

Chapter 2

Approaches to Assessment of Very Young Children in Africa in the Context of HIV

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2.1 HIV and the Children of Africa

Although there have been major advances in the treatment and prevention of HIV disease worldwide, the HIV epidemic continues to present dire challenges to the health, well-being, and quality of life for the children of Africa. The overall burden of HIV is present across the continent and remains highest in sub-Saharan Africa. Of the 33.3 million people in the world living with HIV in 2009, 22.5 million were living in sub-Saharan Africa, including 2.3 million children (UNAIDS 2010).

Efforts to prevent and manage HIV in Africa over the past decade have resulted in some reduction of the impact of the disease. Much of this positive trajectory is due to greater, though not yet universal or consistent, availability of antiretroviral medications for HIV treatment and prevention. In sub-Saharan Africa, increased access to treatment was associated with a 20 % decrease in AIDS-related deaths between 2004 and 2009 (UNAIDS 2010), though coverage remains below 40 % for those in need of medications, leaving ample room for continued reduction in mortality. Medications to prevent mother-to-child transmission of HIV have also dramatically reduced the number of children born with HIV in recent years.

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For the 2.3 million children currently living with this disease in Africa, and for the many more children secondarily *affected* by HIV in their families and communities, there is an imperative need to understand the impact of HIV on their lives in order to better develop efficacious interventions. For children with HIV who do not have consistent access to treatment, there are health issues from and related to HIV. Studies of neurocognitive outcomes have shown that children with early HIV infection are at greater risk for disease-related encephalopathy, with measures documenting delays in development and deficits in functioning across multiple domains (Abubakar et al. 2008b; Sherr et al. 2009; Van Rie et al. 2007).

Children who are HIV-exposed, that is, children who are uninfected but whose mother is HIV-positive, are also at substantial risk for poorer developmental outcomes. HIV-exposed children in Africa currently are at risk for increased morbidity and mortality, though the potential impact on neurocognitive outcomes is inconclusive (Filteau 2009). The possible risk factors for HIV-exposed children include biological factors such as low birth weight (Wei et al. 2004) or possibly exposure to prenatal maternal infections or ARV medications. Environmental factors may also play a role in outcomes for children who are HIV-exposed, such as parental illness, which can dramatically affect the child's experience (Steele et al. 2007). Multiple additional issues related to the cycle of poverty can complicate the lives of children affected by HIV, similar to those of other children in need in Africa. Children are at risk for experiencing inadequate nutrition, decreased cognitive stimulation, caregiver depression or absence, and other chronic health issues.

Given the multiple risk factors, it is essential to follow the development of these children to determine the impact of HIV disease and treatment on their lives with an eye toward maximizing the efficacy of interventions. Disentangling the effects of the disease, other biological factors associated with HIV disease, and environmental repercussions related to HIV is extraordinarily complex but also necessary to develop appropriate interventions that directly address documented problems. Understanding these children also requires a true comprehension of the many factors in child rearing and community integrity that *support* resilience in unique ways within the diverse cultures in Africa (Marfo et al. 2011).

In developing a comprehensive understanding of the impact of HIV, interventions, and other risk factors and protective factors in children at risk in Africa, it is important to measure and track their development longitudinally. Development in most respects (e.g., cognitive, motor, social, emotional) is the result of a dynamic interplay between factors related to the biological aspects of the child and the environment in which they grow in a co-constructivist manner, described as a brain-behavior "omnibus" (Boivin and Giordani 2009). The earliest period of this dynamic developmental process is immensely important to the child's long-term outcome since it is a time of primary brain development and plasticity. Negative effects of disease or environmental stressors such as poverty can have greater impact during early development, but interventions to reduce risk factors and support corrective factors may also be more beneficial in altering the developmental trajectory (Nelson 2000; Richter 2004). Indeed, both positive and negative neural and behavioral plasticity are "among the hallmarks of individual lifespan development and

foundational to a co-constructivist approach” (Boivin and Giordani 2009, p. 119). Interventions during early development are sorely needed to establish critical skills and to provide essential stimulation for children, as these early years create a foundation which can determine much of a child’s long-term potential (Shonkoff and Phillips 2000).

Given the importance of early intervention for children at risk for HIV, measuring the impact of early biological and environmental interventions on later development will maximize the efficacy and utility of limited intervention resources. Although assessment methodologies for measuring the impact of risks and resiliencies in the lives of children are relatively well developed in Western countries (or other industrialized countries that have developed assessment tools), these methodologies do not necessarily directly translate to assessment appropriate for other countries, cultures, or languages. Indeed, most assessments of the children in Africa, as well as from other countries, have been exceptionally complex due to a lack of assessment instruments that were developed, standardized, and validated for each purpose (e.g., cognitive, executive function, social–emotional), country, and culture. The role of culture in neuropsychological assessment has been studied only to a limited extent (Byrd et al. 2008). The lack of systematic measurement made possible by appropriately adapted or developed culturally sensitive tools for measuring the effects of HIV on children’s development threatens to negate the accurate interpretation of data, particularly across studies conducted in different countries (Sherr et al. 2009). Without reliably interpretable assessment data, Sherr and colleagues (2009) noted that it is difficult to generalize across studies and there is “no guidance from the literature on which interventions would be most appropriate to ameliorate, reduce, or avoid” the effects of HIV exposure (p. 399).

This chapter reviews the current status of assessment of very young children in Africa, with a model of the impact of exposure to HIV. Critical variables in selection, development, adaptation, and use of assessment tools for this age group will be reviewed. Specific testing instruments are not recommended, as this choice depends on the purpose and population of the assessment, but commonly used measures are discussed.

2.2 Current Approaches to Assessment

Researchers interested in assessment of very young children have historically developed a number of methods for measuring development. Ideally, assessment materials, demands, and the assessment setting, itself, should be familiar to the children, reflect the intended constructs, exhibit appropriate evidence of reliability and validity, and demonstrate sensitivity to developmental changes and aberrations. Assessment tools should also be carefully developed to sample a broad array of abilities and be standardized against a typically developing population appropriate for comparison. While tasks employed for assessment of very young children do not have the same ability to discriminate between cognitive functions (e.g., language,

spatial, executive) as do neuropsychological instruments for older children, they must nonetheless be well grounded in developmental neuroscience in order to measure the effects of disease processes or environmental stressors on the developing brain. This is a challenging set of demands even for measures commonly used in developed nations, though many measures widely used in Western countries do meet these stringent criteria. The same is not the case for assessment approaches of young children in the diversity of African cultures.

In most assessment situations of young children in Africa, the ideal “test” is not available, and the costs in time and money to develop culturally specific tests are often prohibitive. Approaches to assessment have thus followed two primary paths: developing culturally consonant measures derived from existing Western measures or adapting existing measures for use with children in Africa. A third path that entails pre–post-intervention or education measurement and using the size of change as an indicator of cognitive or other domains of functioning has recently emerged with some success (Boivin and Giordani 2009). In each method, assessment stems from analysis of the specific study goals, domains to be measured, and behaviors to be observed/reported. With an understanding of the goals of assessment, the most appropriate measures can be chosen, translated, adapted, tested, and eventually implemented. At the same time, it is important to accurately measure the array of biological and environmental factors that may impact the results of an assessment.

2.3 Measures Developed Within Africa

Instruments developed in the Western context are not directly applicable to assessing children in Africa. It cannot be assumed that an instrument developed for children in the United States (USA), for example, would measure the same constructs or abilities in children in other cultures. While children of different cultures may be able to perform the same set of tasks at similar levels, they may rely on different strategies or brain pathways to arrive at their solutions. Even simple motor response speed tasks, often considered universal in the Western context, may be culturally dependent (Hedden et al. 2002; Verney et al. 2005), as some cultures may favor accuracy over speed, while others favor the reverse.

One solution is to create a new measure specifically for the cultural group to be assessed. While potentially more costly in terms of time and resources, this allows for tasks to be chosen from materials and activities that are typical in the specific setting, domains of interest to be explicitly covered (e.g., language, motor, cognitive, social–emotional functioning), and norms that can be developed from a typically developing cohort from the same region in order to more accurately reflect children’s functioning relative to expectations. Examples of this strategy are the Kilifi Developmental Checklist (KDC), later modified to become the Kilifi Developmental Inventory (KDI; Abubakar et al. 2007), and the associated Developmental Milestones Checklist (DMC; Abubakar et al. 2010a) both developed in Kenya and a screening instrument developed in Malawi, the Malawi

Developmental Assessment Tool (MDAT; Gladstone et al. 2010a, b). The development of each of these instruments followed rigorous test construction procedures beginning with identifying the domains to be measured; reviewing available, largely Western measurement instruments; selecting, reviewing, and piloting potential test items; assessing reliability characteristics; and initially demonstrating evidence of validity. Focus groups were used to ensure appropriateness of tasks and acceptability of the procedures. The rigorous development processes yielded measurement instruments with evidence of reliability and validity for use in the countries in which they were developed. Given the greater similarities between cultures within Africa than between Western and African cultures, many of the tasks and materials are likely more appropriate for many groups within Africa than are Western measures. It cannot be assumed, however, that norms or content developed for one cultural group within Africa would automatically be appropriate for use in other African countries. Application of these measures with other cultures within Africa remains to be examined.

Kilifi Developmental Checklist and Kilifi Developmental Inventory: Abubakar and colleagues (2007) developed the KDC by pooling culturally and developmentally appropriate items based on a broad review of established measures. The measure was subsequently modified to form the KDI (Abubakar et al. 2008a) that focused on locomotor, eye–hand coordination, and psychomotor skills in children aged 6–35 months. An initial study suggested appropriate internal consistency, inter-rater agreement, test–retest reliability, and sensitivity to maturational change. Children with known neurodevelopmental impairments achieved significantly lower scores than a typically developing community sample, suggesting sensitivity for detecting developmental delays or deficits. Children with HIV infection had lower scores than either an HIV-exposed group or a reference group (Abubakar et al. 2009). Disease stage and weight for age were also associated with KDI scores in this group of children in Kenya.

Developmental Milestones Checklist: To assess development through parent perceptions of their children’s everyday functioning, Abubakar and colleagues (2010a) developed a structured interview for parents of children through 24 months of age in Kenya. Based on existing Western measures, the development process followed a standard course of collecting, reviewing, and reducing a pool of culturally appropriate items reflecting locomotor, fine motor, language, and personal–social development. The initial psychometric studies on typically developing children in Kenya showed high internal consistency and temporal stability, as well as sensitivity to maturational changes and nutritional deficiencies. Follow-up studies revealed that the DMC was sensitive to effects of risk factors in resource-limited settings in Kenya, including limited maternal education, poor health, and limited physical growth (Abubakar et al. 2010b).

Malawi Developmental Assessment Tool: In an effort to create a simple, culturally appropriate developmental screening tool for use in Malawi, Gladstone and colleagues (2008, 2010) collected and culled potential items from both Western measures and tasks suggested by local focus groups as representative of expected developmental behaviors. The tasks were reviewed for developmental and cultural

appropriateness, assessed for evidence of face and content validity, and standardized on typically developing children in Malawi. The MDAT showed adequate inter-rater agreement and appropriate sensitivity and specificity for detecting children with known developmental disabilities. Boivin and colleagues (Boivin et al. 2011a) relied on the MDAT in a study of children in Malawi with cerebral malaria (CM). Children with CM showed significantly lower scores on the MDAT relative to children hospitalized for malaria without cerebral involvement, and scores in children with CM were significantly associated with biological markers of disease severity including coma duration, seizures, and platelet count.

2.4 Measures Adapted for Use in Africa

In many circumstances, creating a new test has not been feasible or desirable, often due to study timing or costs of development. Increasingly, a research goal is also to compare assessment findings across cultural groups, such as comparing the performance of individuals within disease groups between underdeveloped and developed nations (e.g., Africa and Europe or North America). Boivin and Giordani (2009) cogently argue for the use of well-developed, neuroscientifically informed measures in a cross-cultural context in order to facilitate “methodologically triangulating the omnibus” (p. 131) toward Li’s (2003) co-constructive brain–behavior framework. That is, by measuring similar developmental constructs and environmental influences across cultures, the scientific community can better approximate universal “truths” about human brain–behavior relationships and their reciprocal interactions with the environment. Choosing assessment instruments, therefore, involves adapting existing, well-developed measures for use in the cross-cultural African context. Our review of studies, nonetheless, revealed that research articles have not always noted the type or degree of test adaptations used for studies in Africa, despite the importance of this information for understanding, replicating, and extending study findings.

Test adaptation is, however, complex and the rigor used in adaptation directly impacts the quality of assessment findings and generalizability. Adaptation methods range from solely translating the language of test instructions and items to replacing or modifying materials that are not appropriate in the new context to modifying language, procedures, materials, and even measured domains, with separate studies of the psychometric properties of the adapted measure and standardization in the intended cultural context. The most commonly adapted comprehensive assessment instruments for use in Africa with very young children are the Griffiths Mental Development Scale (GMDS; Griffiths 1984) and the Bayley Scales of Infant Development (BSID 1969, BSID II 1993, BSID III 2006), with more recent introduction of an adapted version of the Mullen Scales of Early Development (Mullen 1995).

Bayley Scales of Infant Development (BSID): The BSID are the most widely employed measure of early global development in the cross-cultural context.

There has been substantial variability, however, in the extent and type of adaptations. Early studies with the BSID in South Africa suggested that it was an appropriate tool for measuring development in South African children (Richter et al. 1992) and was sensitive to major risk factors as well as corrective factors (Cooper and Sandler 1997).

Several studies in Uganda adapted the second edition of the BSID, the BSID-II, for use with children with HIV, with cultural adaptations and translation of items and instructions into Luganda, the local language. Researchers relied on the raw number of items passed, as the US norms did not apply in Uganda and did not discriminate well at the lower end of the scale (Drotar et al. 1997; Peterson et al. 2001). More recent use of the adapted BSID-II to compare HIV-infected and HIV-exposed children with healthy controls in the Democratic Republic of Congo (DRC) found that HIV-infected children had the lowest developmental achievement, healthy controls the highest, and HIV-affected children were between the two groups (Van Rie et al. 2008, 2009). A translated BSID-II (no mention of adaptations) found that both HIV-infected and HIV-exposed children in Tanzania showed lower cognitive and motor development as well as a slower developmental trajectory between 6 and 18 months than did controls, suggesting a possible cumulative or interaction effect between HIV and environmental factors such as poverty (McGrath et al. 2006).

Studies in South Africa that relied on the BSID-II with translation, though few noted specifics of the adaptations, found that motor and cognitive development in HIV-infected children were below expectation in over 97 % of the sample (Baillieu and Potterton 2008). With minimal modification of the BSID II, Potterton and colleagues (2009) found that the majority of HIV-infected children had severe motor and cognitive delays. Weight for age and treatment (highly active antiretroviral therapy—HAART) were the most important predictive factors of performance on the BSID II, though the authors hypothesized that poverty was an additional risk factor. Assessment with the BSID II administered via translator (no mention of adaptations) revealed significant motor delays in 66 % of Xhosa-speaking HIV-infected children (Ferguson and Jelsma 2009).

Griffiths Mental Development Scale (GMDS; 1984): The GMDS has been widely used, particularly in South Africa, where multiple modifications have been implemented including translation of test materials and instructions and use of interpreter as needed. Despite frequent use in Africa, there are no consistent normative data for African populations, and scores have typically been compared to the British standardization sample. Children infected with HIV who were treated with HAART in Cape Town showed no measurable change on the GMDS following treatment with HAART (Smith et al. 2008). Children who were HIV-infected children aged 10–15 months who had early antiretroviral therapy achieved better locomotor and global scores on the GMDS than did children for whom therapy was deferred (Laughton et al. 2009). The research group also found that children from low socioeconomic environments who were born to HIV-uninfected mothers showed a decrease in overall scores on the GMDS over a 10–12-month time frame, attesting to environmental influences on overall development (Laughton et al. 2010).

Mullen Scales of Early Learning (Mullen 1995): Recent studies have explored using the Mullen Scales of Early Learning as a multicomponent performance measure of early child development for children in Africa. The Mullen is a comprehensive performance test battery composed of several components reflecting gross motor, fine motor, visual reception, receptive language, and expressive language functioning. Boivin and colleagues (2011b) employed the Mullen at three points in time to measure the impact of a parenting intervention on the developmental trajectory of HIV-infected children in Uganda. Following baseline assessment, the Mediational Intervention for Sensitizing Caregivers (MISC) biweekly intervention was conducted with 60 of 120 children and their caregivers, while the remaining 60 remained in a treatment as usual (TAU) group. By the 12-month follow-up, children in the MISC group showed greater developmental growth on the Mullen composite reflecting global cognitive functioning, mostly due to improvement on the Visual Reception scale. While available data are limited for this study to date, the Mullen may prove to be an adaptable measure of multiple domains of functioning and has the advantage of a wider age range than the Bayley and less intense administration training requirements.

2.5 Guidelines for Adapting Existing Measures

Adaptations that follow a rigorous process are likely to result in better quality assessment tools. Standards have been developed to guide appropriate adaptation of measures for use in developing countries (Hambleton and Kanjee 1995; Hambleton and Patsula 1999; Hambleton 2005). Ideally, a local psychologist should be involved in the adaptation process, and local informants from different disciplines involved in assessment should participate in the process. While it is helpful to have professionals who understand development such as pediatricians and developmental psychologists, the addition of local parents and people working with young children such as nurses or teachers adds important perspective and some assurance gained through consensus. Language translations should be reviewed by a similar multidisciplinary group to insure that the intent of each task or item is correct. All items should be piloted and modified as needed. Video recording of periodic test administrations is often helpful toward monitoring problems in the way test tasks are understood and managed by children. Initial studies of adapted measures are needed to evaluate properties of reliability, including internal consistency and temporal stability. Multiple lines of evidence for validity should be completed based on internal structure (e.g., factor analysis), construct validity (e.g., convergence with measures of the same construct and divergence with measures of unrelated constructs), and ability to detect the presence of problems (e.g., concurrently diagnosed conditions) or development of problems (e.g., predict future conditions). Measures also should ideally be adequately standardized with a local cohort.

2.6 Types of Instrument Adaptations

There are many aspects of an instrument that may require adaptation. Malda and colleagues (2008) describe five different types of adaptations that can each have relevance depending on the nature or desired outcome of the proposed assessment: construct-driven, language-driven, culture-driven, theory-driven, and familiarity/recognizability-driven. Considering each of these adaptation types can systematize choices made during the adaptation process leading to more accurate measurement. Construct-driven adaptation requires considering how the intended constructs, such as “intelligence,” are defined. Although the aim of assessment in Africa is often to measure “intelligence,” the construct may not be defined in the same manner as in the Western context, where most tests have historically been developed. The Western concept of intelligence focuses on level of skill, knowledge, and reasoning development, while, in many parts of Africa, intelligence is defined in terms of social contributions or helping others. The concept of intelligence can also differ according to expectations for each gender. Serpell and Jere-Folotiya (2008) found that even “ecoculturally” grounded early childhood tests in their study differed in their ability to predict later outcomes such as school success and better predicted success for boys than for girls. These construct measurement differences are not limited to intellectual function. For example, simple motor speed is often considered a robust measure of neurological integrity, but some cultures emphasize accuracy as more important than speed (Hedden et al. 2002; Verney et al. 2005).

Language-driven adaptations are required when simple translation is inadequate to adapt a task. Language-driven adaptations necessitate an understanding of the construction of language and the use of words within the language. In the Western assessment context with very young children, the age at which certain vocabulary items or linguistic constructions emerge is commonly used as an index of “language” development and as an early predictor of later cognitive development. Yet, the timing with which words emerge is culturally dependent. For example, in Setswana, the native language of Botswana, color words develop much later than Western test norms suggest, as colors are not emphasized as a primary attribute with most young children (Kammerer 2010).

Theory-driven adaptations include changes in test materials or processes because the theory behind the original items would not apply in a different culture. Malda et al. (2008) have noted that digit repetition will be altered if the translation of the digit names involves a different number of syllables. In Setswana, the possessive form is more complex than the simple English addition of “s” or “’s,” so items related to possessives would not be comparable (Kammerer 2010).

Finally, adaptations for familiarity/recognizability are often required for young children who may not have been exposed to the materials used in Western early developmental assessment. Lack of familiarity with test materials could change a child’s comfort, and therefore, the amount of time spent with the materials, creativity in use of them, or persistence in tasks, all of which can be part of “success” at items used with very young children. In adaptations, pictures of animals and fruit

not seen in the child's environment are typically changed to those found locally. Piloting these adapted materials can be particularly important as it is difficult to choose intuitively what items will be difficult or unfamiliar for a child in a non-Western culture. For example, children in one part of Kenya would not touch certain foam materials on a measure, yet the same material was accepted by children in other parts of Kenya (Holding et al. 2004).

2.7 Considerations in Adaptation of Measures

There are particular areas that should be carefully considered in adapting measures normed outside of a country or culture including language, cultural norms for development, appropriate materials, and demonstrating validity of the adapted measure.

Language: One of the first steps in adapting a measure for use in a different country or culture is translation of instructions and items. The most common method is to translate the test into the native language of the participants then complete a "back-translation" to the original language of the test to evaluate whether meaning has been altered in translation. Translations must reflect the participants' style of language. For example, academic translations of Western words for tests may not be as comprehensible for participants who use a less formal language register. Translations may also need to vary between regions within a country or cultural groups. Particularly in developmental testing, translated items may not reflect the comprehension level of the child given cultural variations in language development, and detailed linguistic ethnographies are required to translate language tasks appropriately. For these reasons, although language is a critical marker of development, comprehensive language measures are not always included in measures either created within or adapted for a new participant group to avoid bias in results. Abubakar et al. (2008b) notes that studies of the impact of HIV on the neurodevelopmental functioning of children with HIV have often cited motor development as being a primary risk, but this finding must be viewed with caution as language development is typically not fully assessed.

Developmental levels: In assessing the suitability of items in tests, researchers and clinicians have typically piloted the tasks for acceptability by the children. Rarely, however, have the resulting adaptations been re-normed. Caution must therefore be used as the tasks may well be attained at a different developmental level when used in a new country. Even items which seem less culture-bound, such as attainment of motor milestones, have been found to differ significantly across countries (WHO 2006).

Materials: In adapting tests, most researchers try to find materials that are culturally appropriate for the children to be evaluated, as Western measures may use materials that are not part of the lives of young children in Africa. Puzzles, for example, a common task in measures designed for young children, are not a typical toy in Africa. Materials are best when familiar and recognizable. Child *comfort* in playing with materials is highly relevant to their ability to demonstrate skills with a material,

even if they have typically not used a material before. For example, a child may not have used blocks, but if the blocks feel comfortable to touch and play with, the child may then try to stack them as requested by an examiner. But child reactions to materials go beyond familiar and often relate to cultural or personal associations to the object. For example, Gladstone et al. (2008) noted that the pink doll on the Denver Developmental Screening Test frightened many children in Malawi. Additionally, a plastic doll on the BSID III was well accepted by the children in Botswana, but a purple teddy bear was seen as a “monster” and was viewed as scary by many of the children (Kammerer 2010).

Validity: Adapting instruments for use with other cultural or linguistic groups typically involves changing tasks or instructions to make them more accessible and appropriate for the particular group. These adaptations typically are designed to maintain face validity of the measure or so that the adapted materials appear on the surface to be measuring the intended skill or construct. Other properties of the adapted instrument, however, may be altered by these adaptations, including reliability and validity. Further, it cannot be assumed that an instrument designed to measure a cognitive construct such as “intelligence” or “memory” in one culture will accurately measure the same construct in a different culture even if face validity appears appropriate. Children in different countries or cultures may employ different neurocognitive processes in completing a task, whether or not the task has been adapted (Sternberg 2004). The goal of adaptation should be to provide a comparable measure of the cognitive construct that is the focus of the assessment. Holding (Holding, P.A., 2013, written communication) noted that measures adapted for use in Kenya have shown that correctly managed adaptation can actually move test demands closer to the construct of the original test. This “better fit,” however, requires examining the basic psychometric properties of the “new” test including reliability, some measures of validity, and often new standardization or normative studies.

2.8 Practical Constraints in Instrument Selection

Apart from the multiple theoretical and cultural issues that need to be addressed in assessing young children’s development in Africa, there are also an important series of practical constraints that also require attention in choosing an assessment instrument. The World Bank toolkit (Fernald et al. 2009) notes the following issues, to which we have added considerations particularly related to assessment of very young children in Africa.

Budget: Western-based tests are often costly, both in initial purchase as well as in purchasing protocols or forms per administration. Assessment instruments vary considerably in cost, however, and some options may be less expensive or, in some cases, free. In addition, the amount of time to adapt the instruments, to train testers, and to administer each test adds to the expense of a using a particular instrument.

Copyright: Using formal published instruments requires attention to copyright issues, as these tests are licensed and have rules for use, for modifications, and often for training of the examiners. Most test publishers deal with requests to adapt measures routinely and should be contacted early in the study planning phase.

Time: The time required for administration of instruments is a particularly critical factor with young children. Young children tire easily, may not perform when tired or hungry, and often do not tolerate lengthy or demanding assessments. Many assessments in Africa have been focused on determining the impact of diseases such as HIV or malaria, which can also mean that the children to be evaluated may be sick and even more vulnerable to fatigue. Parent report measures bypass the issue of sickness or fatigue in the child, but the parent in a clinic or test setting often needs to attend to the child or other children or return to work and cannot spend long periods with lengthy questionnaires or interviews. Allowances for food, naps, child care, and/or multiple appointments should be considered.

Training: Personnel doing the assessments will most often not be trained psychologists with experience in research methods and assessment techniques. Tests vary considerably in the amount of training and testing expertise required to administer the test adequately. Some tests have been specifically developed to be able to be used with personnel such as teachers, nurses, or health care workers (e.g., KDI, MDAT), while other tests were specifically developed to be used by trained psychologists (e.g., BSID) and therefore require particularly careful monitoring to assure that the instrument is administered following the test standards. Videotaping of periodic sessions, double scoring, and use of one monitoring assessor can increase reliability of assessments. With very young children, evaluators must have the ability to relate to this age group and to make caregivers feel at ease, given much of child comfort is associated with the comfort of the caregiver at this stage.

Test setting: Choosing assessment instruments may be driven in part by the type of test setting that is available, though typically some appropriate setting can be found or created in practice. Young children can be easily disrupted by noise, extra people observing, or rooms that are associated with medical procedures. Settings that are unfamiliar to young children may be so disruptive that the assessment would not be accurate, and therefore home assessments may be advisable; at the same time, noise, seating, or other distractions at home may bias test performance (Fernald et al. 2009). Test rooms that are comfortable for young children, allow room to move and/or sit on a caregiver's lap, and are decorated in a familiar fashion are likely to be more conducive to eliciting a child's best performance. Since assessments of young children in Africa may be for health-related issues such as HIV, the rooms for testing may be connected with medical appointments but should not be in the area where uncomfortable or aversive procedures like blood draws occur.

Capacity of the respondent or rater: Respondent interviews or questionnaires may need to be chosen, or adapted, to fit the skills of the respondent. For example, in some

areas, literacy may be an issue and responding to written questionnaires would not facilitate accurate assessment. Similarly, observational measures by a person unfamiliar with the culture may result in inaccurate behavior ratings.

Language and cultural differences: Adapting tests to the language and culture of the children to be assessed is a mandatory part of appropriate testing. Some Western-based tests will require such extensive adaptations that the essence of what items measure can no longer be clear. Extensive adaptations also require lengthy work before the testing begins, which may not be possible, particularly for time-sensitive research or interventions. In these cases, tests created within a country or culture, or tests more easily adapted, should be chosen.

2.9 Additional Assessment Considerations

Aside from the test-focused considerations, evaluators must also consider some fundamental prerequisites that may be overlooked even in Western settings. Few studies note whether vision or hearing is screened as part of the developmental assessment. Countries in Africa differ in the amount of screening available as part of child care (McPherson and Brouillette 2008), but normal vision and hearing should not be assumed. Even if screening of any kind has occurred, good assessment practice includes brief vision (Morgan 2011) and hearing screening at the time of testing to insure that the child has adequate sensory skills to participate in the assessment. Young children in many parts of Africa are at risk for impairment in vision or hearing (Kammerer et al. 2010) due to the frequency of problems known to cause these issues. Children with HIV are at risk for prematurity, persistent ear infections, or infections such as CMV, each of which are associated with hearing loss. Although hearing was not officially screened in a study of CM in Malawi (Boivin et al. 2011a), the authors were well aware of the issue and note this factor, as hearing loss is also associated with malaria (Idro et al. 2007) and caregivers reported that some children had hearing loss. For very young children, screening is particularly important given that hearing loss or visual impairment may not yet have been discovered by caregivers.

Finally, for research and clinical assessments in any setting, participants who are found to have medical, psychological, or cognitive/developmental issues should be referred for follow-up care. This follow-up care is not possible in many parts of Africa when the appropriate services are not available. There are obviously ethical dilemmas for researchers and clinicians when faced with these situations. An important consideration in formulating an assessment project is being able to inform participants in advance as to what care will be available if problems are found. Supporting parents or caregivers in accessing local resources is essential for developmental concerns. Developing a plan for management is essential for studies when other areas are screened, such as depression, when a participant's responses may require immediate access to local resources.

2.10 Types of Assessment Approaches

Assessment may take many forms. Direct assessment with performance measures (i.e., tests) that require the child to respond to demands offers the advantage of quantifying actual skill development. At the same time, direct assessment can be time consuming in terms of administration and can be complex in African settings given the many requirements for adaptation and the lack of familiarity of “testing” for many African children.

Indirect assessment methods, such as structured observations, interviews, and rating scales completed by caregivers, offer advantages of efficiency, convenience, and lower cost, as well as relying on the observers’ or raters’ cultural knowledge and expectations.

Caregiver questionnaires: Assessment of very young children can be accomplished through questions asked of the caregiver about a child’s typical behavior in the home setting. This method is particularly useful since very young children are less reliably cooperative or awake, and performance in an unfamiliar test setting may not be maximal. Interviewing or asking caregivers to complete rating scales in Africa is not without challenges, however, as caregivers may find the setting and demands uncomfortable, and sharing problems with children may be culturally unfamiliar. In Botswana, when caregivers were directly asked if their child had more difficulty with specific developmental tasks than other children they knew, many respondents reported no problems, even when a problem was evident (Kammerer 2009). Using the “conversational” format of the DMC produced more accurate responses.

Observational data: Structured observations of a child’s behavior may provide accurate data, as the child typically would be in a familiar setting doing familiar activities. Behaviors that can be assessed in this manner are limited, however, and similar caveats apply when assessing validity and reliability of measures adapted for African setting. Structured observation methods are useful in assessing the home environment in HIV-affected children in order to better understand the impact of the disease on maternal–child interaction and the influence of the stimulation in the home setting on developmental outcomes, information critical to deciphering the role of HIV disease in neurocognitive outcomes. The Home Observation for Measurement of the Environment (HOME; Caldwell and Bradley 1984) is the most commonly used observation method for this purpose.

In addition to direct versus indirect assessment methods, it is helpful to appreciate the varied goals of available measures, such as whether an instrument seeks to measure comprehensive or global development, serves as a general screen for developmental problems, or focuses on a specific cognitive, behavioral, or social–emotional domain. Direct comprehensive measures such as the BSID and GMDS have been the primary staples in studies of HIV-affected children in Africa, as they seek to measure global development. Direct domain-specific or single-focus measures of language, executive function, or other domains have been only recently employed in Africa though this trend may increase as more measures are successfully adapted.

Screening instruments are most often indirect assessments and are frequently used with very young children given their inherent advantages of reduced time and cost and simplicity of administration. They are useful for large-scale epidemiological studies to provide a quick index of the proportion of children in a given population who have a deficit or to screen a population of children to identify those potentially in need of intervention. The most commonly used screening tool used internationally has been the Denver Developmental Screening Test and its revision, the Denver II (Frankenburg et al. 1992), which taps fine motor-adaptive, gross motor, personal-social, and language development. In HIV-infected and HIV-exposed children in the DRC, the Denver II was sensitive to global cognitive delays (Boivin et al. 1995).

Caregiver rating scales are often used to evaluate children's behavioral and social-emotional development. Social, emotional, and behavioral development is important to measure not only to assess critical aspects of child well-being but also as a reflection of physiological adaptation to disease or environmental influences on brain development. The impact of neurological insult can be reflected in emotional regulation. Perhaps the most frequently used instrument adapted for assessment of social, emotional, and behavioral development in children affected by HIV infection in Africa is the Achenbach Child Behavior Checklist (CBCL; Achenbach and Rescorla 2000), a caregiver rating scale that covers a broad range of problem behaviors. The validity of the measure in Uganda has recently been studied (Bangirana et al. 2009). Holding and colleagues (2013) developed a caregiver interview measure, the Profile of Social and Emotional Development (PSED), to assess problem behaviors in infants and toddlers in Africa based on a similar measure for school-aged children (Holding et al. 2004). The PSED has proven to be a measure that is both reliable and valid for identifying children at risk of social, emotional, and behavioral problems.

Recently, attempts to measure self-regulation, or executive function, have been incorporated in studies of children at risk in Africa. While few direct measures of executive function are available for very young children even in Western nations, there are some initial adaptations for use in African countries of the preschool version of the Behavior Rating Inventory of Executive Functions, a caregiver rating scale of young children's everyday emotional and cognitive regulation (Gioia et al. 2011).

The comprehensiveness and validity of assessment as a whole can be enhanced by using carefully selected combinations of direct and indirect approaches. Given the cautions related to each approach, using a combination of measurement types may provide a more accurate overall picture of the child's functioning. For example, the benefits and caveats of a direct comprehensive measure such as the Mullen may be balanced and extended by accompanying it with indirect structured observations such as the HOME, a developmental screener such as the Denver II, and caregiver ratings such as the CBCL. In a study of effects of antiretroviral therapy for HIV-exposed children in Botswana, an adapted BSID was chosen to allow comparison with US studies of HIV-exposed children. To add information as well as to gauge validity, a parent rating developmental scale (DMC) and social-emotional interview assessment (PSED) developed in Kenya were added (Kammerer 2010). This method

demonstrated convergent validity via strong positive correlations between similar skills assessed through different measures (language with language, motor with motor) and the strong correlation of the tests with maternal factors typically predictive of developmental outcome. The complexities inherent in cross-cultural assessment of very young children often require a multi-trait/multi-method approach to develop a more comprehensive understanding of brain–behavior relationships in children at risk.

2.11 Conclusion

There have been huge strides in HIV prevention and treatment in Africa. For the millions of children who remain infected or affected by HIV, accurate neurodevelopmental assessment is critical to better understand and manage the disease and related problems. Appropriate assessment is equally required for other children in Africa impacted by disease, environmental stressors, and effects of poverty in order to develop and monitor essential interventions and avoid further loss of developmental potential (Engle et al. 2007; Grantham-McGregor et al. 2007; Walker et al. 2007). These assessments must address as well important corrective resiliencies in African cultures that may modify or ameliorate developmental problems.

There are many challenges to accurate and efficient measurement approaches for research and clinical applications in African cultures. This is perhaps more dramatic for assessment in young children, as there are many fewer well-developed measures than for school-aged children even in Western countries where the majority of assessment instruments are published. Thus, the first question is whether to develop a new instrument that is culturally specific to the target population or to adapt an existing measure to be more culturally consonant. While the former option has advantages, the later is more time and cost efficient and allows for comparison with data from studies with other cultures and diseases. Follow-up questions include whether to rely on direct or indirect assessment methods, comprehensive measures, screeners, or domain-specific measures. These may be guided by the purpose, resources, and scope of the research or clinical program. More recent studies rely on a combination of assessment approaches, including both direct and indirect methods covering overlapping domains for convergent validity while also covering unique domains for comprehensiveness.

Standards or common practices are being developed for assessment in the international context to facilitate comparison of findings across cultures, environments, and disease processes. These include a common or shared set of tools, an approach that requires multiple methods and measures and more advanced adaptation practices, expectations for demonstrating evidence of reliability and validity, as well as standardizing measures on the target population or using appropriate controls for comparison and measurement of not only neurocognitive domains of function but also environmental factors. Importantly, enabling comparisons across studies facilitates a co-constructive approach toward understanding the “brain–behavior

omnibus” (Boivin and Giordani 2009) or understanding the complex relationships between genetically determined neural substrate and environmental influences across the lifespan.

Acknowledgments The work and examples in this chapter were supported in part by grant number RO1MH087344 from NIMH.

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Neuropsychology of Children in Africa

Perspectives on Risk and Resilience

Boivin, M.J.; Giordani, B. (Eds.)

2013, XX, 347 p., Hardcover

ISBN: 978-1-4614-6833-2