

## **Exploring the Barriers and Facilitators to Caregiver Engagement in Postural Management Training for Children with Complex Neurodisabilities: a qualitative study**

Karen Crozier\*<sup>1</sup>, Kay Cooper<sup>1,2</sup>, Sharon Blair<sup>3</sup>, Rachel McDermott<sup>3</sup>, Irene Croal<sup>1</sup>

<sup>1</sup> NHS Grampian Physiotherapy Department, Royal Aberdeen Children's Hospital, Westburn Road, Aberdeen, UK

<sup>2</sup> School of Health Sciences, Robert Gordon University, Aberdeen, UK.

<sup>3</sup> NHS Grampian Aberdeen City Central Child Development Team, Mile End School, Midsocket Road, Aberdeen, UK

\*Corresponding author: [karencrozier@hotmail.co.uk](mailto:karencrozier@hotmail.co.uk)

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### **Abstract**

Twenty-four-hour postural management (PM) is widely recognised as being important for children with cerebral palsy (CP) and other complex neurodisabilities. Training for caregivers involved in delivering PM is essential. However, engagement with PM training by caregivers is variable. Little research has been conducted to date to establish how to engage caregivers in PM training.

### **Objectives:**

To explore caregivers' perceptions of the barriers and facilitators to engaging in formal 24-hour PM training for children with CP and other complex neurodisabilities.

### **Design:**

Exploratory, qualitative study.

### **Setting:**

Child Development Teams in one Scottish Health Board.

### **Participants:**

Sixteen caregivers of children with CP or other complex neurodisabilities.

### **Methods:**

Semi-structured online interviews, with the option of an online survey to enhance inclusivity. Data were processed and analysed in NVivo 12 and Microsoft Excel, using the Framework method. Interviews aimed to understand participants' perceptions of the barriers and facilitators to engaging in formal 24-hour PM training for children.

### **Results:**

Three key themes were identified:

(i) Defining postural management: Postural management involves a range of activities, equipment and stakeholders, and can lead to significant daily challenges

(ii) Those promoting the use of postural management need to:

- provide knowledge & understanding of all aspects of postural management

to facilitate improved caregiver participation at an early age & stage

- be mindful of potential psychological impacts in caring for a child with a complex neurodisability

(iii) Delivering postural management training: Those delivering postural management training need to use a flexible range of promotional strategies and invitations and provide relevant and motivational information in a variety of formats to encourage stakeholder participation.

### **Conclusions**

This study provides insight into barriers and facilitators to attending PM training and will inform the development and ongoing enhancement of training provision. Barriers included lack of time, caregiver readiness, and lack of clarity on the target audience. The content and mode of delivery, including shared experiences from caregivers of children with complex neurodisability, were viewed as facilitators to engaging in PM training. Consideration of these issues is important when developing and delivering training to this important client group.

**Keywords:** Posture, Neurological Rehabilitation, CP (Cerebral Palsy), Caregivers, Qualitative research

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### **Introduction**

Children with disabilities caused by a motor dysfunction, such as cerebral palsy (CP), are a highly vulnerable group. Prevention of pain and deformity are key treatment priorities for the most severely affected children with CP and other complex neurodisabilities (NICE, 2016). Twenty-four-hour Postural Management (PM) is widely recognised by therapists as a non-invasive, conservative approach adopted to address these priorities (Humphreys et al, 2012). Postural management programmes should be tailored to meet each child's individual needs, and may include specialised equipment, functional activities, active exercise, orthotics, surgical interventions and individual therapy sessions to increase comfort and reduce deformity (Gericke, 2006). Positioning techniques can be used to enhance functional ability and should be implemented as early as possible to promote development (Wandel, 2000; Goldsmith, 2000).

Stinson et al (2021) highlighted the need to address training and support for families and care companies to successfully implement individualised programmes that incorporate day and night-time positioning. Similarly, in the UK the National Institute for Health and Care Excellence (NICE), 2016) advise that therapists offer relevant and developmentally appropriate information and training to parents and carers.

Training can be a crucial part of raising awareness of the benefits of PM and the consequences of not following this approach. Hotham et al (2017) suggested that a brief postural care training programme could improve knowledge, understanding and confidence. However, it is not known whether training results in adherence with PM or long-term changes in the application of principles (Bacon 2013). Moreover, anecdotal evidence suggests that engagement in training by caregivers may be limited. Little research has been carried out to establish how best to engage caregivers in PM training. Understanding caregivers' experiences of PM training, and their perceptions of the barriers and facilitators to engaging with such training, will help healthcare professionals to tailor training to meet caregivers' needs. Furthermore, by involving caregivers of children with complex postural difficulties, both in identifying the issues addressed and informing the methods adopted, this study aimed to produce findings that can be practically applied to impact those involved in the care of children with significant postural needs.

### **Research Question and Objectives**

The research question articulated for this study was: What do caregivers consider to be the barriers and facilitators to engaging in formal PM training and what strategies can be proposed to enhance caregivers' engagement with formal PM training?

The objectives of this study were to:

1. Gain an in-depth understanding of caregivers' perceptions of the barriers and facilitators to engaging in formal PM training for children with CP and other complex neurodisabilities.
2. Propose strategies for enhancing caregivers' engagement with PM training that can be implemented by those involved in developing and delivering such training.

## **Methods**

The study was ethically approved by the West of Scotland Research Ethics Service (Ref No 20/WS/0120) with management permission granted by NHS Grampian R&D department (Ref No 20/NS/0100).

### ***Study design***

This is a qualitative study underpinned by critical realism (CR), which uses components of positivism and constructivism, making it a comprehensive philosophy of science and useful for analysing problems and suggesting solutions for change (Fletcher, 2017). There are few precise guidelines for methods of data collection and analysis from a CR perspective; this study drew from previous applied qualitative research using CR to inform methods of recruitment, data collection, processing and analysis (Fletcher 2017; Ryan 2016). The design allowed in-depth understanding of the perceptions and experiences of parents of children with CP and other complex neurodisabilities, who had or had not attended PM training. The project steering group included four caregivers who carry out 24-hour PM with their child. The range of personal experiences these caregivers brought to meetings helped to inform the recruitment strategy, interview topic guide and best means of disseminating the study findings.

### ***Study setting and participants***

The study took place in one Scottish Health Board. The population was caregivers (i.e., parents or carers) and other family members of children with CP or other complex neurodisabilities. Eligibility criteria included: any age or sex; caring for a child(ren) with a complex neurodisability; previously invited to attend PM training. Caregivers were identified by a Child Development Team (CDT) secretary, from those who had previously received an invitation to attend a training event, thus ensuring no researcher bias in the selection process. A letter of invitation and information sheet was sent to 35 caregivers, including those who attended or did not attend the training they were invited to take part in. This process was repeated after two weeks. Invitation letters and information sheets were sent to a further 14 caregivers two months after the initial recruitment date due to the low response rate. In addition, posters promoting the study were shared on Facebook pages of local Additional Support Needs schools, the local CP Association and other local community support groups. Participants returned a reply slip to the research assistant (RA), who responded either by telephone or email, to explain the study in more detail and, where appropriate, to arrange a mutually convenient time to conduct the interview. The RA was a paediatric physiotherapist who had no prior association with the caregivers or their children.

### ***Data collection***

**1-1 interviews:** Fifteen participants provided online, recorded verbal informed consent immediately prior to taking part in semi-structured 1-to-1 interviews conducted by the RA via Microsoft Teams. The RA read through the consent form, word for word, with each participant, documented their responses and signed and dated their agreements. A copy of the signed form was subsequently sent to participants, and the recording stored separately from the interview recording. An interview topic guide (available on request) was developed by the study steering group which consisted of the research team and four caregivers of children with complex neurodisability. It was informed by the objectives of the study, previous research in the field, and the knowledge and experience

of the steering group. It was piloted with two caregivers and two paediatric physiotherapists independent to the study team, with minor amendments being made prior to implementation in the study. Table 1 identifies the areas explored in the interviews. Interviews were conducted by the RA and in keeping with ethical requirements, were recorded using a hand-held audio-recorder, with field notes written by the RA immediately afterwards (Holloway and Wheeler, 2002). Participants were each given a unique identification number before transcription of the interviews, during which any person-identifiable data was anonymised. Although transcription by the researcher can facilitate early immersion in the data, outsourcing transcription was time-efficient; immersion therefore began with the research team reading and re-reading transcripts.

**Online survey:** To enhance accessibility to the study, an online survey was also developed, providing an alternative method of gathering participants' views and perceptions of the areas covered by the interview. The survey was piloted for face validity by the steering group and was hosted on Jisc Online Surveys, a GDPR-compliant platform, and is available on request. Whilst a survey elicits more brief and superficial responses than interviews, (De Jonckheere and Vaughn, 2019) it enabled participants who did not wish to be interviewed to take part in the study. One further participant, who did not have the time due to work and caring commitments to take part in an online interview, completed the online survey; their responses were analysed alongside the interview data.

**Table 1: Topics explored in interviews.**

<b>Main topic</b>	Areas explored
<b>Postural management</b>	Understanding and lived experience Perceptions of own and others' roles
<b>Postural management training</b>	Perceptions and experiences of: Invitation process Information provision Attendance (or non-attendance) Barriers to engaging Facilitators to engaging Suggestions for enhancing training provision
<b>Other</b>	Anything else related to postural management training that participant wanted to discuss

### **Data analysis**

Data processing and analysis was supported by NVivo 12 Qualitative data analysis software (QSR International) and conducted by four members of the study team (KCr, KCo, SB, RMcD). The Framework method was used (Ritchie and Spencer, 1994), which involved familiarisation, coding, developing the analytical framework, applying the analytical framework to the data, charting data using framework matrices, and interpretation of the data (Gale et al, 2013). Framework analysis is commonly used in health research and is particularly suited to teams of researchers analysing semi-structured interviews (Gale et al, 2013). It is also a good fit with the CR approach as coding is deductive yet flexible (Fletcher, 2017) and allows for abduction (or theoretical description) and retroduction (identifying causal mechanisms and conditions); important aspects of a CR approach and relevant for this study where we wanted to understand what the barriers and facilitators were in order to suggest changes. In this study we operationalised Framework analysis in the following way. Two researchers (KCr, KCo) familiarised themselves with three transcripts, making analytic notes onto the transcripts. Discussion of these analytical notes led to a coding index being constructed. The coding index was then applied by the researchers independently to three transcripts, with further discussion and refinement of the coding index into a working analytical framework (Gale et al, 2013). Thereafter, the lead researcher (KCr) applied the analytical framework to

all transcripts using NVivo 12 software, with regular review by and discussion with the second researcher (KCo). The data was then charted, using Microsoft Excel, which involved summarising the data under broad initial themes. Analysis of the charted data then involved interpreting the data within and between participants to identify categories, which were grouped into classes by similarity of meaning, and finally into key themes. This was an iterative process, involving both researchers and regular discussion.

## Results

Sixteen participants took part, including fifteen parents and one respite carer (Table 2). Fourteen participants were recruited via invitations sent by the CDT secretary, with two recruited via public facing materials. Interviews ranged from 21 to 75 minutes (average 46 minutes).

**Table 2: Participant demographics (n=16 caregivers)**

<b>Personal experience of PM training</b>	Yes 9	No 7
<b>Sex of participant</b>	Male 3	Female 13
<b>Age of participant</b>	≤ 24	0
	25-44	10
	45-64	6
	>65	0
<b>Education level of participant</b>	Currently in ed/ completed high school or college	6
	University	10
<b>SIMD Quintile</b> -(Quintile 1 contain the most deprived data zones in Scotland)	3	3
	4	10
	5	3
<b>Diagnosis of child*</b>	Cerebral Palsy	9
	Other (includes SMA, Foetal alcohol syndrome, Gene mutation/arthrogryposis, Pompe's Disease, Spina Bifida, Undiagnosed learning disability/ epilepsy)	9
<b>Age of child at time of interview*</b>	≤ 12	10
	13-18	8
<b>Age of child at time of diagnosis*</b>	Under 2	8
	Over 2	5
	Not stated or unknown	5

**Key:** PMT = Postural Management Training; SIMD=Scottish Index of Multiple Deprivation; SMA=Spinal Muscular Atrophy

\*Total 18 as 2 participants had 2 children with complex neurodisabilities

Framework analysis resulted in three key themes, derived from 94 categories and 12 classes of data, following several rounds of independent analysis and team discussion: (i) Defining postural management; (ii) Promoting postural management; (iii) Delivering postural management training. Table 3 provides descriptions of each theme and details the classes of data which contributed to each of the themes. The first theme (defining postural management) did not directly address the research objectives and is therefore not discussed in detail in this paper but is summarised to provide contextual information.

**Table 3: Themes and classes of data**

<b>Theme</b>	<b>Description of theme</b>	<b>Classes contributing to theme</b>
<b>1. Defining postural management</b>	PM involves a range of activities, equipment, and stakeholders (including parents/carers, schools, Allied Health Professionals and children themselves) which in combination may lead to significant daily challenges	<ul style="list-style-type: none"> <li>-Shared roles and responsibilities for PM with school/healthcare professionals &amp; wider team around the child</li> <li>-Parents/carers undertake a range of activities, using a range of equipment for PM</li> <li>-Role of the child in their own PM</li> <li>-Equipment: funding, accessing, meeting child&amp; family needs, quality of life, moving and handling, time taken, space/accessibility, benefits</li> </ul>
<b>2. Promoting postural management</b>	Those promoting the use of PM need to provide knowledge & understanding of all aspects of PM to facilitate improved caregiver participation at an early age & stage. They also need to be mindful of the potential psychological impacts of caring for a child with a disability	<ul style="list-style-type: none"> <li>-Those providing training need to provide relevant &amp; motivational information to encourage parents and/or carers/ healthcare professionals to attend training</li> <li>-PM starts early, often from birth</li> <li>-Negative aspects of PM (frustrating/overwhelming/time-consuming/family life balance)</li> <li>-Intrapersonal factors: acceptance; limited understanding; anxieties, frustration, guilt</li> </ul>
<b>3. Delivering postural management training</b>	Those organising training need to use a flexible range of promotional strategies and invitations and provide relevant and motivational information in a variety of formats to encourage stakeholder participation	<ul style="list-style-type: none"> <li>-Those organising training need to use a flexible range of promotional strategies and invitations</li> <li>-Practicalities of PM training: time/timing, venue, childcare</li> <li>-Content/ delivery of PM Training/ different stages</li> <li>-Voices of experience, importance of PM</li> </ul>

PM=Postural Management

### ***I: Defining postural management***

Participants reported that PM had been a natural part of their daily lives from early in their child's development, with mothers primarily taking a lead role in meeting their child's postural needs and as such feeling they had acquired the necessary knowledge and skills to undertake the range of activities required. Participants felt that having a good understanding of the benefits of and consequences of not using PM was crucial in facilitating engagement by all caregivers, including other family members, paid carers, NHS and education staff. Common challenges such as time constraints, juggling work/ home life balance and the role the child plays in their postural care caused frustrations and anxieties which could become overwhelming. Funding and provision of appropriate postural equipment were also reported as a significant challenge for participants. However, when equipment was working well, participants reported that their child was more comfortable and had improved functional abilities with a positive impact on wellbeing and social inclusion.

### ***II: Promoting postural management***

Despite PM largely being seen as part of daily life, some participants highlighted that it could be frustrating, or overwhelming at times, especially when struggling to come to terms with and accepting their child's diagnosis:

*"I thought it was a baby thing I didn't know it was a disabled thing. I think I would have persevered with more had I understood the latter effect. However, I don't know if I was ready for that information at that time,"* [Participant 13, Female]

In this study, mothers tended to be the main caregiver of a child with a disability, especially in the early years, and participants recognised that fathers' acceptance and engagement in their child's care may have taken longer as a result of different work/life priorities:

*"He was in a bit of denial at that time, wasn't really coping with everything that was going on and I would say that he is only really got to grips with everything as our son has got older"* [Participant 3, Female]

Seeking information on all aspects of PM and knowledge of the long-term benefits and consequences of undertaking PM were viewed as motivators in encouraging and maintaining participant engagement, for example:

*"Someone can tell you this is how you need to position him, but unless you know why you are doing that, you don't really know what you're doing".* [Participant 6, Female]

The perceived benefits of having a PM programme in place at home and in school was reported by some participants:

*"I think she might have been in a worse state in terms of her scoliosis, so I think it has helped as she has grown, but it is hard to tell."* [Participant 5, Female]

Some participants had not anticipated changes in their child's body shape as they grew:

*"I think that you don't really get that sometimes when they are wee, it is as they get bigger that becomes even more relevant. So it is all about knowledge if we don't do this the knock on effect that is going to have"* [Participant 3, Female]

These participants felt it was important to share information with caregivers, regarding potential changes in their child's posture, at an early stage in order to help prevent possible deterioration at times of rapid growth.

In addition, some participants reported frustrations that limited opportunities for PM at home had contributed to a deterioration in their child's posture or abilities:

*"You have got that balance of is she no longer able to do that because we have not spent the time with her to do those things?"* [Participant 11, Male]

Participants who had attended a PM training event reported that the varied content and delivery methods used were key to enhancing their understanding and thus promoting their engagement in PM:

*"It was the course content, the setup of things, you were given handouts, there was like physical demonstrations, you were put in little groups and things, you were given little challenges"* [Participant 10, female]

In addition, participants appreciated learning from the personal experiences of other families:

*"...anything that would just give us a bit more kind of insight because there would possibly be other people who have got kids at different ages who have been through it as well."* [Participant 12, Male]

Suggestions regarding the most appropriate time to attend a PM training event varied; some participants thought it would be most beneficial early in their child's development, whilst others thought that repetition of training during key stages in the child's life may also be of benefit:

*"I feel like if right from newborn stage, I'd have known how much easier that could make her life as a toddler, but at that age I would have worked much harder. I just feel like if I got it in a couple of years earlier would have been so beneficial."* [Participant 13, Female]

### **III: Delivering postural management training**

Participants agreed on common barriers and facilitators to attending a formal PM training event. One of the main barriers was the duration of the training event itself and taking time out of a busy daily schedule to attend:

*“Having a child with a disability your time is, your time is precious.....so trying to juggle work commitments along with appointments as well so then you see a course like that you think oh it’s not an appointment I have to be at, oh I don’t have time for that right now.”* [Participant 3, Female]

In addition, the location of the training event may have contributed to transportation difficulties for non-drivers and potential childcare issues due to travel time. Online or pre-recorded training was perceived as being beneficial, by offering caregivers the flexibility to attend an event where these barriers would be of less concern:

*“Zoom might work for people, maybe people that don’t drive and also people who are at home,”* [Participant 2, Female]

Some participants, however, felt that online training offered reduced opportunity for interaction and sharing of personal experiences with other caregivers and professionals.

Targeting the appropriate audience and highlighting the potential benefits of PM for their child were also suggested facilitators to encourage caregivers to attend a training event:

*“...they may feel like I can’t attend that because it is more sort of for OT’s and not for me,”* [Participant 9 Female]

The means by which participants were invited to a training event could act as a barrier or facilitator to attendance. Some participants thought that invitations sent by post or email were the best means; however, others reported being overwhelmed by the amount of correspondence they received regarding their child’s care. Word of mouth from therapists or other parents, and advertisement via social media or posters displayed in hospital and community clinics were suggested by many participants as being an appropriate means of sharing information about training more widely:

*“I guess it is just being recommended, [name] a family support sort of group on Facebook and things like that so they could say to their families oh look by the way there is this course available, here is what it is.”* [Participant 11, Male]

### **Discussion**

The findings identified key barriers and facilitators to engaging with PM training from the caregiver’s perspective. These are summarised in Figure 1, along with proposed strategies for overcoming the barriers, also informed by the study findings.

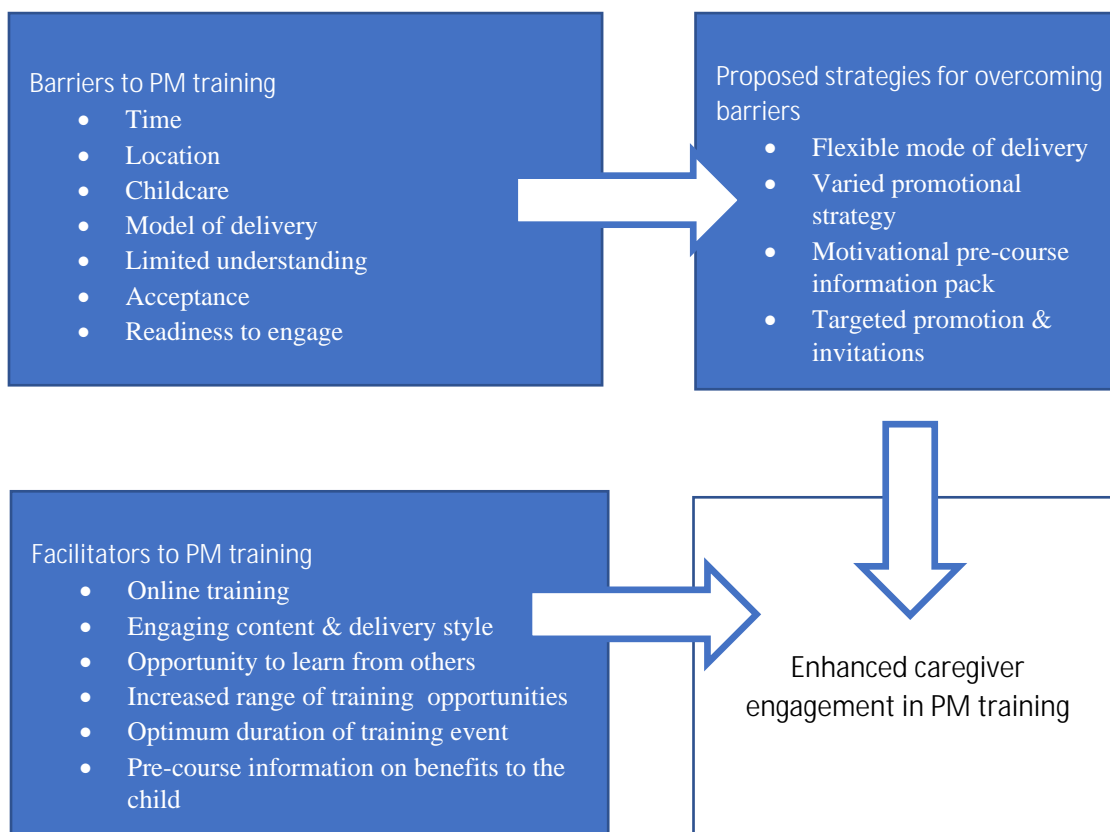
The finding of practical issues such as time, location, and childcare posing as barriers to attending PM training, were identified by most participants, and particularly those caring for younger children. This is in-keeping with previous research by Tadema and Vlaskamp (2009) who found that children are dependent on caregivers for all basic care tasks during the day and night and that learning to live with the needs of a child with multiple disabilities is more difficult for younger parents than for those of an older child. The finding of being overwhelmed and frustrated with the additional daily responsibilities faced by caregivers in managing their child’s posture are also in keeping with previous research (Moorcroft et al ,2019), with higher rates of stress, depression and burnout having been reported by family caregivers of children with a disability compared to those of typically developing children (Nicolson et al, 2012).

Strategies to overcome these barriers, such as online and asynchronous delivery, as suggested by the participants in the current study, could offer additional flexibility for busy caregivers. This may be particularly relevant today,



due to the widespread uptake of virtual modes of communication during the COVID-19 pandemic (Wright and Clayton, 2020), making virtual delivery of training potentially more acceptable than in the past. However, a recent randomized trial of two online training programs (Hutson et al, 2021) found that although caregivers receiving training by interactive videos showed greater self-rated competence, the actual positioning abilities of this group were no greater than those of the caregivers who received summary information with web-links, with some practical tasks requiring additional hands-on training for competence.

**Figure 1: Key Barriers and Facilitators to caregivers attending postural management training**



Engaging in PM training, as for engaging in any health promotion activity, requires an element of behaviour change by caregivers (Goldsmith, 2000). Boland et al (2019) in their systematic review of the barriers and facilitators of shared decision making in paediatric practice from the perspectives of HCPs, parents, children, and observers, suggested that the emotional status and stage of acceptance of the caregiver, and the quality of information about the condition and whether it was tailored to the child and family's literacy needs, may act as potential barriers to changes in behaviour. In our study we observed that participants experienced psychological barriers such as denial, frustration and guilt with the realisation that their child was not going to improve, which they found physically draining and impacted on their readiness to engage with PM. An understanding of behaviour change theories, such as those incorporated in the behaviour change wheel (Michie et al, 2011), and associated techniques to positively support behaviour change, may be useful for therapists working in the field of complex neurodisability. Appropriate techniques could be used to help address caregivers' psychological barriers and facilitate better uptake and engagement with PM training and clinical services. For example, discussing the risks and rewards related to managing their child's posture, as suggested by participants in this study, is congruent with the behaviour change technique of 'health consequences' (Michie et al, 2013), and may help to motivate the adoption of behaviours that promote ongoing PM.

Participants in this study appreciated learning from the personal experiences of the trainers and other caregivers, relating it to their own life experiences, demonstrating the equal importance of professional and lived experience. Bacon (2013, pp31) also found that parents “enjoyed talking to other parents in similar situations” in their study that evaluated whether a PM training programme improved the understanding of the importance of PM for children with complex movement disorders. Co-production (Filipe et al, 2017) of future training events, whereby there is shared decision making by caregivers and service providers in the design and delivery of training and training materials (Boland et al, 2019), may help to facilitate increased engagement by the target audience by creating a more relevant and acceptable training programme. In addition, delivering training in a less formal way, such as during a mother and baby group, may help to facilitate engagement with caregivers who might otherwise be reluctant.

Most of our participants were caregivers of children above 10 years of age, therefore the findings may not be generalisable to caregivers of younger children. However, most had been introduced to and were actively involved in their child’s posture from an early age and consequently recognised, from personal experiences, the benefits of early intervention. It was not possible to ascertain from the data whether participants had been invited to attend training in the early stages of their child’s development but it was known that they attended at a relatively later stage. Despite a targeted approach by therapists towards caregivers of children at an early age, challenges remain regarding engagement in PM training at this crucial stage. In the current study, only 50% of participants who had attended a PM training event did so before their child reached the age of 5-years, which may have been due to limited availability of appropriate training events. The inaugural report of a UK All-Party Parliamentary Group on CP (2021) suggests the need for effective, early intervention, to improve life outcomes and minimise secondary complications. Guidance by NICE (2021) advises NHS staff to offer children, young people and their caregivers’ information about the potential risks and benefits of healthcare options to allow them to make informed decisions. Offering training at key stages in a child’s development could be highly beneficial in supporting the changing needs of the child and their caregivers and may serve to reinforce the importance of effective PM in the longer term. It is important that providers of training acknowledge this when designing future training offerings.

### ***Strengths and limitations***

We have presented an in-depth exploration of caregivers’ perceptions of barriers and facilitators to PM training, with suggestions for overcoming some of the key barriers. Our findings should therefore be useful for anyone designing new or enhancing existing PM training opportunities for caregivers of children with complex neurodisability. We recruited both males and females from a range of socioeconomic backgrounds to take part in the study. However, participants from socially disadvantaged groups were under-represented, potentially due to the study taking place in one Scottish Health Board. We also recruited caregivers of relatively older children, and it is therefore difficult to generalise the results of this study to caregivers of younger children. Further study with a more diverse sample is indicated as there may be barriers specific to socially disadvantaged groups and caregivers of younger children that we have not identified. Our interviews also generated extensive data on the topic of ‘PM Equipment’, particularly in relation to its funding and provision. This was not the focus of the current study but was clearly of significant concern to many caregivers and may be worthy of exploration in future research.

## Conclusion

This study provides insight into the barriers and facilitators to attending PM training which will be used to inform future service provision, by the study team, and we hope by others. Restrictions posed by the COVID-19 pandemic resulted in the research team adapting their existing training for virtual delivery. The study findings have also influenced how we promote PM training, resulting in invitations and promotional materials being advertised and distributed more widely via social media and family support groups, resulting in increased attendance to recent training. Further initiatives such as the co-production of training programmes and a blended approach to delivery, including both online tutorials and practical face to face elements are avenues for future exploration.

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