

Neurological & Functional Outcomes in Paediatric HIV Infection: A multidisciplinary approach for monitoring progress

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Summary

The following has been developed from published evidence on neurological and functional outcomes from paediatric HIV populations together with clinical reports from UK centres.

Multidisciplinary approaches to care and assessment of need are proposed in the Acute Hospital Standards of Children's National Service Frameworks (DOH, 2003) and this initiative also emphasizes the importance of attending to children's emotional, social and developmental needs in physical health care pathways.

The shared care networks within paediatric HIV also provide a framework for collaborative working at both service provision and individual case levels.

Ethos of developmental care

In order to enhance well being and quality of life for children with HIV infection, attention needs to be given to monitoring all aspects of developmental progress (physical, cognitive, behavioural, social and emotional). This needs to include addressing the changing demands of daily life e.g. self-care, independence, growth and appearance, family routines and relationships and school achievements etc, as the child moves through childhood and adolescence.

Background

HIV affects all organs and systems of the body including the central nervous system.

The prevalence of children with their HIV infection who have central nervous system involvement has been recorded as those with 'HIV encephalopathy' and sometimes a distinction has been made between those with progressive and static difficulties. As better care and treatments have evolved outcomes have improved and what constitutes encephalopathy has become less easy to define. Also distinctions between static and progressive presentations are now less relevant

Earlier US studies indicated rates of 15-25% of encephalopathy or central nervous system impairments in paediatric HIV populations (Browers et al 1995). European cohorts have generally reported lower rates of progressive encephalopathy, possibly due differing factors in the populations. For example many US populations have a higher incidence of maternal IV drug use in pregnancy and early exposure to such drugs has itself been found to affect development (European Collaborative Study, 1994,). More recent studies have reported fewer HIV infected children with progressive neurological problems and severe functional problems and suggest a wide spectrum in the severity of impairments exacerbated by the relationship between disease progression, and other factors (Mitchell 2001, Wachslar-Felder and Golden

2002, Koekkoek et al 2008). At particular risk for ongoing neurological and developmental problems are those children with severe clinical symptoms of HIV infection (CDC classification: Category C) occurring in the first months or years of life (Foster et al 2006).

Developmental and functional weaknesses, particularly in the absence of neurological signs, are usually multifaceted in cause and cannot be attributed solely to central nervous system damage or physical health changes. Other factors such as temperament, experiences and opportunities as well as illness episodes, nutritional status, and treatments affect developmental progression and functions (Mellins et al 2003, Grant 2008, Battles & Weiner 2002, Melvin et al 2007). However the consistencies in the kinds of developmental weaknesses reported across different populations of perinatally infected children suggest that there are some organic factors at play which increase developmental vulnerability. Also studies have found that groups of children with vertically acquired HIV consistently score less well on later neuro-cognitive tasks than uninfected controls from similar backgrounds or compared to children who acquire HIV later through behavioural means such as contaminated blood products (Willen 2006). This suggests that the presence of HIV when the brain and CNS is still developing is a contributing factor to this vulnerability.

UK population: Neurological signs

There is little reporting of numbers of children with neurological signs in the UK paediatric HIV populations. An ongoing case note review at the St Mary's Family clinic identified abnormal neurological signs in approximately 10 - 15 % of the population, with those children having severe complications of HIV early in life being at greatest risk (Foster et al 2006). Hyper-reflexia of limbs with increased muscle tone, particularly in the lower limbs, is the most frequent presentation (Biggs & Melvin 2007).

There is a broad spectrum in the severity of functional motor impairments arising from this neurological involvement. This ranges from wheelchair users, children ambulant with assistive walking devices, to children with abnormal gait but able to manage daily functional mobility. Whilst there may be functional gains from effective anti-retroviral therapy, neurological signs persist throughout and beyond childhood. These children usually require referral to local child development services for intervention.

Sensory Impairments: Vision and hearing may be affected by illness and opportunistic infections as well as by underlying CNS involvement. Any impairment may persist and influence developmental abilities at all stages.

UK population: Developmental Presentations

It is not possible to provide accurate levels of incidence of difficulties in the UK cohort and there is a great deal of variation in severity of any problems.

However there is a common profile in the kinds of developmental weaknesses being noted:

- Younger children: Slowness in acquiring early developmental milestones especially expressive language skills and sometimes gross motor skills. Concerns about appetite and eating behaviours are also frequent.
- School Age children: Poor attention and concentration frequently reported and observed. Subtle motor difficulties e.g. poor motor planning, coordination and balance. Learning achievements and ability to apply and sustain skills can be poor compared to national standards but also when compared to underlying cognitive potential (if available).
- Adolescents: Increase in reports of poor memory and in learning and application skills and difficulties associated with weaknesses in 'executive functions'. Coping and adjustment difficulties more common than psychiatric disturbance but increase in mental health concerns

generally. Some distortions in growth, puberty and sexual development.

Of note in the most recent case review at St Marys Hospital (Biggs & Melvin 2007) nearly 50% of the school age cohort were receiving some extra learning support in primary school.

Practice Issues

Aims of Developmental Monitoring

The primary aim is early detection of developmental weaknesses in order to facilitate intervention to prevent and/or reduce the impact of severe problems.

Further aims:

- To provide ongoing data about specific population needs (audit); both to try to meet those needs and for service development.
- To help in understanding effects of treatments (particular ART combinations, length of treatments, timing of starting etc).
- To promote a greater understanding of the chronic influence of HIV infection on developmental processes and identify possible risk and resilience factors.

Guidelines for Developmental Monitoring

Not all centres involved in the care of HIV infected children will have access to a specific multi-disciplinary developmental team. However, all those involved in delivering care to these children need to be alert to the findings that these children are vulnerable to neuro-developmental and functional difficulties, and by identifying weaknesses early enable access to appropriate assessment and intervention when needed. As shared care networks further develop, there could be access to a specialist multi centre developmental assessment service, although interventions will still need local involvement.

Reports from parents or carers or weaknesses noted at clinic or home visits by a range of professionals should lead to further developmental screening or referral for more in depth assessment or intervention. For older children, discussion about nursery or school progress can also serve to identify when further assessment may be necessary.

Screening assessments

Where resources are limited, the use of developmental screening tools or a developmental checklist within clinic may be appropriate in order to identify those children for whom a more detailed assessment is required. Different centres will have access to different resources and tools so the following suggests which functions. With parental permission access to the annual school record can provide a useful indicator of educational progress.

The table below suggests the focus of developmental screening at different key stages. It is suggested that an annual review could be arranged during one of the clinic outpatient appointments to complete this screening.

Examples of possible interventions are given where weaknesses are identified.

Key Stage	Functions to be screened	Examples of Interventions
Infancy (Less than 3 years)	Neurological Signs Sensory Functions Milestones – Motor & speech Growth & feeding	Referral to local services:- Health Visitor Child Development Services SALT, Physio Home learning e.g. Portage Dietician
Pre-school (Early Years)	Neurological & Sensory Mobility Language & communication Behaviour: Activity & attention Self care & routines	Referral to local services (as above) Opportunity playgroup Nursery placement Speech and Language Therapy
Primary School age	Behaviour checklist Concentration School Report/ SATS results e.g. reading	Referral for detailed assessment SENCO Educational Psychologist Child Development Services
Adolescent	Self report scales: quality of life, coping, School Report – learning & behaviour Exam results Growth & Puberty Independence & self management	Detailed Neuropsychology assessment Peer group opportunities Access to CAMHS or Adolescent counselling services Connexions

Helpful hints when screening or assessing developmental progress:

- Care needs to be taken in the selection of tests used given the wide ethnic mix of the population e.g. assessing speech and language. would need to take account of the language(s) spoken in the home
- Annual reviews of progress are helpful and should include checks of vision and hearing.
- Throughout school age performance or progress at school can be a useful guide to knowing how a child is managing general demands of life and learning.
- Knowledge of developmental stage can help with conversations aimed at understanding health, diagnosis and treatments (see 'Talking with Children Protocols CHIVA 2009).
- Factors influencing adjustment need to be taken into account in the timing of any assessment and review.

In general assessments will be less reliable if carried out during or immediately following:

- Periods of ill health or hospital admission.
- Times of excessive change or loss including first months of child's arrival into UK).
- In the immediate time after the start or change of combination therapy.

Service Issues

Reporting Outcomes

A useful way of reporting information on longer term developmental outcomes is to distinguish between **neurological** consequences, often resulting from early or acute illness events, and weaknesses in **functions and neurocognitive processes** resulting from the chronic effects of HIV and its treatment interacting with physical and psychosocial influences.

The following general categories are suggested:

- 'Evidence of neurological damage. Indicated by the presence of abnormal neurological signs (reflexes, abnormal muscle tone, microcephaly, sensory impairment.)
- Significant functional impairment: A demonstrable discrepancy or delay significantly interfering with ability to manage age appropriate activities. Where assessment is available this would result in scores greater than 2 standard deviations below the population mean on cognition, learning or motor tasks.
- Reduced performance in one or more specific areas of functioning compared to general abilities of child e.g. poor expressive skills, attention or concentration difficulties.

Systematic reporting of core measures of developmental outcome

In order to identify levels of need in this population which help to plan for service provision at both a specialist and local level, there is a need for basic reporting of indices of developmental difficulties across HIV centres and services. The following are suggested as core measures to be reported from all clinics seeing children with HIV infection irrespective of access to wider resources for assessment.

- Number with neurological signs.
- Significant motor or cognitive impairment (identified by assessment on standardised test and/or noted in more than one setting as severely impairing child's ability to access age appropriate activities).
- Significant sensory impairment (hearing & vision).
- Number referred to local developmental services e.g. physiotherapy, SALT, CDC and for what reason.
- Number attending special schools or units.
- Number on the Code of Practice with Special Educational Needs requiring assistance in schools e.g. school action, action plus, full statement of educational need.
- Number referred to CAMHS services.

Summary

- A proactive approach to developmental monitoring and interventions using multidisciplinary approaches is most effective in achieving this aim.
- Parents generally welcome an holistic and multifaceted approach to assessing and supporting their child's changing developmental needs.
- A regular screening (annual?) programme for all children attending the service helps integrate the process into the general care being provided. This screening can range from a carer questionnaire to more indepth assessments.
- The child and parents or carers need to take an active part in the assessment process and should have an understanding of the reasons for assessment.
- Developmental monitoring should provide a review of abilities and give a picture of the child's strengths as well as weaknesses.
- Assessments and interventions need to be appropriate to age and take account of ethnic and cultural as well as illness factors.

- Early detection of any weaknesses or difficulties and can help identify available resources both within family and locally to help address these difficulties.
- Monitoring helps establish families' confidence in accessing local services if difficulties are identified (although difficulties sometimes remain in accessing resources either because of the over stretched local services or because of concerns around disclosing the HIV diagnosis.
- Disclosure of the diagnosis to local services needs to be handled sensitively and with full knowledge and agreement of parents or carers. Conversations about if and why services may 'need to know' the diagnosis and the benefit for the child's care is important. A discussion about confidentiality and who will be informed can help reduce parental concerns.
- Local services have generally welcomed access to more detailed knowledge about the child's health or HIV needs where there has been sharing of the diagnosis, and collaborative working has often been possible to negotiate.

References

- Biggs & Melvin 2007 Audit of Neuro-developmental outcomes in children from a specialist paediatric HIV London Clinic CHIVA conference London
- Brouwers P, DeCarli C, Civitello L, Moss H, Wolters P, Pizzo P. **Correlation between computed tomographic brain scan abnormalities and neuropsychological function in children with symptomatic human immunodeficiency virus disease.** *Archives of Neurology* 1995,52:39-44.
- NSF: Acute Hospital Standards of children's care: National Service frameworks . Dept of Health 2003
- Foster CJ, Biggs RL, Melvin D, Walters MD, Tudor-Williams G, Lyall EG. **Neurodevelopmental outcomes in children with HIV infection under 3 years of age.** *Developmental Medicine and Child Neurology* 2006,48:677-682.
- Grant I. **Neurocognitive disturbances in HIV.** *International Review of Psychiatry* 2008,20:33-47.
- Koekkoek S, de Sonnevile LM, Wolfs TF, Licht R, Geelen SP. **Neurocognitive function profile in HIV-infected school-age children.** *European Journal of Paediatric Neurology* 2008,12:290-297.
- Mellins CA, Smith R, O'Driscoll P, Magder LS, Brouwers P, Chase C, Blasini I, Hittleman J, Llorente A, Matzen E. **High rates of behavioral problems in perinatally HIV-infected children are not linked to HIV disease.** *Pediatrics* 2003,111:384-393.
- Melvin D, Krechevsky D, Divac A, Tacconelli E, Miah J, Waugh S, Hekster B, Byard K, Giannakopoulou **Parental reports of emotional and behavioural difficulties on the SDQ for school-age children with vertically acquired HIV infection living in London.** *Psychology, Health and Medicine* 2007,12:40-47.
- Mitchell W. **Neurological and developmental effects of HIV and AIDS in children and adolescents.** *Mental Retardation and Developmental Disabilities Research Reviews* 2001,7:211-216.
- Wachsler-Felder JL, Golden CJ. **Neuropsychological consequences of HIV in children: a review of current literature.** *Clinical Psychology Review* 2002,22:443-464.
- Willen EJ. **Neurocognitive outcomes in pediatric HIV.** *Mental Retardation and Developmental Disabilities Research Reviews* 2006,12:223-228.