Title: Constraint Induced Movement Therapy in hemiplegic Cerebral Palsy: a national survey of its use by physiotherapists in the UK

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Abstract

Background/aims: There is an emerging evidence base into the use of Constraint Induced Movement Therapy (CIMT) in hemiplegic Cerebral Palsy (CP). However, there is little evidence of its use in the UK. This study aimed to conduct a national survey of physiotherapists to explore their use of CIMT in hemiplegic CP and to identify barriers and facilitators to its use.

Methods: An online survey was distributed to members of the Association of Paediatric Chartered Physiotherapists (APCP) within the UK. At this time, there were approximately 2300 members on the professional database. Participants were asked about their experience and views regarding CIMT use/training, including their beliefs regarding delivery of CIMT in the UK health system.

Findings: Responses were from 121 therapists from 12 regions of the UK, working across the National Health Service, private sector and education; based in inpatient, outpatient, community and school settings. Fifty three percent had never used CIMT although 73.6% felt it was an appropriate treatment. Most therapists felt they did not have enough training to use CIMT.

Barriers included ethical issues, resources and training. Facilitators to its use included treatment modification, support of others and outcome appraisal. The ethical and legal ramifications of restraint were a common concern which prevented therapists from using CIMT. Family compliance influenced therapists' decision to use CIMT.

Conclusions: There is evidence to suggest physiotherapists in the UK are using CIMT to some extent in this patient group and that there is established clinical interest. Further research is needed to clarify ethical and legal ramifications of restraint.

Keywords: "constraint induced movement therapy" "hemiplegic" "cerebral palsy"

Introduction

Cerebral Palsy (CP) is the most common paediatric disability in the UK, with an estimated 1 in 400 people living with the condition in the UK (National Health Service, 2015). Cerebral Palsy describes a group of disorders affecting activity and function due to a non-progressive disturbance in the developing foetal or infant brain (Hoare *et al.*, 2007). Hemiplegia is a type of CP which describes motor impairment on one side of the body; the severity of impairment and classification is dependent on the location and extent of damage to the brain (Hoare *et al.*, 2007). Hemiplegic CP can result in decreased function due to reduced sensation, fine and gross motor skills, weak grasp and changes in tone. As the child is born with a weaker and less coordinated side, they learn to disregard the affected limb and tend to favour the unaffected side, known as 'developmental disregard,' (Taub, 1980; Hoare *et al.*, 2007; Taub *et al.*, 2011).

Constraint Induced Movement Therapy (CIMT) is a treatment technique used to improve upper limb function in hemiplegia, using restraint of the unaffected limb which encourages use of the affected arm. CIMT is also referred to as Forced Use Therapy (FUT) and there has been some modification to the original protocol, such as reduced restraint hours; this is referred to as modified CIMT (mCIMT). CIMT was first used in primates (Taub *et al.*, 1980) and later in humans in a range of conditions such as stroke, brain injury and multiple sclerosis (Taub *et al.*, 2011). In 1995, CIMT was used in children with CP, who demonstrated the same improvement in upper limb function as adult stroke patients (Taub *et al.*, 2011). On this basis, a growing number of trials investigating the effect of CIMT on children with Hemiplegic CP have been published, advocating CIMT as an effective treatment approach (Eliasson *et al.*, 2014).

The use of CIMT in adult stroke patients in the UK is more established, with recommendations for its use in appropriate patients (Royal College of Physicians, 2012). A large, multicentre, randomised controlled trial of CIMT in 220 adult stroke patients demonstrated significant improvement in arm function and quality of life which was maintained long term (Wolf *et al.*, 2008). Despite efforts to implement this therapy into the National Health Service (NHS) practice for adult patients (Bradshaw, 2012), there appears to be little evidence of the same development in the use of CIMT in children with CP. The National Institute for Heath and Care Excellence (NICE) guideline for spasticity management in under 19 years of age recommends that CIMT is considered, followed by bimanual training for an intensive period of 4-8 weeks (NICE, 2012). It remains unclear however, the extent to which this recommendation is followed.

The objectives of the study were to conduct a national survey of physiotherapists in the UK to explore their use of CIMT in children with hemiplegic cerebral palsy and to identify potential barriers and facilitators to its use.

Methods

Context

A survey was used to collect data as this is an effective way of reaching large populations, and self-completed questionnaires are a low-cost investigation allowing wide dispersal amongst a population (Meadows, 2003). As there was no appropriate existing tool, a unique questionnaire was developed by the authors. Closed questions were included to gain background information from the respondents including geographical location, their professional experience, experience of CIMT and their current working environment. Open questions were added to gain insight into the reasons for their response and their perceptions of CIMT.

The survey was piloted with a qualitative researcher and with a physiotherapist working with children with neurological deficits. Minor changes were made to the layout and phrasing of the questions on the basis of this feedback in order to make questions more explicit and the questionnaire easier to complete. These two pilot questionnaires were not included in the actual survey analysis and the physiotherapist did not participate in the final survey. The survey was delivered online (www.surveymonkey.com).

Sampling strategy

To access physiotherapists specialised in paediatric physiotherapy, the specialist interest group, The Association of Paediatric Chartered Physiotherapists (APCP) was approached during the initial development of the survey tool. The association agreed to participate in the distribution of the survey; by emailing a letter describing the background and objectives of the study to their database of an estimated number of 2300 members. The email invited recipients to take part and contained a link to the online survey. Participation, completion and submission of, the survey was deemed to be providing consent.

All responses were provided anonymously and no participant identifiable information was collected.

Ethics

Ethical approval and sponsorship for the study was obtained from Nottingham University Hospitals NHS Trust (reference 16PT001).

Data collection and analysis

The survey platform was a password protected survey site <u>www.surveymonkey.com</u>. Data collection commenced upon distribution of the survey to the APCP database via email. The survey was 'live' for two weeks in March 2016. The data collection period ended at the closing of the survey.

The survey included a mix of closed and open questions and responses to each question were analysed. Closed questions were analysed using descriptive statistics whilst open questions were analysed using thematic analysis to identify common words and phrases. The qualitative data generated from the open questions was analysed using thematic analysis as described by Braun and Clarke (2006). The process of data analysis was conducted between March and June 2016.

Findings

Sample

A total of 121 participants completed the survey. The length of time qualified ranged from 9 months to 41 years; mean time was 20.8 years (SD±10.2). Time of specialism in paediatric physiotherapy ranged from 3 months to 40 years, with a mean of 16.5 years (SD±9.4).

Participants were based across 12 regions of the UK; the highest response rate was from the South West of England (15.7% n=19), followed by London (14.0% n=17). One participant chose not to answer so was not included in the analysis for this question. The complete demographics of the sample are displayed in Table one.

[Insert Table 1 here]

Participants were from the NHS (74.4% n=90), private sector (8.3% n=10), both NHS and private (9.9% n=12), and 7.4% (n=9) came from 'other' backgrounds such as charities or the education sector.

The majority (67.8% n=82) worked in the community; 0.8% (n=1) worked in inpatients and 2.5% (n=3) worked in outpatients. Twenty-six participants worked in a mixed setting (21.5%) and 6.6% (n=8) worked in charity, education or specialist clinic settings. One participant did not answer this question (0.8%).

When asked if they had received any training on CIMT, 31.4% (n=38) had within post training, 9.1% (n=11) had completed a postgraduate course and 17.4% (n=21) had some other training. This consisted of attendance at conferences, journal reviews and discussion with peers. A total of 41.3% (n=50) had received no training into CIMT. One participant did not answer this question (0.8%).

When asked if they had ever used CIMT in clinical practice, the majority had not (52.9%; n=64). The remaining 46.3% (n=56) had used CIMT; one participant did not answer the question (0.8%). In response to the question 'do you think CIMT is an appropriate treatment for upper limb function in hemiplegic CP?' the majority 76% (n=92) responded 'yes'; no participants answered no to this question, the remaining 24% (n=29) were not sure. In response to 'do you think CIMT can be used in NHS practice?' 73% (n=89) felt it could, 2% (n=2) said no and 23% (n=28) were not sure. Two participants did not answer this question (2%).

Qualitative Data

The quantitative data demonstrated a variation in practice in relation to the use of CIMT; consequently, the qualitative data sought to further explore the participants' differing perspectives. A number of themes emerged which were attributable to the meta-themes of 'barriers' and 'facilitators' **Error! Reference source not found.**2. These themes are discussed below, with verbatim quotes used to illustrate the themes, and the participant number represented, e.g. (P36).

[Insert Table 2 here]

Barriers

Ethical issues

The ethical and medico-legal implications of restraining an unaffected limb was a considerable factor for therapists in their decision not to use CIMT. The concerns surrounding CIMT were around the notion of restraint:

'I have been told it is unethical to use and was under the impression that, other than for research purposes, therapists weren't using it for that reason. (P35)'

'There is an element of restraint which could be seen as potentially a child protection issue. (P86)'

'The legal ramifications would need to be clarified. (P34).'

The responses suggested a lack of guidance or consensus, especially at local level:

"...not sure of ethics and morality of CIMT in paediatrics - would need departmental consensus. (P23)"

Some therapists were apprehensive about the professional ethics of restricting use of a functional limb:

'I have reservations about not encouraging a young child to use both hands at a time when neural pathways are plastic. (P26)'

Others suggested appropriate selection and informed consent was the key to permitting ethical use of CIMT:

'...for the right child at the right time with informed consent. (P35)'

Resources

Many participants felt that they did not have the time, money or staffing to implement CIMT, given the high intensity therapy required. They felt they could not deliver the treatment to its full potential and as a consequence, may not attempt it. Demands on the service were cited as barriers to CIMT use:

'The amount of time we have with children is not sufficient to provide this intervention - the demands on the service are too high to offer such an intensive intervention programme (P62).'

'I am unsure whether this treatment approach can be sustained within the restrictions (financial, staffing, time) on service delivery within the NHS (P21).'

Resource constraint was also implicated as dictating the nature of many participants' caseload, with higher functioning patients receiving monitoring only. For example: '*NHS is limited [in] how involved we can be with less severely affected children (P39)*' and '*Our GMFCS [gross motor function classification system] level 1/2s tend to be under orthotics-only reviews (P28)*.' This suggested less affected children may be limited in their ability to access CIMT.

There were however some outlying opinions, with some respondents claiming that although a potentially demanding and resource intensive programme, CIMT should be used due to its robust evidence base: '*Any effective treatment should be available and used in the NHS (P40)*' and 'We should be using techniques with proven efficacy (since there is so little research for the good work we already do) (P30)'.

Training

A lack of training was identified, with a proportion of the participants (41.3% n=50) having received no training in CIMT. Across the responses, there were more than 35 statements of *'I have no or little training,'* when asked why they have not used CIMT. Even some who had some training did not feel competent to provide CIMT:

'I feel my knowledge is too incomplete to implement this into my practice (P20).'

Most participants expressed a desire for more training if it was available but suggested the resources were not available due to, *'financial issues with training budget (P52).'*

Despite a reported lack of training, most respondents still acknowledged their awareness of the extant evidence base for CIMT:

'There is evidence out there to back this up (P10)' and 'Research shows that when done intensely, CIMT is an effective treatment for upper limb function (P62).'

Overall, therapists felt CIMT had a convincing evidence base to support its use in improving upper limb function.

Facilitators

Modified CIMT

For those participants who utilised CIMT, many discussed modifications of the intervention. These appeared to be attempts to address perceived barriers such as ethical concerns as well as resource limitations. For example, a common modification related to the nature of the constraint applied:

'I have used modified CIMT...slightly less restraint and for shorter periods (P19).'

'...use of arm gaiters, weight bearing on unaffected limb and arm tucked in vest (P45)'

'I use a soft cast which is cut and fastened with straps...it can be used for short periods in the day (P27).'

Furthermore, therapists discussed their efforts to make CIMT more cost effective via use of custom made mitts or via delivering the intervention in a group setting to reach a larger number of children:

"...children are brought in for a daily group for a week and then parents continue at home (P41)."

Support of others

Participants recognised the role of others (both formal and informal) in assisting the delivery of CIMT. Nineteen participants made reference to occupational therapists (OT) in their responses. Specifically, a collaborative approach with OTs was often emphasised:

'...run jointly with OT (P92)'

'...as long as you have a good relationship between OTs/PTs within the service (P107)'

A number of therapists suggested that CIMT constituted upper limb management and therefore would fall within the remit of the OT:

'...no knowledge of use by physiotherapists; have always regarded it an OT area (P21)'

'OTs tend to work on upper limb function in our bi-professional team (P38)'

The relative contribution of OTs and physiotherapists depended on area and local service provision, and there was evidence of both OTs and physiotherapists assuming primary responsibility for upper limb treatment. The extension of the survey into the OT population may offer further detail on this issue.

The support from the child's family was a significant factor in CIMT delivery. There was consensus that CIMT would not be achievable without adequate compliance from the family. Respondents emphasised the importance of multi-agential collaboration:

'it is about family, child and education colleagues working together with the health professionals (P20).'

'I have also had schools involved where they do the exercises for 15-20 minutes a day (P26)' and 'parents or others can be easily taught the programme and they can carry it out at home, nursery or school (P48).'

The answers emphasised the importance of creating and maintaining good relationships with those in the child's environment. The empowerment of parents, allowing them input into their child's therapy, was perceived to improve motivation/compliance and outcomes.

Appraisal of outcomes

Participants in the study associated CIMT with significant improvements in upper limb function, symmetry, balance and posture. There was reference to neurophysiological change and neural pathways, improvement in proprioception and increased awareness of the neglectful side. Therapists felt CIMT provided children with more experience of using the affected arm and decreased reliance on the unaffected limb. No therapists identified any specific outcome measures as being particularly beneficial in the evaluation of CIMT, however they did recognise the need for an *'agreed outcome measure (P2).'*

Discussion

Therapists returned questionnaires quickly suggesting this was an area of interest and topical, with almost fifty percent of therapists having used CIMT in some form. The qualitative data identified significant factors which may influence a physiotherapists' decision to adopt CIMT as an intervention for children with hemiplegic CP. These are further discussed below.

In terms of the ethical/medico-legal debate, there was apprehension surrounding restraint and some therapists chose not to use the treatment for that reason. The responses suggested a lack of confidence with using restraint, particularly if things were to go wrong. There was concern about the legal position of therapists and some felt that the guidance surrounding restraint was ambiguous. This concern may be warranted, as the most recent guidelines suggest the use of restraint should be a 'last resort' (Royal College of Nursing 2008; Royal College of Nursing 2010; The Association of Anaesthetists of Great Britain and Ireland, 2013). The guideline for restraint and therapeutic holding for children and young people, published by the Royal College of Nursing (2010), differentiates between the two by the degree of force used to immobilise and the intention for restraint. Moreover, this guidance exists for nurse led interventions during medical procedure or to prevent harm. There is a lack of similar, appropriate guidance in physiotherapy or occupational therapy and therefore, it is not clear how restraint should be applied in a therapy context. This guidance offers a theoretical framework basis, with little practical application; for example, there is little information on the possible side effects of restraint or recommendations should things go wrong.

Furthermore, given that the intent of physiotherapy is to improve functional mobility rather than restrict it, it is perhaps understandable that this was an area of ambiguity. Nevertheless, an emerging evidence base suggests that CIMT may be an effective treatment (Smania *et al.*, 2009; Lin *et al.*, 2011; Sakzewksi *et al.*, 2011a; Sakzewksi *et al.*, 2011b; Sakzewksi *et al.*, 2011c; Case-Smith *et al.*, 2012; Chen *et al.*, 2012; DeLuca *et al.*, 2012; Rostami and Malamiri, 2012; Sakzewksi *et al.*, 2012; Fedrizzi *et al.*, 2013; Chen *et al.*, 2014) and this was acknowledged empirically and anecdotally by many participants. CIMT is a clinical conundrum, whereby the healthcare professional is required to reconcile complex legal, ethical and professional tensions and thus local policies should be agreed with relevant clinical, managerial and legal input. Formal training in CIMT (acknowledged by the respondents in this survey as lacking) should ensure that this aspect is addressed.

The responses also highlighted a broader issue in healthcare; the limitation of services due to the lack of resources or financial restrictions. The UK King's Fund (2015) predict that an additional £8 billion of NHS funding per annum will be required by 2020. Considering the mandated £20 billion efficiency savings that the NHS was required to make between 2010-2015 (Fatoye, 2013), it is not surprising that the consequences were felt on the 'frontline' of healthcare. There has been some discussion surrounding the ethics of such austerity in the literature. Molina-Mula and De Pedro-Gómez (2013) highlighted the extra burden this places upon health care professionals. They suggested the health service is increasingly seen as a 'business,' creating a system which is based upon pre-determined goals and targets, rather than considering patients as individuals (Molina-Mula and De Pedro-Gómez, 2013). In this study, respondents emphasised the lack of staffing and, as a result, the pressure placed on therapist's caseload. This often created a perceived inequality in service provision, whereby only the more severely affected children could be considered for CIMT and/or physiotherapy intervention. This study was the first of its kind investigating the use of CIMT by UK physiotherapists working in paediatrics; the findings suggest a number of factors which influence the 'lottery' of CIMT provision. Further research into the ability of service providers

to deliver CIMT and a comparison of regional differences may offer insights into discrepancies in service provision across the UK and possible factors influencing this.

This study has however highlighted the endeavours made by physiotherapists to address and manage fiscal constraints, in particular the modification of CIMT and the use of supporting 'others'. It has been acknowledged in previous work that contemporary healthcare practitioners acknowledge productivity improvement as a professional responsibility and make efforts to reconcile a culture of efficiency with a culture of caring (Moffatt, Timmons and Carey, 2016).

In the case of CIMT, such efforts (to improve productivity or to reconcile professional-ethical tensions) warrant further consideration. Firstly, this study identified that CIMT modification was a common strategy. Within the literature, trials have demonstrated the effect of reduced dosage CIMT. Case-Smith *et al.* (2012) and DeLuca *et al.* (2012) compared three hours of therapy to six hours of therapy a day over 26 days. The children wore a cast at all times and this was only removed for weekly skin checks. They found that there was no significant difference between groups and suggested that equivalent gains could be achieved with reduced dose.

A common modification revealed in this study was use in the domiciliary setting. Chen *et al.* (2014) investigated the effect of 3.5-4 hours of home based CIMT twice weekly for four weeks and compared this to dose matched 'traditional rehabilitation.' Home CIMT showed significant improvement on the Bruininks-Osretsky Test of Motor Proficiency (BOTMP), the Peabody Developmental Motor Scales (PDMS-2) and the Functional Independence Measure for children (WeeFIM) when compared to the traditional rehabilitation group (p=<0.005) which was maintained at three and six month follow up. This suggests a home based programme can still achieve significant improvement.

Therapists suggested conduction of CIMT in larger groups as a way of improving costeffectiveness. Sakzewski *et al.* (2011a; 2011b; 2011c; 2012) delivered CIMT in a group day camp in the community setting for six hours daily for ten days. The CIMT group demonstrated significant improvement on the Melbourne Assisting Hand Assessment and this was maintained one year after treatment (Sakzewski *et al.*, 2011b). Improvement was demonstrated at one year on the Assisting Hand Assessment (Sakzewski *et al.*, 2011b). Sakzewski *et al.*, 2011c). There was also significant improvement on some domains of the Cerebral Palsy quality of life questionnaire (Sakzewski *et al.*, 2012); these studies suggested that conducting CIMT in a group environment is effective in improving outcomes. The importance of engagement and collaboration with other professionals and the patient's family was highlighted as a key facilitator for sustaining CIMT. Therapists felt they would only select families who were committed and likely to engage with such an intensive programme of care. There is extensive literature into the burden of long term conditions within the family unit. Families raising children with cerebral palsy are more likely to experience levels of psychosocial dysfunction (Bemister *et al.*, 2014). These issues can significantly affect their ability to comply in therapy. Learning how to best engage with and empower parents in therapy has been long debated (Fielding and Duff, 1999), but once obtained it can be a valuable influence on outcome. Future research should focus on the unique barriers to familial participation in home-based CIMT.

Limitations

Our study had some limitations, the first around the uncertainty regarding the number of therapists reached, which has implications for the generalisability of the results. The APCP had just over 2300 members on their database, but it is not possible to know how many professionals actually received or read the email. Equally, the snowballing effect (therapists passing on the survey to colleagues or those who were not APCP members) is not clear. Therefore, an accurate response rate was not calculable. Another limitation may have been the timescale; the survey was open for two weeks after the email link was first dispatched; a reminder email after one week of opening may have increased the response rate.

Surveys are limited to analysing what is returned. Although there was a good response to the survey and to the qualitative questions, data may have been richer and more informative if additional semi-structured interviews with individuals had been conducted.

Conclusion

A significant number of physiotherapists in this survey believed CIMT to be an effective treatment method to improve upper limb function in hemiplegic CP, and based this on their clinical experience or their awareness of an emerging evidence base. This study addressed the gap surrounding use of CIMT clinically, providing evidence of use by physiotherapists in the UK to treat hemiplegic CP in some settings. The data allowed for identification of the barriers and facilitators to CIMT use. Participants highlighted the problematisation of restraint in the clinical setting and lack of guidance surrounding this. Participants responses also reflected a wider issue within healthcare: a lack of resources, funding, time and staffing. Consequently, the facilitators were often adopted to accommodate for these issues, such as the modification of CIMT. There is evidence to suggest that modified CIMT can continue to be effective. Further research into these issues in the NHS setting would elucidate more

depth and knowledge in this area. The reconciliation between professional responsibilities and evidence based practice was highlighted and further exploration into the use of restraint to achieve increased function, alongside increased training amongst therapists, may further enable CIMT in this population.

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Conflict of interest

No conflict of interest

Answer Options	Response Percent	Response Count N=121
Northern Ireland	1.7%	2
Scotland	10.7%	13
North East	5.0%	6
North West	12.4%	15
Yorkshire	3.3%	4
West Midlands	7.4%	9
East Midlands	3.3%	4
Wales	5.0%	6
South West	15.7%	19
East Anglia	9.1%	11
London	14.0%	17
South East	11.6%	14
Did not answer	0.8%	1

Table 1: Geographical location of participants

Barriers	Facilitators
Ethical issues	Modified CIMT
Resources	Support of others
Training	Appraisal of outcomes

Table 2: Meta-themes and themes

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