding, rational thinking, stating alternate treatment preferences and vulnerabilities of the minor were highlighted. The next section outlines the methodology adopted to explore how health care staff operationalise the notion of “sufficient maturity” in their daily interactions with minors.

3. Aim/rationale

Currently in South African law, children from the age of 12 years can consent on their own to treatment, provided they show “sufficient maturity.” The term sufficient maturity has been adopted in various contexts for determining competence and understanding in minors . However, there has been little conceptual and empirical research conducted on this requirement (Jamieson, Mahery & Seyisi-Tom, 2009/2010). As mentioned in the literature review, most studies regard chronological age as the most important factor in determining maturity. However, conceptually, it remains unclear what is meant when assessing “sufficient maturity” in minors. Of interest to this study is how health care workers working in this area, conceptualise, understand and apply “sufficient maturity” in their encounters with minors presenting for treatment in order to identify key elements of sufficient maturity.

4. Key questions

The major question to be answered is: How do stakeholders conceptualise and apply the concept of “sufficient maturity” in practice when working with minors presenting for treatment?

When addressing this question, other questions arise:

What are the key criteria health care practitioners use to assess minors’ sufficient maturity?

How do they view minors’ abilities to be regarded as mature or immature and what perspective do they base their decision on?

What challenges have health care practitioners faced when having to assess a minor’s maturity?

5. Methodology

Participants were selected primarily from two areas within the health care sector. One group of participants was specialist paediatricians, working at local clinics and government hospitals, while the other group of participants consisted of female nurses working mainly within the emergency and maternal ward in a private hospital. An initial eight participants were contacted, via email, requesting their participation in this study, of which two participants responded. A second email was sent, requesting participation of those potential participants who had not responded. Snowball sampling (Neuman, 2006) however enabled the researcher to contact more participants, referred by the initial two participants as well as other health care staff. Of these, eight participants responded and were interested.

5.1) Study design:

An interpretative paradigm was used in conducting this research study because of the decision to seek qualitative data. A qualitative design was used in order to explore the concept of “sufficient maturity,” more specifically how stakeholders understand this concept and how they apply it to various cases of treatment regarding minors of the age 12. This design was chosen because of its ability to “understand the essence of experiences among a phenomenon” (Whittaker, 2002, p. 254). Of primary concern here is to develop an in-depth understanding of this abstract concept. An interpretative thinking frame, informed by Braun and Clarke (2006) was adopted and nested in interpreting and describing common-sensical, taken for granted events. It allowed the researcher to see that the “social world is largely what people perceive it to be. Social life exists as people experience it and give it meaning through encounters with others. It is fluid and fragile” (Neuman, 2006, p. 89). Qualitative researchers can, in most cases, be regarded as an instrument in the research process. “Considerable interest has been focused on who the researcher is and what values, assumptions, beliefs or

biases he or she brings to the study” (Mertens, 1998, p. 175). Qualitative researchers immerse themselves in the texts of the participants, making sense of what has been said during data collection procedures. They therefore have to engage in a constant iterative process as data constantly emerges (Neuman, 2006).

5.2) Research participants:

Participants consisted of staff from the University of KwaZulu-Natal, particularly the Nelson, R. Mandela School of Medicine, in Durban, as well as from a private hospital in KwaZulu-Natal. Participants (viewed as the stakeholders) consisted of 8 staff specialising in the areas of Paediatrics, labour and maternal as well as trauma wards of government and private hospitals. Participants consisted of two paediatricians, and six registered nurses. Seven of these were female, and one male participant. Their age ranged from 35 – 55. These health care workers were chosen in order to provide relevant information that was needed to conceptualise the construct of sufficient maturity within the framework provided by South African law. The reason for selecting staff from these institutions was mainly because they were professions dealing with minors presenting for treatment on a daily basis. These key informants facilitated the development of understanding, how sufficient maturity is assessed, and more specifically - where the various key informants’ understandings were consistent, overlapped or differed. The researcher was “attempting to gather some insider or expert knowledge that goes beyond the private experiences, beliefs and knowledge base of the individual you are talking to...working with key informants means you believe the answer to your research questions lies with select individuals who have specialised knowledge and know what’s going on” (O’Leary, 2010, p. 169).

5.3) Sampling:

Reliance was placed on key informants' knowledge and experience regarding decision-making and sufficient maturity. It is for this reason that a mixed method was used to gain access to participants. The sampling strategy adopted was purposive snowball sampling. It was necessary to use purposive sampling techniques as the information required was specific to a select group of people (Dey & Frankel, 2000). Without the informants' knowledge and experience in this field, there would be no point in conducting this study as the researcher would run the risk of gathering the wrong type of information from the wrong informants.

5.4) Data collection techniques:

Semi-structured, in-depth, face-to-face interviews were used as the primary method of data collection. An interview schedule was drawn up beforehand (see Appendix 1) covering some of the key questions to be explored as well as some probes to facilitate information collection and conversation. A scenario/vignette was also included in the interview for the practitioner to indicate how they would go about assessing sufficient maturity. This provided a more practical step-by-step insight into the construct.

The reason for collecting data in the form of an interview was because "it is a more natural form of interacting with people than making them fill out a questionnaire" (Terre Blanche & Kelly, 1999, p. 128). The semi-structured interview format was chosen because it allowed a flexible component to the interview. Furthermore, it allowed the researcher to cover relevant topics as well as "unexpected data that emerges" (O' Leary, 2010, p. 195). Therefore, "interviewers can start with a defined questioning plan, but will shift in order to follow the natural flow of conversation" (O' Leary, 2010, p. 195).

5.5) Instruments:

a) Interview schedule

As already mentioned, an interview schedule (see Appendix 1) was drawn up. It formed the core of the interview and ensured that the main topics of interest were covered and explored. Certain themes linked to the practice and expertise of the health worker were covered. These themes were based on the literature on decisions practitioners make when working with adolescents and children presenting for treatment, as well as on criteria used to base these decisions on. In developing the schedule, problematic questions were rephrased in order to assure that the participant had a clear understanding of what was being asked. Probes were used to avoid leading the participant as well as to facilitate discussion between the researcher and participant (O'Leary, 2010).

b) Hypothetical scenario/vignette

A second component was worked into the interview where a scenario was given, asking participants how they would go about assessing the given situation. This was one of the main sections of the interview where a lot of rich information was given. Vignettes, also known as hypothetical scenarios, are best defined as a technique used in qualitative interviews (Jenkins, Bloor, Fischer, Berney & Neale, 2010). There are various ways in which scenarios/vignettes are presented to participants such as via computers, videos and on paper (Jenkins et al., 2010). The chosen format in which the scenario was given to the participant was on paper. Justifying the use of a vignette in this study was based on the fact that in “psychological studies, the research interest is primarily on predicting behaviour” (Jenkins et al., 2010, p. 176). The scenario/vignette served as a tool to attain rich information in relation to questions asked in the interview schedule. Furthermore, it served as a confirmatory tool to

verify whether the key criteria identified, were consistent with, or differed from the scenario's responses. Vignettes also compliment interpretive frameworks such as those of Braun and Clarke (2006) as they seek to explore a phenomenon. Jenkins et al. (2010, p. 178) argue that "the researcher should reject the somewhat reductionist notion that belief and actions are binary opposites, [but] instead conceiving of interviewees' responses to vignette stimuli as social actions in their own right." It is important to consider that hypothetical scenarios elicit responses from interviewees based on their experiences and interpretation (Jenkins et al., 2010). While constructing the scenario, it was important to maintain plausibility because literature suggests that the higher the plausibility of a scenario, the more the researcher is able to gather rich information as opposed to unlikely scenarios that elicit disbelief (Jenkins et al., 2010).

c) Digital audio recorder

A digital audio recorder was used to capture verbal communication during the interviews. It facilitated data analysis when transcribing the interview. Furthermore, it assisted the researcher to attend to the tone of the participant's voice when certain questions were asked, and to reflect on themes when transcribing data. It allowed the interview to flow and stimulate discussion because the researcher was not so concerned about remembering everything that was being said, but instead listened and asked questions that were regarded as important for the gathering and collection of rich data.

5.6) Reliability and validity

Reliability is best defined as "the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions" (Hammersley, 1992; as cited in Silverman, 2006, p. 282). Producing a reliable study in

qualitative work is challenging. Therefore, two strategies are proposed by Silverman (2006) to produce results that are regarded as reliable in qualitative research. The first strategy he proposes is that of transparency. Here the researcher must “describe the research strategy and data analysis methods in a sufficiently detailed manner in the research report” (Silverman, 2006, p. 282). He then emphasises, as the second strategy, “attention to theoretical transparency through making explicit the theoretical stance from which the interpretation take place and showing how this produces particular interpretations and exclude others” (Silverman, 2006, p. 282).

Validity refers to the accuracy of the results being studied in context. Hammersley (1992; as cited in Silverman, 2006, p. 289) argues that validity is the extent to which an account accurately represents the social phenomena to which it refers.” Triangulation (a combination of strategies and methods employed to see if it is a true representation of what is being studied) is used as well as respondent validation (validation of the respondents’ experiences by going back to them with results). Given the limited time and resources available to conduct this study, the researcher was not able to validate themes and therefore, results must be read with some caution.

5.7) Procedure:

Relevant staff in the School of Psychology (Pietermaritzburg Camps) were consulted to generate a list of potential participants. The list of potential participants (8) was contacted via email to ask permission to conduct an interview. Hereafter, interviews were scheduled at a convenient time and place for participants and the researcher. Informed consent was obtained from the participants prior to the commencement of the interview. The informed consent form (see Appendix 2) covered the necessary information about potential risks and benefits of

the study as well as a brief overview of and the aim of the study. One-hour interviews were conducted using the interview schedule and necessary probes. On average, the interviews lasted for 40 minutes after informed consent and a background to the study had been given. Interviews were transcribed and analysed during this process identifying various themes as the researcher immersed herself in the data continuously adding more themes to the interview as data was generated and reflected on. Themes were identified and examined and compared to emerging themes as data was transcribed. With a sample size of 8 participants, it was estimated that the point of redundancy with data would have been reached from which the researcher could thereafter develop a holistic idea of the construct of 'sufficient maturity' and thereby being able to identify criteria that overlap between the various institutions as well as those that are unique to governmental or private hospitals.

5.8) Data analysis:

The method of analysis chosen for this study was thematic analysis, incorporating qualitative frameworks outlined by (Braun, & Clarke, 2006; Smith, 1992; as cited in Terre Blanche & Kelly, 1999). The data collected during the interviews were transcribed prior to data analysis. After the verbatim transcription of each interview, common steps of thematic analysis were followed as proposed by Terre Blanche and Kelly (1999). The researcher read and reread the transcripts in order to familiarise and immerse herself with the text. Primarily, a theoretical and semantic approach was adopted. This allowed the researcher to use interpretation, which was facilitated by theoretical constructs in the area in which the study was conducted. This type of thematic analysis presented with a trade-off between rich descriptions as opposed to specific accounts of the phenomenon. In theoretical thematic analysis rich detail is not analysed, but rather provides the tools for more detailed accounts of a specific phenomenon (Braun & Clarke, 2006). Semantic analysis is the level at which thematic analysis was done.

The aim of this study was to provide, on-the-surface accounts of how health care practitioners applied the notion of sufficient maturity. However, latent themes (First two themes, see results) were also identified and considered important for discussion.

Stepwise thematic analysis

The next step of the thematic analysis included identifying significant emerging themes. According to Boyatzis (1998, p. 161), a theme is “a pattern in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon.” It was important throughout the process to note that the “themes should ideally arise naturally from the data, but at the same time they should also have a bearing on your research question” (Terre Blanche & Kelly, 1999, p. 141). Coding was the next step that can also be best defined as “marking different sections of the data as being instances of, or relevant to, one of your themes” (Terre Blanche & Kelly, 1999, p. 143). Boyatzis (1998) describes this step as looking for critical events and coding them. He argues that a “good code is one that captures the qualitative richness of the phenomenon” (p. 1). Coding procedures occurred by using different coloured highlighters to identify certain key phases, words and sentences. This phase required the researcher to go through the transcripts “line-by-line” (O’Leary, 2010, p. 264). The function that coding serves in thematic analysis is essentially to capture and organise important phrases that the respondent has mentioned in the interview relevant to the research area. After coding was completed, a further exploration of themes was needed to focus and clarify. This step was critical in that it allowed the researcher to look at the finer details of the text and was an “opportunity to revise the coding system - either in small ways or drastically” (O’Leary, 2010, p. 144). The last stage of data analysis was the final product of the identified themes. Identified themes were guided by the responses given by interviewees in the interviews. These themes were then linked to

interpretation to convey an understanding of the information derived during the interviews. This last stage was used to reflect on biases and prejudices that might have influenced the interpretation process and to hopefully capture the essential themes talked about during the interview process as validation.

6. Results

From the interviews conducted, two main themes were identified. These themes were based on the differing viewpoints health care practitioners had of the abilities of minors presenting for treatment. Some of the subthemes were identified as being present in both of the institutions (private and government), whilst others were viewed in opposition to each other. The perceptions that health care practitioners had of minors affected the key factors that were used to assess sufficient maturity. Therefore, key factors for assessing sufficient maturity was the main objective of analysis, but challenges to sufficient maturity was an apparent subtheme identified. Another emergent theme was the importance of how information regarding the procedures and treatment was conveyed in facilitating understanding and cooperation. An overview of the results is presented in Appendix 3, Table 1.

I = Interviewer, P = Participant

Theme 1: Viewing minors in terms of their abilities

Despite the *Children's Act* (2005) stipulating that children from the age of 12 can give consent to treatment, some participants indicated that they assess sufficient maturity from as early as the age of 8-years. These participants were certain that 8-year olds have the mental capacity to understand and process the information when treatment and diagnosis was explained at an appropriate age level.

1.1) Subtheme 1: Demonstrating competence through developmentally appropriate methods

Analysis indicated that information on treatment was transferred from the health care practitioner differently when communicating with young children as opposed to adolescents. When communication of treatment and diagnosis was tailored according to the appropriate developmental level of the minor, cooperation was facilitated and a better understanding of information was received, which demonstrated signs of competence and sufficient maturity.

Extract 1: Participant B

I: Uhm would you treat, or would you use different strategies for an 8-year old as opposed to an adolescent of 15-years old? Do you have different strategies of getting their cooperation and how would you go about?

P: You see we often, with younger children we would use visual aids etcetera,

I: Ok

P: And more colourful things and try to explain to them or do role acting or whatever depending on what it is and uhh for instance uhh if you want to put in a dialysis catheter, ehh you going to be much more careful about explaining to them using ehh you know role play who says this is what is going to happen this is how we insert it, so they understand why it is there right. Obviously when it comes to an adolescent who can understand charts we just explain it in a more abstract way because they understand what

I: Ya

P: What is going on you know what I mean so depending on the meds, depending on how much you feel that the patient understands what you are doing and how mature they are, we will tailor make our, our explanation accordingly

The child patient

As can be seen in the above extract, there are ways to informing a minor of their diagnosis and treatment plan that enables them (the patient) to respond in an appropriate, more developmentally mature manner. Below, two extracts are provided to highlight different ways in which the health practitioner would go about informing the patient of the diagnosis and the treatment plan. These are tailored at a level to meet developmentally appropriate ways of informing on procedures that lead to cooperation for the duration of the treatment plan.

Extract 2: Participant A

P: Then I would sit with the child and say listen you have to take your medicines, now can you take your medicines in the morning, can you remind your mom that you've gotta take your medicine, you know that kind of thing and we make it a little fun thing and I might even say to them, next time you come bring me the bottle of that medicine so I can see how much you have taken. (Pause) ok, so we also need to motivate

In this extract, Participant A refers to the patient as the child. She tailors her way of communicating with the child on a level of understanding that is appropriate and critical for the child taking the medicine. The health care practitioner (participant) turns it into a game in order for the patient (child) to understand what is required. When the child is briefed on the treatment procedure and understands it, a very mature stand can be taken. Furthermore, referring to the developmental stage of a child, play has been indicated to be a critical requirement for development. Studies conducted by Piaget in 1959 (as cited in Swartz, De la

Rey & Duncan, 2006) indicate that play is vital for developing certain abilities and strengthening competencies necessary to display maturity. According to Piagetian studies (as cited in Swartz, De la Rey & Duncan, 2006, p. 65) “intellectually, play provides a context for using language to communicate and the mind to fantasise, plan strategies and solve problems. Children often show more advanced intellectual skills during play than they do when performing other activities, suggesting that play fosters cognitive development.” Therefore, the point can be made that by relating to a child patient through play facilitates understanding of information and cooperation.

The adolescent patient

For the purpose of this study, the theme of developmental appropriateness had to be divided into two types of patients: the child and the adolescent (Swartz, De la Rey & Duncan, 2006). The former is aged between 6 – 12 years of age and the latter 12 – 18 years of age. The justification for this is due to the importance of these distinct types of patients. Minors can understand and make an informed decision about treatment when information is given at a level of their understanding, relating to their phase of development. Two subthemes were identified by the participants relevant to minors. These subthemes are in line with developmental benchmarks of childhood and adolescence. Unlike children, where optimal understanding can be achieved through methods of play, adolescents have other developmental requirements that facilitate optimal understanding and information processing.

Extract 3: Body image concern

I: Have you ever found resistance from an adolescent and you have to change your strategy to get cooperation?

P: They are the most difficult ones to deal with (hehe) particularly when it comes to side effects that cause body image changes, like putting on weight or hair growth or something, I mean no 15-year old girl wants to have hair growth in her face (haha) you see what I mean most often the patient says no I don't want it . Now obviously you know we try and choose medication that is going to be more tolerant for that age group and tailor make our treatment according to the side effect profile not the other way around.

Adolescence is a transitional phase where body image becomes a concern. Participant B highlights this developmental concern in order to facilitate cooperation when discussing various treatment alternatives. Elkind (1984) (as cited in Papalia & Olds, 1988) argues that adolescents display forms of egocentric thought. They become very self-conscious and create an imaginary audience, which may consist of admired prototypes, where special attention is given to clothing and other objects in order for others to admire them. Therefore, it is critical for the health care practitioner to take into account the importance of body image when treating an adolescent. This concern with the self during the adolescent developmental phase is linked to cognitive changes, therefore, implying that “adolescent's reflection extends to a preoccupation with thoughts about the self, which may exacerbate their growing self-consciousness due to physical changes in their bodies” (Swartz, De la Rey & Duncan, 2006, p. 76).

Extract 4: Need for independence

P: The more deeper you gonna have to delve because I don't think, about 14, 15 they can, but then also there is that element of the adolescent negativity, you know what I mean, we know that if we've looked after a child from renal disease, when they've reached 14, 15, 16, they become obstreperous and don't want to take their medications, and why should I do this and

that sort of thing so they fail therapy sometimes because of adolescence, it's just the way of the psyche

I: Their rebellion phase

P: You see, so that's where you need to pick up how they feel and what their responses are and then you have to try and adapt accordingly and if you can get them to think the way you would like them to think, it's obviously and sometimes you know you can't hammer them, you've gotta let them say, ok you think about that and come back to me.

Adolescence can be a very disruptive period where body image becomes important, as does the need for independence. In the above extract, Participant A (health practitioner) is aware of this phase and therefore adapts her manner of speaking in such a way that the adolescent feels like he/she has the ability to make the decision, meeting the need of independence.

Adolescence is a period of developing autonomy, where the adolescent wants the required space to develop and create an identity. The participant in the above abstract informs the adolescent about the treatment, but then shows that the adolescent patient has the ability to make the decision. Taking this phase of development seriously can be a critical part in the treatment process.

1.2) Subtheme 2: Displaying sufficient maturity – key criteria

Apart from understanding as the cornerstone of sufficient maturity, the most frequent responses given when assessing sufficient maturity was the ability to communicate and answer questions, ability to apply and ability to assess the risk – benefit ratio to treatment.

The notion of ability refers back to expected competencies that minors have developed or mastered during their development. This is a positive viewpoint of minors emphasising their competencies rather than the lack thereof.

a) Questioning as a way of assessing understanding and maturity

According to Grisso and Vierling, (1978), three types of consent exist. This subtheme captures the first type of consent, which is termed knowing consent. The importance of this type of consent is based on the minor's understanding of the content verbally produced by the health care practitioner. It requires the minor to understand the information. Therefore, what the patient (minor) knows is based on the interplay of verbal communication between what the health practitioner has said and the ability of the minor (patient) to understand the information given. The health care practitioner measures the understanding of the minor by assessing the conceptualisation that the minor has of the information. This is achieved by asking certain questions that are relevant to the treatment and illness and listening to the response of the child.

After the information has been given in a developmentally appropriate manner to the patient, the participants said that they would ask questions to assess whether the patient understands. During this process, the health practitioner not only assesses understanding, but also the level of maturity that the minor displays. Participant B gives an example of this. Note again the way Participant B would talk to the child on a level pitched just right to understand.

Extract 5:

P: And say you know look if you take this medication, what do you think is going to happen with your eating of chips and biscuits and all that and they will say no if I take this I'm not suppose to eat that, you know what I mean, and I'm gonna tell my grandpa not to buy me this, so then you understand, get the notion that the child is taking in the fact that they've gotta have dietary modification on medication and can't do this etcetera, so you get a sense of what is going on

b) Ability to apply (Rational action)

Extract 6:

P: (In breath), I think you need to assess do they understand what their illness is and the impact of the illness and do they understand why you have to treat them those are the crucial things,

I: The two most

P: Yaya, do they understand what their illness is about, do they understand why you're treating them and do they understand what their treatment is and what it entails. If they can understand that then I feel you can work with them.

I: Understanding in terms of what? What understanding? Uhm, information?

P: Ya, how they have to take their medication, why they have to take their medication, what impact does treatment have on this process in simple language

I: And will they be able to carry it through

Participant A not only stresses the importance of the patient's understanding, but also highlights the importance of applying what the patient has now heard and understood that treatment is required. Therefore, by understanding what the illness is about, the patient (minor) has to be able to integrate that understanding into action. It illustrates understanding on a level that is thought to be mature when the minor is able to apply what has been told. The outcomes of choice, also referred to as anticipated consequences, are also considered a prerequisite for competency. This is not only thinking about what the consequences of the treatment might have for the minor, but also being able to think of how the consequences will affect others.

c) Ability to reflect on risk-benefit ratio

Extract 7:

P: Ya, whatever is going to happen but it's not just procedures, because I think you also have to talk to them about, because many of the children are chronically ill, if it's an acute issue, it's fine, you can get the consent and go ahead provided you explain repeatedly what you are doing to the individual, when its chronic, the child can challenge you

I: Yes,

P: Now a 9-year old can easily challenge me and I've dealt with chronically ill patients and a 9-year old said to me after we had given a series of therapies and it really didn't make much difference to his clinical state, I said, I have got another drug and I would like to try this one, and he said ok, how much is it going to help me

I: Ok

P: So I said we've got about half-half chance (uhh) so he said what would happen if I didn't take it now? So I said, we could watch and look, the mother was frantic of course

I: Yes yes (haha)

P: I said we can watch and look but you know the numbers that we look at when those numbers go wrong, then maybe we can start if you think that would be ok. Would you like a break from treatment, and he said yes I would like a break from treatment. So I said ok, you can have your break from the certain treatment, but you have to continue the other things we give you, you know we give them vitamins and we give them this and that.

This subtheme can also be explained using the second type of consent Grisso and Vierling (1978) termed 'intelligent consent.' Overall, this type of consent requires the patient to have

competence in the ability to think rationally, independently and logically. These three abilities must be present in order to assess the risks and benefits of treatment. Therefore, the risks and benefits can be presented in a logical and rational manner in order to facilitate an informed decision. Furthermore, Weithorn and Campbell (1982, p. 1590), Roth, Meisel and Lidz (1977) as well as Meisel (1979) have operationalised the test of competency with certain concepts being key. These tests of competency include “a) evidence of choice (the simple expression of a preference relative to the treatment alternatives) , b) reasonable outcome of choice (the option selected corresponds to the choice a hypothetical reasonable choice a person might make), c) rational reasons (the treatment preference was derived from rational or logical reasoning), d) understanding (comprehension of the risks, benefits and alternatives to the treatment).”

Extract 7 illustrates the interaction between the participant (Participant A) and her patient. Here a 9-year old patient was able to gather enough, developmentally appropriate information to weigh up the potential risks and benefits to make an informed decision. He is not only competent enough to say he wants to stop the treatment for a while, but also inquires about the consequences in a logical and rational manner of how that would affect his health.

Theme 2: Minors viewed as a vulnerable population

The second overarching theme emphasised the vulnerabilities of minors. It could be argued that it was based more on a deficiency model, as opposed to the first theme, which was based on abilities and competencies that children indeed have in their possession. Theme 2 then, one could argue, is based on a historical view of children which were seen as property belonging to parents (Aries, 1962). As argued earlier, the government possesses ‘*parens patriae*’ in order to protect children from harm. This viewpoint is based on the underlying assumption that children (minors) are not mature enough to understand the implications of

their decisions and that parents still possess more rights than their children. Maradiegue (2003) argued that this is due to the perception that most people have to foster children in a protective environment for as long as they possibly can. This line of reasoning argues that children are vulnerable; they are not competent to make decisions and are dependent on their parents (caregivers) for at least the first 18 years of their lives. Children are regarded as inexperienced in life, lack physical strength and are therefore seen as incapable of making their own life choices and treatment decisions. As Landsdown (1994) points out, it is the emphasis placed on biological and psychological vulnerabilities which are used to inform the development and practice of law, leaving them as a vulnerable population. This perspective is nested in the incompetence of minors and their lack of cognitive development to be regarded as sufficiently mature.

Analysis also indicated that some participants were reluctant to view children aged 12 as mature enough to make decisions regarding treatment without any assistance from parents (caregivers). Instead, a different perspective of a minor was taken. This perspective was based more on the child being uninformed, lacking the cognitive ability and not being able to understand fully what was required when information was given. However, there was a minority of participants who thought that it is possible for a 12-year old to be mature enough to take part in the decision making of treatment but for minor procedures such as a toenail being removed.

Extract 1: Participant F

P: Personally, I think it is absolute stupidity, because most 12-year olds don't know what they want for supper tonight and I don't believe are capable of making that decision. I mean if it is something really simple like a toenail removed yeah I guess, but to be informed as to the

major stuff I think is hard, I think they might bring it down because of child headed household families

2.1) Subtheme 1: Financial dependence limiting independent decision-making

A minor's involvement in the decision-making of the treatment seemed to be somewhat limited by the fact that the parents (caregivers) were responsible for paying the fees at a private hospital. The minor had limited autonomy and merely becomes the patient, an outsider to the decision making process which, in turn, limits their ability to display sufficient maturity. Independent behaviour is what parents eventually would want for their children. Limiting participation in decision making of treatment can be detrimental to the development of a minor's maturity and independence. Not only does it have implications for the acquisition of certain life skills necessary in later life, but also implies a kind of ignorance of the rights of children, and more specifically the principle of autonomy.

Extract 2: Participant C

P: Ok well I've always for the last 10, 13 years worked in private practice, so it's a little bit different in government practice in that usually their parents are paying

I: Mmm

P: But you still have to get consent from the actual patient, whether it is verbal or written, you have to get consent from them to perform a procedure or whatever on them...and language groups, how much they understand because particularly the black girls are very uhhm under their parent's subjection and they will come in for a delivery or termination or whatever it is and sometimes it's difficult to assess whether they have made the decision or it has been forced on them

Dependence seems to be the main theme running through in the above abstract. The dependence on parent's financial support may lead to the minor being viewed as unable to make an informed decision. This is not only because they are viewed as not capable, but also because of their dependence on fees being paid by family or parents.

2.2) Subtheme 2: Lack of cognitive ability and life experience

Extract 3: Participant D

P: It is important, but our concern is we might say, no she is not matured enough but now explain to me what age can you define as maturity, and what does maturity mean *uybona*, is it a person that can be able to think and take wise decisions on her own

I: Yes

P: Can a 13-year old decide ehh, whether to undergo this treatment, the consequences, is the brain matured enough for that, no, does she ehh have any experience like an 18-year old and over who have been through difficult situations during their maturity, maybe they will have an understanding of no I'm 18 now I was 12 I can't do that now, I'm matured, can a 12-year old really decide I must go for this treatment or no treatment. Uhh I don't think my own point of view they do have a right to say, to decide for their own treatment, but in a maturity point of view, they are not matured enough to take decisions and to ehh understand that their decisions, what will be the consequences of those decisions that they have taken, like me and you

Participant D argues that in order to display sufficient maturity, the minor must be able to make informed decisions seen as a skill not yet acquired. She is very doubtful that a minor has that ability and required cognitive skill to do so. She also argues that a minor has not yet had enough life experience in order to make informed decisions and reflect on previous

situations. Informed consent is based on the principle of autonomy. However, when minors are presenting for treatment, their autonomy becomes limited and dependent on the opinions of their parents. Such reasoning is based on the fact that “developing competence for informed consent decisions is associated with cognitive capacity” (Pohlman, Dickey, Kiefner & Beidler, 2002, p. 179). The assumption that competence only comes when reaching a certain level of cognitive capacity, limits the minor’s participation and opinions in decision-making when presenting for treatment.

2.3) Subtheme 3: Lacking comprehension

I: How do you see the level of understanding is mature, or immature?

P: Because if they don’t understand the simplest of things, you know, like it’s going to be really painful,

I: Mmm

P: How painful, you know

I: Yes

P: If they say to me how painful and I say to them really painful, then they obviously don’t get it you know, I mean also in labour ward I don’t know about other departments, but in labour ward a lot of people see how labour is on tv which is not how it is in real life

I: Mmm

P: So if they don’t understand by a tv programme that she is screaming and shouting and swearing at her partner, if they don’t realise that that indicates painful the

Theme 3: Challenges when assessing sufficient maturity in minors

Sufficient maturity emerged as a very subjective concept, which was evident as only becoming easier to identify with experience in the health field. Participants highlighted some challenges that they have been faced with when having to assess a child's maturity. Note however that there is not much, if any, body of literature or extensive research touching on the challenges faced when health care practitioners have to assess sufficient maturity.

a) Language barriers

Extract 1: Participant G

P: Ok, uhhm, the first thing we have to look at is, the level of understanding of the child, if and that may be determines not just by their, their own uhhm, their level of maturity, but maybe a language barrier, for instance if you get someone who doesn't speak the language you are less likely to assess their level of maturity as you would with someone who spoke the language you speak, I mean here, we speak mainly through the medium of English, ok, but if we get Zulu-speaking patients or Afrikaans speaking patients etcetera, you might find that, it's not because they are not mature enough, they just don't understand what you are trying to say because look if you working through an interpreter etcetera, they may not be as effective as you would like them to be

Extract 2: Participant B

P: And then we are less likely you know to consider that child mature enough you understand not because he may not have the intellectual maturity or ability, but because of the language barrier. Then the other thing is cultural differences, ok, it plays a role, I mean there are some cultures where you know they do not want certain things done, right, and so if you

try and force the procedure or something they would say no, you understand what I mean, so it's not because they don't understand that

b) Parents/caregivers

Extract 3: Participant A

P: Sometimes you just can't make up your mind whether the child is, really does understand or not and you sometimes have to go into a trial talking to the parents and see if you can succeed. Often it is the parents of the child, so you may need to go into that. For example, I will tell the child in front of the parents ok you are now on this form of treatment, remind your mom to give you the tablets, yes, but it's a scatterbrain family, they don't have many resources, they live in poor conditions and the mother can't cope

I: Mmm

P: If you ask her to bring the tablets, she brings you back all the tablets, so yes, ya you, then you set up so the social worker becomes important and support systems become important. For the parents very often, not so much for the child.

In the above extract, the family plays an important role in fostering and developing maturity in the child. The mother is perceived as not competent enough to understand what is required of her, which may lead to the detriment of the child's treatment. In this case Participant A suggests that a social worker be involved in order to assist the parents. The child may be willing, but the parent may limit the ability of the child to display his or her maturity.

Extract 4:

P: Or ask questions about it so, there are definitely some 13, 14, 15-year olds you know that they have done something about it, they understood, you know, but there is some who just are clueless.

I: Do you think that that's an adolescent phase where they just don't care or do you think they have never been taught how to think

Pause

P: I think it could be both

I: Ok

P: You know because some kids have, and I'm not saying there is good parents and bad parents, but there are unfortunately good parents and bad parents and I'm not saying that the parents who haven't prepared their children are bad

I: Yes

P: Uhhm, but I think some parent wanna keep their babies, babies for as long as they can even if its mothering them, not letting them reach potential that that child can actually get to

I: Ya

c) The God Complex

In most cases doctors are regarded as people in a position of authority and more often than not, are not questioned when it comes to treatment. Participant E however argues that it may

be difficult to assess sufficient maturity of children and their understanding of the treatment because they would be reluctant to ask questions due to the submission to authority.

Extract 5: Participant E

I: And I guess that's also taking responsibility in order to make an informed decision, you ask

P: Ya

I: So that would be responsible to ask which is a sign of maturity I guess

P: Ya and also the other thing about medical is that if you have fully understood what the doctor said you know and he said, I'm gonna chop off your leg, and you say ok that's fine, to me I would say well why do you want to chop off my leg

I: Yes definitely, are there other ways of

P: And ya, and ya if he says no its just because I don't like the look of your leg, some people say oh ok that's fine, other people will say no hang on I think I'll rather go get a second opinion so there is, and again its certain race groups you say I'm gonna chop off your leg and they say ok that is fine

I: Isn't it the power of authority, where they submit to

P: I think a lot of it in the medical background because people think doctors are gods, why they think that I have no clue, because they are not all powerful all knowing, you know...

I: Mmm

P: Too scared, but ultimately it's your body

I: Ya you want

P: Surely you should actually you know

I: Ya you should know what is happening to it

P: Ya, ya and I think it's this god complex that these doctors have you know and I think it's because people have treated them like gods, ya there are some people who are too scared to ask because the doctor might turn around and say you know go somewhere else if you want to ask all these questions, if the doctor said that to me I would say fine I will go somewhere else

Theme 4: Using the vignette/scenario to contextualise sufficient maturity of minors

A scenario/vignette was given during the interviews that assisted with the construct of sufficient maturity in context (scenario/vignette can be found in Appendix 2). Even though some participants displayed a reluctance to acknowledge that minors are mature, participants were better able to relate to this example in such a way to illustrate how sufficient maturity is achieved. Subthemes that came from this scenario were similar to those given when practically assessing sufficient maturity, with the first theme focussing on the abilities of the minor:

Extract 1: Participant D

P: So there, we will see the responsibility there, because she was responsible enough to understand that she is not feeling well and to make a decision voluntarily to go to the clinic on her own, she is 12 I mean a 12-year old needs to go with his parents, my son is 15 even now he is 18 but I take him to the doctor. There you understand her thinking processes she can think ehh what can I say there is a word I want to use, at least, rational thinking that's the word I want to use, she can think rationally cos she has been coughing, everybody coughs. I don't go to the clinic when I'm coughing second day third day maybe I'll go get a cough

mixture. Rational thinking, she went to the clinic, responsibility, that is a responsibility and being diagnosed that she is having TB, how is she going to take it

Participant D argues that the minor was responsible in going to the clinic because she understood that she was feeling ill for a while. Furthermore, she took the responsibility to plan to go to the clinic, which requires ability to plan ahead, for example transport fees and alike.

The second important phrase is where the participant highlights the fact that the decision was voluntary. There was no parent to tell her or force her to go to the clinic. She therefore not only went voluntarily, but also showed that she possessed autonomy in that her decision was independent, rational and logical.

Cognitive ability was illustrated in that a rational and logical decision was made to go to the clinic. Rational and logical decision-making is based on the ability to understand and process information given by the health care practitioner about the relevant treatment options available.

Based on the four main themes identified, these results are discussed critically in the section that follows.

7. Discussion

Authors such as Kunin (1997), Lidz, Meisel, Zerubavel, Cater, Sestak and Roth(1984) and Kuther (2003) argue that adults have the ability to provide informed consent purely because they are seen as being able to cognitively understand and process treatment options. Adults are encouraged to actively participate in the decision-making process of their own medical treatment. The aim of this study was to draw on experiences of health care practitioners in arguing for minors' ability to be regarded as sufficiently mature and able to provide informed consent when they present for treatment. Four main themes were identified using thematic analysis. These included demonstrating sufficient maturity in developmentally appropriate ways, minors viewed in relation to their vulnerabilities, challenges health care workers face and feedback given from the scenario. These four themes occurred throughout the interviews that were conducted and transcribed. Themes included the importance of taking into account the developmental phases of the patient in order to facilitate cooperation and understanding. This resulted in an exploration of the minor's ability to understand, resulting in mature decisions and informed questions. The perceptions health care practitioners had about minor patients, influenced their ability to assess minors as sufficiently mature. Due to these perceptions, some participants highlighted the lack of experience that minors have as opposed to the abilities that they do have.

Theme 1: Viewing minors in terms of their abilities

What emerged from the analysis and results, but only identified after numerous reviews of the texts, was that viewpoints of sufficient maturity differed among the participants. It was discovered that participants from the government hospital area were more likely to view

minors as sufficiently mature, highlighting abilities and competencies minors possess. As explained by the first theme, health care practitioners, speaking from a background of working in government hospitals and clinics, emphasised the abilities of minors. This was consistent with competency-based models referred to in the literature (McCabe, 1995; Roth et al., 1977; Grisso & Vierling, 1978). These participants also argued that minors as young as 8 years old possessed the maturity needed to understand and process important information. A diagrammatical overview of the themes is provided in Appendix 3, Diagram 1.

1.1) Using developmentally appropriate methods

Important subthemes were identified under the theme of viewing minors in terms of their abilities. Of importance to this theme was using developmentally appropriate methods to facilitate understanding and cooperation. Here differences were highlighted between a child and an adolescent patient.

Relevant literature regarding this topic suggests that cognition and the ability to decide are major factors that need to be considered in order to regard the patient as mature. It is for this reason that the same argument applies to the minor. In order to regard the minor as mature, they need to display cognitive ability and psychosocial competencies that illustrate their understanding of illness.

a) The child patient

According to Burbach and Peterson (1986, as cited in Kuther, 2003, p. 346) play provides some insight into how young children understand mental illness from a developmental perspective. Minors tend to view illness differently, based on their relevant cognitive and developmental level. At first, it is viewed as a form of punishment for misbehaving due to the association with bad and unpleasant behaviour. As the minor gets older, they develop a more

realistic idea of what illness is that extends beyond their immediate interpersonal relationships. At this stage, symptoms are associated with illness rather than misbehaving.

Rushforth argues (1999, as cited in Kuther, 2003) that children's' potential to understand illness is not as easily recognised as children's performance of measures taken to understand illness. When presented in developmentally appropriate ways, the minor finds it easier to understand, which is then viewed as a sign of maturity. Similarly, results found similar themes to authors like Kuther, (2003), Kister and Patterson (1980, as cited in Kuther 2003, p. 347). As it became evident in the results, child's play was used as a form of communication with young minors. Here the child is provided with a context that they can relate to and respond, which is not abstract and allows for optimal understanding of treatment, which facilitates further required understanding.

b) The adolescent patient

Regarding adolescent patients, the need for independence and physical and cognitive changes were identified. However, the major contributor said to facilitate cooperation from the adolescent, was their ability to feel that they were able to make their own decisions. This can be linked to the primary bioethics principle of Autonomy. Participants argued that adolescents displayed the need to be included in their decision making regarding their treatment. The need for independence did not only consist of understanding, but also the opportunity to use the necessary skill and capabilities to make informed decisions. Lewis (1987, as cited in Kuther, 2003, p. 348) argues that "during the adolescent years, minors become better able to consider information and opinions from diverse sources and capable of owning their own judgements." A primary characteristic of adolescence is the need to move away from parental, towards peer influences. This brings into question how adolescents' ability to make informed decisions is compromised. Scherer and Repucci (1980) examined

this statement by applying varying degrees of parental involvement to hypothetical situations. The aim was to see how the decision-making abilities of the adolescents would be affected by parental involvement. Results indicated that “adolescents were mindful of and deferential to parents, but were more likely to resist parental influence when they perceived the consequences of the decision as having serious implications for health” (Kuther, 2003, p. 348). Decision-making capacity is present during early adolescence as this phase of development consists of “the ability to reason abstractly about hypothetical situations, to reason about multiple alternatives and consequences, to combine multiple variables in complex ways and to examine information in a systematic, exhaustive manner” (Kuther, 2003, 348).

1.2) Displaying sufficient maturity – key criteria

The second subtheme indicated criteria that some participants used to assess sufficient maturity in minors. It was assumed that the minor must be able to show some level of understanding. Therefore, cognitive abilities for the understanding of illness and treatment must be present.

a) Asking questions as a way of assessing understanding and maturity

When the patient shows that they comprehend the information, different reactions are elicited. “Some patients and subjects are calm, attentive and eager for dialogue, whereas others are nervous or distracted in ways that impair or block understanding. Many conditions limit their understanding, including illness, irrationality and immaturity” (Beauchamp & Childress, 2001, p. 88). Understanding is therefore a concept that is based - and relies on access to information about the treatment, are able to rationally justify the assumptions and consequences of a choice. This is vital for processing and understanding information because

“in some cases, a person’s lack of awareness of even a single risk or missing fact can deprive him or her of adequate understanding” (Beauchamp & Childress, 2001, p. 88). Assessing the level of understanding in minors still proves to be somewhat challenging and therefore Beauchamp and Childress suggest that the patient being treated should have an understanding that the health care practitioner believes to be the right level of understanding. Some authors may however argue that patients lack the ability to fully comprehend treatment and can therefore not make informed decisions based on their limited ability to understand information. Beauchamp and Childress however produce a counterargument to the above mentioned authors and state that this belief is simply an overgeneralisation. Furthermore, they argue that if “actions are never fully informed, voluntary, or autonomous, it does not follow that they are never adequately informed, voluntary or autonomous” (Beauchamp & Childress, 2001, p. 89). Research based on how much patients understand is somewhat limited. It mainly focuses on studies based on memory and the recall of events or information. The fact that these studies are concentrated around recall can be flawed in that memory may be very subjective and patients may be forgetful. These studies can therefore not assess the level of understanding at the current stage when information is given, but rather relies on later recall.

b) Ability to apply (Rational action)

This study, however, found that when the minor was informed about the treatment, questions were asked as a common way of assessing their level of understanding. The response given by the minor served as an indication of their understanding and ability to apply the processed information. Once it is clear that the minor understood the information by asking questions, the second criterion would be to examine whether the minor would be able to apply the information of treatment to his or her behaviour or condition. Therefore, in the extract(extract

6, p. 59), it could be seen, that once again, applied questions are asked to serve as a guide to assess maturity.

There are however certain patients that do have problems processing the necessary information. Health care practitioners are required to give their patients as much detail concerning treatment as possible in order to facilitate understanding. On the other hand, a health care practitioner must balance the amount of information given, as too much information may be overburdening and difficult to process. Information overload therefore also impedes the ability to understand and comprehend, which is vital to assess maturity. Some studies have focused on areas where it is difficult to process information. Such instances are normally associated with risks. These studies indicated that “risk disclosures commonly lead subjects to distort information and promote inferential errors and disproportionate fears of risk” (Beauchamp & Childress, 2001, p. 90).

c) Ability to reflect on risk-benefit ratio

The last criterion as identified by participants, and perhaps the most important, is the minor’s ability to assess the risks and benefits of the proposed treatments. This requires rational thinking capacities and decision-making on behalf of the minor. This is perhaps the most important criterion, but builds on the previously mentioned criteria. This is because rational decision making capacity “demonstrates an understanding and appreciation of the relevant information disclosed about the treatment (including consequences, risks, benefits and alternatives) and an ability to use the information to weigh the risks and benefits of different options while making a choice” (Kuther, 2003, p. 348). Rational thinking is however only acquired during adolescence and therefore the ability of children to make rational decisions and their ability to foresee risks and benefits of treatment may prove to be problematic.

Studies regarding decision-making indicate that children aged between 7 and 12 have trouble pinpointing and describing risks and benefits to research participation (Kuther, 2003). “In middle to late adolescents, minors’ goals extend a greater length of time into the future and entail more planning and a greater number of steps” (Kuther, 2003, p. 349). A well known study combining developmental phases and decision-making is that of Weithorn and Campbell (1982). The study set out to examine the differences in decision-making capacities of participants aged 9, 14, 18 and 21. The participants were given hypothetical situations and assessed on four different criteria: “evidence of choice, reasonable outcome, rational reasons and understanding” (Kuther, 2003, p. 349). Results indicated that nine year olds displayed evidence of choice and reasonable outcome, as opposed to 14-year olds having the capacity to score similar to adults of all four criteria.

To be regarded as sufficiently mature, the minor has to exercise the ability of reasoned action or choice. This requires the ability to weigh the potential costs or risks against the potential benefits. Risk is defined as “a possible future harm, where harm is defined as a setback to interests, particularly in life, health and welfare” (Beauchamp & Childress, 2001, p. 195). The risk-benefit ratio of treatment can also be referred to as risk assessment. That is, the evaluation of risks as well as considering the level of severity. The level of risk or severity associated with a particular treatment is commonly referred to in terms of minimal, reasonable and high risk. Benefits on the other hand is based on minimal risk and “in biomedicine it refers to something of positive value, such as life or health” (Beauchamp & Childress, 2001, p. 195). Risks and benefits to treatment alternatives are then evaluated in order to make an informed decision.

Theme 2: Minors viewed as a vulnerable population

Analysis seemed to indicate that theme two was more prevalent for participants working at private hospitals. Literature does not suggest why this is the reason, but the reasoning behind this could be explained in terms of contextual factors that may facilitate or inhibit development. These participants encounter their minor patients mostly accompanied by parents or caregivers. Based on the fact that it was a private hospital, people with medical aid, or of higher socio-economic status go there more often than those of lower socio-economic status. It can almost be argued that children growing up in a safe environment are more protected and less independent. They may seem more inexperienced based on the fact that their parents or caregivers look after them and take them to the hospitals. Minors growing up in this context might not feel the need to reason or think about taking responsibility for decisions, because they have not yet acquired those skills. Therefore, the perceptions participants have about minors may be viewed from the point that they are not ready to be given the ability to make decisions because their parents are more involved in what they believe to be their children's best interest. This results in taking a viewpoint of a child as vulnerable and incapable.

It can be argued that this theme is based on a deficit model, as the results indicated that participants highlighted the lack of independent decision-making due to financial dependence, lack of cognitive ability and life experience as well as a lack of comprehension or understanding of the information given regarding the minor. Theme two is also related to models used by Landsdown (1994), Weithorn and Campbell (1982) and McCabe (1995) that emphasise biological and psychological vulnerabilities and limited decision-making capacity.

a) Financial dependence limiting decision-making

Subtheme one is based on the notion that minors are financially dependent on their parents or caregivers to pay for treatment when going to a private hospital. For this reason, minors may be unable to exercise their ability to make informed decisions, purely because they might feel that if they disagree with the proposed treatment plan, their caregivers will not pay. There is not much literature regarding the correlation between financial dependability and decision-making of minors in a hospital setting when presenting for treatment. The results of this study however indicated that minors were viewed as immature and lacking decision making capabilities on the one hand, but also highlighting the fact that unlike governmental hospitals, these minors were dependent on financial assistance. Dickey et al. (2002) and Diaz et al. (2004) discuss this dilemma of financial dependence and the effects that it has on the minor's ability to make his/her own decisions regarding treatment.

b) Lack of cognitive ability and life experience

Subtheme two highlights a lack of cognitive ability and life experience. Despite the evidence that minors in private healthcare settings have the cognitive ability based on appropriate developmental levels, some participants argued that the minor does not have enough life skills and experience to reflect on. Furthermore, participants emphasised their concern that minors do not have the mental capacity that is required to reflect on such experiences, which is regarded necessary for decision-making. This perspective is based on the underlying assumption that children (minors) are in fact not mature enough to understand the implications of their decisions. Parents currently still possess more rights than their children in order to protect the welfare of the child as well as keeping them out of harm's way.

Maradiegue (2003) argued that this is because of the perception that most people have to foster children in a protective environment for as long as they possibly can. Children are then

perceived as vulnerable. They are not competent to make decisions and are dependent on their parents (caregivers) for at least the first 18 years of their lives. Children are regarded as inexperienced in life, lack physical strength and are therefore seen as incapable of making their own life choices and decision to treatment. As Landsdown (1994) points out “there is a tendency to rely too heavily on a presumption of children’s biological and psychological vulnerability in developing our law, policy and practice, and insufficient focus on the extent to which their lack of civil status creates their vulnerability” (as cited in Morrow & Richards, 1996, p. 97).) This perspective therefore highlights the incompetence of minors and their lack of cognitive development.

c) Lacking comprehension

The third subtheme as identified under this perspective of minors’ vulnerabilities was the fact that minors may lack comprehension capacity. In other words, they lack understanding of concepts based on pain and risk. Thus, when information is given to them, they do not have the necessary comprehension skills. This, as described above can be due to problems of processing information. Beauchamp and Childress (2001) however argue that patients can distort information, which decreases the level of understanding of risk and pain. They emphasise that attention be paid to how the health care practitioner frames and explains the treatment process. For this reason, “some ways of framing information are so misleading that both health professionals and patients regularly misconstrue the content” (Beauchamp & Childress, 2001, p. 90). This has implications for ethical practice. Applying the principle of autonomy, as “misconceptions [can] prevent a person from adequately understanding the risk of death and this risk is material to the person’s decision, then the person’s choice of surgery [treatment] does not reflect a substantial understanding and does not qualify as an autonomous authorisation” (Beauchamp & Childress, 2001, p. 91).

Decision-making for treatment is compromised by misunderstanding or as Beauchamp and Childress (2001) put it, a “breakdown in a person’s ability to accept information as true or untainted, even if he or she adequately comprehends the information” (p. 91). As mentioned earlier, studies on comprehension and understanding of information are based on the reliance of recall test which is somewhat dependent on, and limited by memory. Therefore, comprehension and understanding can never be fully tested to ensure that sufficient understanding is achieved. Beauchamp and Childress (2001) therefore suggest that examining truth claims will provide an overall understanding. They therefore argue that “probabilities and uncertainties that surround many beliefs suggest that we should judge truth claims by the available evidence, which is often subject to interpretations” (Beauchamp & Childress, 2001, p. 91).

Some participants argued that minors are not competent for the three-abovementioned reasons. Beauchamp and Childress (2001) suggest that standards of incompetence should be determined. What makes this standard of incompetence relevant to this section is the fact that it highlights inabilities which participants mentioned. It therefore, focuses on the deficiency of the ability to judge immaturity as opposed to the amount of ability the minor does indeed possess. These standards are evaluated by requiring the least ability, to standards that progressively require more abilities. It is a spectrum drawing on a specified range of standards of inabilities currently required by competing standards of incompetence. Here three types of abilities (or lack of abilities) are explored. These abilities draw primarily on stating a specific preference, understanding of relevant information, as well as rational thinking that requires reasoning skills. The seven standards comprise the spectrum according to Beauchamp and Childress (2001).

When comparing the inabilities of minors by participants with identified Beauchamp and Childress's rival model of incompetence, various similarities are seen. The participants firstly argued that minors are under the submission of their caregivers, especially because they are responsible for paying hospital fees. Secondly, some participants emphasised the lack of cognitive ability on the behalf of the minor to make a decision. Furthermore, minors were perceived as lacking life experience. Lastly, they argued that minors do not comprehend or understand treatment processes and the reality of treatment. Therefore, participants argued that minors lack the ability to "understand information" which is in line with standards 2 and 3. Also, minors lack the ability to "reason" which is in line with standards 4 to 7. The participants therefore used the middle to last standards that are progressively more important than the first two standards. These are regarded as weak to judge incompetence.

There seems to be a clinical need for competence/incompetence testing that health practitioners can use to make a well-informed judgement in relation to competence of minors. Beauchamp and Childress suggest that the above mentioned standards be operationalised to construct a scale. Currently "dementia rating scales, mental status exams and similar devices test for factors such as time and place orientation, memory, understanding and coherence. These tests are clinical assessments that are generally administered when incompetence is suspected" (Beauchamp & Childress, 2001, p. 74).

Theme 3: Challenges when assessing sufficient maturity in minors

Participants highlighted not only criteria used to assess sufficient maturity in minors, but also challenges that impeded their ability to assess the construct. Among these, the most dominant challenges were parents as the primary decision makers for treatment, language barriers as well as the influence of authority figures on decision-making, referred to as the God complex.

a) Language barriers

Language barriers were identified as the most common challenge that could impede a health care practitioner's ability to assess a minor's level of maturity. Results indicated that the mere fact that the child had difficulty expressing himself or herself in English, instead of in their home language had an effect on the assessment of their maturity and ability to understand. Not much research has been conducted on this topic in the South Africa context. Three articles were however found about the level of understanding Xhosa patients had when visiting a doctor and how that affected treatment (Levin, 2006; Schlemmer & Mash, 2006). Similarly, many Zulu-speaking patients have difficulty articulating themselves in English, not always being able to explain themselves properly. This creates some difficulty around questioning and limits the health care practitioner's ability to assess maturity. Many assessment instruments lack cultural fairness. A result of such instruments has been that "when assessing areas such as language, cognition and problem solving," the performance of Black South African children is low (Solarsh & Alant, 2005, p. 110). The interaction between language and thought processes are vital for assessing sufficient maturity, however, the language in which you are spoken to and the 'language' of your thinking might be different. Solarsh and Alant (2005, p. 110) however emphasise that even though "an explanation given by a child demonstrating reasoning is a complex phenomenon representing more than the integration of language and thought. It is the culmination of the child's individual ability, nutritional status and socio-economic realities, social structures, cultural norms etc."

Understanding, communication and thought are all linked to the cognitive ability of the child. This becomes somewhat problematic when assessing a child's ability to relate to health care practitioners in English. According to Solarsh and Alant then, (2005, p. 110) "in evaluating cognitive skills such as verbal reasoning and explanations in rural Africa, the context of how

culture and social circumstances influence linguistic and cognitive processes, as well as problem solving skills, must be considered.” Solarsh and Alant (2005) make the following argument regarding the use of secondary language and cognitive reasoning:

Culture and disadvantage are two of the significant factors that affect the development of language and cognition. Culture is a fundamental factor affecting primary language development, early cognitive development and communication competence, with a particular emphasis being placed on mother–child communication style. Disadvantage has been shown to impact on secondary language development especially on the development of abstract thinking skills and the acquisition of literacy skills, which contribute to academic achievement. Further, cognitive style, and the tradition, oral or literate, to which a culture belongs, also play a significant role (Solarsh & Alant, 2005, p. 111).

Similar to language barriers experienced in South Africa, 11% of U.S.A patients can only speak Spanish, therefore relying primarily on English as the main language of communication. (Bernard, Whitaker, Ray, Rockich, Barton-Baxter, Barnes, Boulanger et al., 2006). Language barriers have far-reaching implications regarding the quality of care as well as the cost thereof. For example Bernard et al. (2006, p. 355) argued that “non-English speakers are also more likely to report problems with care, communication and diagnostic tests than are English speaking patients.”

b) Parents/caregivers

It was found that parents could influence the health care practitioner’s ability to assess sufficient maturity in the child. As was discussed by Polman (2002) and Diaz et al. (2004) parents may ignore treatment plans as suggested by health care practitioners. Furthermore, specific to the extract (extract 3, Participant A, p. 67) given, the parents might not have the relevant knowledge to facilitate development in their children. This pertains specifically to the fact that the parent does not understand the instructions given by the health care

practitioner. Alternatively, parents might be too protective; not allowing the child to take responsibility for their treatment or medicines. This inhibits the health care practitioner's ability to see if the minor truly is mature and can take their treatment independent of their parents or caregivers. On the other hand, results indicated that some minors living in hostels away from home were perceived as responsible and mature enough to take their medicines without any supervision.

c) The God complex

The inability to ask the health care practitioner questions was assessed as a sign of not being mature enough. From the perspective of the health care practitioner, if the patient does not ask questions, how can they make an informed decision? On the other hand, analysis indicated that some health care practitioners do not invite questions about diagnosis and treatment. As minors develop, they learn to submit to authority figures for example parents, teachers and other older people, people of the law and alike. As a child gets older, he or she learns to respect the norms and values of society. For instance, in school they are disciplined and learn to respect others around them. As a result, a minor is brought up to respect and submit to people in a position of authority. This dynamic seems to be a paradox in the patient-doctor relationship. McCabe (1995) emphasises the importance of the relationship, what he terms the 'relational style with authority.' The health care practitioner wants the minor to ask questions in order to weigh the risks and benefits of the treatment. On the other hand, the patient might be reluctant to raise concerns because the health care practitioner is perceived as the expert.

Theme 4: Using the scenario/vignette to contextualise sufficient maturity of minors

The scenario/vignette was intentionally added to the interview guide as a way to assess the coherence and confirmability of the key criteria identified of sufficient maturity. In using a

hypothetical situation, participants who perceived children as vulnerable were guided to assess the ability rather than the inability of the child in the scenario. A constant comparative analysis of themes indicated somewhat of an overlap between key criteria and the criteria used in the scenario. Three important criteria were identified from the scenario: responsibility, voluntariness and rational thinking capacity.

Reasoned action

Participants indicated that this minor was mature as she was responsible in going to a clinic due to her cough lasting longer than a normal cough would. This was therefore a reasoned action that she performed. Her ability to notice that she was ill and has to get better, resulted in her going to the clinic. Furthermore, she had to plan how to get to the clinic, therefore showed ability to plan ahead and make the necessary arrangements to get to the clinic.

Voluntariness

The minor displayed the ability to make a decision regarding her health without any coercion, persuasion or influence. Beauchamp and Childress (2001) argue that voluntariness can be easily mistaken for the principle of autonomy as both are linked to the person's ability to make an independent decision. The difference between the two concepts is that the former is based on "the presence of adequate knowledge, the absence of psychological compulsion and the absence of external constraints" (Beauchamp & Childress, 2001, p. 92). This definition highlights the importance of a wilful action that is not brought about by influence of others. Therefore, the action is as a results of the person himself or herself.

Limitations of the study

Pitfalls and limits to the method of analysis in this study were carefully considered during the analysis procedure and discussion of the results (Braun& Clarke, 2006).Participants wereonly

selected from the health care sector. The initial design included staff from Psychology and Social work, which however did not respond. This might have shed some light on how “sufficient maturity” was operationalised across different disciplines and fields of work. Furthermore, the study only interviewed a small number of health care practitioners. A larger sample might have yielded more themes. Thematic analysis can be regarded as a limitation to the study in that its results may be very broad and limit higher order analysis. Furthermore, due to limited time in conducting the study, the researcher did not report findings to the participants and could therefore not validate their experiences.

8. Conclusion

This study aimed to explore how health care practitioners conceptualise and apply the concept of “sufficient maturity” when minors present for treatment. Furthermore, this study set out to identify criteria that participants used to assess this construct in minors. More importantly, it was necessary to explore what perspective or viewpoint informed this set of criteria. The participants’ perspectives were primarily informed by their perceptions of the competence and abilities that minors possess. According to the *Children’s Act* (2005) minors can consent on their own to treatment, provided they show “sufficient maturity”. Results indicated that there are two primary perspectives participants used to assess “sufficient maturity” when minors present for treatment. The first perspective was informed by the abilities that minors have which are relevant to giving consent to treatment. The latter perspective however placed more emphasis on the inability of a minor to make important decisions such as treatment options. Furthermore, these perspectives affected how the participants understood and applied the construct in their daily interactions with minors in a health care setting. The study also identified additional themes such as the challenges to treatment when working with minors in a health care setting. Most studies regard chronological age as the most important factor in determining maturity. In conclusion, this study provides some guidance that chronological age alone, is not sufficient to assess minors’ maturity and ability to assess risks and benefits of treatment. It is the context of the minor, as well as their developmental stage that should be considered to assess their maturity when health care practitioners assess minors’ “sufficient maturity.”

9.Recommendations

Results indicated that health care practitioners' ability to assess sufficient maturity in minors was dependent on their perceptions. These perceptions may have been informed by the health care context they work in. This study was however situated within two different types of medical settings (government and private). It would have been interesting to explore the different understandings applied in different contexts such as social work, legal practices and educational environments. A constant comparative method could then be used to identify common themes across these contexts to facilitate a broader understanding of sufficient maturity as the next step to operationalise this construct.

Regarding the theoretical framework in which this study was embedded, it was considered important to use Piaget's well-known framework as well as Fisher's comprehensive model. It would be interesting to understand the cognitive development of minors from a Vygotskian framework (1986). His theory highlights the importance of the cultural context in which minors develop. Furthermore, it becomes relevant as a framework for understanding how the role of a cultural mediator and prior experience are critical factors in terms of children's cognitive capacity and adherence to medical regimes.

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APPENDICES

Appendix 1

Jonelle du Plessis

207516721

Interview Guide

Date/time: _____

Setting: _____

Respondent no: _____

Introduce self

Permission to record

Purpose of the study

- What do you do at present when young adolescents (aged 12) present for treatment?
In other words, what *is the procedure involved before they receive treatment?*
- With regards to the importance of assessing sufficient maturity of these young adolescents, *what do you think the key criteria are when assessing sufficient maturity?*
- How would you assess these key criteria in terms of importance? *What is your justification?*
- Have you ever had any challenges or issues that you had to face when assessing young adolescents' sufficient maturity? Tell me more...
- Any additional information you would like to add?

- **Scenario:**
- A child of the age of 12 has come to clinic X. She is suffering from Tuberculosis and needs to be treated. Her parents are however not present. As she is already 12 years of age, the only way for her giving independent consent to treatment is by assessing her competence with regard to “sufficient maturity.”

What would you do as the health practitioner/ nurse/ psychologist to assess this minor’s sufficient maturity? What criteria might be used to assess this construct?

Appendix 2

Jonelle du Plessis

207516721

‘Operationalising’ the notion of sufficient maturity to provide independent consent when adolescents present for treatment

INFORMATION SHEET AND CONSENT FORM

Who we are

Hello, I am Jonelle du Plessis. I am a Masters student in Research Psychology at the University of KwaZulu-Natal- Pietermaritzburg Campus.

What we are doing

I am conducting research on assessing the notion of ‘sufficient maturity’ when adolescents present for treatment. We are conducting a preliminary study using staff from various disciplines (Nursing, Psychology and Paediatrics) to find out more about how the concept of ‘sufficient maturity’ is understood among various staff in the above mentioned disciplines and applied in context.

Your participation

We are asking you whether you will allow us to conduct one interview with you about your knowledge and opinions of this practice. If you agree, we will ask you to participate in one interview for approximately one hour (telephonically or face-to-face). We are also asking you to give us permission to tape record the interview. We tape record interviews so that we can accurately record what is said.

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. If you choose not

to take part, you will not be affected in any way whatsoever. If you agree to participate, you may stop participating in the research at any time and tell me that you don't want to go continue. If you do this there will also be no penalties and you will not be prejudiced in any way.

Confidentiality

Any study records that identify you will be kept confidential to the extent possible by law. All identifying information will be kept in a locked file cabinet and will not be available to others. We will refer to you by a code number or pseudonym (another name) in any publication. If however, you feel that you would like to reveal your identity, you may do so.

Risks/discomforts

At the present time, we do not see any risks in your participation. The risks associated with participation in this study are no greater than those encountered in daily life.

Benefits

There are no immediate benefits to you from participating in this study. However, this study will be extremely helpful to us in developing a research proposal on this topic that we hope will promote understanding of this abstract concept of 'sufficient maturity.'

If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper and can send you the results of the study when it is completed sometime after September 2011.

Who to contact if you have been harmed or have any concerns

This research has been approved by the Research Ethics Committee. If you have any questions or complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please contact Professor D. Wassenaar on (033) 260 5373.

If you have concerns or questions about the research you may contact the researcher of this project on 073 897 4815 or email: 207516721@ukzn.ac.za

CONSENT

I hereby agree to participate in research on ‘operationalising’ the notion of sufficient maturity when adolescents present for treatment. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop participating at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally in the immediate or short term.

I understand that my participation will remain confidential.

.....

Signature of participant

Date:.....

I hereby agree to the tape-recording of my participation in the study.

.....

Signature of participant

Date:.....

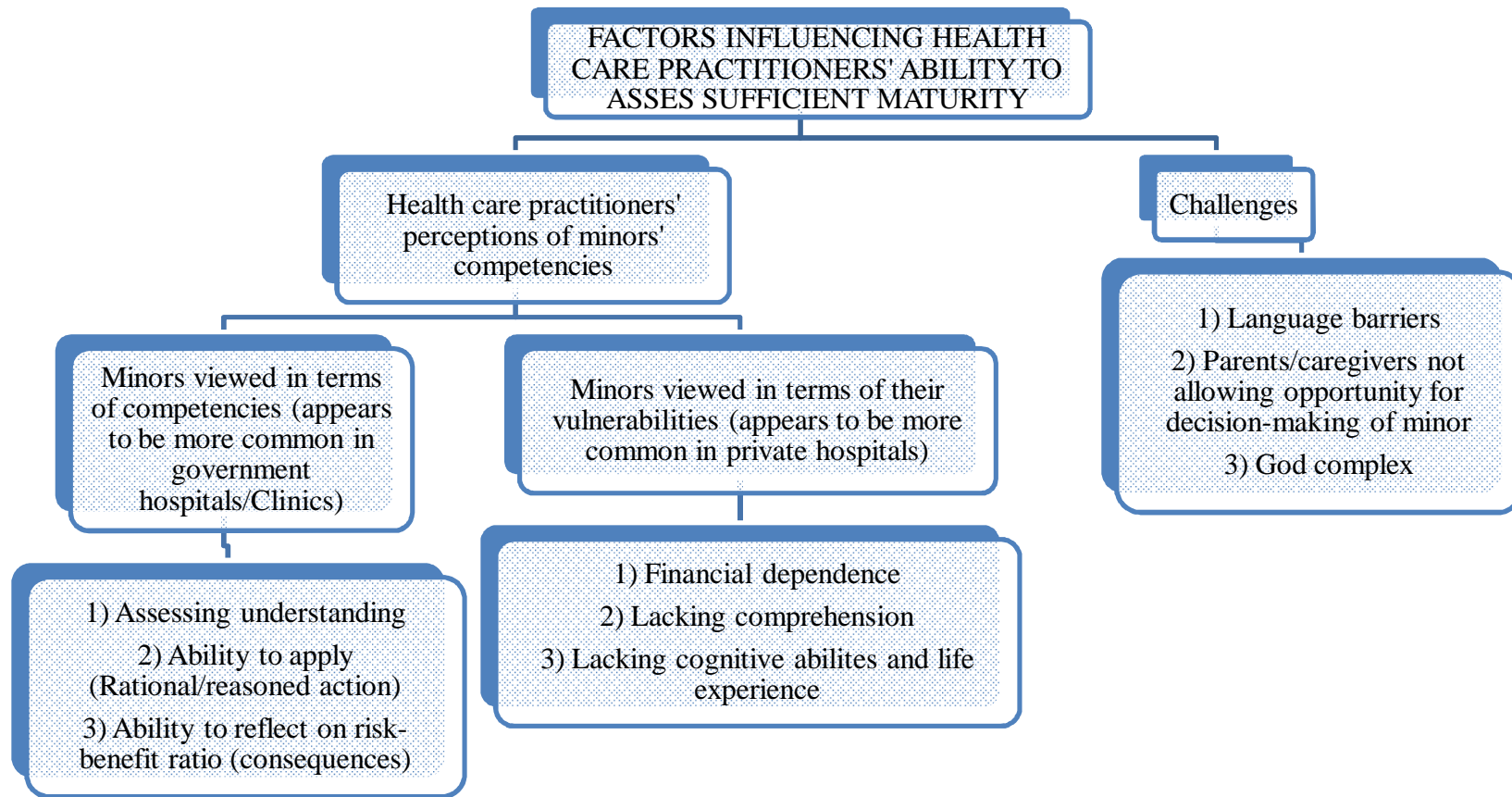
Appendix 3

Table 1: Overview of themes

<u>Main themes</u>	<u>Subthemes</u>	<u>Explanation</u>
Viewing minors in terms of their abilities	Using developmentally appropriate methods	Use of play with children, as opposed to bodily changes in adolescents. This perspective is based on the assumption that children can be regarded as sufficiently mature, provided developmentally appropriate methods of communication is used.
	Key criteria for assessing sufficient maturity	<ul style="list-style-type: none"> i. Asking questions to assess understanding ii. Ability to apply (Rational action) iii. Ability to reflect on risk benefit ratio
Minors perceived as vulnerable	Financial dependence	This theme is based on the assumption that children are not competent in certain areas of their life, they are still dependent on their parents .
	Minors lack comprehensiveness of treatment	
	Minors lack the cognitive ability and life experience	

Challenges health care practitioners face when assessing sufficient maturity	Language barriers	These subthemes were identified to be the most common challenges health care practitioners face. The language barrier was seen to be the most important in the South African context.
	Parents/ caregivers misunderstanding or overprotection	
	The God complex	
Scenario themes (confirmatory technique)	Reasoned action	The scenario confirmed some of the criteria the participants used when initially identifying key criteria. Implicit in these two subthemes, are presence of cognitive abilities, ability to reflect on the risk and benefit.
	Voluntariness	

Diagram 1: Diagrammatical presentation of key influences in assessing sufficient maturity



Appendix 4

Act 41 of 2007

Biological mothers

The biological mother of a child, whether married or unmarried, has full parental responsibilities and rights. However, if the biological mother is under 18 years, the guardian of the biological mother is also the guardian of the child (s19). Notwithstanding this section, a child may consent independently to the medical treatment of her child. However, in cases of an operation on such child, the under-18-year-old mother must be assisted by her own parent or guardian (Mahery, Proudlock & Jamieson, 2010, p. 11).

Biological fathers

The biological father of a child has full parental responsibilities and rights in respect of the child if he is married to the mother of the child or was married to the child's mother at the time of the child's conception, birth or anytime between conception and birth. However in the case of a divorced father (and mother) the court order will indicate which rules apply with respect to guardianship, care (new term for 'custody') and contact (new term for 'access') when it comes to the child. For unmarried fathers the situation is slightly different. Under the old law, an unmarried father had no parental rights and responsibilities and he had to approach the High Court to be assigned parental rights and responsibilities. The Children's Act has now changed the law so that an unmarried father who is committed to caring for his children can have equal parental rights and responsibilities without having to approach the High Court. Section 21 of the Act provides that the father acquires full parental responsibilities and rights under two distinct sets of circumstances:

He has full parental rights and responsibilities if he is living with the child's mother at the time of the child's birth in a permanent life-partnership. Regardless of whether he has or has not lived with the mother, he can also acquire rights if the following three conditions are present:

- he consents to be identified as the father or applies to the court to be recognised

as the child's father or pays damages in terms of customary law;

- he contributes or has attempted to contribute in good faith to the child's

Upbringing for a reasonable period; and

- he contributes or has attempted to contribute in good faith to the expenses in connection with the maintenance of the child for a reasonable period (Mahery, Proudlock & Jamieson, 2010, p. 12).

If however the minor does not have a parent, caregivers are able to give consent for

treatment. According to Section 129 and 32 of the *Children's Act*, caregivers are defined as:

Such a person would include anyone who voluntarily cares for the child either indefinitely, temporarily or partially, including a caregiver. This clause is aimed at assisting the many children being cared for by relatives to access health care services more easily (Mahery, Proudlock & Jamieson, 2010, p. 12).

Who is a caregiver?

A 'care-giver' is anyone who factually cares for a child, and includes:

- grannies, aunts and other relatives;
- a foster parent;
- the head of a child and youth care centre;
- a child and youth care worker supporting children in the community without care in the family; and
- a child (16 years and older) heading a household (child-headed household) (Mahery, Proudlock & Jamieson, 2010, p. 12).

