Current thinking in the health care management of children with cerebral palsy

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Cerebral palsy is a movement disorder that encompasses a wide range of non-progressive neurological disabilities;[1] it is the most common cause of physical disability in childhood.[2] At present, cerebral palsy affects about 2.1 per 1000 live births in Australia,[3] a rate similar to other developed nations.[4] A recent article has suggested that the incidence and severity of cerebral palsy in Australia is decreasing, with the authors postulating that improved neuroprotective strategies may account for some of this change.[5] These strategies include the use of maternal magnesium sulphate during labour,[6] the use of maternal antenatal steroids,[5] and better ventilation protocols in pre-term neonates.[7]

The causal pathways to cerebral palsy are multifactorial and are incompletely understood. Events that result in cerebral palsy can occur prenatally, perinatally or postnatally[1,4] — about 70–80% of all cases originate prenatally.[4] A meta-analysis of the use of antenatal magnesium sulfate significantly reduced the risk of cerebral palsy.[6] A recent systematic review found that, since the short term benefit on lung function does not sufficiently outweigh the long term risk of neurodevelopmental impairment, the use of postnatal steroids for ventilation weaning should be abandoned.[7] Less than 10% of all cases are now believed to occur due to acute intrapartum hypoxia-ischaemia.[8] A recent Cochrane review found that brain cooling for term infants with hypoxic ischaemic injury improves outcomes by reducing the level of ongoing neuronal loss after the initial insult.[9] While prematurity remains a common risk factor, about 60% of children with cerebral palsy are born at term.[10] Common risk factors (Box 1)[1,4] are potential targets for prevention of cerebral palsy.

It is increasingly recognised that genetic and epigenetic factors may contribute to cerebral palsy.[11] Mutations in single genes have been found to be associated with ataxic (eg, *KCNC3*, *ITPR1*, *SPTBN2*) and spastic (eg, *KANK1*, *ADD3*, *AP4M1*) forms of cerebral palsy, and genomic copy number variants were found in 20% of cases in a recent study.[12] Gene products that are involved in thrombosis and in the response to cell injury may also be implicated in cerebral palsy causal pathways. Knowledge in this area is likely to expand rapidly over the next decade, providing an increased understanding of causal pathways and offering potential avenues for prevention and/or treatment.

This review provides current thinking in cerebral palsy and summarises common challenges associated with managing the condition. Recently published guidelines have been highlighted to help guide evidence-based practice. We searched Medline and EMBASE using the search terms "cerebral palsy" and "treatment" in order to identify Australian and landmark reviews and studies over the past 20 years, as well as articles that emphasise emerging treatment for cerebral palsy.

Summary

- Cerebral palsy is a developmental disorder of movement and posture which is often associated with comorbidities.
- While there is currently a limited range of evidence-based treatments that change the underlying pathology of cerebral palsy, there are many areas in which health care professionals can change the natural history of cerebral palsy and improve participation and quality of life for children with this condition.
- Early identification has become of paramount importance in the management of cerebral palsy, and it is hoped that it will allow earlier access to cerebral palsy interventions that may improve the natural history of the condition.
- Common challenges in the management of cerebral palsy include spasticity and dystonia, management of pain, hip surveillance, sleep and feeding, swallowing and nutrition.
- The six Fs framework (function, family, fitness, fun, friends and future) provides a guide to developing shared goals with families in the management of cerebral palsy.

Early identification and diagnosis

Early identification has become a key theme in the management of cerebral palsy around the world. Cerebral palsy is often diagnosed between 12 and 24 months of age, but it is hoped that earlier identification will allow earlier access to cerebral palsy interventions that may improve the natural history of the condition.[13]

Clinical assessment remains the main diagnostic tool in establishing whether a child has cerebral palsy or is at high risk of developing cerebral palsy.[13] Delayed motor milestones, asymmetry of movement or abnormal muscle tone are all indicators of possible cerebral palsy diagnosis, but historically identifying children through these methods alone can be slow.

A number of tools have been validated for the early identification of cerebral palsy in high risk populations. The General Movements Assessment has a high sensitivity and specificity in the prediction of cerebral palsy and can be used in children from birth to 20 weeks of age (corrected for prematurity).[14] The best age to perform the assessment is 12–14 weeks after the baby's due date, and is therefore best suited to high risk neonatal follow-up. The assessment is made from a 3–5-minute video of the child's movements taken in a standardised method. Baby Moves is a current trial in Victoria using a phone-based app to record movements as part of screening for extremely pre-term babies.[15] If this study finds a high predictive ability for the app, it could improve access to early identification assessments, as they will not be limited to patients in metropolitan areas with specialist trained therapeutic and medical staff.

The Hammersmith Infant Neurological Examination is not a new tool nor is it specific for cerebral palsy, but it has recently been promoted for use in high risk infant follow-up programs.[16] It can be performed from age 2 months to 2 years and is fast to perform and score, but some training in its use is recommended. Using this standardised neurological assessment provides a framework for monitoring and allows early identification of deviation from normal development, facilitating faster referral for diagnostic assessment and treatment.[16] It has been shown to have

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1 Risk factors for cerebral palsy

	Common risk factors
Prenatal risk factors	• Maternal factors: TORCH infection (toxoplasmosis, other [syphilis, varicella-zoster, parvovirus B19], rubella, cytomegalovirus, herpes simplex virus), maternal hypothyroidism, iodine deficiency, thrombotic disorders (including factor V Leiden), chorioamnionitis • Fetal factors: teratogen exposure, genetic and metabolic disorders, multiple births, prematurity • Social factors: low socio-economic status
Perinatal risk factors	• Birth asphyxia and trauma, non-vertex presentation, placental abruption, rupture of the uterus, prolonged or obstructed labour, post-maturity
Postnatal risk factors	• Hyperbilirubinaemia, neonatal sepsis, respiratory distress, early onset meningitis, intraventricular haemorrhage, head injuries before 2 years

high sensitivity and specificity for predicting cerebral palsy, with defined cut-off scores corresponding to severity of potential cerebral palsy. This assessment helps identify children at risk of cerebral palsy who do not have immediate infant risk factors.

Magnetic resonance imaging (MRI), in conjunction with clinical assessment, has high predictive value in identifying cerebral palsy,[17] and many international guidelines recommend that suspected cases of cerebral palsy should be investigated with neuroimaging.[18] However, there are some international variations, such as the recent National Institute for Health and Care Excellence (NICE) guideline, in the United Kingdom, on the assessment and management of cerebral palsy in patients aged under 25 years, suggesting only offering an MRI scan to assess the cause of cerebral palsy when it is not clear from clinical history, developmental progress, clinical findings or the result of cranial ultrasound.[19] About 10% of children with cerebral palsy have normal neuroimaging, but this may change with higher resolution scanning and newer imaging techniques such as tractography[20] (Box 2).

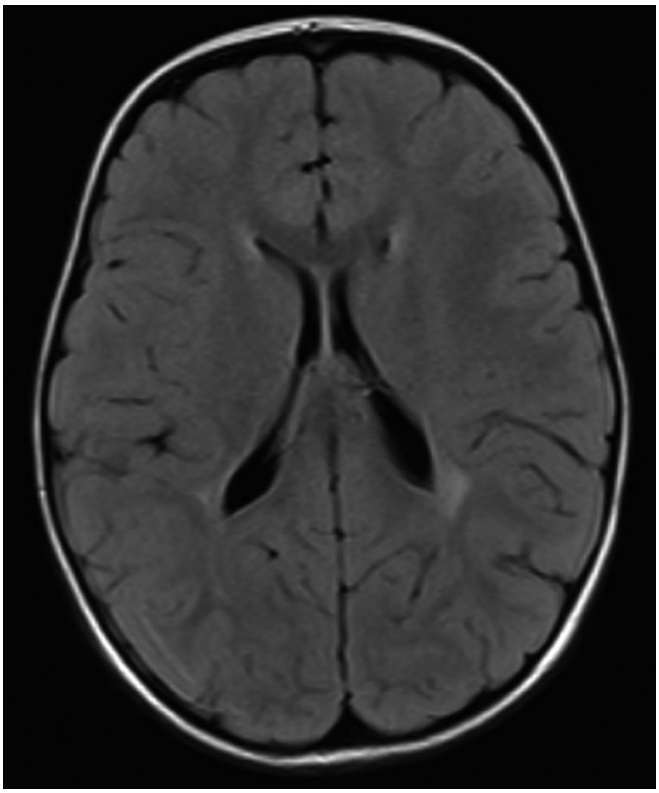
Early intervention in cerebral palsy

Historically, there has been a lack of evidence for early intervention in cerebral palsy compared with intervention in older children with cerebral palsy. A recently published systematic review of early intervention to improve motor outcome in cerebral palsy showed weak but promising early results, and identified a lack of high quality trials.[17] There is evidence that therapy is most beneficial when goal-directed and intensive; further studies are now underway to evaluate the timing and types of therapies that are most beneficial.[21]

In Australia, there are currently two multicentre national trials that are evaluating the effect of early intervention in infants identified to be at high risk of developing cerebral palsy:

- GAME (goals, activity, motor enrichment) is a goal-oriented, activity-based, environmental enrichment therapy program that is designed for children under 6 months of age who are at high risk of developing cerebral palsy;[22] and
- REACH (Rehabilitation Early for Congenital Hemiplegia) is a trial for children aged between 3 and 9 months who have been identified as having congenital hemiplegia; the study is designed to compare the efficacy of modified constraint-induced movement therapy with infant bimanual therapy.[23]

2 T1-weighted magnetic resonance imaging brain scan showing periventricular leukomalacia



3 Describing spasticity and dystonia[27]

	Definition
Spasticity	Hypertonia with "clasp-knife" rigidity that is velocity-dependent resistance to passive movement
Dystonia	Involuntary sustained or intermittent muscle contractions that cause twisting, abnormal postures or both

The aim of these trials is to establish an evidence base for early intervention; children at high risk or children with an early diagnosis of cerebral palsy can then be streamlined into evidence-based interventions.

Describing and classifying cerebral palsy

Cerebral palsy is primarily described by topography (parts of the body affected) and predominant movement disorder. Motor involvement in cerebral palsy may include predominantly the lower limbs (diplegia), the arm and leg on one side (hemiplegia) or all of the body (quadriplegia). Cerebral palsy can also be referred to as unilateral or bilateral to simplify description.[24] There are various classification systems for the movement disorders seen in childhood cerebral palsy.[25–27] Movement disorders commonly involve either differences in neurological tone (hypertonia or hypotonia) and/or abnormalities of movement (dyskinesia).

The most common movement disorders seen in cerebral palsy are spasticity and dystonia (Box 3). However, it is increasingly clear that spasticity and dystonia alone do not adequately describe either the complexity of the movement problems that

children with cerebral palsy have or the functional impact of these problems. Children with cerebral palsy often have difficulties with coordination, strength, selective motor control and sensation (including vision) and have often not had the same opportunities to develop motor patterns as typically developing children. Moreover, spasticity and dystonia often coexist, so it is arguable that classifying cerebral palsy either as spastic or as dystonic may not be useful.[28]

A number of functional classification systems have been developed in order to aid in the assessment of prognosis, communication with parents and other clinicians, and enable objective comparison for research. Common classification systems include the Gross Motor Function Classification System (GMFCS), the Manual Ability Classification System, the Communication Function Classification System and the Eating and Drinking Abilities Classification System. Descriptions for each of these classification systems are shown in the online Supporting Information, table 1, and the GMFCS descriptors are shown in Box 4.[29]

Management of cerebral palsy

Cerebral palsy is best managed in multidisciplinary settings. As disease-modifying treatment options are limited, treatment should be focused on treating disability and managing associated comorbidities. The model provided by the International Classification of Functioning, Disability and Health (ICF) offers a framework to treat disability by focusing on interventions that improve a child's activities and participation[30] (online Supporting Information, figure 1).

Rosenbaum and Gorter[31] have proposed a novel framework to help clinicians and families work jointly towards participation goals, the six Fs framework:

- **Function:** how a child performs an activity is not important, the goal is to allow them to try.
- **Family:** the family is the essential environment of the child and they know the child best; supports and resources for the whole family are vital to the child's health.
- **Fitness:** all children need to be physically active, regardless of the disability status; health promotion is more than a focus on remediating disability.
- **Fun:** childhood is about fun, and it is incumbent upon caregivers to find out what the child wants to do.
- **Friends:** social development is an important aspect of child development, regardless of ability; it is the quality of relationships that matters.
- **Future:** child development is all about becoming, and this encompasses the other five Fs; the goals and expectations need to be considered in light of the present realities.

Current treatment often includes a combination of physical and pharmacological therapies as well as surgical interventions. A 2013 landmark systematic review of interventions for cerebral palsy assessed 64 distinct interventions.[32] The review graded interventions using a traffic light system against the quality of evidence and the ability of the intervention to deliver the ICF outcomes that they were designed to achieve. A total of 15 interventions were assessed as effective, and they collectively target the ICF domains of "body structures and function" and "activities" (online Supporting Information, table 2). These interventions represent the current "standard of care" for children with cerebral palsy.[32] This study highlights that many accepted interventions in cerebral palsy management still require a stronger evidence base to support their use, especially long term outcome data.[32]

Spasticity and dystonia

Treatment of spasticity and dystonia should be guided by the child's functional level and with consideration of other factors that influence the child's abilities. In ambulant children (GMFCS levels I–III), treatment goals are often centred around improving mobility. In non-ambulant children (GMFCS levels IV and V), treatment goals may be more directed around managing posture in relation to comfortable seating, dressing, bathing and pain management.

First-line treatment for spasticity and dystonia should include non-pharmacological interventions, such as physiotherapy and occupational therapy and the use of splints and orthotics. Botulinum toxin A injections can be useful for the treatment of spasticity and dystonia, particularly when these are focal (limited to individual muscles or groups of muscles) and affecting a child's function or comfort.[32]

Medications such as baclofen and diazepam are used commonly in the management of spasticity and dystonia. In the past few years, there has been emerging evidence for the use of other medications, such as gabapentin and clonidine, in the management of dystonia[33,34] (Box 5). Gabapentin has relatively few side effects and can be effective not only for managing dystonic hypertonia but also for treating neurogenic pain. In addition, it appears to have an anxiolytic effect, which can be very useful as dystonia is often exacerbated by psychological stress. Clonidine is also safe but can have the side effect of hypotension; thus, dose adjustments need to be monitored carefully. Furthermore, clonidine has a sedative effect at higher doses and can therefore be very helpful for sleep management. These medications are usually started in the specialist setting and, with adequate monitoring, their prescription can be safely continued in primary care.[34]

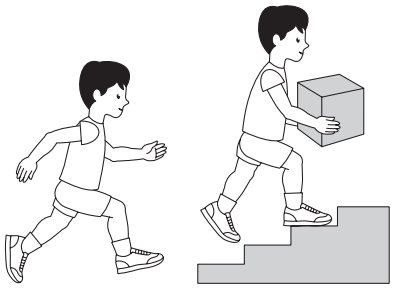
Neurosurgical interventions for hypertonia management in children have become more readily available throughout Australia. Children are usually assessed within complex movement disorder services as part of neurology or rehabilitation services. Deep brain stimulation of the globus pallidus internus has emerged as an effective therapy for dystonic and dyskinetic movement disorders in some children with cerebral palsy.[35] A study has indicated that early treatment with deep brain stimulation results in better outcomes, and the authors suggest this might be due in part to an increased ability for this treatment to influence neuronal plasticity earlier in development.[36]

Selective dorsal rhizotomy is a neurosurgical procedure that reduces sensory input in the lumbar and sacral nerve roots, resulting in significant and permanent reduction in spasticity in the legs. It is an effective intervention in specific cohorts of children with cerebral palsy in relation to improving spasticity and mobility.[37] Patients must be assessed by a specialist interdisciplinary team before considering selective dorsal rhizotomy and have access to comprehensive orthopaedic and rehabilitation long term follow-up.

Intrathecal baclofen allows the delivery of high concentrations of baclofen directly into the cerebrospinal fluid, avoiding many of the side effects of high dose oral baclofen.[38] In Australia, it is commonly used in more severe types of cerebral palsy (GMFCS levels IV and V) and has the benefit of working for both spasticity and dystonia. The goals of treatment are usually around

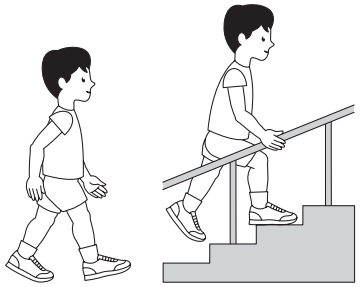
4 Gross Motor Function Classification System (GMFCS) descriptors[29]

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations



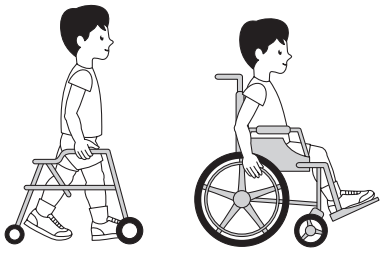
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



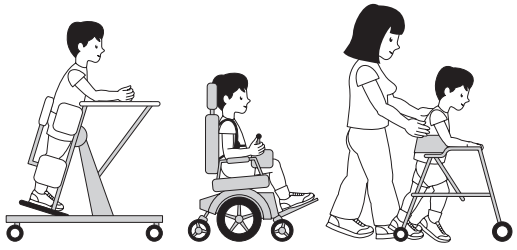
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



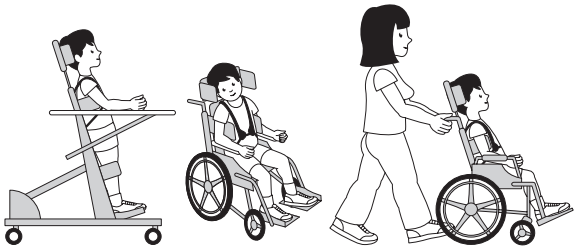
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

E & R = expanded and revised. Source: CanChild (www.canchild.ca). Illustrations copyright: Kerr Graham, Bill Reid and Adrienne Harvey, Royal Children's Hospital, Melbourne, VIC. Published with permission.

5 Hypertonia management in childhood

Treatment	Comments	Spasticity	Dystonia
Oral medication			
Baclofen		Yes	Yes
Diazepam		Yes	Yes
Tizanidine		Yes	No
Dantrolene	Rarely used in paediatrics due to liver toxicity	Yes	No
Levodopa	Limited effectiveness in paediatric secondary dystonias	No	Yes
Trihexyphenidyl	Often first line in treating secondary dystonias	No	Yes
Gabapentin	Increasing utility in difficult to control dystonias	No	Yes
Tetrabenezine	Rarely used in paediatrics due to effect on mood	No	Yes
Clonidine	Sedative and hypotensive side effects	Yes	Yes
Injectables			
Botulinum toxin A	Intramuscular in all muscle groups	Yes	Yes
Ethanol	Intramuscular in larger muscle groups	Yes	Yes
Phenol	Nerve block in larger muscle groups	Yes	Yes
Surgical procedures			
Orthopaedic	Muscle and tendon lengthening, transfers, disconnection	Yes	Yes
Intrathecal baclofen	Higher doses needed for dystonia	Yes	Yes
Selective dorsal rhizotomy	Lower limb spasticity	Yes	No
Deep brain stimulation	Useful for primary dystonia, limited effectiveness for secondary dystonia	No	Yes

comfort and care. A recent Cochrane review highlighted the limited evidence available to support the use of intrathecal baclofen and, despite potential side effects, care giver satisfaction has been reported to be high.[38]

Hip displacement

Children with cerebral palsy are at increased risk of hip displacement, which if not recognised can result in hip dislocation. The risk of femoral head migration is related to the severity of motor disability rather than the type of cerebral palsy.[39] The Australian hip surveillance guidelines have been developed to support hip surveillance for children with cerebral palsy.[40] Assessment involves clinical and radiographic assessment based on a child's GMFCS level. The pelvic x-ray is taken in a standardised supine position and is usually repeated between 6 and 12 months, depending on the severity of cerebral palsy and the rate of progression of migration of the femoral head out of the acetabulum (Reimers migration percentage). Once migration approaches 30%, referral for orthopaedic assessment is recommended (online Supporting Information, figure 2)

Pain

It has been increasingly recognised that many children with cerebral palsy regularly experience pain, with studies suggesting that the proportion may be as high as 75%.[41] Contributors to pain are multifactorial and include hip subluxation, muscle spasms, dystonia and constipation.[42] Pain has been shown to be a key barrier to participation in community life, school and recreation for children with cerebral palsy, and it can also affect sleep, having an impact on the whole family's quality of life.[43] Assessment of pain in children with cerebral palsy can be complex, particularly in those with intellectual disability and/or communication impairments. Validated measures exist to assist clinicians in the assessment of such children; a chronic pain toolkit has been published recently to provide guidance in this area[44] (www.hollandbloorview.ca/toolbox). It is important to actively ask about pain; a detailed history is often sufficient to help identify and treat the primary cause. Simple analgesia, such as paracetamol and non-steroidal anti-inflammatory drugs, is often helpful for the treatment of pain; botulinum toxin A injections[45] and intrathecal baclofen[46] may have a secondary effect in reducing pain in patients with spasticity, and gabapentin[33] may be helpful in reducing pain in patients with dystonia.

Feeding, swallowing and nutrition

Difficulties with feeding may be the first presentation of cerebral palsy. Feeding may present as overt swallowing difficulty, nutritional inadequacy or as a consequence of aspiration, such as chest infections. Adequacy, safety and enjoyment of the eating and drinking process are key features of the feeding history. Feeding concerns should prompt referral to a dysphagia-trained speech pathologist or to a specialist feeding service. Numerous factors affect a child's ability to eat and drink, including food and fluid texture, utensils, general posture, sensory difficulties, the environment, and the person feeding the child. Decisions around tube feeding need to be made in collaboration with the family, as this can be a very emotive subject.[47]

Excessive drooling may be a presentation of swallowing difficulty and can have a significant effect on feeding, care and self-esteem for a person with cerebral palsy. Tools such as the Drooling Impact Scale can be used to assess severity of drooling and can measure change after the intervention.[48] Multidisciplinary team assessment is recommended to advise on interventions, including oromotor techniques (sensory awareness training to limit anterior drooling, strengthening exercises to improve head position and mouth closure); general postural management; medications such as glycopyrronium bromide, hyoscine patches and salivary gland botulinum toxin; and surgical interventions such as duct transposition and duct ligation. Results from a recent UK trial showed glycopyrronium to be as effective as hyoscine patches but better tolerated due to fewer anticholinergic side effects.[49]

Children with cerebral palsy are well known to have a different body composition; therefore, assessment of nutritional status on

weight alone can be difficult. Bone health is an area of special nutritional interest, particularly in more severely affected children. Low bone density can lead to an increased risk of fracture, especially low impact fractures that may occur on normal handling of a child.[50] Optimising vitamin D and calcium levels is paramount. There is a role for bisphosphonates to improve bone density in patients who have sustained fractures as a result of low bone density.[50]

Conclusion

The incidence of cerebral palsy is decreasing and early identification is not only important for families but may help to target treatment. Early interventions with targeted therapies are showing promising results in altering the natural history of cerebral palsy as well as enhancing patient activities. There remain many challenges in the management of a child with cerebral palsy, but there exist a number of interventions with a good evidence base. A child's ability should be viewed in context of their development and current evidence used to guide treatment with what is important for the child and their family. The six Fs framework provides a guide to developing shared goals with families.

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Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.