

NEW WRITING

Therapeutic positioning: Working in partnership towards tangible outcomes for children

Sarah Hill



Sarah Hill, BSc (Hons), PGCE: I graduated in 1997 with a 2:1 in Biology and then worked for a year on The Mansfield Project (see below). Following this I went to University of Birmingham to study for my Postgraduate Certificate in Education. I taught Science up to

GCSE, Biology A Level and sexual health at an inner city Birmingham school for five years. In 1994 I wrote the Postural Care Skills Programme in my spare time and the courses were accredited through the Open College Network West Midlands Region. Later that year I started PCSP (UK) Ltd, an independent training provider. Since that time we are very proud to have become a Community Interest Company, **Postural Care CIC**. I am currently working to deliver training both in the UK and overseas as well as being a wife and a mum to my three wonderful kids.

During 2007 and 2008 I did not work as my eldest daughter, Abi, was receiving treatment for a malignant brain tumour. This was obviously a very stressful time and we felt very isolated as a family. Following this experience a friend and I started a support group for parents whose children face a life-threatening or limiting

illness. In March 2009 I was very proud to be named Tesco's Positive Mum of the Year.

Summary

Protection of body shape is a fundamental need for any child with a movement problem. Body shape distortion can lead to a number of potentially life-threatening secondary complications. Therapeutic positioning, particularly at night, can be used to protect and restore body shape. The efficacy of this approach can be monitored using validated, non-invasive measurement of body symmetry. Parents need extensive support and training in order to implement therapeutic positioning at night. There are difficulties associated with funding for equipment and training for families. Measurement provides parents, children, commissioners of services and healthcare professionals with tangible outcomes for therapeutic intervention.

Introduction

We use measurement of body symmetry at the very beginning to give us a starting point, an idea of existing difficulties, and an indication of the bio-mechanical forces we will need to

apply to correct the problem. As time goes on measurement of body symmetry tells us whether we are getting it right, if we need to do more, and supports plans for future intervention.

My name is Sarah Hill. I manage a small not-for-profit training company called Postural Care CIC and work alongside my parents John and Liz Goldsmith. As a child I grew up in a rather unusual house with the main topic of conversation being measurement of body symmetry, protecting body shape, or design of therapeutic positioning equipment. We were often used as guinea pigs, as were many of our friends – adding considerably to my teenage angst. Having left university in 1997, I was privileged to work alongside 31 families in Mansfield who were trying to get to grips with the latest therapy – night-time positioning.

The idea was simple, support children to sleep in a comfortable, neutral position, rather than leaving them unsupported and unable to change their position without help. The results of that original work are widely used when considering the implications for families of this approach (Goldsmith, S. 2000). A fundamental principle of supporting families to protect body shape is partnership. All partnerships, be they businesses, marriages or friendships, require a number of factors for success – trust, mutual respect, a common goal, investment of time and resources, and good communication.

I would like to take this opportunity to discuss the outcome measures used in this field and to consider a possible future service direction. Families and professionals have worked in partnership in pursuit of therapeutic positioning for some time, and I think it is useful to revisit the idea of our common goal. Whenever I am lucky enough to work directly with families, we think through what it is that we all hope to achieve as we progress through the care pathway (Hill, S. and Goldsmith, L. 2008). Common goals may be to achieve a better quality of sleep or to make the child more comfortable. One of the key goals to acknowledge is the protection or restoration of a symmetrical body shape. To help parents understand this, we use measurement of body symmetry at the very beginning to give us a starting point, an idea of existing difficulties, and

an idea of the biomechanical forces we will need to apply to correct the problem.

I am sad to say that I now write both as someone with a keen interest in postural care and as a parent of a child with a life-threatening illness. During the past two years I have learned a great deal about what it feels like on the other side of the desk. I have experienced the great honour of meeting some of the most professional, dedicated and intelligent healthcare professionals working within the NHS, the exhaustion of attending countless appointments, and the fear of watching powerlessly as others attempt to save our daughter's life. For me the policy documents, white papers, initiatives and statistics now boil down to one family. I have learned a great deal and will continue to support families to challenge service provision in order to improve the life chances of their children.

Measurement of body symmetry

Back to the subject at hand – therapeutic positioning and tangible outcomes for children. Like many parents I have managed to compartmentalise the professionals in our life in relation to the perceived outcomes they may deliver for my child. The dietician and the NG feeds relate to her nutritional status and weight, the endocrinologist to her growth and so on. I am not alone in this – many of my friends will discuss at length the benefits they derive from the time they commit to particular professionals. Physical therapy services often use functional assessments in order to assess progress and this means that parents do too. Use of such functional assessments would appear completely justified when considering a child's functional abilities. But functional assessments cannot be used to measure physical characteristics – as practitioners attempt to do when they mistakenly use functional assessments in the field of therapeutic positioning and measurement of body shape. This is like trying to find out your weight with a ruler.

One of the key success criteria for the use of therapeutic positioning is the protection or restoration of a symmetrical body shape. Therefore, would you not think, one of the key outcome measures for providers of therapeutic positioning services would naturally be the measurement of body shape? Statistically valid

measures of body symmetry were first published in 1992 (Goldsmith, L. et al 1992) and are currently being used by some therapists in Australia, Canada and the UK in order to provide tangible outcomes for therapeutic positioning alongside functional measures, giving a complete picture of progress for both parent and child.



Measurement of body symmetry can begin early

For many parents their child's physiotherapist will be the main point of contact in relation to this aspect of care. The role of the physiotherapist for children with complex and continuing healthcare needs was recently summarised in *Physiotherapy Frontline*, the **Chartered Society of Physiotherapy** magazine in a piece entitled 'A Complex Scenario':

Physiotherapists provide equipment, devise new movement strategies and enable families and teachers to create a supportive environment. They work both to improve impairment and to prevent or limit secondary problems.

(Physiotherapy Frontline 2009)

We are able to think of therapeutic positioning as having a role to play in both the improvement of a child's functional ability and as a preventative measure. Accordingly, the child's physiotherapist is likely to spend a great deal of time and effort working with families to ensure a comprehensive 24-hour postural care programme.

The skeletal system has six functions but for the purposes of this article we will consider only

three – to support softer tissues, to allow movement and to protect delicate structures such as the lungs and brain. It is important that we safeguard the skeletal system in order that we might also protect the softer tissues and delicate organs that it in turn defends. In the past, the Gross Motor Function Classification System (GMFCS) (Palisano, R. et al 1997) has been used as a guide for the provision of night-time positioning equipment. It might be argued that a more appropriate system for identifying children at risk would be to measure their body shape and to consider the amount of time they spend in one position during the night. This method of assessment by professionals identifies those children who score well in terms of Gross Motor Function but who remain at risk of developing changes in body shape.

The National Context

A recent publication from the NHS Purchasing and Supply Agency's Centre for Evidence-Based Purchasing (NHS Buyers' Guide, 2009) groups the 'wider consequences' of a failure to protect body shape as follows:

- The musculoskeletal system (contractures, loss of joint integrity, e.g. hip dislocation, decreased bone density, reduced range of joint motion and deformity, e.g. spinal scoliosis)
- The neurological system (spasticity/muscle tone, primitive reflexes, altered sensation and joint position sense, pain, weakness)
- Respiratory function
- Digestion (including swallowing and choking, both of which are compromised by poor head and neck posture) and kidney/renal function
- Personal hygiene, ease of toileting and changing
- Functional ability
- Environment interaction (sensory perception, body aesthetics, learning, communication)
- Sleep pattern and irritability

Given this rather stark warning of the risks faced by children one could be forgiven for thinking that robust funding and awareness-raising initiatives would be underway across the UK to help parents avoid such long-term complications. The same report however goes

on to detail a worrying picture of the difficulties faced by parents and therapists alike when trying to implement this form of therapy.

The document clearly highlights the need for extensive training for parents and personal assistants, describing it as 'vital' – yet this training appears to be delegated to equipment manufacturers. I am sure that this causes as much concern to therapists as it does to parents. It is clear to me that the relationship needed for a mother to speak confidentially about personal aspects of her family life cannot be established in a one-off session with a company representative. The introduction of therapeutic positioning is complicated. Both social and medical considerations must be taken into account and the highly personal nature of the family home at night-time must be respected. The document highlights some of the safety concerns – including issues around thermoregulation – that must be taken into account, and this is most welcome. However, aspects of thermoregulation not covered include the interaction of anticholinergic drugs such as Hyosine which have been known to cause hyperthermia (Frampton, A. and Spinks, J. 2005) and the possibility of increased seizure activity associated with elevated temperature.

The *Buyers' Guide* highlights key findings of a national survey of prescribing issues for therapists when supporting children in need of therapeutic positioning. 55% of therapists stated, 'Parents/carers did not want the equipment' as a reason for a child not having access to a sleep system. 40% of these therapists said families found the equipment 'too difficult to use'. However, the document also cites Goldsmith (2000) that 'Adequate training was reported to influence the degree of compliance.' These *Buyers' Guide* figures would surely imply that there is a worrying lack of support and training currently being invested in families.

Therapists understand the levels of support and training needed to successfully introduce therapeutic positioning and are often unsupported by managers to do this. The delegation of responsibility for training to company representatives, who could quite conceivably have been selling double-glazing the week before, causes me much frustration and concern. Perhaps it is time for serious debate concerning the advantage of introducing such accreditation systems as

RESNA (Rehabilitation Engineering and Assistive Technology Society of North America: <http://www.resna.org/>) here in the UK. If we are to avoid the complications cited in the *Buyers' Guide*, managers and commissioners must assist therapists and other healthcare professionals to train and support families to use this form of therapy and recognise it as a valid part of their role.

Funding difficulties

Could measurement of body symmetry have a part to play in supporting therapists and families with funding difficulties? At present there is:

No consistency of funding provision for Night Time Positioning Equipment throughout the UK...the lack of robust clinical efficacy data can make the justification for funding problematic.

(NHS Buyers' Guide, 2009)

Funding of equipment is another major issue highlighted within the *Buyers' Guide*, which comes as no surprise following Newlife's *It's not too much to Ask* report (Newlife Foundation, 2007). In this, 59% of respondents to their survey of PCTs and Local Authorities claimed that there is no funding or budget for sleep systems or beds within their area. Of the therapists surveyed for the *Buyers' Guide*, 48% stated that they were unable to obtain funding for equipment despite identifying a clinical need for a particular child. That a clear need identified by a clinician is not met causes grave concerns in the light of the *Buyers' Guide* outline of the distressing secondary complications associated with failure to protect body shape. This situation exposes children to risks which could be guarded against (Bolitho vs City and Hackney H. A.).

Issues such as this can be raised with the National Patient Safety Agency who should be made aware of the risk we are exposing children to. Anyone can report a patient safety incident by visiting <http://www.npsa.nhs.uk/nrls/reporting/>

Measurement of body symmetry in support of future service development

Therapists could use statistically validated outcome measures, both to support families in their understanding of the long-term goals of therapeutic positioning and to demonstrate their clinical efficacy. In a world dominated by outcome-based investment in service provision surely this is a win-win situation? (See Dept. of Health, 2007) Measurement of body symmetry supports therapists in demonstrating what it is that they do. Many therapists that I know who work in the community are monitored by counting face-to-face or other contacts – and are increasingly frustrated with this situation. The assumption that there is a direct positive correlation between the number of contacts with a child and the outcome for that child seems naive. This monitoring system does not recognise the hard work and commitment required from those supporting families in their effort to introduce night-time positioning and does not provide the family with evidence of the outcome we are all looking for.

High quality preventative medicine, which I am advocating for here, is also a top priority in the light of Lord Darzi's review, *High Quality Care for All* (Dept. of Health, 2009). He states:

The economic challenge now facing the country makes this quest for quality an absolute necessity. High quality care is not an unaffordable luxury but the centrepiece of an efficient health service.

Without appropriate intervention, serious complications, leading in some cases to premature death, may occur. Following Mencap's report, *Death by Indifference* (Mencap, 2007), Sir Jonathan Michael's inquiry, *Healthcare for All* (Michael, J. 2008) noted that:

Families receive no support or advice about how to manage the sleeping position of their child and the Inquiry heard examples of cases where later wheelchair use and/or back surgery could have been avoided if effective early intervention had been provided.

(Inquiry report, **July 2008**)



Measurement of body symmetry is painless

Conclusion

Therapeutic positioning, evidenced by measurement of body symmetry, has the potential to provide cost savings in the medium to long-term, to prevent secondary complications for children, and to support partnership working between therapists and families. As larger numbers of parents become aware of the possibilities associated with protecting and restoring body shape, we must equip healthcare professionals with the means to demonstrate that they are addressing the issue. Measurement of body symmetry will enhance the accountability of professionals to the families they serve and improve access to appropriate funding for equipment. Exciting times!

(Thankyou to Simple Stuff Works www.simplestuffworks.co.uk for the use of the AMI pictures and to Ted, my youngest, for acting as our model.)

References

A Complex Scenario. (Anon) 6th May (2009) *Physiotherapy Frontline*. Vol 15, (8), p.16.

Bolitho vs City and Hackney Health Authority (1997). Available at: <http://tinyurl.com/mx9obf>

Buyers' Guide: Night Time Postural Management Equipment for Children. June 2009. NHS Purchasing and Supply Agency; Centre for Evidence-based Purchasing. Available at: http://www.google.co.uk/search?hl=en&q=night+time+positioning+buyers+guide&meta=&rlz=1W1ADBF_en-GB&aq=f&oq=

Death by Indifference. (2007) Mencap: <http://www.mencap.org.uk/document.asp?id=284>

Frampton, A. & Spinks, J. (2005). Hyperthermia Associated with Central Anticholinergic Syndrome caused by a Transdermal Hyoscine Patch in a Child with Cerebral Palsy. *Emergency Medicine Journal*, 22, pp.678-679. Abstract Available at: <http://emj.bmj.com/cgi/content/extract/22/9/678>

Goldsmith, L., Golding, R. M., Garstang, R. A. & Macrae, A. W. (1992). A technique to measure windswept deformity. *Physiotherapy*, 78, (4), pp.235-242

Goldsmith, S., (2000) The Mansfield Project: Postural Care at night within a community setting. *Physiotherapy*, 86, (10), pp.528 – 534

High Quality Care for All: NHS Next Stage Review Final Report, (2009). Available at: <http://tinyurl.com/4t6uf8>

Hill, S. & Goldsmith, L., (2008) Posture, Mobility and Comfort. In: Carnaby, S. & Pawlyn, J. (Eds) *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. Wiley Blackwell Publishing.

Michael, J. (2008) *Healthcare for All*. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Available at: <http://www.iahpld.org.uk/>

Newlife Foundation, 2007. *It's not too much to ask*. Available at: <http://tinyurl.com/nzyolq>

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E. & Galuppi, B. (1997) Gross Motor Function Classification System for Cerebral Palsy. *Developmental Medicine and Child Neurology*, 39, pp.214 – 223

Rehabilitation Engineering and Assistive Technology Society of North America. <http://www.resna.org/>

World class commissioning (2007) Department of Health. Available at: <http://tinyurl.com/28qnry>

Note: There was an article on postural care, *Postural Care Provision*, by Anna Goldsmith in IQJ issue No. 2 in July 2008.