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Exploring the beliefs of young people with cerebral palsy and their families about sport and physical activity in relation to paediatric physiotherapy exercise programmes

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ABSTRACT

Background and Purpose

Physiotherapy programmes are an important part of therapeutic input for young people with cerebral palsy (YPwCP), but adherence can be problematic. The involvement of physical activities (PA) could be a possible solution, but YPwCP have lower levels of physical leisure participation than their typically developing peers.

Method

This qualitative study aimed to explore the beliefs of young people with disabilities and their families about PA in relation to physiotherapy programmes. PA was broadly defined to include not only disability sports, but any aerobic exercise and 'beliefs' as perceptions, knowledge and attitudes. A purposive sample of participants from the researcher's physiotherapy service was invited to undertake semi-structured interviews. Inclusion criteria were 8-19 years of age, having a disability, cognitively able and able to understand and express themselves in English. Parents/care givers were included to capture their discrete perspectives and enable reflective discussion about any synergies or differences between their beliefs and those of their children. Data was analysed using Interpretative Phenomenological Analysis (IPA).

Results

Two YPwCP and their mothers participated.

Three main themes arose:

- The feelings evoked by PA, in particular feelings of otherness were underpinned by the desire for 'normal' participatory experiences alongside typically developing peers.
- External factors and others attitudes affect participation in PA, in particular unfavourable judgements and tokenism within mainstream environments contrasted with a normalising acceptance in disability sports settings.
- Physiotherapy and PA are different, participants believed that physiotherapy, physiotherapists and medical venues possessed superior quality, legitimacy and potency.

Conclusion

The study revealed YPwCP and families' unique beliefs and preferences concerning PA and the status of physiotherapy and physiotherapists within daily life. Physiotherapists should consider the influence of these beliefs when seeking to signpost to PA or enhance longer-term adherence to programmes within a context of reduced clinical contact.

Introduction

Long-term motivation and adherence are key rehabilitation issues for physiotherapy (Chartered Society of Physiotherapy (CSP) 2018; Tsekleves et al (2014). Furthermore, non-adherence has been reported as being a significant issue within the paediatric population (Chappell and Williams 2002; Basaran et al 2014; Beresford et al 2018). More recently, McGrane et al (2015, p11) contextualised adherence within a future dominated by chronic long-term conditions and stated; *“enabling adherence to exercises and increasing PA must become an integral part of physiotherapy treatment”*.

Utilising PA has been suggested as a possible solution to non-adherence within young people with cerebral palsy (YPwCP) (Moore et al, 2019). Sports participation and competition for young people with disabilities, including cerebral palsy, is also associated with positive psychosocial benefits such as affect, motivation and enthusiasm (Chin, 2015; Hunter, 2009; Jaarsma et al, 2015; Maher et al, 2016 and Scarpa, 2011) and improved peer relations (Shapiro and Martin, 2010). All these personal factors could potentially drive adherence to life-long rehabilitation programmes with qualitative studies additionally reporting an increased sense of normalcy created through team sports (Hunter, 2009; Lauruschkus et al, 2014). Despite this, research suggests that young people with disabilities have lower levels of physical leisure participation than typically developing peers (Leo et al, 2018; Wright et al, 2019).

Paediatric physiotherapists are utilising community-based exercise programmes and dance sessions for young people with disabilities, to achieve therapeutic goals (Priestley, 2013; SSOTP, 2016; Stoker, 2014). Wiart et al (2015) identified community-based therapy programmes as a way to promote a long-term interest in fitness and which may *“situate therapy into a social rather than medical model of service delivery”*. Such contextualisation is echoed within the National Service Framework, which promotes living ordinary lives for young people with disabilities and their families (Department of Health and Department for Education and Skills, 2004).

With an increasing PA and disability sports profile, health professionals are encouraged to promote PA and health/disability sport pathways (CSP, 2019; Chin, 2016). Additionally, a survey of paediatric physiotherapists found that sport can play a positive role in the lives of young people with disabilities (English Federation of Disability Sport, 2014). Therapists should also consider their impact beyond the impairment domain, as outlined in the International Classification for Functioning, Disability and Health – Child & Youth paradigm (Rosenbaum and Gorter, 2011).

There is limited published research overtly linking PA with paediatric physiotherapy programmes. Early studies were characterized by sole focus on ‘fixing’ the impairment, with physiotherapeutic programmes unconnected to other PA; even when the exercises were analogous and there was recognition that programmes could be time-intensive and repetitive.

Within recent qualitative studies parents ascribed more importance to meaning, context and direct relevance of physiotherapy programmes to their children’s interests and enjoyment, whilst addressing physiotherapeutic objectives (Palisano et al, 2011a/b; Peplow and Carpenter, 2013; and Piskur et al, 2016). Wiart et al (2010, p252), identified a crossover for some parents where:

Therapy activities were viewed as a potential strategy for enhancing physical fitness, and sometimes recreational activities were viewed as having therapeutic benefits

In contrast, other parents viewed physiotherapy as a separate activity (Hunter, 2009). Verschuren et al (2012, p493) identified that promoting PA involved *“facilitating transition between traditional rehabilitation and community-based sports/activity programs”*, implying they remain two mutually exclusive concepts.

Some authors have argued for an integration of PA and physiotherapy, such as Maher et al (2016) who noted clinicians have increasingly incorporated PA within their interventions to enable community sports participation. Shikako-Thomas et al (2014) concluded that the evidence supported such an integration of physiotherapeutic management and goal setting with health promotion and fitness strategies and an expert task force concurred (Rowland et al, (2015). Whilst a Delphi survey by Gorter et al (2016) proposed that school health support teams, including physiotherapy, should consider offering Therapeutic Recreation support as an additional service.

The driver for this study was to deepen our understanding of beliefs, particularly concerning the integration of PA and physiotherapy. Such a study might suggest possible exploratory avenues that would better support patients to achieve lifelong adherence and be a possible precursor to quantitative studies (Greenhalgh, 2014) that could favourably impact on service resources.

Method

A qualitative approach using grounded theory (Interpretative phenomenological analysis (IPA)) was selected for this study. The inclusion and exclusion criteria for the study is shown in figure1. Physiotherapy colleagues within the author’s Trust were briefed to identify a purposive sample. Twenty-five participants were identified and invitations, participant information sheet, consent form and stamped addressed envelope were posted sequentially.

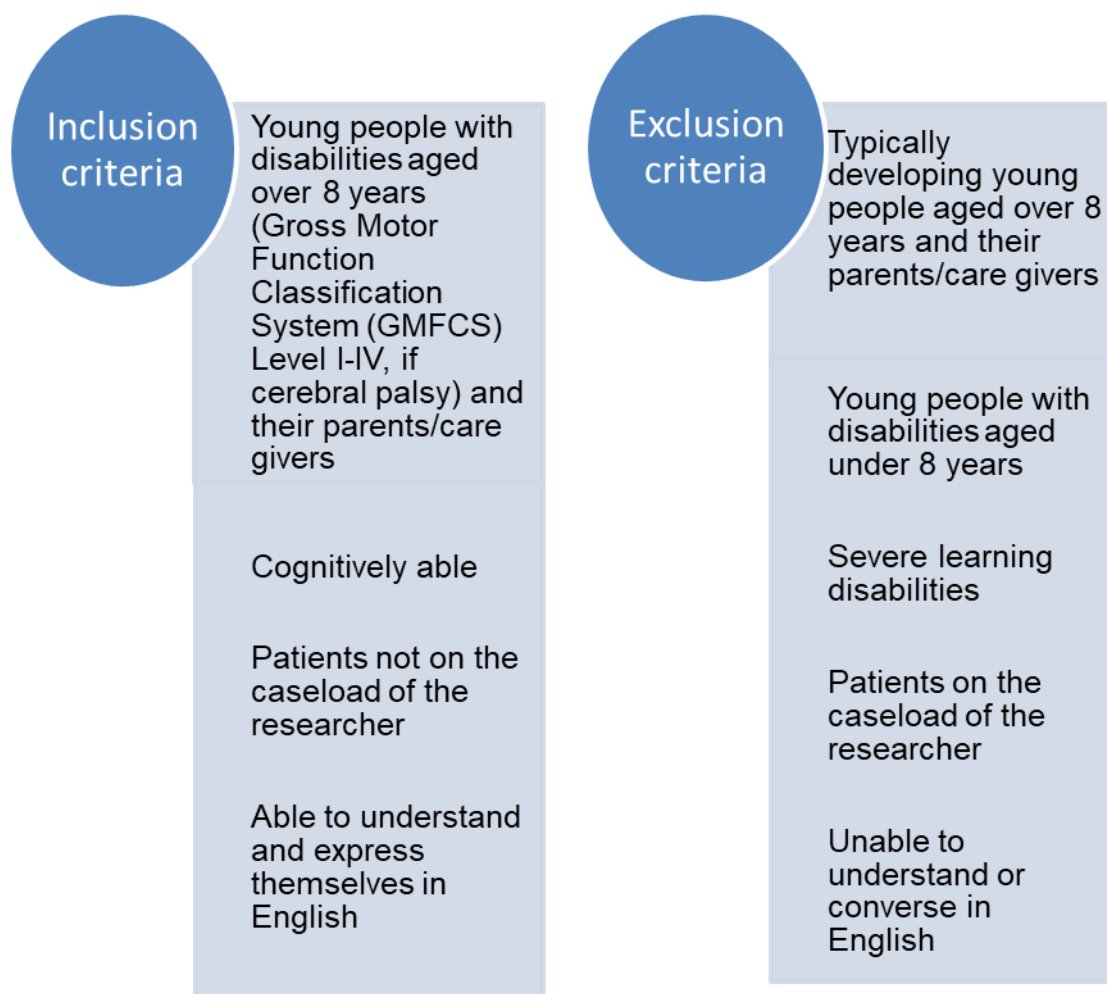


Figure 1- Inclusion/Exclusion Criteria

A

The planned sample size of up to six young people and their parents/care-givers reflected the smaller numbers suggested within IPA to generate a depth of rich data (Dean et al, 2006). It also reflected the practical realities of a busy NHS administrative team.

Ethical considerations

This study received ethical approval from Sheffield Hallam University and NRES (Office for Research Ethics Northern Ireland -ORECNI).

Confidentiality and anonymity of participants was preserved through pseudonyms and their informed consent was recorded. Participants were under no obligation to take part and the researcher had no direct contact with them, unless they responded; nor were they patients of the researcher.

As the study involved vulnerable participants, an adapted information sheet was used and parental consent was also obtained (Modi et al, 2014). Parents/care givers decided if they wished to be interviewed separately or with their child.

Data Collection

Semi-structured interviews were employed to facilitate improved information sharing and this was combined with the use of an interview schedule, prompts and pictorial materials to ensure continued focus (Britten, 2006), understanding and engagement for young people (Coates and Vickerman, 2010).

The data was recorded on an electronic tablet and then transcribed by the researcher onto a template (Dean et al, 2006), using field notes to capture any non-verbal cues. The transcripts were emailed to participants to verify accuracy.

Data analysis

The particular qualitative approach of IPA was appropriate, as the aim was to explore the lived experience of what the topic area meant both to participants (Larsson et al, 2012) and researcher (Finlay, 2006b; Greenhalgh, 2014; Robson, 2011), in a way that facilitated transparency and reflexivity (Dean et al, 2006; Finlay, 2006b; Pope and Mays, 2006). Furthermore, IPA was appropriate, because of its idiographic, contextualized and psychological approach to rich and possibly ambiguous data (Finlay, 2006a), specifically participant's beliefs concerning PA in relation to paediatric physiotherapy programmes and consequential influences on adherence behaviours.

IPA is grounded within a relativist/Interpretivist philosophy, which assumes individuals will bring multiple meanings to any phenomena. Therefore the findings may not identify commonality of belief or behaviour or a simplistic formula to increase adherence to programmes.

The IPA process outlined within Smith et al (2009) was followed throughout; beginning with deep immersion within the data (Larsson et al, 2012), through reading and re-reading transcripts, with initial noting in the margin and reflexive notes. Analysis continued through simultaneously applying the three 'discrete processes' of descriptive, linguistic and conceptual commentary. Key emergent themes were then added (Pope et al, 2006) to deepen the interpretation and locate layered meanings. This included contextualising responses through the prism of participants' situations and mental/emotional states and their possible influence on behaviour (Dean et al, 2006).

The next phase sought connections between emergent themes within each transcript; particularly using the methods of polarization e.g. disability versus mainstream sport; contextualisation e.g. age stages and generational impact; and abstraction e.g. conceptualization of disability. Fragment theme strips were printed and placed on a large board to identify spatial relationships between themes for each transcript. Super-ordinate and sub-ordinate themes were created for the transcript and the whole process replicated for the next transcript. Finally, by identifying patterns across both transcripts, it was possible to create a thematic master table.

To summarise, the double hermeneutic IPA process enabled conception of beliefs underlying participant's words and reported behaviours as an 'iceberg' (Figure 2) and aligned to the super-ordinate themes.

Finally, in order to facilitate verification data was checked with the supervisor (NS), to ensure themes accurately mapped to the data.

Results

Two young people with mild cerebral palsy aged nine and eighteen and their mothers were recruited (Table 1). This was less than the ideal number of three to six.

Pseudonym	Familial relationship	Diagnosis of child or young person	Age of child or young person at time of interview	Educational setting of child or young person
Steve	Son of Jessica	Cerebral Palsy (Right Hemiplegia) GMFCS 1	9	Mainstream
Jessica	Mother of Steve	N/A	N/A	N/A
Oliver	Son of Lynda	Cerebral Palsy (Diplegia) GMFCS 2	18	Mainstream
Lynda	Mother of Oliver	N/A	N/A	N/A

Table 1 – Participant details

An overview of emerging themes are summarised in table 2 and the thematic 'iceberg' is shown in figure 2.

<u>Super-ordinate themes</u>	<u>Sub-ordinate themes</u>	<u>Themes</u>
<u>Theme 1</u> The feelings evoked by PA	1.1 Negative feelings 1.2 Positive feelings 1.3 Aspirations 1.4 Contextual factor	1.1.1 Physical otherness 1.1.2 Separation/excluded 1.1.3 Disadvantaged 1.2.1 Resilient 1.2.2 Included 1.3.1 Acceptance/Inclusion 1.3.2 Equity of opportunity 1.3.3 To compete 1.4.1 Family culture
<u>Theme 2</u> External factors and others attitudes affect participation in PA	2.1 Negative feelings 2.2 Positive feelings 2.3 Aspirations 2.4 Barriers/facilitators 2.5 Contextual factors	2.1.1 Judgement, tokenism, unfairness 2.2.1 Acceptance 2.3.1 Participation/competition 2.4.1 Awareness 2.4.2 Equipment 2.5.1 Age/school stage 2.5.2 Generational impacts

<p><u>Theme 3</u> Physiotherapy and PA are different</p>	<p>3.1 Brand/identity/practice of physiotherapy and it's comparison to PA</p> <p>3.2 Practice of PA in relation to physiotherapy</p>	<p>3.1.1 Negative feelings in relation to programmes – guilt, pain, dull, obligated, effort</p> <p>3.1.2 Barriers/facilitators of programmes – Structure, content, personal factors, relationship and contextual factors</p> <p>3.1.3 Positive feelings in relation to the brand of physiotherapy - worthy, beneficial, superior, legitimate</p> <p>3.1.4 Separation of concepts</p> <p>3.1.5 Negative associations</p> <p>3.2.1 Yoga, adapted cycling and racing wheelchairs examples</p>
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Table 2 – summary of super-ordinate themes, sub-ordinate themes and themes from participants

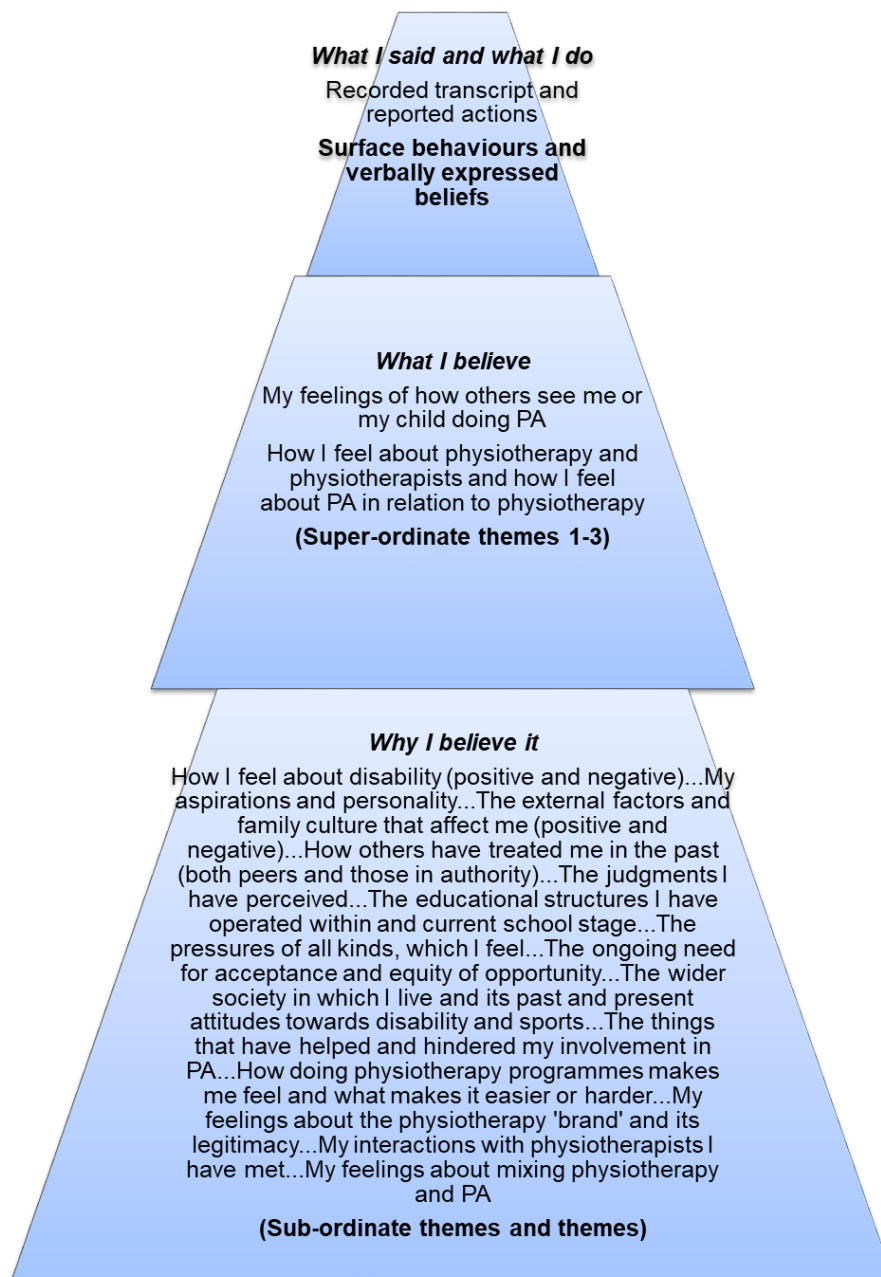


Figure 2 – Thematic ‘iceberg’

The feelings evoked by PA

Participants conveyed their deep seated desire for ‘normal’ experiences when undertaking PA; but engagement, especially in mainstream settings with typically developing peers, highlighted a profound sense of physical difference and otherness:

He can't do the running, erm...he can't do the throwing, he, he can't do the catching properly, it's sort of like, nothing....it, it's like you're included, but you're always going to come last, because you can't do it (Jessica).

Lynda similarly identified and added that her son's interests in PA had been profoundly shaped by his early experiences:

You weren't interested in mainstream sport; from a very early age, being...disabled affected your ability to keep up with people, you never, you never got to like it, you never enjoyed it (Lynda).

Oliver added *I had that negative association with it [sport]*. He compared himself unfavourably with his typically developing peers, showing mature insight into his situation, *I was held back by my legs*. Furthermore, Oliver's typically developed identical twin made physical comparisons more immediate, *disheartening to be not as good as him [and] he tries his best a lot, a lot more than his brother does (Lynda)*.

Participants elaborated further regarding the consequential losses they had experienced in terms of exclusion, separation and reduced opportunities, both physical and social, *You weren't always involved; you couldn't keep up with them (Oliver)*. However on the positive side, Lynda felt this unfavourable environment had built resilience in her son, *He's a strong character and he's had to put up with a lot*.

Jessica had positive feelings when experiencing PA within a disability setting because Steve's physical differences did not impede his physical and social participation/inclusion/acceptance:

So for sports what he's got at the minute are great, yeah and it's nice seeing a smile on his face, and we love going watching as well and the kids bond so well, it doesn't matter what the disability is, what their ability, how good they are, it's...they just get on with it, and they're great, it's great.

Jessica emotionally recounted the *absolutely amazing* meaningful participation experienced at a mainstream community running event (IronKids), as did Steve, *it's taking part*. Oliver identified the positive social benefits of doing PA, *I liked, I guess the whole thing about being involved with my friends* and how it improved his self-esteem, if there wasn't too much running and he could keep up.

It was Lynda's aspiration to offer equitable PA to Oliver and his typically developed twin; this sometimes presented difficult dilemmas and she was conflicted about always keeping things the same, without making allowances.

External factors and others attitudes affect participation in PA

The second super-ordinate theme is inextricably related to the first, since participants' perceptions of other's attitudes and contextual structures greatly influence self-perception.

Participants had experienced unfavourable judgements and tokenism from typically developing peers/staff during mainstream PA and these had negatively shaped their feelings about PA. This contrasted strikingly with the acceptance experienced within adaptive sport settings, where Jessica felt 'safe' enough to reveal their true selves.

He loves it: it's so nice to see him able to...compete on his level, err and take part in it. Never judged by anybody at all, it's just, it's great [and] the parents get as much out of it as the kids ; versus the perceived judgement of Steve within a mainstream club, It's the parents, it's like well...what's wrong with him?

This flowed on into feelings of being ignored within mainstream physical education (PE), *like all his friends, like I said they're on all the teams at school...but he just gets, sort of like overlooked (Jessica)*. She also felt she experienced unfair treatment and tokenism there, *It annoys me because it's like they know he's disabled, but...they're not sort of like accommodating him* and recounted school responses about an outdoor pursuits trip, *If he can't do it, there's puzzles...or he can...what is it? Cheer his friends on... they didn't do anything to find out what he could have done.*

However, both parents realistically accepted that their sons could not meaningfully engage in competitive sports with their typically developing peers in mainstream school, *I know he can't do it, so they wouldn't win (Jessica) [and] they don't want you to be in the team, do they? If you don't, can't run up and down the same (Lynda)*.

Jessica identified structural barriers and facilitators regarding PA engagement. Firstly, a lack of knowledge, *to find an activity what a child with a disability can do, it's really difficult*, and so it helped when activity was advertised. Participants recognised that sometimes special equipment was needed, *He can't just jump on a normal bike (Jessica) and I do...bikes for like, for cerebral palsy with your arms (Steve)*;

also how mainstream equipment sometimes fell short, *The technology...isn't tweaked enough for a child who can't sort of do what it's asking... then he gets frustrated (Jessica).*

Lynda identified that the usual activities of his typically developed teenaged friends now influenced Oliver's preferences.

You know the people that you hang out with are all stuck on computers or watching T.V just as much as you are, aren't they? They're not playing out...your brother is a prime example sat in that room there; to which Oliver replied yeah...I'd like to think I'm not as lazy as he is and I'm the one with cerebral palsy!

Another major contextual factor affecting beliefs about PA is the rising profile and changing societal attitudes to disability sport in the UK, partly due to the Paralympics (Swartz et al, 2018). More of Steve's lived experience is set in this era and so he had more positive experiences of disability sport locally. This cultural context has also lifted parental expectations of mainstream school PE, such as Jessica's belief that PE staff should facilitate inclusion and participation better,

If they know they've got a child with a disability...then they should think right well what can he do, we'll work it round that and it's not about winning; it's about taking part and well...if it's about taking part, then you should have children of all abilities taking part, not just the ones who are good at it.

Physiotherapy and PA are different

Participants separated the concepts and believed that physiotherapy, physiotherapists and medical venues possessed a superior quality, legitimacy and potency.

Participants had mixed feelings about their physiotherapy programmes; such as fatiguing, *it's dead hard...he's tired* or a burden where, *we've got to try and do them all and it is, it is a lot (Jessica)*. Lynda recognised Oliver's dislike of physiotherapy exercises, *he just sometimes doesn't want to do it [and] he did struggle to want to put himself through the rigmarole of all the physio exercises*. Although Oliver said, *I used to hate my physio exercises*, he felt bound to them as an obligatory duty, *I know it's something that needs to be done*; and Lynda perceived them as dull, *the monotony of just doing physiotherapy exercises*.

Both Jessica and Oliver associated effectiveness with pain, *the whole thing about physio is, I mean yeah it hurts...but that's the point, it does like stretch your muscles that hurt to be stressed*. However with age, Oliver rationalised and admitted, *now I'm eighteen and older, erm I...I understand that they are good for me and I'm already feeling the benefit*. The only time he associated fun with physiotherapy related to aquatic physiotherapy.

The presence of the physiotherapist lent credibility to the whole process for Steve as *the proper physio, not the helper [and] physiotherapists...know how to stretch you properly (Oliver)*. Aside from being perceived as experts, their personal qualities had a positive impact, *the physios...have been fab (Jessica)* and *the encouragement of the physios helped me see it a bit better (Oliver)*. Jessica recognised the importance of a relationship between patient and physiotherapist, *you need to have a sort of like a bond with the person who's doing it as well* and Lynda also highlighted personal contact with the service as important, *he does much better when he's got someone to report to*.

Oliver felt that the contextual factors of his particular post-operative situation created a sharper personalised focus for his physiotherapy programme, *I think a big part of my recovery from the operation was erm...the physio itself*. He acknowledged that current examination pressures were hampering his adherence, but having a routine helped, *he's in a bit of rhythm now with it, with seeing them at physio and then also coming more and doing some yoga (Lynda)*.

When participants compared PA in relation to physiotherapy, physiotherapy's superior 'brand' was deeply embedded and underpinned a legitimacy and primacy over identical PA undertaken within another setting:

I guess if you don't like physio, there are alternatives that will do the same job, I mean it's probably not on the same level (Oliver).

At points, participants regarded them as two discrete concepts, *Yoga...it's not technically physio (Oliver)* and Jessica, who acknowledged the paradox,

I don't know why I don't, cause it is...like he is doing things, he is keeping fit, he is moving, so that's what it should come under as well, but I just think because it's like, it's your physio, it's your exercises, so that's, that's just where it stays in my head.

Similarly medical venues, as opposed to other settings, brought legitimacy, *I find that keeps me err...focussed on what to do...it's like not as relaxed, but that's a good thing (Oliver).*

Oliver was ambiguous about whether combining PA with physiotherapy would work,

I'd like to say yeah, cause like it would be more fun activity, but I don't know really, because for a long time like, I'd associate sport with the thing I couldn't do and I'd associate physio with the things I didn't like doing and therefore I'd probably wouldn't do my physio as much.

Lynda pointed out how substituting PA for physiotherapy would fail and offered a constructive suggestion for where the emphasis should lie within any possible integration.

If physios put themselves to doing what sport he did, he didn't do any...so you wouldn't have been doing anything with him...it would be better if it worked the other way, that physios incorporated sport activity, to encourage them to do more of their physio around that, that would work better.

She also offered insight into the familial factors reducing her son's engagement in PA, *we aren't that sort, like type of family where, where it's been a culture of exercise within it and it's not like err...massively enthusiastic for sport and exercise in this household.*

Ultimately, the participants' reported actual physiotherapy exercises provide an interesting paradox to their theoretical beliefs, such as *The racing wheelchairs...that's just building up his like upper strength (Jessica)* and *he's doing his few stretches ...and then he gets in.* Yet in answer to whether this activity was physiotherapy, Jessica says *he doesn't see that then as doing physio* and Oliver on yoga *it does stretch a lot of the same muscles that some of my exercises do, so it does help my legs in that way*

Discussion

PA behaviours and beliefs were partly underpinned by a profound need for acceptance and inclusion in the ordinary PA of peers and be 'normal'. Coates and Vickerman (2010) described this as an internal pressure to conform to an idealised body image. Parents recognised this is impossible, which led them to prioritise the psychosocial benefits of PA participation (Wuart et al, 2015). Mainstream school PA proved a stark reminder of participant's physical differences and created the most vulnerability in them, especially for Oliver, as skills gaps widened and more competitive sport was introduced. These challenges required participants' confidence, as well as trust and understanding from their typically developing peers and school staff to meaningfully manage. This concurs with the body of quantitative literature that found participation in PA by YPwCP is positively associated with favourable environments and attitudes (Badia et al, 2013; Colver et al, 2012). Maintaining these favourable conditions and motivation in teenage years is reported to be challenging, as it was for Oliver; but Palisano et al (2011b) noted reduced PA participation is multifactorial and not solely attributable to being in the school phase of adolescence.

Although participants recognised their lesser physical capabilities, they paradoxically felt 'normalised' in adapted sports settings; this mirrors other studies, which described them as a safe space to be yourself, have fun and comfortably manifest your physical difference (Laruschkus et al, 2015). Contrastingly, Coates and Vickerman (2010) found participants with disabilities preferred competitive school PA over inclusive activities, which could possibly be explained as a reaction against tokenism. Whereas Wuart et al (2015) found parents identified benefit within all PA types, depending on individual circumstances. The immediate environment also influences PA

participation; for example, Oliver's diminished familial PA culture contrasted with the 'sporting families' identified by Shields and Synnot (2016), who better engaged with PA.

These contradictory findings within research underline the fact that individuals bring multiple meanings to any phenomena. It is therefore important that physiotherapists appreciate this and adopt an agile stance when personalising any promotion of PA to YPwCP. As Ullenhag et al (2014, p464) found,

Age, gender, parental educational level, and disability only explain a small proportion of the variance in leisure participation patterns. Thus, client-centred and individually tailored interventions are needed that are based on the individual's unique situation.

In theory, participants' desires for normalcy and inclusion could make a community-based, therapeutic model attractive; using PA as a vehicle to sustainably deliver long-term physiotherapy (Wuart et al, 2015; and Clarke et al, 2015) and a discharge pathway to self-management. However, paradoxically, despite lacking enthusiasm for physiotherapy programmes, participants still espoused a more medical model of care with the physiotherapist as expert, displaying superior quality, primacy and legitimacy over PA, even when exercises were analogous. Participants showed no desire to 're-badge' PA as physiotherapy; in Steve's case it is possible he enjoyed PA because it was *not like therapy* and so he, like others (Shimmell et al, 2013) purposefully separated them. This contrasted with other studies, which outlined a process of co-existence and ongoing dialogue, such as PA is an important beneficial physiotherapy goal and physiotherapy activities can enhance fitness (Kairon et al, 2017; Wuart et al, 2010). Although this study revealed limited dialogue between PA and physiotherapy, participants did recount positive experiences of disability sports, which would suggest physiotherapists should consider the risks, benefits and resilience applying to each YPwCP before encouraging involvement in mainstream PA and sports.

The use of 'sport as a therapy choice' was almost universal within a survey conducted by the English Federation of Disability Sport, using a self-selected sample of paediatric physiotherapists (EFDS, 2014, P14) and has parallels with intervention models explored by several studies (Clark et al, 2015; Pickering et al, 2012; Pickering, 2018). Wuart et al (2015, p73) suggested that *fitness programs for children and youth with motor disabilities [are] emerging as an innovative alternative to traditional individual therapy sessions*. Wuart et al (2015) cautioned that this approach could risk medicalizing community-based fitness programmes, but equally it is theoretically possible to visualise how such an approach has the potential to usefully de-medicalize physiotherapy and make it more palatable to some YPwCP.

Jessica had highlighted the benefits of a single local point of information about suitable PA and physiotherapists could consider collaborative local partnerships between themselves and voluntary sectors that would facilitate this (Public Health England, 2019; Shields and Synnot, 2016).

A possible consequence of promoting and increasing PA in people with disabilities is the reduced need for contact with health professionals (Chin, 2015), but study participants might experience this negatively because of the 'expert' status they attached to physiotherapists and the diminution of relationship. Nevertheless, supported self-care and community fitness programmes (Rowland et al, 2015) are increasingly underpinning all stages of the patient journey, to reduce demand on health services (Department of Health, 2014; NHS England, 2019; Reilly, 2016; SSOTP, 2016). Herein lies a great challenge, since implementing supported self-care will require re-educating YPwCP and their families about the therapeutic value of PA in relation to physiotherapy and re-defining our role as physiotherapists and our relationship to PA. Success will be measured when self-care and reduced clinical contact is perceived not as a loss of physiotherapeutic entitlement, but as a successful conduit to living ordinary lives (DoH & DfES, 2004).

Strengths and limitations

The strength of the study was the generation of rich data in an under-researched area. However, it is limited by the small purposive sample of male young people within a specific cerebral palsy subset and female parents, which meant certain gender-specific perspectives were not gathered and findings cannot be transferred to the all YPwCP or other disabilities and their families. Richer data could have been gathered if the planned sample size had been reached; and by using a longitudinal interview approach (Finlay and Ballinger, 2006).

Conclusion

This study provides an insight into the beliefs of young people with milder cerebral palsy and their families about the possible disadvantages of attempting to integrate PA into physiotherapy or to substitute PA for physiotherapy. The use of PA cannot therefore be regarded as a universal panacea for improving long-term physiotherapy adherence, as every YPwCP and their family will socially construct themselves differently.

Participants felt they had justifiable reasons for maintaining a separation between their physiotherapeutic and PA activities and further qualitative research about why some people might compartmentalise physiotherapy and PA would be beneficial.

Additional research using suitably designed methodologies to establish any association or correlation between adherence to physiotherapy programmes and integration into PA would further increase the knowledge base.

As health services move towards more self-care models, the challenge to physiotherapists will be re-educating YPwCP and their families to accept a new relationship of PA and physiotherapy.

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