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Decisional Capacity among Minors with HIV: A Model for Balancing Autonomy Rights with the Need for Protection

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Abstract

The purpose of this paper is threefold: (1) to describe the relevant ethical and legal issues associated with decisional capacity among minors and to discuss the importance of these concepts for children and adolescents living with HIV; (2) to provide a framework for assessing the decisional capacity of children and adolescents with HIV; and (3) to present a model for thinking about how to use this assessment data to guide action along the protection-autonomy continuum.

Keywords

HIV; AIDS; decisional capacity; competence; assent; consent; children; adolescents; pediatric; protection; autonomy; model

Many ethical and legal issues surround pediatric health care. Among these are concerns about the involvement of minors in clinical research and how to proceed when minors refuse medical treatment. Arguments in favor of children and adolescents' meaningful involvement in their health care are grounded in both morality and practicality. Moral arguments revolve around children's right to autonomy and the preservation of dignity while practical arguments revolve around improved treatment outcomes (Walker, 2002). Arguments against minors' participation in medical treatment decisions surround claims of immaturity, parental authority, and fear that granting autonomy to children will negate protective efforts. These arguments inevitably unveil the competing rights of children, parents, and the state. Meaningful participation in decisions about medical treatment requires decisional capacity, which rarely is addressed in the medical arena. The question becomes whether or not minors possess the decisional capacity necessary to actively participate in their medical treatment.

The answer to this question has important ethical and legal implications, and thus, a thorough understanding of what decisional capacity is and how to assess it is necessary.

The extent to which children and adolescents possess the decisional capacity necessary to meaningfully participate in their medical care is important for all minors, even those who are healthy, but is of particular concern for those with chronic, debilitating, or life threatening illnesses. Children and adolescents with HIV provide a good example of the need to consider decisional capacity as it relates to medical treatment for a variety of reasons. Of particular relevance is the prevalence of HIV infection among youth. In 2006, the largest number of new HIV infections occurred in 13–29 year olds (Centers for Disease Control and Prevention, 2007). Further, some youth with HIV are largely responsible for their own medical care due to parental absence, literal or figurative. Children with perinatally acquired HIV may have survived maternal death due to AIDS, and because HIV disproportionately affects minority and low income groups, some minors with HIV (perinatally or behaviorally acquired) do not reside with biological parents because of abandonment, out-of-home placement resulting from parental abuse or neglect, and/or parental incarceration. Even in cases where minors with HIV have not been separated from their families, physical problems, emotional problems, or competing demands on time and resources (e.g., work, other dependent care, transportation) may limit parental involvement. Therefore, it is incumbent on pediatric health care workers to encourage children and adolescents to become effective consumers of medical services. Even for intact and high functioning families, teaching children and adolescents to participate as developmentally appropriate in their health care is necessary as part of the transition into adulthood. Barriers to, and consequences associated with, the transition from pediatric to adult care, are not specific to HIV (Alpay, 2009; Tuchman, 2008). However, the social stigma associated with HIV combined with its transmissibility further complicate the transition process (Wiener, Zobel, Battles, & Ryder, 2007; Foster, Waelbrouck, & Peltier, 2007).

Because HIV medical regimens often are complex and time consuming, the meaningful participation of minor patients is necessary and, in fact, may be critical. Given the prevalence of neurocognitive deficits (Franklin et al., 2005; Llorente et al., 2003; Pumariaga, Shugart, & Pumariaga, 2006) and psychiatric problems (Rao, Sagar, Kabra, & Lodha, 2007) among youth with HIV, decisional capacity as it relates to medical treatment is an important consideration. Additionally, children and adolescents with HIV frequently are the target of clinical trials and social-behavioral research; thus, decisional capacity related to assent/consent to participate in research is of concern.

In this paper, we will describe the ethical and legal issues associated with decisional capacity with a special emphasis on the importance of these concepts for children and adolescents living with HIV. We also will provide a framework for assessing the decisional capacity of children and adolescents with HIV. Finally, we will present a model for using assessment data to guide decisions along the protection-autonomy continuum.

Decisional Capacity among Minors with HIV: Ethical and Legal Considerations

In this section, we will define decisional capacity, discuss the landmark Convention on the Rights of the Child, and review relevant ethical and legal issues associated with medical treatment and research. Finally, we will delineate specific ethical and legal considerations related to decisional capacity for children and adolescents with HIV.

Defining Decisional Capacity

Professionals often use the terms decisional capacity and competence interchangeably and the definitions for each vary across the literature (Appelbaum, 2007). Many definitions of competence include the constructs underlying decisional capacity (Walker, 2002), which suggests that decisional capacity is a component of competence. However, because the distinction between decisional capacity and competence is negligible, some experts in the field have abandoned the effort to differentiate between the two terms (Appelbaum, 2007).

According to experts in the fields of psychology, law, and bioethics (Grisso & Appelbaum, 1988; Dunn, Nowrangi, Palmer, Jeste, & Saks, 2006), decisional capacity is comprised of the following four components: (1) understanding, (2) appreciation, (3) reasoning, and (4) the ability to express a choice. Consistent with Appelbaum's (2007) descriptions, these components are defined below. *Understanding* refers to the extent to which an individual can "grasp the fundamental meaning of the information communicated" (Appelbaum, 2007, p. 1836) by a physician or other medical staff about his/her disease including information about the diagnosis, the prognosis, and the available treatments as well as any other information that may be relevant to decision making. *Appreciation* refers to the extent to which an individual acknowledges his/her medical condition and the impact of the disease on his/her life. Thus, appreciation extends beyond mere understanding. Someone may fully understand the various aspects of a disease and the potential consequences of treatment without fully acknowledging that s/he actually has the diseases or the extent to which the disease affects his/her own life. An individual must be able to apply the information to his/her own situation to realize its impact. *Reasoning* refers to the extent to which an individual can apply a logical thought process when thinking, and making decisions, about his/her disease. Rational decisions are based on the processing and/or manipulation of information. Finally, the *ability to express a choice* refers to the extent to which an individual can "clearly indicate [a] preferred treatment option" (Appelbaum, 2007, p. 1836) that is stable versus fluid (T. Grisso, personal communication, July 30, 2009).

Convention on the Rights of the Child

In November 1989, during the *Convention on the Rights of the Child*, non-negotiable standards for the protection of children were adopted by the United Nations (UN). The newly established standards created a dramatic shift in the previously undisputed perception of "minor incapacity" that framed the social, cultural, medical, and legal infrastructure in prior history. The UN child standards incorporated the continuum of human rights previously addressed in the *Universal Declaration of Human Rights* with the additional recognition of the special needs and care required for the population of individuals under the

age of 18 across the world (General Assembly of the UN, 1990). The landmark decision of the Convention requires international governments and the continuum of providers working with children in their respective nations to uphold the standards established. Ironically, while the United States supported the United Nations' drafting and adoption of the Convention (Limber & Wilcox, 1996), it is one of only two countries that have yet to ratify the treaty (Melton, 2005). However, given its widespread adoption, it may nonetheless be binding in the United States as a customary international law. Either way, as Melton (2005) argues, the Convention provides an excellent framework from which to advocate for the rights of children.

Of particular importance is the required consideration of the "child's voice" in all decisions relevant to their well-being. In fact, respect for the views and opinions of the child are one of the core principles addressed in the document (General Assembly of the UN, 1990; LeMoyne/UNICEF, 2005). Application of this principle requires that all individuals working with children consider the views of the children in their care and incorporate those views into decisions as developmentally appropriate (Lansdown & Karkara, 2006; Santos Pais & Bissell, 2006).

The implementation of the UN standards into legal, ethical, and practical functioning has resulted in a range of challenges and prominent awareness of the complexities of the issues at hand. Prior to the finalization of the UN's document, some researchers had begun exploring the invalidity of the arbitrary age categorization of maturity as a determining factor in a minor's legal decision making capacity when relevant to medical decisions, including those affecting mental health (Weithorn & Campbell, 1982; Starr Edwards, 1996). Since 1989, there has been a proliferation of articles in the areas of medicine, clinical research, and juvenile justice exploring, clarifying, and emphatically reiterating the importance of and need for empirical studies addressing minors' capacities (Campbell, 2006; Cauffman & Steinburg, 2000; Dixon-Woods, Young, & Heney, 1999; Doig & Burgess, 2000; Hartman, 2002; Kuther, 2003). Miller, Drotar, and Kodish (2004) provide an excellent review of the empirical literature on children's competence to assent/consent to medical treatment and to participate in clinical research. This review highlights the complexities involved in this type of research and provides a conceptual model to guide future research in this area. Also emphasized is the importance of a best interests approach (*What is the best decision for this child?*) as opposed to an autonomy approach (*Who should make this decision?*) (Miller et al., 2004).

Medical Treatment

There is a longstanding history of research related to children's competence to consent (Melton, Koocher, & Saks, 1983). A number of medical associations have developed practice standards and ethical guidelines specific to pediatric care (Campbell, 2006). The American Academy of Pediatrics (1995) developed specific language and guidelines to assist physicians in obtaining informed consent, parental permission, child assent, and addressing conflict. Efforts to include children in medical decisions as developmentally appropriate are resulting in changes in practice guidelines and ethical standards (Perez-Carceles, Osuna, & Luna, 2002; Sanci, Sawyer, Weller, Bond, & Patton, 2004). The salience

of the issue is underscored by the empirical evidence that the United States health care system often fails to meet the needs of children with life threatening conditions and their families (Browning & Solomon, 2005). One response to this evidence is the ongoing rapid development of services tied to pediatric palliative care. Evan and Zeltzer (2005) note little research exists on challenges that specifically impact adolescents especially when related to forms of treatment. In some countries, laws that define minors' rights are changing from delineations based on specific age markers and parental consent to the inclusion of additional factors such as maturity and situational risk related to medical research and treatment (Sanci, Sawyer, Weller, Bond, & Patton, 2004). As a result, conflicts between various laws and medical ethics guiding practice standards related to the rights of minors are being identified (Campbell, 2006).

In the United States, legislation requires parental consent on most decisions involving individuals under the age of 18 years of age. However, variations exist across states with regard to issues surrounding pregnancy, sexually transmitted diseases including HIV, mental health, and substance abuse treatment (Campbell, 2006; Hartman, 2002). Essentially, minors are considered incompetent decision makers except in cases of emancipation, when particular medical or mental health services are needed, or when the *mature minor* status has been granted (Kuther, 2003; Weithorn, 1982). Further, the fact that minors can be tried as adults reveals a contradiction in the law with regard to assumptions about minor incompetence. Improving legal standards and developing consistent definitions is difficult because methods to assess minor capacity or competence are limited and without current consensus (Dixon-Woods, Young, & Heney, 1999; Kuther, 2003; Miller, Drotar, & Kodish, 2004; Perez-Carceles, Osuna, & Luna, 2002; Runeson, Elander, Hermeren, & Kristensson-Hallstrom, 2000). Additional challenges extend beyond establishing more effective laws, principles, and guidelines. Actual clinical practice standards, even with increased awareness of minor rights, are lacking (Dixon-Woods, Young, & Heney, 1999).

The issues of decisional capacity become even more convoluted when addressing end of life situations, refusal of treatment, or in cases of disagreement between the minor and his parents (Kuther, 2003; Doig & Burgess, 2000; Weithorn, 1982). In a survey of approximately 500 clinicians from three children's hospitals and four general hospitals with pediatric intensive care units, researchers found that participants rated themselves as "somewhat to very knowledgeable" of end-of-life care ethic guidelines and recommendations. However, in an assessment of ethical practice guidelines, many lacked awareness of key components (Solomon et al., 2005). An additional complicating factor is that in situations requiring the individualized assessment of competence and a determination of a mature minor status, the assessment is contingent on a physician's subjective evaluation.

Research

Efforts to improve the "child's voice" in research has resulted in challenges and concerns similar to those expressed in the medical practice arena (Hoehn & Nelson, 2004; Macklin, 1992; Sanci, Sawyer, Weller, Bond, & Patton, 2004). The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research,

1979), a guiding document for research, identifies the principles of respect for persons, beneficence, and justice as key components of ethical research. Factors such as autonomy, self-determination, and capacity provide the functional framework from which an individual is capable of meaningfully and voluntarily participating in research. Further addressed in the Belmont Report (1979) is the importance of protection for the immature and incapacitated acknowledging that “the judgment that any individual lacks autonomy should be periodically re-evaluated and will vary in different situations” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Some of the areas addressed in relation to research include consideration of a mature minor clause in research ethics guidelines, integration of risk/benefit and proportionality factors in evaluating level of competence required for consent, and expectations of inclusion of minor informed assent (Hoehn & Nelson, 2004; Kuther, 2003; Sanci, Sawyer, Weller, Bond, & Patton, 2004).

Considerations for Minors with HIV

The standards set forth in the Convention on the Rights of the Child (1989) are especially important for children and adolescents with HIV who represent a particularly vulnerable population. As primary consumers of medical services, it can be argued that children and adolescents with HIV have a right to be involved in the medical treatment decisions that directly affect their lives. However, some children with perinatally acquired HIV are not even aware of their diagnosis. Historically, it was considered appropriate to shield pediatric patients from information about their life threatening illness based on the assumption that children lack the ability to understand concepts related to death and, further, lack the maturity to cope with illness-related information (Toch, 1964 as cited in Hardy, Routh, Armstrong, & Albrecht, 1995). But, research in the area of pediatric oncology suggests that non-disclosure does not necessarily protect children (Claflin & Barbarin, 1991). While protectionism still exists (Clemente, 2007), there has been a shift toward open communication and the increased involvement of children in decision making (Patenaude & Kupst, 2005) coinciding with medical advances resulting in prolonged survival. Even though there are a number of similarities between HIV and cancer, disclosure of disease status to children with perinatally acquired HIV is complicated by a variety of factors including fear related to maternal guilt about transmission and forced secrecy (Vallerand, Hough, Pittiglio, & Marvicsin, 2005). Fear of public disclosure of disease status or lifestyle also may be an issue and, in the case of maternal death, fear of disclosure about the cause of parental death and/or adoption status may be present. Kouyoumdjian, Meyers, & Mtshizana (2005) describe fear of stigma, emotional unpreparedness, lack of knowledge and skills, and general lack of comfort discussing HIV and illness as barriers to HIV disclosure to children. Based on a thorough review of research in the area of pediatric HIV disclosure, Weiner, Mellins, Marhefka, & Battles (2007) conclude that no consensus exists with regard to the best age for disclosure or the psychological outcomes associated with disclosure. In contrast to the issue of disclosure described above, decisional capacity also becomes a central issue in states allowing adolescent minors (ages 13–17) to consent to HIV testing and treatment (Ho, Brandfield, Retkin, & Laraque, 2005). Clearly, some minors may be “competent” consumers of medical services while others may require additional support by way of medical education or patient advocacy.

Another area where decisional capacity is relevant for minors with HIV is clinical research. For many children and adolescents infected with HIV or diagnosed with AIDS, medical care and participation in research become synonymous as patients with HIV often are recruited to participate in AIDS clinical trials. While there clearly are risks associated with participating in clinical research, there also are potential benefits. For example, the option to participate in research may provide children and adolescents with HIV access to high quality medical care which may not otherwise be readily available or affordable. In addition, participation in research may yield financial remuneration, which may be particularly important for this population who, as previously stated, are often socioeconomically disadvantaged. Of course, the benefits must outweigh the risks, and existing risks, including the risk of exploitation, must be minimized (Ballantyne, 2005). This notwithstanding, the irony remains that while adolescent minors can legally consent for HIV testing and treatment in some states (Ho, Brandfield, Retkin, & Laraque, 2005), many research protocols prohibit these same minors from being able to provide informed consent for participation in research.

Minor adolescents who do seek testing and treatment for HIV without parental consent typically do so because of lack of parental involvement or the fear of revealing high risk behaviors associated with HIV infection. It stands to reason that adolescents who do not seek parental consent for testing and treatment will not seek parental consent to participate in research. Thus, the prohibition described above, while clearly well intentioned, virtually eliminates an entire population of adolescents who may benefit from participation in research without taking into consideration the fact that at least some may possess the decisional capacity to provide informed consent. Institutional review boards sometimes will grant a waiver of parental consent, allowing minors to provide consent for participation in research, but such waivers represent exceptions to otherwise stringent rules designed to protect minors who are considered inherently vulnerable.

Recommendations for Assessing Decisional Capacity among Minors with HIV

As established above, legitimate arguments exist in support of both ends of the protection-autonomy continuum. Decisional capacity is an important variable when deciding whether an individual minor should be protected or granted autonomy. Beyond moral relevance, decisional capacity has practical implications with regard to the extent minors with HIV can meaningfully contribute to their medical treatment and participate in research. Therefore, it is prudent that decisional capacity be assessed systematically and that assessment results are used to guide treatment planning and decisions about research. Dunn et al. (2006) reviewed instruments designed to assess decisional capacity related to consent for treatment and research published between 1980 and 2004 in journals available in medical and legal databases. The content, format, administration features, and psychometric properties of 23 instruments were evaluated. Results suggest a wide degree of variability among measures across the evaluation criteria. Less than half (47%) evaluated decisional capacity using all four of the components (i.e., understanding, appreciation, reasoning, ability to express a choice) identified by experts in the fields of psychology, law, and bioethics. Acknowledging the limitations of all the instruments currently available and the importance of contextual

factors, Dunn et al. (2006) concluded the MacArthur Competence Tool for Clinical Research (MacCAT-CR) and the MacArthur Competence Tool for Treatment (MacCAT-T) have the most empirical support. It is important to note that the measures reviewed by Dunn et al. (2006), including the MacCAT-CR and the MacCAT-T, were designed for use with adults. Unfortunately, formal measures of decisional capacity measures for children and adolescents are lacking in the literature. However, the authors of the MacCAT-T deem its use with minors appropriate (T. Grisso & P.S. Appelbaum, personal communication, March 10, 2005).

Applying Grisso and Appelbaum's (1998) definition of decisional capacity and the framework for assessment described in the MacArthur Competence Tool for Treatment (MacCAT-T) (Grisso & Appelbaum, 1998a; Grisso & Appelbaum, 1988b; Grisso, Appelbaum, & Hill-Fotouhi, 1997), Table 1 provides an example of specific areas to be assessed (understanding of disease and treatment including the risks/benefits; appreciation of disease and treatment; reasoning; and ability to express a choice) and the types of questions that may be used when trying to assess the decisional capacity of minors with HIV. These, and other, questions and a similar format were used in a research protocol designed as part of a pilot study to assess the decisional capacity of children and adolescents with HIV, the results of which are described in a manuscript currently under review (Chenneville et al., n.d.). The content, particularly for the questions designed to assess understanding, are based on current knowledge of HIV (Knox & Chenneville, 2006; Centers for Disease Control and Prevention, 2009) and were reviewed by clinical and academic experts working in the field of HIV (e.g., pediatric infectious disease physicians, psychologists, pediatric nurses, social workers). These questions have not yet been formally validated and should be modified based on the age and developmental level of the child.

It is important to remember the questions designed to assess understanding are based on the assumption that the information in question has been disclosed to the patient (P.S. Appelbaum, personal communication, July 30, 2009). Without such disclosure, questions of this nature will assess merely background knowledge, which is not the intent of assessing understanding within the context of decisional capacity. Rather, the purpose is to assess an individual's capacity to understand the relevant information when presented. To this end, probing may be required to ascertain the individual's true level of understanding. Readers are discouraged from conducting "competency" evaluations of minors with HIV using these questions without proper training in the assessment of decisional capacity. For those interested in learning more about assessing decisional capacity, please refer to Grisso and Appelbaum (1998a and 1988b) and Grisso, Appelbaum, & Hill-Fotouhi (1997).

Several assumptions about decisional capacity must be understood in order for assessment data to be useful. Decisional capacity is task specific, situational, and variable (Grisso and Appelbaum, 1998). Task specificity refers to the idea that you may be capable in one area or domain of functioning but not another. For example, a child with HIV may be capable of making treatment decisions but not capable of living independently or vice versa. The point here is that we should not assume that a child has or does not have the capacity to meaningfully participate in their medical treatment based on their capacity in other areas. Rather, assessment of decisional capacity related to medical treatment should be specific to

the area in question. Situationality refers to the idea that you may be capable in one situation but not in another. For example, an adolescent with HIV may be capable of making decisions about whether or not to take medication but not capable of managing his/her own adherence. For example, an adolescent with HIV may agree to a complicated treatment regimen but may require parental or other assistance to adhere to that regimen (e.g., the adolescent may require verbal or other reminders from a parent or other guardian). Variability refers to the fact that decisional capacity may change (i.e., increase or decrease) over time. For example, research suggests that development affects decisional capacity with older children and adolescents displaying higher levels of decisional capacity than younger children. Because decisional capacity is not static, assessment must be ongoing. Also, we must recognize that deficits can be ameliorated. For example, consider an adolescent male newly diagnosed with HIV. Initially, he may not understand much about his disease or the recommended treatment. Further, he may not appreciate the impact of his disease on his life (e.g., either under or over estimating the effects of disease management on quality of life). However, over time, with appropriate medical education and support, he may gain a better understanding and appreciation for his illness. Another example would be a younger child who initially lacks a solid understanding of his/her diagnosis but whose understanding increases with age consistent with the developmental trajectory related to cognitive functioning. Further, as presented in Miller, Drotar, and Kodish's (2004) conceptual model to guide research on children's competence to consent and assent, there are a multitude of factors that may affect decisional capacity (e.g., predisposing factors, child factors, parent factors, provider factors). The need for protective action or increased autonomy should vary as decisional capacity increases or decreases in response to these factors.

Protection-Autonomy Decision Model

As described, ongoing debates exist about the view of children and adolescents within the context of medical treatment and research. Are minors a vulnerable group in need of protection, and should adults ultimately be responsible for protecting them? Or, are minors capable of making decisions for themselves, and should they be afforded the opportunity to meaningfully participate in the medical decisions that affect their lives? Ultimately, the question becomes whether or not autonomy rights should outweigh the need to protect minors or vice versa. Miller, Drotar, and Kodish (2004) point out that the questions being asked differ according to placement on the protection-autonomy continuum. While autonomists focus on *who* should be making the decision(s), protectionists focus on *what* decisions should be made, presumably in the best interest of the child. Some might consider the former as a moral issue and the latter a practical one.

While it may be tempting to categorize those with the authority to ultimately make decisions about minors' involvement in their medical care as protectionists or autonomists, we argue for a data-based decision making model. In this model, the who and what of decision making is based on data obtained from a thorough assessment of the decisional capacity of the minor in question as opposed to the philosophical viewpoint of the authority figure (e.g., parent or health care provider). Protective action is warranted in cases where decisional capacity is deemed to be low whereas respecting autonomy may be more advantageous

where decisional capacity is deemed to be high. Health care providers and others with the authority and means to protect or grant autonomy must understand the assumptions that underlie the construct of decisional capacity. Moreover, it should be understood that protection and autonomy are not mutually exclusive terms. Rather, it is possible to incorporate the child's voice in a developmentally appropriate way and based on medical treatment needs even when protection is clearly warranted.

Conclusion

Decisional capacity is an important construct especially as it relates to the protection-autonomy debate for children and adolescents with HIV. Many ethical and legal issues exist with regard to the participation of minors with HIV in their medical treatment and research. Although it is assumed that children's interests can be served best by adults with decision making authority, over-protection may lead to the denial of children's rights, which may not be in their best interest. However, under-protection, while it may preserve autonomy rights among minors, may not serve the best interest of the child. Legally, children typically are not afforded the right to provide informed consent for medical treatment and/or participation in research. However, in some cases, minors are afforded the right to consent, without parental permission or notice, to HIV testing and treatment. Because contradictions exist between and within law, policy, and ethics, it seems prudent that rules about the extent of minor participation be avoided in favor of case-specific decisions based on an individual assessment of decisional capacity. For children and adolescents with HIV, this assessment should include disease-specific questions designed to assess the four components of decisional capacity outlined by Grisso and Appelbaum (1998). The data yielded from an assessment of decisional capacity could be used to determine how best to balance the autonomy rights of minors with HIV and the need to protect this vulnerable population while maximizing minors' involvement in their medical care.

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References

- Alpay H. Transition of the adolescent patient to the adult clinic. *Peritoneal Dialysis International Society for Peritoneal Dialysis*. 2009; 29(S):180–182.
- American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission and assent on pediatric practice. *Pediatrics*. 1995; 95:314–318. [PubMed: 7838658]
- Appelbaum PS. Personal communication. 2009 Jul 30.
- Appelbaum PS. Assessment of patients' competence to consent for treatment. *The New England Journal of Medicine*. 2007; 357(18):1834–1840. [PubMed: 17978292]
- Ballantyne A. HIV international clinical research: Exploitation and risk. *Biotethics*. 2005; 19(5–6): 476–491.
- Browning D, Solomon M. The initiative for pediatric palliative care: An interdisciplinary educational approach for healthcare professionals. *Journal of Pediatric Nursing*. 2005; 20:326–334. [PubMed: 16182092]
- Campbell A. Consent, competence, and confidentiality related to psychiatric conditions in adolescent medicine practice. *Adolescent Medicine Clinics*. 2006; 17:25–47. [PubMed: 16473292]

- Cauffman E, Steinberg L. (Im)maturity of judgment in adolescence: Why adolescents may be less culpable than adults. *Behavioral Sciences and the Law*. 2000; 18:741–760. [PubMed: 11180420]
- Centers for Disease Control and Prevention. HIV/AIDS: Basic Information. 2009. Retrieved June 23, 2009 from <http://www.cdc.gov/hiv/topics/basic/index.htm>.
- Centers for Disease Control and Prevention. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2007. HIV/AIDS Surveillance Report, 2007, 19. Retrieved June 19, 2009 from <http://www.cdc.gov/hiv/topics/surveillance/resources/reports>.
- Chenneville T, Sibille K, Lujan-Zilberman J, Rodriguez C, Brown M, Emmanuel P. Medical decisional capacity among children with HIV: Results from a pilot study. *AIDS Care*. (n.d.). Manuscript under review.
- Clafin CJ, Barbarin OA. Does 'telling' less protect more? relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology*. 1991; 16(2):169–191. [PubMed: 2061787]
- Clemente I. Clinicians' routine use of non-disclosure: Prioritizing 'protection' over the information needs of adolescents with cancer. *CJNR: Canadian Journal of Nursing Research*. 2007; 39(4):18–34.
- Dunn LB, Nowrangi MA, Palmer BW, Jeste DV, Saks ER. Assessing decisional capacity for clinical research or treatment: A review of instruments. *American Journal of Psychiatry*. 2006; 163(8): 1323–1334. [PubMed: 16877642]
- Dixon-Woods M, Young B, Heney D. Partnerships with children. *British Medical Journal*. 1999; 319:778–780. [PubMed: 10488013]
- Doig C, Burgess E. Withholding life-sustaining treatment: Are adolescents competent to make these decisions? *Canadian Medical Association Journal*. 2000; 162:1585–1588. [PubMed: 10862235]
- Evan E, Zeltzer L. Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*. 2006; 107:1663–1671. [PubMed: 16921479]
- Foster C, Waelbrouck A, Peltier A. Adolescents and HIV infection. *Current Opinion in HIV and AIDS*. 2007; 2(5):431–436. [PubMed: 19372923]
- Franklin S, Lim HJ, Rennie KM, Eastwood D, Cuene B, Havens PL. Longitudinal intellectual assessment of children with HIV infection. *Journal of Clinical Psychology in Medical Settings*. 2005; 12(4):367–376.
- General Assembly of the United Nations. Convention on the Rights of the Child. 1990 Retrieved May 7, 2006 from <http://www.unicef.org/crc/>.
- Grisso T. Personal communication. 2009 Jul 30.
- Grisso T, Appelbaum PS. Personal communication. 2005 Mar 10.
- Grisso, T.; Appelbaum, PS. Assessing competence to consent to treatment. New York: Oxford University Press; 1998a.
- Grisso, T.; Appelbaum, PS. MacArthur Competence Assessment Tool for Treatment (MacCAT-T). Sarasota, Florida: Professional Resource Press; 1988b.
- Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: A clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services*. 1997; 48(11):1415–1419. [PubMed: 9355168]
- Hardy MS, Routh DK, Armstrong FD, Albrecht J. Interpersonal distance and coping in children with HIV and cancer. *Children's Health Care*. 1995; 24(2):119–131.
- Hartman R. Coming of age: Devising legislation for adolescent medical decision-making. *American Journal of Law, Medicine, & Ethics*. 2002; 28:409–453.
- Helwig, CC. Culture and the construction of concepts of personal autonomy and democratic decision-making. In: Jacobs, JE.; Klaczynski, PA., editors. *The development of judgment and decision making in children and adolescents*. Mahwah, NJ: Erlbaum; 2005. p. 181–212.
- Ho WW, Brandfield J, Retkin R, Laraque D. Complexities in HIV consent in adolescents. *Clinical Pediatrics*. 2005; 44(6):473–478. [PubMed: 16015393]
- Hoehn K, Nelson R. Advising parents about children's participation in clinical research. *Pediatric Annals*. 2004; 33:778–781. [PubMed: 15559704]
- Knox, MD.; Chenneville, T. Prevention and education strategies. In: Fernandez, F.; Ruiz, P., editors. *Psychiatric aspects of HIV/AIDS*. Baltimore: Lippincott Williams & Wilkins; 2006.

- Kuther T. Medical decision-making and minors: Issues of consent and assent. *Adolescence*. 2003; 38:343–358. [PubMed: 14560886]
- Lansdown G, Karkara R. Children's right to express views and have them taken seriously. *The Lancet*. 2006; 367:690.
- LeMoyne/UNICEF/UNICEF. Convention on the rights of the child, HQ05. 2005 Retrieved May 7, 2006 from <http://www.unicef.org/crc/>.
- Limber SP, Wilcox BL. Application of the U.N. Convention on the Rights of the Child to the United States. *American Psychologist*. 1996; 51(12):1246–1250.
- Llorente A, Brouwers P, Charurat M, Magder L, Malee K, Mellins C. Early neurodevelopmental markers predictive of mortality in infants infected with HIV-1. *Developmental Medicine and Child Neurology*. 2003; 45:76–84. [PubMed: 12578232]
- Macklin, R. Autonomy, beneficence, and child development: An ethical analysis. In: Stanley, B.; Seigler, J., editors. *Social research on children and adolescents: Ethical Issues*. Newburg Park, CA: Sage Publishing; 1992. p. 88-105.
- Melton G. Building human communities respectful of children: The significance of the Convention on the Rights of the Child. *American Psychologist*. 2005; 60(8):918–926. [PubMed: 16351445]
- Melton, GB.; Koocher, GP.; Saks, MJ., editors. *Children's competence to consent*. New York: Plenum; 1983.
- Miller VA, Drotar D, Kodish E. Children's competence for assent and consent: A review of empirical findings. *Ethics & Behavior*. 2004; 14(3):255–295. [PubMed: 15875339]
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. U.S. Food and Drug Administration, Guidance for Institutional Review Boards and Clinical Investigators 1998 Update, Appendix F; 1979. *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*.
- Patenaude AF, Kupst MJ. Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*. 2005; 30(1):9–27. [PubMed: 15610981]
- Perez-Carceles M, Osuna E, Luna A. Informed consent of the minor. Implications of present day Spanish law. *Journal of Medical Ethics*. 2002; 28:326. [PubMed: 12356963]
- Pumariega, AJ.; Shugart, MA.; Pumariega, JB. HIV/AIDS among children and adolescents. In: Fernandez, F.; Ruiz, P., editors. *Psychiatric aspects of HIV/AIDS*. Baltimore: Lippincott Williams & Wilkins; 2006. p. 259-266.
- Rao R, Sagar R, Kabra SK, Lodha R. Psychiatric morbidity in HIV-infected children. *AIDS Care*. 2007; 19(6):828–833. [PubMed: 17573605]
- Runeson I, Elander G, Hermeren G, Kristensson-Hallstrom I. Children's consent to treatment: Using a scale to assess degree of self-determination. *Pediatric Nursing*. 2000; 26:455–459. [PubMed: 12026334]
- Sanci L, Sawyer S, Weller P, Bond L, Patton G. Youth health research ethics: Time for a mature-minor clause? *Medical Journal of Australia*. 2004; 180:336–338. [PubMed: 15059054]
- Santos Pais M, Bissell S. Overview and implementation of the UN convention on the rights of the child. *The Lancet*. 2006; 367:689–690.
- Solomon M, Sellers D, Heller K, Dokken D, Levetown M, Rushton C, et al. New and lingering controversies in pediatric end-of-life care. *Pediatrics*. 2005; 116:872–883. [PubMed: 16199696]
- Starr Edwards L. Adolescents' abilities to render competent treatment decisions: A comparison of mentally ill and non-mentally ill samples. *Dissertation Abstracts International: Section B. The Sciences & Engineering*. 1996; 57:2165.
- Toch R. Management of the child with a fatal disease. *Clinical Pediatrics*. 1964; 3:418–427. [PubMed: 14192464]
- Tuchman LK, Slap GB, Britto MT. Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*. 2008; 34(5):557–563.
- Vallerand AH, Hough E, Pittiglio L, Marvicsin D. The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care and STDs*. 2005; 19(2): 100–109. [PubMed: 15716641]

- Walker. Meaningful participation of minors with HIV/AIDS in decisions regarding medical treatment: Balancing the rights of children, parents, and the state. *International Journal of Law and Psychiatry*. 2002; 25(3):271–297. [PubMed: 12148153]
- Weithorn L. Developmental factors and competence to make informed treatment decisions. *Child and Youth Services*. 1982; 5:85–100.
- Weithorn L, Campbell S. The competency of children and adolescents to make informed treatment decisions. *Child Development*. 1982; 53:1589–1598. [PubMed: 7172783]
- Wiener LS, Zobel M, Battles H, Ryder C. Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Social Work in Health Care*. 2007; 46(1):1–19. [PubMed: 18032153]
- Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics*. 2007; 28(2):155–166. [PubMed: 17435473]

Table 1

Examples of the Types of Questions to Consider when Assessing the Decisional Capacity of Minors with HIV

Understanding	
<i>Understanding Disease</i>	
<u>Diagnosis</u>	*Can the child/adolescent identify the full name of his illness (Human Immunodeficiency Virus and/or Acquired Immune Deficiency Syndrome), just the acronym (HIV and/or AIDS), or both?
<u>Features of Disease</u>	*Can the child/adolescent identify all the ways in which HIV can be transmitted (e.g., via blood, semen, vaginal fluid, breast milk)?
<u>Course of Disease</u>	*Can the child/adolescent identify that HIV can lead to AIDS, which may result in death?
<i>Understanding Treatment</i>	
<u>Name/Type of Treatment</u>	*Can the child/adolescent identify that medication is available for the treatment of HIV?
<u>Features of Treatment</u>	*Is the child/adolescent aware and able to describe the importance of taking medication as prescribed (e.g., right time of day, with or without food, with or without other medications)?
<i>Understanding the Potential Benefits and Risks of Treatment</i>	
<u>Benefits</u>	*Is the child/adolescent able to describe the potential benefits associated with medical treatment in terms of reducing the risk of illness and increasing longevity and quality of life?
<u>Risks</u>	*Is the child/adolescent aware and able to describe the possible side effects of medication?
<i>Important Considerations</i>	
* The evaluation of responses to these questions assumes the information in each question has been disclosed to the child/adolescent. Questions assessing understanding are not intended to assess background knowledge. Similarly, it must be understood that information may need to be repeated, and probing may be necessary to ascertain the minor's capacity to understand.	
Appreciation	
<i>Appreciation of Disease</i>	
*Beyond merely understanding HIV as a disease, does the child/adolescent acknowledge that he suffers from the disease (i.e., Does the child/adolescent believe he is infected with HIV)?	
<i>Appreciation of Treatment</i>	
*Beyond merely understanding the mechanics of HIV medication, does the child/adolescent acknowledge the potential impact that medication has on her own life?	
<i>Important Considerations</i>	
*The evaluation of responses to these questions assumes the child/adolescent has been provided with ample evidence about his/her diagnosis and treatment options. Rationality also must be taken into consideration. To conclude that someone lacks appreciation for his/her disease or treatment assumes s/he has been provided ample evidence to the contrary and that his/her beliefs are irrational despite such evidence. Rational ambivalence (e.g., I do not believe I have HIV because someone told me my test results were negative) differs from a failure to appreciate one's diagnosis.	
Reasoning	
*Is the child/adolescent able to demonstrate consequential reasoning skills? That is, can he describe at least two specific consequences associated with a stated choice about whether or not to take medication?	
Ability to Express a Choice	
*Is the child/adolescent able to manifest a stable decision with regard to his medical care including treatment options?	

Note. Please be aware that this table is not intended to provide a comprehensive list of the questions that should be included in an assessment of decisional capacity. Rather, the questions listed here provide an example of the types of questions that should be a part of an assessment of decisional capacity among minors with HIV. These questions have not yet been formally validated, but have been used in a pilot study, the results of which are described in a manuscript currently under review (Chenneville et al., n.d.). Questions such as these should be used judiciously within the context of a validated instrument such as the MacArthur Competence Tool for Treatment (MacCAT-T) and responses interpreted within the context of the age and developmental level of the minor being assessed.