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# Participatory Design in the Development of Therapy Intervention for Perinatal Stroke

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**Abstract**

Perinatal stroke is the leading cause of unilateral (hemiparetic) cerebral palsy, with life-long personal, social and financial consequences. Translational research findings indicate that early therapy intervention has the potential for significant improvements in long-term outcome in terms of motor function. By involving families and health professionals in the development and design stage, we aimed to produce a therapy intervention which they would engage with.

**Keywords:** Intervention development; Perinatal stroke; Early intervention; Therapy; Motor system; Normalisation process theory; Participatory design; Unilateral cerebral palsy; Hemiparesis; Infant

## Introduction

Promoting activity in the potentially affected limb improves outcome Animal studies indicate that the consequences of perinatal stroke can be mitigated by promoting activity of the potentially affected side. In a study undertaken in kittens, muscimol was used to silence the motor cortex unilaterally, leading to an abnormal pattern of corticospinal tract projections and adverse consequences for motor function. By using electrical stimulation of the inactivated corticospinal tract fibres, the normal pattern of corticospinal tract projection was partially restored and motor function also improved [1]. Subsequently it was shown that early therapy intervention (constraint plus training on a reaching task), rather than invasive electrical stimulation of the corticospinal tract, led to similar improvements in this animal model . However, constraint is problematic as an immediate intervention following neonatal stroke because of the potential for harm . Instead, early environmental manipulation to promote activity of the potentially affected side is proposed . Environmental manipulations can influence activity from an early age From birth, infants will demonstrate early "pre-reaching" movements preferentially with the arm nearest a toy presented to one side [2]. The play environment can be manipulated to encourage activity of the potentially affected side. This principle can be extended to a pervasive intervention affecting the carer-based , play-based and physical environment around the baby, delivered in the home with therapist support . The immaturity of the infant motor system at birth means that in the first months after unilateral perinatal.

## Methods

Rationale for initial content Based on the literature discussed above, we chose an approach suitable for infants with predominantly unilateral perinatal stroke including haemorrhagic parenchymal infarcts, aiming to promote activity of the potentially affected side of the body during a time period of active central nervous system plasticity and ongoing corticospinal tract wiring. We named the approach "Early Therapy in Perinatal Stroke", abbreviated to eTIPS. We chose an input in the first 6 months of life because this was identified as being the period during which the greatest changes in corticospinal tract wiring occurred postnatally , as well as a period during which there was no consensus regarding the approach to assessment and intervention [3]. In addition, infants in this age range are relatively immobile so lateralisation of the environment around the infant remains possible. The initial content of the therapy was based on identifying aspects of everyday life for the infant for which a lateralised approach could be provided – i.e., increasing sensory input and opportunities for movement of the potentially affected side of the body [4]. A parent-delivered therapy intervention seemed the most appropriate option because in the first months of life the infant is usually looked after by a small number of close family members. A therapy designed to utilise that input within the context of the carer/child relationship could be delivered in a far greater dose than that achievable through therapist input alone. We were mindful of the potential difficulty parents might have in being cast in the role of therapist, and aimed to make the approach and manual as accessible, pervasive and play-based as possible [5]. Of major importance was the issue of achieving pervasiveness of the approach so that the therapy dose would be high, whilst minimising the burden to parents. Pervasive but relatively minor changes to everyday activities were felt to be more deliverable than therapy blocks based on infant lifestyle and attention span considerations. In addition, a lateralised approach can be applied during many aspects of the infant's daily routines, potentially providing a large therapy dose through a bioecological approach.

## Discussion

This is to our knowledge the only early therapy intervention aimed at the first 6 months of life after perinatal stroke [6]. The rationale for this very early intervention in terms of a high level of central nervous system plasticity has been discussed above. Intervention in this time window brings particular challenges as discussed below, which make a participatory design approach and Normalization Process Theory framework particularly important in developing an intervention which will be understood and accepted by stakeholders. Behaviour change interventions are notoriously difficult to implement , even outside the context of sleep-deprived families coming to terms with the disruption of a new diagnosis in their infant child . Furthermore, following a diagnosis of perinatal stroke, families experience a range of emotions including feelings of guilt and self-blame. There is also uncertainty about the future in terms of the nature and severity of difficulties their child

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may face. Some parents express feelings of helplessness, wishing there is something they can do [7]. We were sensitive to the need to create materials and activities designed for parents in their capacity as parents during everyday interactions with their children, rather than requiring them to take on therapist roles during defined "therapy sessions". This pervasive approach has a high potential for interactional workability, embedding the therapy into everyday routines and thus normalising the method, as well as avoiding conflict between perceived roles as parent versus therapist. Supporting parents to deliver therapeutic input to their infants in this context can be seen as appropriate but challenging, and requires consideration for the welfare of both parties (Figure 1).

Furthermore, engagement of such young infants in activities is highly dependent on positive parent/infant interactions, with parents providing the physical, interactional and emotional setting in which the infant is motivated to initiate the required behaviours [8]. However, parents are in general highly motivated to improve outcomes for their infants, and our experience with the parent focus groups also revealed a wish to have been able to engage with a program like TIPS. We deliberately made our materials as visually appealing as possible and framed most of the activities within the context of everyday parenting and play, allowing some tailoring to the specific requirements of individual families. In our on going pilot feasibility study we formally monitor parental wellbeing and parenting sense of competence [9]. The evolution of motor difficulties following perinatal stroke adds a further layer of complexity in explaining an early intervention approach to parents and indeed to healthcare professionals. Whilst early definitive neuroimaging is highly predictive of motor outcome after perinatal stroke, it is difficult for parents and therapists to understand why doctors may be worried about the future development of hemiparesis in an infant who may initially have no lateralised motor signs [10]. This requires careful explanation and support. A major strength of the eTIPS approach is the use of participatory design processes during intervention development, involving parents and healthcare professionals. Furthermore, the materials developed were considered straightforward, user-friendly and appealing [11]. A challenge for monitoring intervention fidelity is the ecological nature of the approach (which in every other way we see as a strength) – it is designed to be pervasive and flexible around the child's microenvironment rather than occurring in predefined windows of intensive input of a fixed nature [12]. It is not possible to quantify the "dose" of an intervention delivered in this format. However, the basic message and strapline is straightforward and the explanations are clear. Manual contents can be used as a fidelity checklist, and correctness of the approach observed and discussed at home visits, or videoed by families. In our pilot feasibility study we use qualitative research methods including comprehensive observations and in-depth interviews to explore to what extent different aspects of the approach are found to be helpful, adopted and routinized by different families

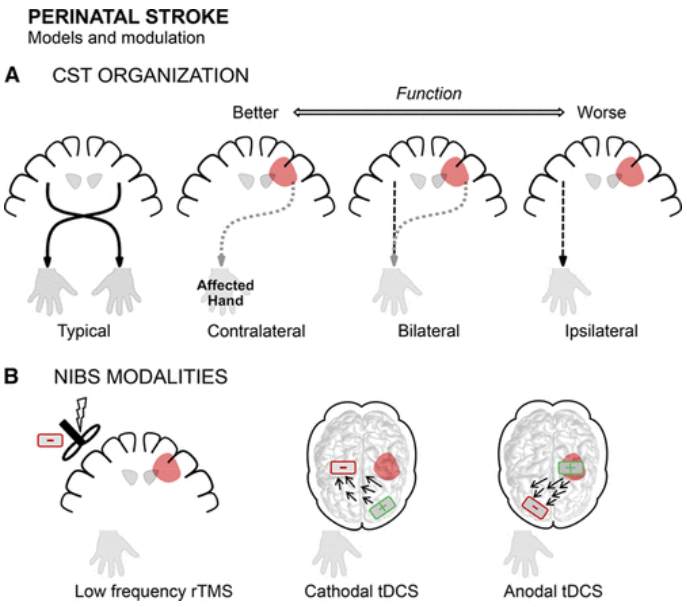


**Figure 1:** shows the perinatal stroke model and modulation.

## Conclusions

A participatory design process and Normalisation Process Theory framework have helped us to develop a parent-delivered complex intervention, namely the early therapy in perinatal stroke (eTIPS) program. This program addresses a current gap in therapy intervention practice for infants with perinatal stroke during a period of high central nervous system plasticity. We are currently undertaking a pilot feasibility study of the eTIPS approach with a view to further evaluation within a randomised controlled trial.

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