Early identification of infants at risk of cerebral palsy: developing the use of general movement assessment in routine clinical practice in a tertiary neonatal unit in New Zealand

Meghan Sandle, Alison Sheppard, Angelica Allermo Fletcher, Max Berry, Nathalie DeVries

ABSTRACT

BACKGROUND: Preterm infants have a high risk of neurodevelopmental disability, including cerebral palsy (CP). Often, CP is not diagnosed until after 12 months, leading to delay in targeted interventions. The General Movements assessment (GM) evaluates the spontaneous movements of high-risk infants from birth to 20 weeks corrected postnatal age (CPA), and accurately predicts the risk of CP. This allows for earlier diagnosis and intervention, potentially changing the trajectory of disability, yet routine use of GM is not well established in New Zealand.

AIM: To describe the process of setting up GM in a tertiary neonatal unit.

METHODS: We reviewed the process and progress made to date setting up GM in our service.

RESULTS: Challenges and potential solutions for the implementation of GM were identified. Key areas of development included staff training and support, IT services, resources, medical documentation, interdisciplinary communication and establishing clinical pathways.

CONCLUSION: GM has become successfully integrated into the assessment of high-risk infants in our neonatal unit, with the aim to provide valuable information to health professionals and families to optimise intervention and improve outcomes. Efforts will continue to ensure there is robust and sustainable system for using GM in our service.

Infants born preterm (<37/40 gestation) have an increased risk of a range of neurodevelopmental disorders including learning difficulties, language and motor impairments, and social and emotional problems. Advances in medical care have led to improved survival of preterm infants, especially around the cusp of viability, yet this group continues to face a significant burden of long-term disability.

In 2017, 7.5% of babies born in New Zealand were preterm. Developmental surveillance of at-risk infants is recommended to identify challenges and provide early targeted support. Recognising emerging disability is vital as to allow early intervention during the window of brain plasticity in infancy with the aim to improve outcomes. However, many developmental screening tools commonly used in
this population identify difficulties outside this critical window of plasticity.

Prematurity is a significant risk factor for cerebral palsy (CP). CP is often diagnosed after the age of 12 months, however there is good evidence that it can be identified at an earlier age. The use of Prechtl’s Qualitative Assessment of General Movements (GM) is highly sensitive for identifying infants at risk of CP under five months corrected age.

GM assess the spontaneous movement patterns of infants that can be observed from birth until up to 20 weeks corrected postnatal age (CPA). The GM is achieved by taking a video of the infant, which is scored by a qualified practitioner. By recognising absent or abnormal general movements, the risk of CP can be determined in a time-sensitive manner during early infancy.

GM can be assessed at pre-term, term and post-term ages up to 20 weeks CPA. Ideally several assessments should be done within this time. The fidgety period occurs between 9 and 20 weeks CPA and is characterised by the presence of small amplitude, moderate speed rotational movements. The absence of these fidgety movements is strongly associated with an increased risk of CP; assessment at this age has 97% sensitivity and 87% specificity.

There is also evidence that GM are associated with cognitive outcome, with studies showing association between persistently abnormal general movements in infants born preterm and lower IQ at school age. Standard developmental surveillance include preterm (<30 weeks gestation), low birth weight (LBW <1,200 grams) moderate-severe hypoxic ischaemic encephalopathy, central nervous system infection or other conditions associated with risk of developmental issues. Specialised neurodevelopmental therapists provide developmental input and assessment until at least two years CPA.

A local review of follow up and outcomes for extreme preterm and LBW infants in our region showed that 75% of infants do not have significant neurodevelopmental disability after two years of follow up (Unpublished data: Sandle M, 2018). Given the resource intense nature of longitudinal developmental care, it is hoped that using abnormal general movements as an early marker for disability will help our service target resources to those most at risk as well as providing the opportunity to intervene early to make a positive difference to the outcomes for preterm infants in our community.

Methodology

This section describes the methods used to set up a clinical pathway to use GM as part of our routine practice.

Staff training

To start using GM, staff attended basic training courses to develop skills in interpretation of general movement patterns. This
training is provided by licensed instructors from the general movements trust, and training courses are regularly held around the world, including Australasia. A neurodevelopmental physiotherapist working in the neonatal unit was the first staff member to be trained, followed by community paediatric advanced trainee/researcher and a neonatologist with a special interest in infant development. Three neurodevelopmental therapists are also enrolled for upcoming basic training. This will create a multi-disciplinary core group of trained assessors and provide an opportunity for partnership between neonatal and child development services.

Although awareness of GM and how they are used in clinical practice is important for all staff working in this area, we feel having a smaller group of health professionals with range of expertise trained to interpret assessments is a good use of resources.

Scoring GM is based on the gestalt perception of the assessor and it is vital that scorers maintain this by regularly seeing and scoring videos and re-calibrating with “gold standard” videos of normal general movement patterns. Our group meets regularly, at least fortnightly to score videos together, discuss any difficulties with scoring and re-calibrating as needed.

Support and networking

Intra- and inter-observable reliability of GM is very good, however assessment relies on individual interpretation and it is vital to ensure there is standardisation of scoring and quality assurance. Support from experienced assessors has provided this and helped to develop our learning, especially in more difficult cases. Given the nature of video-recorded assessments, we have been able to gain remote advice from an experienced GM assessor and trainer from a different hospital.

We have found this collaborative approach essential for both building competency in assessment and developing clinical pathways. A useful platform for information sharing is via the general movement special interest group which has been set up to connect professionals working with GM from all around New Zealand. We have also used the opportunity to link in with a trained assessor from a neighbouring DHB to support our development using this tool.

Identifying infants for GM

Although GM are highly predictive of cerebral palsy in preterm and moderately to severely asphyxiated infants, its sensitivity in the general population of term infants has been shown to be lower. It is therefore important to use this assessment in a carefully selected group for whom GM will have the most clinical utility to use time and resources effectively.

To identify which infants admitted to NICU should have GM, we established a set of criteria (Figure 1). This was based on infants that would be at increased risk of adverse neurodevelopmental outcome and eligible for follow-up from child development services. The general movement special interest group was also utilised to share information about criteria that was being used at different hospitals.

Figure 1: Criteria for GM in Wellington neonatal unit.

- Prematurity (<30/40)
- Low birth weight (<1100 grams)
- Hypoxic-ischaemic encephalopathy grade 2-3 or received 72 hours therapeutic hypothermia
- Central nervous system infection in neonatal period
- Major surgical intervention in neonatal period
- Abnormal neurological examination
- Other high risk of neurodevelopmental disability
Serial GM are more valuable than one-off assessments. The developmental trajectory of an infant's general movements is important and the quality of an infant's movements can change over time. One type of abnormal general movement, poor repertoire, is common in preterm infants before term CPA, and in isolation is not predictive of later motor function. On the other hand, infants with consistently abnormal GMs are more likely to have adverse neurodevelopmental outcomes and lack of normalisation of movements by four-month CPA is associated with lower IQ at school age.

In our pathway, infants will have assessments at 35 weeks, term and 12–14 weeks CPA as a minimum.

IT infrastructure
The availability of secure IT systems to transfer and store video files is an integral part of developing the clinical use of GM. In our service, videos are recorded by parents or staff using smart phones. Files need to be transferred in a user friendly and safe way. Video files are generally too large to be sent as email attachments so we used Dropbox to share files. Dropbox is a file hosting service that allows sharing of files and cloud storage. Parents or health professionals upload videos to Dropbox and invite the staff to view them. Videos are then transferred to a folder on the hospital system which is only accessible by the GM assessors.

To access Dropbox on our DHB system, special permission from the hospital IT service was required.

There are however some limitations of this method. Parents are required to have Dropbox account and be able to use this system, and there have been some recent concerns about data ownership with cloud storage. In Victoria, Australia, a mobile phone application (Baby Moves) has been developed for parents to record videos of their infant's movements at home; this was used successfully for GM assessment and found to be user friendly for most parents. There would be scope to develop a similar mobile phone app in New Zealand.

For services using GM, early involvement of hospital IT teams with clear communication about what is required is a key component for the successful use of this tool.

Resources
We have developed several resources including a GM information leaflet for parents and standardised instructions for taking videos. In conjunction with the hospital privacy officer, we designed a written consent form that can be given to parents prior to taking videos and stored within the infants notes.

Interface between services
It is essential for all team members involved in the care of high-risk infants to understand the role of GM in order to use this tool effectively. We have organised teaching sessions about the use of GM for neonatal nurses, paediatricians and developmental therapists. Identifying and involving stakeholders is key to the successful implantation of a service and consultation with staff in both neonatal and community setting has been part of our process since the early stages. Input from families is important; informal feedback has been positive and formal audit will be undertaken once the use of GM is well established in our service.

To document results, we created an electronic medical template with the standardised descriptions of GM as per Prechtl methodology and free space for notes for further interpretation and recommendations as needed. The documents can be edited and new assessments added at different time points so the trajectory of GM can be recorded and visualised. The electronic template is available on the infant's electronic medical record so is accessible by DHB staff both in hospital and community setting to allow easy and efficient communication.

Clinical pathway: Summary
The clinical pathway we have developed is shown below (Figure 2).

This begins with identifying eligible infants, giving information to parents,
including written handouts and obtaining written consent for videos. Videos are taken at around 35–37 weeks and 40 weeks CPA by therapists or doctors in the neonatal unit and uploaded to the secure restricted access folder. They are assessed by at least two trained assessors, with additional support from experts as required.

Videos at 12–15 weeks CPA are taken in the community either by parents who have been given written instructions on how to take and upload videos, or by neonatologists or community therapists who are following up the infant. Files are transferred via Dropbox and reviewed in the same way as the earlier assessments. Information is recorded as a trajectory for individuals which is saved as part of the infant’s electronic record. Results are also verbally discussed with professionals coordinating the infant’s ongoing follow up and communicated to parents.

**Discussion**

GM form an important part of assessment process for high-risk infants and are now routinely used in Wellington neonatal unit. There has been significant progress made in the implementation of GM over the last 18 months, however there still remain potential challenges, and continued effort is required to ensure the sustainability of the ongoing use of this tool.

Competition for limited resources is a reality in a publicly funded health system. Training costs, staff time and IT systems require funding which may not always be available, however it is important to advocate for the use of tools that identify risk early as a cost effective strategy. In New Zealand, the neurodevelopmental follow-up of preterm infants is inconsistent between services and inadequately funded. Using GM in combination with other clinical assessments and investigations is a practical way to help utilise resources efficiently and there is good evidence for this approach in preterm infants.

Moving forward, we will continue to work alongside our IT providers to establish more robust ways to transfer and store videos with the aim to eventually have videos stored on the infant’s electronic record. Competency in assessing GM needs to be maintained with regular opportunities to review videos and we will continue to work together with our wider networks to support our professional development with this tool.

GM is a reliable, valid and easy to use tool with high clinical utility, however it is important to be aware of potential limitations. GM is not a screening tool for general use, nor a diagnostic test for CP. It is essential that we understand what high risk of CP means and communicate this
effectively to families, while understanding that this may create unnecessary anxiety.\(^{21}\) Although GM has high specificity, false positives can occur. Identifying infants as high risk of CP may be a negative experience for parents, and some of these infants will never go on to develop CP.

Using GM to identify infants at high risk of CP facilitates earlier diagnosis and intervention. Early referral for CP targeted intervention is considered best practice,\(^{22}\) however the long-term benefit of intervention in infants who develop CP is unclear.\(^{23}\)

A systematic review of early motor intervention in infants diagnosed with or at high risk of CP found a lack of high-quality evidence in this area, with much variation in both the intervention and standard care provided, difficulties in assessing whether infants had been diagnosed with CP correctly and a lack of reproducibility of interventions due to inadequate detail provided.\(^{24}\)

A Cochrane review of early intervention in infants born preterm also found variation in intervention programmes and included only 12 randomised control studies. Meta-analysis, however, did show a positive effect on cognitive outcome and a small effect on motor outcome in early childhood associated with early developmental intervention.\(^{25}\)

It is clear that further research with quality larger multi-centred studies using valid and well-designed intervention programmes and long-term outcome measures is required to help guide the effective use of early intervention in high-risk groups.

GM also has a role in identifying high-risk infants who could then enter studies of early interventions and changes in GM over time has been used as an outcome measure for early intervention programmes for preterm infants used in the neonatal unit.\(^{26}\)

Limited availability and resources is a potential barrier to the use of early intervention programmes, especially in smaller centres. A New Zealand guideline for early identification and specific targeted intervention for infants at high risk of neurodevelopmental disability is urgently needed to support the implementation of standardised, evidence based and adequately resourced programmes.

Using GM does not take away the need to further understand the mechanism of preterm-related brain injury to be able to develop strategies to prevent this and to minimise neurological dysfunction.

In conclusion, GM can be successfully used alongside existing tools to determine risk for developmental disability and optimise early monitoring and intervention. We have demonstrated that this tool can be implemented into routine clinical care and provided a framework for its use. Collaboration and communication between stakeholders has been essential in rolling out this assessment and for its use to be of value as a part of the holistic assessment of at-risk infants.
Competing interests:
Nil.

Author information:
Meghan Sandle, Paediatric Registrar, Capital and Coast DHB, Wellington; MSc student, Paediatrics and Child Health, University of Otago, Wellington; Alison Sheppard, Neurodevelopmental Physiotherapist, Capital and Coast DHB, Wellington; Angelica Allermo Fletcher, Consultant Neonatologist, Capital and Coast DHB; Max Berry, Consultant Neonatologist, Capital and Coast DHB, Senior Lecturer, Paediatrics and Child Health, University of Otago; Nathalie DeVries, Consultant Paediatrician. MidCentral District Health Board, Palmerston North.

Corresponding author:
Meghan Sandle, Paediatric Registrar, Capital and Coast District Health Board, 69 Riddiford Street, Wellington 6021. meghan.sandle@ccdhb.org.nz

URL:

REFERENCES:
1. Allotey J, Zamora J, Ceong-See F, et al. Cogni-
tive, motor, behavioural and academic perfor-
mances of children born preterm: A meta-analysis
and systematic review involving 64061 children.
BJOG. 2018; 125:15–25.
intervention in cerebral palsy. Advances in diagno-
5. Einspieler C, Marschik P, Bos A. Early markers for
cerebral palsy: insights from the assessment of
validity of spontaneous early infant movement
for later cerebral palsy: a systematic review.
Dev Med Child Neurol. 2018; 60:480–49.
general movement assessment helps us to identify
preterm infants as risk for cognitive dysfunction.
8. Spittle A. How do we use
the assessment of general
movements in clinical
practice? Dev Med Child
9. www.general-move-
m ents-trust.info
the qualitative assessment of
general movements in
preterm, term and
young infants. Early Hum
12. Olsen J, Allinson L, Leesa G, Doyle L. Preterm and
term-equivalent age
general movements and
1-year neurodevelopmental
outcomes for infants
born before 30 weeks’
gestation. Dev Med Child
Neurol. 2018; 60:47–53.
General movements in
full-term infants with
perinatal asphyxia are
related to basal ganglia
and thalamic lesions. J
ment quality in term
infants predict cerebral
palsy and other forms of
limited mobility at 6 years?
Dev Med Child Neurol.
2016; 58:1310–1316.


18. www.dropbox.com


