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## Medical decisional capacity among children with HIV

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### Abstract

Medical decisional capacity refers to the ability to understand, appreciate and make meaningful decisions about one's health. This is an important construct for children living with HIV whose involvement in their medical care has important implications for disease management. In this study, we assessed the relationship between decisional capacity, developmental stage, intellectual ability, and social-emotional functioning of children with and without HIV infection (n=50). We hypothesized a positive correlation between variables, but did not expect to find a difference in decisional capacity between groups. Results provided partial support for our hypotheses. There was a positive relationship between developmental stage and understanding, which is but one dimension of decisional capacity. Children with HIV infection obtained significantly lower scores on measures of intellectual and adaptive functioning, but there was no significant difference in decisional capacity between groups. Findings suggest that children living with HIV have the capacity to meaningfully participate in their health care despite lower intellectual and adaptive functioning.

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Despite prevention efforts, a large and growing number of children and adolescents suffer from HIV/AIDS and are in need of medical intervention. This disease disproportionately affects minorities and the poor who are at increased risk for comorbid health and psychological problems and who may be victims of health disparities. Because many children and adolescents with HIV lack adequate social support, often they must advocate for themselves and become active participants in treatment planning. In order to meaningfully participate in decisions regarding medical treatment, children with HIV/AIDS must have the capacity to make these decisions, an issue which is rarely addressed within the medical arena. Existing research suggests that meaningful participation in treatment positively affects medical outcomes (Walker, 2002), a finding which carries particular importance for pediatric healthcare workers. To date limited research is available on

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treatment decisional capacity (DC) among children in general, and even less among children with HIV who represent a particularly vulnerable population.

Arguments in favor of children's participation in their medical treatment are based on moral contentions focused on protecting the rights and affirming the dignity of the child (Walker, 2002; Melton, 1998; Ackerman, 1990) and existing research that suggests that medical adherence and overall treatment success is positively correlated with meaningful patient participation (Walker, 2002). Meaningful patient participation involves more than mere consent or assent and refers to the extent to which patients understand their illness and are actively involved in decisions related to their treatment.

For children and adolescents with HIV, meaningful patient participation is of particular importance. Medication adherence is a serious issue among this population, particularly for adolescents living with HIV. In the United States, many states allow for minors age 13 and older to consent for testing and treatment of sexually transmitted infections, including HIV; therefore, there are a number of adolescent patients who receive medical care unsupervised by a parent or guardian. In addition, many families affected by HIV are dealing with comorbid substance abuse and mental health problems and, as a result, children and adolescents with HIV sometimes are prematurely responsible for illness management. Illness management can require decisions about doctor's appointments, medication adherence, disclosure, and secondary prevention among things.

Arguments against children's participation in their medical treatment are based on the presumption that children are "incompetent" (i.e., lack decisional capacity) and that this may have a negative effect on the child. While children who possess adequate DC should be encouraged to participate in their medical treatment given the associated positive outcomes, efforts should also be made to involve children in a developmentally appropriate way who lack DC so that they may participate in their medical treatment. To do so requires an understanding and assessment of the dimensions of DC. A previous study suggests that cognitive dysfunction and certain psychiatric symptoms are associated with impaired DC among adults with HIV and schizophrenia (Moser et al., 2002). However, research specifically addressing the factors affecting DC among children and adolescents with HIV infection is lacking.

The primary purpose of this study was to examine the factors relating to DC among children with and without HIV with respect to participation in the medical treatment process. We hypothesized a positive correlation between DC, developmental level, intellectual ability, and social-emotional functioning across groups. We expected no differences in DC between children with and without HIV.

## Methods

### Study Design

This project employed a field-based descriptive study design to assess the correlation between decisional capacity (DC), intellectual ability, and social-emotional functioning. Data collection included the administration of an intellectual screening measure, a parent

report of behavior to assess social-emotional functioning, and a structured interview to assess DC. We obtained Institutional Review Board approval prior to data collection.

## Participants

Participants included fifty children between the ages of 7 and 17. Since the DC measure is based on cognitive constructs (see *Instruments* below), Piaget's theory of cognitive development (7–11 year olds, concrete operational stage and 12–17 year olds, formal operational stage) provided the framework for age selection, consistent with Weithorn's work in the area of children's competence (Weithorn, 1982; Weithorn & Campbell, 1982). Twenty-five children were diagnosed with HIV (clinical group), and 25 children did not have a diagnosis of a chronic or life threatening illness (comparison group). Participants from each group were matched on age and gender.

Participants for the clinical group were recruited from a convenience sample of two outpatient clinics in the Tampa Bay area that are part of the University of South Florida (USF) Pediatric and Adolescent Infectious Disease Program (PAIDP). These clinics serve 227 children and adolescents with HIV ages birth to 24. Of these, only 128 fell in the age category (7–17 years) for this study. In order to maximize enrollment, potential participants included patients with perinatally and behaviorally acquired HIV despite the potential differences between these groups. Patients unaware of their diagnosis, approximately 15% of the sample pool, were excluded from the study.

Participants for the comparison group were recruited from the Bayfront Family Health Center (BFHC) and the surrounding community. The BFHC is an outpatient primary healthcare facility located in the Tampa Bay area which serves infants, children, and adults. Patients within the specified age category and without a diagnosis of HIV or another chronic or life threatening illness were eligible. Incorporating a "healthy" sample allowed for the comparison of possible developmental differences in DC between children and adolescents with and without an HIV diagnosis.

Foster children were excluded from both groups due to guardianship issues. Flyers were posted as a recruitment tool. Additionally, during regularly scheduled clinic appointments, a member of the multidisciplinary medical team approached eligible patients about the study. Those interested were referred to the principal investigator or a trained research assistant. Parental consent and child assent were obtained, and data typically was collected on the same day as initial contact.

## Instruments

DC was assessed using the *MacArthur Competence Assessment Tool for Treatment (MacCat-T)* (Grisso & Appelbaum, 1998; Grisso, Appelbaum, & Hill-Fotouhi, 1997), a structured interview designed to assess DC along four dimensions: understanding, appreciation, reasoning, and ability to express a choice. In this study, the MacCat-T was used as a criterion measure. A protocol was created for each group (clinical and comparison). Protocols were identical in format but varied in content. Participants in the clinical group were queried about HIV/AIDS, and participants in the comparison group were

queried about strep throat. DC assessment is based on an individual's experience and understanding of a disease. Querying children without a diagnosis of HIV would be neither appropriate nor ethical. Strep throat is a common childhood illness that most children and adolescents are familiar with either through personal experience or the experience of a friend or loved one. Therefore, it provided a frame of reference in which to assess capacity related to medical decision making for the comparison group. The protocol for both groups included the following components: (a) an assessment of the participant's capacity to understand the disease including its features and course; (b) an assessment of the participant's capacity to appreciate the impact of the disease on his/her own life; (c) an assessment of the extent to which the participant was capable of expressing a choice; and (d) an assessment of the extent to which a participant was capable of using appropriate reasoning skills and/or to apply a logical thought process when making decisions related to the disease.

For each dimension, a criterion scoring protocol was developed whereby participants earned 0–2 points for each response, consistent with the MacCat-T protocol. For example, responses to questions assessing understanding of modes of transmission as one of the features of the disorder for the HIV scenario was scored by assigning two points for responses that included a discussion about all possible modes of transmission (e.g., via birth, sexual behavior, drug use, and, although less common, via breast feeding, blood transfusions or other blood exposures), one point for responses that included a discussion of only two modes of transmission (e.g., via sexual behavior or drug use) and zero points for responses that included a discussion of only one mode of transmission or none at all. Scoring criteria were developed based on current knowledge and were reviewed by clinical and academic experts working in the fields of infectious disease (for the HIV protocol) and pediatrics (for the strep throat protocol).

The *Kaufman Brief Intelligence Test, Second Edition (KBIT-2)* (Kaufman & Kaufman, 2004) was administered as a screening measure of intellectual ability. The KBIT-2 is a brief, individually administered screener of verbal and nonverbal ability appropriate for use with individuals between the ages 4 and 90 that has shown relatively good reliability with the Wechsler scales.

The *Behavior Assessment Scale for Children, Second Edition (BASC-2), Parent Report Form* (Reynolds & Kamphaus, 2004) was used to measure social-emotional functioning. The BASC-2 is an integrated system designed to facilitate the differential diagnosis and classification of a variety of emotional and behavioral disorders.

## Data Analysis

We analyzed data using descriptive statistics, independent t-tests to look at the differences between groups, and Pearson bivariate correlations to look at the relationships between DC, developmental stage, intellectual ability, and social-emotional functioning.

## Results

### Population Demographics

Our sample included 25 males and 25 females. The majority (n=34) of participants were 12–17 years old (formal operational stage). Only 16 participants were 7–11 years old (concrete operational stage). Younger children were more difficult to recruit, especially in the clinical group, given the issue of disclosure, a well documented problem in the area of pediatric HIV (DeMatteo et al., 2002; Mellins, Brackis-Cott, Dolezal, Richards, Nicholas, & Abrams, 2002; Wiener, Battles, & Heilman, 1998). The majority of participants were minorities (60% of clinical group and 56% of comparison group). Participants were not matched based on ethnicity, due to recruitment feasibility, but there were approximately equal numbers of minorities and non-minorities in each group. Detailed information on the demographic information of participants is reported in Table 1.

### Intellectual Ability between Groups

Differences in KBIT-2 scores were determined using independent t-tests. There was a significant difference in mean scores between the clinical and comparison groups (Table 2). Scores on the IQ composite were, on average, 14 points lower for the clinical group (clinical group mean = 84.72, SD = 14.95; comparison group mean = 98.76, SD = 16.14) ( $t = -3.267$ ,  $df = 48$ ,  $p < .05$ ), representing a large effect size (Cohen's  $d = .9$ ). On the verbal IQ, the clinical group scored, on average, 10 points lower than the comparison group (clinical group mean = 87.56, SD = 12.25; comparison group mean = 97.92, SD = 16.75) ( $t = -2.725$ ,  $df = 48$ ,  $p < .05$ ). On the nonverbal IQ, the clinical group scored, on average, 12 points lower than the comparison group (clinical group mean = 85.56, SD = 19.47; comparison group mean = 97.46, SD = 14.52) ( $t = -2.718$ ,  $df = 48$ ,  $p < .05$ ). The differences between groups on the verbal IQ and nonverbal IQ represent a medium effect size (Cohen's  $d = .7$ ).

### Social-Emotional Functioning between Groups

Scores between groups on the BASC-2 were analyzed using independent t-tests. There was no significant difference between the clinical and comparison groups on the Internalizing or Externalizing Composite scores, nor was there a significant difference between groups on the Behavioral Symptoms Index (Table 2). However, there were significant differences between groups on the Adaptive Skills Composite ( $t = 2.447$ ,  $p < .05$ ), representing a medium effect size (Cohen's  $d = .7$ ), and two of the individual subscales that factor load on this composite to include the Adaptability subscale ( $t = -2.96$ ,  $p < .01$ ) and the Functional Communication subscale ( $t = -2.161$ ,  $p < .05$ ). In each case, scores for the clinical group were lower than scores for the comparison group.

### Decisional Capacity between Groups

Scores on the MacCat-T were analyzed using independent t-tests. Consistent with existing literature, there was a significant difference in understanding for disorder based on developmental stage with 7–11 year-olds (concrete operational stage) scoring lower (mean = 4.39, SD = 0.94) than 12–17 year olds (formal operational stage) (mean = 5.09, SD = 0.71) [ $t = -2.906$ ,  $p < .01$ ]. However, the effect size was small (Cohen's  $d = .35$ ).

There was no significant difference in mean scores between the clinical and comparison group on the MacCat-T (Table 2). Please note that higher scores on the MacCat-T indicate higher levels of decisional capacity (DC). Overall, scores on the MacCat-T for both groups were relatively high, indicating an adequate level of DC across the domains measured. However, scores on the understanding (81% correct) and reasoning (84% correct) subscales were somewhat lower relative to the range possible compared to scores on the appreciation (94%) and ability to express a choice (98%) subscales.

### Relationship between Variables

There was a significant relationship between age and scores on the Understanding subscale of the MacCat-T for the clinical group ( $r=0.595$ ,  $p<.01$ ), but not for the comparison group. Other subscales on the MacCat-T did not correlate with age. Because there was a significant difference between groups on IQ composite scores, we computed correlations between intellectual ability and DC independently for each group. Results revealed a significant correlation between IQ composite scores and the Understanding subscale of the MacCat-T for the comparison group ( $r=.619$ ,  $p<.01$ ), but not for the clinical group (Tables 3 & 4). There was no significant relationship between Internalizing and Externalizing Composite scores on the BASC-2 and the summary rating scores for subscales on the MacCat-T (data not shown). We did not compute correlations for the overall sample because there was no significant difference between groups on the composite scores.

### Qualitative Data

In addition to quantifying responses on the MacCat-T, the content of responses was examined qualitatively in an attempt to unveil more detailed information about the thought processes underlying the DC of children with HIV. Of particular concern, from a qualitative perspective, was appreciation of the disorder for children with HIV given that quantitative data suggests that appreciation for diagnosis varied for some participants. Responses to questions assessing appreciation of disorder were reviewed and themes examined and categorized. For this group, while understanding of disorder and the risks and benefits of treatment appears to be relatively high, appreciation for the diagnosis varied for some participants. When asked if they believed or had reason to doubt their HIV diagnosis, several participants reported disbelief or skepticism about their own diagnosis. For younger children, ambivalence appeared to be associated with stereotypes about the illness (e.g., younger children made statements such as “I play outside and go to school and, if I really were HIV positive, I would not be able to do that” or “I would be in the hospital all the time if I really were HIV positive”). For older children/adolescents, deficits in appreciation for diagnosis appeared to be associated with misinformation or a lack of knowledge about viral load, one of the primary markers of HIV progression (e.g., older children/adolescents made statements such as “I do not believe I am HIV positive because my doctor tells me my viral load is undetectable”).

### Discussion

Consistent with existing literature (Starr Edwards, 1996; Weithorn, 1982; Weithorn & Campbell, 1982), results from this study provide support for the relationship between





Current findings do not provide evidence of a relationship between social-emotional functioning and DC. However, the significant difference in adaptive skills between children with HIV and those without is important. In this study, children with HIV infection scored significantly lower than their non-infected counterparts in the area of adaptive functioning, specifically adaptability and functional communication. Yet these scores did not correlate with the four dimensions of DC (i.e., understanding, appreciation, reasoning, ability to express a choice). This finding is interesting and may be a function of important protective factors. For example, research suggests that resilience may serve as a protective factor for mental disorders among families with HIV (New, Lee, & Elliott, 2007). It is possible that resilience also serves as a protective factor for DC. This and other hypotheses need further attention and research.

While policy and practice recommendations may be premature given that results reflect pilot data, this line of research clearly has important implications. From a legal standpoint, the results of this type of research, regardless of the direction of findings, have the potential to provide lawmakers with important data about the DC of minors to participate in a meaningful way in the medical decisions that affect their lives. Legally, the current presumption is that minors are not competent to participate in medical decision making. Findings from this study, combined with findings from prior research, challenge this notion.

There are several limitations to this study, the most significant being the small sample size, which limits the generalization of findings. Selection bias also is a limitation given the lack of random selection and use of a convenient sample. Factors attributing to selection bias, especially for the clinical group, included: (1) crises at the time of clinic recruitment (e.g., patients who met eligibility criteria but were not approached due to physical or mental health issues that needed to take precedent, for example, when suicidal ideations were present), (2) exclusion of foster children who comprise a significant percentage of eligible participants, (3) exclusion of children with HIV without knowledge of their diagnosis, (4) parental consent requirement which excluded adolescents whose parents were unavailable, and (5) other differences between families who choose to participate in research and those who do not. As a result of these factors, the participants who enrolled may have been higher functioning in terms of mental health and family/social support, which may serve as covariates. Mode of transmission (perinatal versus behavioral infection) for the clinical group also may serve as a confounding variable. Differences may exist in DC between children who have been living with HIV their entire lives and those who contracted HIV during adolescence. HIV affects a developing central nervous system for children with perinatal infection and subsequently, developmental delays and/or other neurocognitive deficits (e.g., learning disabilities) are common among this group, which may affect DC. Further, some of these children may not reach the formal operational stage until they are older which may affect comparisons based on Piaget guided cut off selections. The impulsivity and high risk psychological profile of behaviorally infected youth also may affect dimensions of DC. Similarly, the influence of living with a parent who also is HIV positive, which is the case for at least some children with perinatal acquired HIV, is unknown. It seems reasonable to at least hypothesize a correlation in DC between children with HIV and their parents with HIV who also live in the same home. Future studies should



examine the differences between children with perinatally acquired and behaviorally acquired HIV.

## Conclusion

Combined, results from this study suggest that while there is a significant correlation between intellectual functioning and understanding of disease related information, there do not appear to be any significant differences in DC between children with HIV and those without despite lowered intellectual and adaptive functioning among children with HIV. Developmental stage, as opposed to age, appears to be a more important correlate of DC overall, while social-emotional functioning appears unrelated to this construct. Clearly, replication studies using larger and more representative samples are needed as well as studies examining the contributing influence of individual factors (e.g., age, intellectual ability, adaptive functioning, disease status) on DC. Intervention studies to address the ways in which deficits in DC can be ameliorated and the impact of the “doctor-patient” dialogue on the DC of chronically ill children are needed. Further, as mentioned above, future studies should consider protective factors related to DC such as resilience. These studies will assist providers in addressing some of the most complex issues of caring for children and adolescent with HIV.

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**Table 1**

## Gender, Age, and Ethnicity of Participants

	Clinical Group	Comparison Group	Total
Gender			
Males	9	9	18
Females	16	16	32
Total	25	25	50
Age			
Range	8–17	8–17	
7–11 year olds	8	8	16
12–17 year olds	17	17	34
Combined	25	25	50
Mean	13.32	13.32	13.32
Median	13	13	13
Ethnicity			
Caucasian/White	10	11	21
African American/Black	9	11	20
Hispanic/Latino	3	0	3
Mixed	3	1	4
Asian	0	0	0
Other	0	2	2
Total	25	25	50





**Table 3**  
Correlations of Intellectual ability and Decisional Capacity Measure for Clinical Group

	IQ Composite	Understanding Summary	Appreciation Summary	Reasoning Summary	Express Choice Summary
IQ Composite	1				
Understanding Summary	.180	1			
Appreciation Summary	.319	.564 <sup>**</sup>	1		
Reasoning Summary	.315	.220	.090	1	
Express Choice Summary	-.102	-.275	-.113	.081	1

\*\* Correlation is significant at the 0.01 level (2-tailed).



**Table 4**  
Correlations of Intellectual ability and Decisional Capacity Measure for Comparison Group

	IQ Composite	Understand	Appreciate Disorder	Appreciate Treatment	Appreciate Summary	Reasoning Summary	Express Choice Summary
IQ Composite	1						
Understanding Summary	.619(**)	1					
Appreciate Disorder	.(a)	.(a)	1				
Appreciate Treatment	-.098	.101	.(a)	1			
Appreciate Summary	-.148	.246	.(a)	1.000(**)	1		
Reasoning Summary	.049	.108	.(a)	-.018	.239	1	
Expressing Choice Summary	.312	.412(*)	.(a)	-.058	.(a)	.153	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

a Cannot be computed because at least one of the variables is constant.