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The physical education experiences of pupils with juvenile idiopathic arthritis: An ableism-critical perspective

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Abstract

There is an ever-growing body of research relating to disabled pupils' experiences of physical education (PE). However, our research is novel because it draws on an ableism-critical perspective to amplify the voices and centre the PE experiences of pupils with juvenile idiopathic arthritis (JIA). We used an online survey to gather quantitative and qualitative data from 100 participants with a diagnosis to explore their perceptions of: (a) the influence of JIA on participation in PE; (b) relationships with same-aged peers and their influence on experiences in PE; (c) relationships with teachers and their influence on experiences in PE; and (d) the appropriateness of the PE curriculum. Microsoft Excel was utilised to analyse quantitative data and produce descriptive statistics that were used to map views and experiences of PE, while qualitative data generated from open questions were analysed thematically. We discuss data in relation to the following themes: (a) pain, fatigue, and fear of injury restricted participation in PE; (b) awareness and (mis)understanding of JIA; (c) the negative judgements of others and peer bullying in PE; and (d) the (in)appropriateness of the PE curriculum. We end this article by emphasising the importance of disrupting ableist ideologies, discourses, and knowledge, particularly as these all relate to (mis)understandings of JIA and negative perceptions about the ability of such pupils in PE, because they are contributing to the marginalisation and ostracisation of pupils with JIA.

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disability, inclusion, ableism, invisible illness, schools, student experience

Introduction

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in paediatric populations and has an incident rate of 9.66 per 100,000 UK children <16 years old, equating to approximately 2250 people (Costello et al., 2022). JIA is defined as arthritis persistent for longer than six weeks, with an onset before the age of 16 (Martini et al., 2019). Arthritis can be categorised as a chronic invisible illness/disability, thus meaning the physical, mental, or neurological condition is not externally visible but can affect an individual's ability to carry out 'normal' day-to-day activities (Ainsworth, 2018). Alongside the visible and non-visible physical effects of JIA, such as chronic pain and swelling, JIA can present as psychological distress attributed to the medications taken to manage the condition (Heale et al., 2021). Non-visible symptoms can lead to misunderstandings and negative judgements from others (Ainsworth, 2018), including teachers, which is indicative of the ableism that pupils with JIA may experience. We explore ableism in the next section.

Arthritis in childhood has been associated with low levels of physical activity and poor physical fitness (Houghton, 2012). Whilst rest was previously recommended for children with arthritis, consistent exercise programmes alongside a more active lifestyle are now considered necessary to help manage the condition and have been shown to improve exercise capacity, decrease disability in adulthood, improve quality of life, and decrease disease parameters (Klepper et al., 2019). Despite emerging evidence supporting the benefits of physical activity for individuals with JIA, children with JIA are significantly less physically active when compared with their peers of the same age (Limenis et al., 2014).

As the subject uniquely tasked with corporeal development, physical education (PE) is increasingly being recognised for the role it can play in setting a foundation for lifelong engagement in physical activity (Ekblom-Bak et al., 2018; ICSSPE, 2010). The national curriculum for PE in England is non-prescriptive, other than requiring swimming to be taught during key stage two, which provides the freedom and flexibility for schools and teachers to determine what to teach and how (DfE, 2013). Yet, in England, since the 1950s competitive team games have dominated the PE curriculum (Griggs and Fleet, 2021; Kirk, 2005) and extra-curricular sporting opportunities, with an emphasis on performance, excellence, and skills (Haycock and Smith, 2011). Whilst most PE teachers share the goal of inclusion (Morley et al., 2021), they often perceive it to be difficult to achieve in practice due to a lack of support from senior leaders (Maher and Macbeth, 2014) and teaching assistants (Goodwin et al., 2022), limited preparation through initial teacher education and continued professional development (Coates et al., 2020), insufficient pedagogical knowledge (Overton et al., 2017), inadequate resources and challenges in planning and organising lessons for groups with such varied abilities (Morley et al., 2021).

For young people with JIA, negative experiences and restricted participation in PE have been attributed to a range of factors including pain in joints and/or muscles, but also non-arthritis-related factors including shortness of breath/side stitches, lack of competency in specific activities, and lack of support from teachers (Chomistek et al., 2019; Nørgaard et al., 2016). It has also been recognised that disease symptoms and medication side effects, as well as concerns from parents and teachers, may contribute to reduced exercise capacity and participation in PE, sport, or physical activity for those with JIA (Houghton, 2012). Due to the fluctuating nature of the symptoms and associated disability characteristics of JIA (Hanns et al., 2016), children are at increased risk of experiencing disruption to their schooling journey compared with children with other long-term conditions (Nordal et al., 2019). Another important factor is teacher knowledge and understanding of JIA. Chomistek et al. (2019) found most pupils to be open with their teachers about their condition and supported by their school. However, other studies have reported problems communicating with teachers (e.g. Secor-Turner et al., 2011) and issues with a lack of overall understanding about JIA (e.g. Tong et al., 2012). In secondary schools, pupils are often taught by several PE teachers. Therefore, teacher knowledge and support when teaching pupils with JIA may differ, in turn impacting upon the quality of the PE experience for those pupils (Jordan et al., 2021).

While we acknowledge that PE teacher views and experiences are crucial for better understanding: (a) the ways and extent to which teacher education prepares them for teaching pupils with special educational needs and disabilities (SEND) (e.g. Coates et al., 2020); (b) the appropriateness of the support that they receive from senior leadership and special educational needs coordinators (e.g. Maher and Macbeth, 2014) and learning support assistants (e.g. Goodwin et al., 2022); and (c) the inclusiveness of pedagogical (e.g. Overton et al., 2017) and assessment practices (e.g. Maher et al., 2023) in PE, it is crucial to remember that teachers are not the recipients of attempts to enact inclusion. Indeed, there has been a drive to centre the experiences and amplify the voices of those with SEND because of their lived, embodied knowledge of so-called inclusive practices in PE (see Maher and Haegele, 2022). Hence, this paper is novel because, for the first time in research, it amplifies the voices of under-25s with JIA, who reflect on their experiences of PE. To make sense of and construct meaning about the PE experiences of people with JIA, we draw on an ableism-critical perspective because others have found it useful as a tool to *think with* when exploring the concept of ‘inclusion’ in PE (e.g. Giese and Ruin, 2018), PE initial teacher education (e.g. Alfrey and Jeanes, 2021), and assessing the learning of pupils with SEND in PE (e.g. Maher et al., 2023).

An ableism-critical perspective in PE

Our ableism-critical perspective is inspired by the work of Fiona Kumari Campbell. We use ableism when referring to networks of ideologies, values, discourses, traditions, rituals, and behaviours (in society, school, and PE) that (re)produce a hegemonic, normative, mind–body–self that is projected and celebrated as perfect, species-typical, and therefore essential to being considered fully human (Campbell, 2019). In this regard, Braidotti (2013) suggests that the normative mind–body–self is anchored to European enlightenment period ideas about the human, best captured by Leonardo Di Vinci’s white, non-disabled, Western European Vitruvian Man. As such, disability generally and JIA specifically are cast as ‘diminished state[s] of being human’ (Campbell, 2001: 44) because they are perceived as not conforming to ableist expectations about how the mind–body–self should think, look, and move (in PE). It follows then that ableism is intersubjective because it permeates all social relations and interactions in schools and PE, producing processes and systems of entitlement for non-disabled pupils, and oppression, marginalisation, and exclusion for disabled pupils, including those with JIA, because they do not conform to normative expectations. According to Goodley et al. (2019):

> Schools [to that, we add PE specifically] are built upon highly regulated principles and policy discourses of individual achievement and progression. They are inherently individualistic and reward the entrepreneurial achievements of self-governing learners. The school is a literal and metaphorical ableist playground (p. 987).

As such, ableist systems such as school and PE, and hegemonic practices relating to policy construction and enactment, curriculum, pedagogy, and assessment, act as mechanisms of cultural (re)production that contribute towards creating hierarchised mind–body–selves through the 'differentiation, ranking, negation, notification, and prioritization of sentient life' (Campbell, 2019: 287–288). We see this most starkly through the neoliberal performative culture that pervades the field of PE (Evans, 2013), with its enduring emphasis on competition, winning and corporeal dominance and prowess. Such neoliberal performative cultures shape perceptions of corporeality and thus the construction of legitimate forms of ability-related (physical) capital. According to Croston and Hills (2017), pupils who are positioned and perceived as possessing such capital are privileged over others. Too often, these hegemonic beliefs about (physical) capital are based on normative perceptions of how the (able) mind–body–self should think, look, and move, thus resulting in many disabled pupils and some with special educational needs having their bodies and movement patterns judged negatively through an able-mind/body gaze (Lynch et al., 2023). In this regard, the able-mind/body gaze infiltrates associated practices that work to police and regulate nonnormative mind–body–selves in PE by, for example, using normative tools for assessing learning as a way of reinforcing ableist normalcy (Maher et al., 2023).

According to Wolbring (2008), ableism is so pervasive that it manifests as common-sense cultural ideologies and discourses underpinning taken-for-granted logics and thus is considered the 'natural' way of being. So much so, in fact, that ableism becomes internalised – that is, it shapes the individual and collective habitus or personality structure (Elias, 1978). It can be said, therefore, that ableism is structural, cultural, intersubjective, intrasubjective, and psycho-emotional in nature (Reeve, 2020). Disabled young people, including those with JIA, are not immune to the internalisation of ableist modes of thinking, doing, and being, which has been found to impact negatively on their self-esteem, self-confidence, mental health, and general well-being because they attempt, and frequently fail, to hold themselves to often unrealistic ableist thresholds (Reeve, 2020). Hence, it is crucial that ableism-critical perspectives are utilised to disrupt, dislodge, and transform hegemonic ideologies, discourses, and practices (in PE and schools) that subordinate the nonnormative mind–body–self because of the negative consequences it can have for their sense of self and personhood. We hope that this article, which centres pupils with JIA in PE and uses an ableism-critical perspective to make sense of their views and experiences, contributes in some small way to that cause.

While this brief discussion falls short of exploring the theoretical complexity and sophistication of ableism, we hope it sufficiently explains the lens through which we considered the PE views and experiences of pupils with JIA. In that respect, it is noteworthy that an ableist-critical perspective has largely been ignored in PE scholarship. Indeed, while some researchers have drawn upon it as a theoretical tool to make sense of and construct meaning about the concept of 'inclusion' (e.g. Giese and Ruin, 2018), PE initial teacher education (e.g. Alfrey and Jeanes, 2021), and assessing the learning of pupils with SEND (e.g. Maher et al., 2023), none of the research currently available has explored the PE views and experiences of people with JIA from an ableist-critical perspective.

Methodology

Philosophical position

Our research was underpinned by interpretivism in that it was characterised by ontological relativism and epistemological social constructionism (Sparkes and Smith, 2014). As such, we ascribe to the view that there is an external world outside of the individual that is inhabited by subjects and objects, but that we as humans make sense of and construct meaning about our worlds by interacting with those subjects and objects. Accordingly, what the participants perceived as ‘real’ when it came to their intersubjective experiences of PE had developed as they interacted with teachers, teaching assistants, pupils, parents, and others who were part of their relational networks. Hence, we did not seek to ‘discover the truth’ because there are multiple mind-dependent truths that are tied to the embodied experiences of the participants (Papathomas, 2016). Instead, we gathered both qualitative and quantitative data to construct a rich tapestry of knowledge that encapsulated the complexity and nuance of PE experiences according to people with JIA.

Given our epistemological positioning, we believe that researchers’ intersubjective ideologies, values, and inclinations inevitably shape the interpretive process. Therefore, it is crucial that we explicate our positionalities so that others can do as we did by considering how they may have shaped methodological decisions and interpretations of data. Tania is a disabled, white, cisgender female who was diagnosed with JIA at 13 years of age. She had positive experiences of PE at school, participated in sport from a young age, and has always felt encouraged by others to be physically active, which she thought was contrary to the experiences of others with a diagnosis of JIA. These embodied views and experiences led her to study for an undergraduate degree in Physical Education and School Sport and a Master’s degree in Occupational Therapy, and inspired her to want to research the PE views and experiences of others with a diagnosis of JIA. Tania led the research project. Kirsty is a non-disabled, white, cisgender female with 10 years of experience teaching secondary school PE, followed by six years of experience teaching and researching PE provision within higher education. Ben is a non-disabled, white, cisgender male with 14 years of PE teaching experience in mainstream secondary schools, further and higher education. Both Kirsty and Ben supported Tania to craft the research aim and purpose, explore the extant literature, design the methodology and gain ethical approval. Anthony is a non-disabled, white, cisgender male. At the time of writing, he was employed as a professor at a university in England, with 15 years of research and practice experience relating to pupils with SEND. Anthony drew upon his embodied knowledge and experience to help shape the philosophical positioning, theoretical underpinning and methodology, and contributed to writing the paper.

Method and procedure

An online survey was designed for the purpose of exploring the intersubjective, mind-dependent (Papathomas, 2016) PE experiences of individuals diagnosed with JIA. The survey was developed by and therefore through the lens of Tania around topics derived from reflections about her own embodied views and experiences of PE and a review of the extant peer-reviewed literature relating to: (a) special educational needs and PE; (b) disability and PE; and (c) JIA and PE. Specifically, the survey included questions under the following section headings: (a) the influence of JIA on participation in PE; (b) relationships with same-aged peers and their influence on experiences in PE; (c) relationships with teachers and their influence on experiences in PE; and (d) the appropriateness of the PE curriculum. An online survey was used because participants were geographically dispersed, and data were gathered when COVID-19 physical distancing measures were in place. Additionally, the anonymity that an online survey affords can encourage greater honesty, particularly with sensitive topics such as this (Wolter and Herold, 2018).

The survey included both closed and open questions, thus falling into the wider repertoire of mixed or multi-method approaches to generating data (Bryman, 2016). While the survey inevitably meant that we could not generate the thick, rich descriptions that are possible through, say, interviews, it did enable us to generate data that provided what Braun et al. (2021) called a 'wide-angle lens' relating to a diversity of perspectives, experiences, and sense-making while, at the same time, gathering rich qualitative data that captured the complexity and nuance of participant views and experiences of PE. The closed questions had a 5-point Likert response scale and included questions such as: (a) To what extent does your JIA affect your participation in PE? (b) To what extent do you feel your peers within PE understand your JIA? (c) To what extent do you feel your teacher understands your JIA? (d) How suitable do you feel your PE curriculum is for students with JIA? For the open questions, we were inspired by Braun et al. (2021) to carefully consider the: (a) clarity, accessibility, and focus of questions to ensure that they would elicit thick descriptions of views and experiences; (b) order of the questions to ensure that the flow was logical and did not result in repetition; and (c) length of the survey to ensure that it was not too onerous to complete. Example open questions, which were again influenced by Tania's embodied experiences of JIA and PE, the literature she had read, and tied to our aim of exploring the PE views and experiences of people with JIA, were: (a) How, if at all, did JIA influence your experiences of PE? (2) Please describe the relationships that you had with other pupils in PE. (c) Please describe the relationship that you had with your PE teachers. (d) How appropriate was the PE curriculum for you? (e) How could PE have been changed to better meet your needs and abilities? The research instrument and protocols received university ethical approval before being administered.

We targeted people under the age of 25 who lived in the UK and had been diagnosed with JIA because this age range was covered by the SEND Code of Practice (DfE/DoH, 2015), which details the legal requirements and duties that local authorities, health bodies, schools, and colleges must follow when supporting those with special educational needs and/or disabled people. A Facebook group set up to support individuals diagnosed with JIA and their families was used to recruit participants. While we were acutely aware that Facebook is used by more people who identify as male, and that age, geographical location, internet coverage, and socioeconomic status all shape the platform's demographics (Mellon and Prosser, 2017) and thus potentially the population that we recruited our sample from, we determined the JIA support group to be the best mechanism for targeting a large sample of people with JIA. In this regard, it is crucial to note that Tania had been a member of this group for approximately eight years, so had already developed trust and rapport with group members because of their shared embodied experiences of JIA. As such, Tania was considered an 'insider' by group members, which helped her to navigate the ethical sensitivities associated with using support groups to recruit research participants. A research advertisement was first posted to the Facebook JIA support group to briefly explain the aim and purpose of the research. Next, the online survey link was posted, which included an information letter and consent form that needed to be completed before participants were able to advance to the survey. It was specified that all under-18s must have assented to the research and required parental consent to participate. Parents and carers were invited to complete the survey in collaboration with participants under 18 years of age. In total, 100 participants (27 males and 73 females; 62 aged under 18, 38 aged 18–24) completed the survey.

Data analysis

Microsoft Excel was utilised to analyse quantitative data and produce descriptive statistics that were used to map views and experiences of PE from the perspective of individuals diagnosed with JIA. Qualitative data generated from the open questions were analysed thematically. The thematic analysis was inspired by guidance offered by Braun et al. (2018). First, Tania read all participants' responses to open questions several times until she became intimately familiar with their views and experiences of PE. As part of this initial sense-making process, Tania engaged reflexively by writing reflections about her own embodied experiences of PE to explore the ways and extent to which what she read resonated with her. Next, Tania drew upon her embodied experiences of JIA and PE, experiences as a member of the JIA support group, and knowledge of literature relating to JIA and PE, to code participant extracts as part of continuing meaning construction and sense-making processes, the result of which was the development of candidate themes. Following this, themes with similar meanings were clustered together until they became more established. Throughout, Tania wrote reflections relating to the ways and extent to which her own embodied knowledge and experience was seeping into the analytical processes to increase transparency and critical reflexivity as hallmarks of quality in research (Tracy, 2010). Established themes and their associated raw data participant extracts were then sent to Kirsty and Ben who acted as critical friends through a process of peer debriefing. Specifically, Kirsty and Ben reviewed the themes and data separately, drawing upon their extensive experience as former teachers of PE and current knowledge about researching PE to provide reflective notes that aimed to check and challenge Tania's construction of knowledge. The purpose here was not to validate the analysis because that would have been incompatible with our philosophical position. Rather, the intention was to support Tania to reflexively engage in the analytical process and question the assumptions that inevitably shaped it, which enhanced the quality (Richardson and St Pierre, 2017). Once themes were finalised, the qualitative survey data were harvested for data that aligned with the finalised themes that were missed during the initial stages of the thematic analysis (Braun et al., 2018). The finalised themes that are used to structure the 'Findings and discussion' section are: (a) *pain, fatigue, and fear of injury restricted participation in PE*; (b) *awareness and (mis)understanding of JIA;* (c) *the negative judgements of others and peer bullying in PE; and* (d) *the (in)appropriateness of the PE curriculum.* Pseudonyms are used to protect identities and participant extracts are presented throughout the 'Findings and discussion' section to ensure authenticity (Tracy, 2010).

Findings and discussion

Pain, fatigue, and fear of injury restricted participation in PE

According to the online survey, 77% of participants failed to participate in all their timetabled PE lessons. There were several factors that constrained the ways and extent to which participants could participate in PE, including the influence of JIA symptoms:

> If my joints are swollen, it feels almost impossible to join in during PE, as I even struggle to walk when they're swollen. (Olivia)

> I got picked for the netball team for a tournament and played really well, but the next day I was in so much pain. I've not been able to do PE since (about a month). (Alicia)

> If I'm having a bad flare or any pain, even if the activity is one I really enjoy usually, I struggle to get enjoyment from the activity as I am focused on the pain. (Ava)

Pain and inflammation appear to be key factors that contributed to lower levels of participation and reduced enjoyment of PE among the participants, and this was still the case when participants rated their enjoyment of PE to be high. This finding is unsurprising as inflammation has previously been found to contribute to reduced exercise capacity for children with JIA (Takken et al., 2008). Nonetheless, what the participants have said here is significant for several reasons: chief among them is that disabled young people's stories of pain have received very little attention in academic literature generally and hardly any in PE. Rather, research in sport, exercise, and physical activity has concerned itself mainly with narratives of pain as constructed by adults generally (e.g. Hunt and Papathomas, 2020) and elite-level adult sportspeople specifically (e.g. Bluhm and Ravn, 2022; Tynan and McEvilly, 2017), which is perhaps indicative of the ableist, normative percept that young bodies should be fit, healthy, and painless, rather than painful and leaky and thus faulty and flawed. According to Sheppard (2018), pain is understood through the ableist lens as dehumanising and thus the person living with chronic pain is understood as not human, abnormal, and disabled. Moreover, while most of the research focuses on pain and the disabled body as social–cultural–historical constructs (Sparkes and Smith, 2008), which aligns with a social-model perspective of disability (Hughes and Paterson, 1997), it is crucial to note, as Best (2007) did, that:

> People need to recognize that not all is social construction, ideology or discourse, all people have bodies and our bodies are often fragile and feel pain. There is more to pain than signification and narrative. … Language and metaphor may well be vehicles for making sense of bodily sensations and actions, but this is not the same as the suggestion that bodily experience solely exists at the level of language and metaphor (pp. 169–170).

Indeed, it is noteworthy that pain had a detrimental effect on mobility and accordingly some of the participants' experiences of PE. For example, some participants struggled to perform what from an ableist perspective would be considered basic human functions, such as 'getting changed for PE' (Daisy), which meant reduced learning time:

> I also took longer to get changed so a good portion of my PE lesson would be spent in the changing room whilst everyone else was out participating. I'd have to leave 5–10 minutes early and I'd get into the sports hall 5–10 minutes late, which took a decent chunk out of actual participation time. (Ava)

Together with pain, fatigue was reported by participants as being a symptom of JIA that influenced participation in and experiences of PE:

> My arthritis was badly managed so I was experiencing flare ups very often. So, I was in lots of pain and felt too tired to participate in every lesson. (Ella)
>
> If my ankles or legs are bad I can't join in because it hurts too much and I get too tired. (Savannah)

Given the dominance of the physical domain of learning in PE, with its associated focus on perpetuating and celebrating an able mind-body-self through normative modes of increasing cardiovascular fitness and performance in competitive sport (Maher and Fitzgerald, 2022), it is perhaps unsurprising that experiencing fatigue may restrict participation in PE. Children with JIA are said to feel perpetually caught between having hope and control over their bodies and overwhelming pain and despair (Tong et al., 2012).

The online survey highlighted participant concerns about 'fear of injury' as a reason why they could not participate in their PE lessons:

> I feel like I can't join in with stuff because I won't be as good because of my JIA. I fear that I'm being judged and that I won't be able to continue as my pain levels will go up. (Grace)

> I was more nervous of injury, high pain levels could become unbearable, and I was embarrassed I could no longer do sport as I once did. (Maya)

> Sometimes it stopped me from doing what everyone else was doing due to fear of feeling unwell afterwards or hurting my joints. (Zara)

While there is an ever-growing body of research that explores how elite athletes, including youth athletes, internalise pain and normalise injury in sport (e.g. Schubring et al., 2015) because of their assimilation into an elite sport culture of risk (Tynan and McEvilly, 2017), our research is the first to explore how pain and injury shape, or more accurately restrict, participation in PE among pupils with JIA. In fact, there is hardly any research to date that has explored how pain and injury influence the PE experiences of disabled or non-disabled pupils.

Awareness and (mis)understanding of JIA

Only 8% of participants felt their peers understood their JIA, particularly the unpredictability of the condition:

> They [other pupils] don't understand JIA. They don't understand that one day I can be feeling really bad and another day be fine. (Alicia)

Consequently, many participants suggested their peers thought that they used their diagnosis to avoid participating in PE:

> Some [pupils] think I fake my illness to get out of joining in PE. (Charlie)

> They [pupils] think I'm doing it for attention and think 'I wish I could get out of PE too'. (Ivan)

Similarly, just 10% of the participants felt that their condition was understood by their teacher. The lack of teacher understanding perhaps explains why several students reported feeling that their teacher questioned their diagnosis and symptoms:

> My teacher was never considerate of my JIA and always just treated me as though I was lazy and couldn't be bothered despite having doctor's letters and letters from the physio. (Lily)

> It honestly felt like they didn't believe me or my notes from my consultant. (Chloe)

> I feel they thought I was trying to get out of it and use my JIA as an excuse. (Alex)

As was the case with the pupils' peers, the unpredictability of the condition was difficult for the teachers to accept and again the participants felt that they were often dismissed by their teachers because of the lack of visible signs and symptoms of JIA:

> I felt that most teachers forgot that I was struggling during PE because they can't visibly see my disability. (Katie)

> When it's cold I was made to wear shorts outside which affected my knees hugely! (Luis)

It is perhaps unsurprising that there is a general absence of understanding about JIA given that it is now well known that young people and even teachers lack the knowledge and understanding of invisible conditions and impairments (Kattari et al., 2018; Sparkes et al., 2019). It seems, also, that the variable nature of JIA clashes with ableist assumptions that disability is and should be fixed and rigid rather than dynamic, temporal, and transient. One consequence of teachers comparing some of our participants to normative beliefs about what young mind-bodies should be able to do in PE was that those young people who fell below this ableist threshold were marginalised and even excluded from PE. This was certainly the case for Ava who, it could be argued, was punished for being disabled:

> Often teachers would automatically assume that I would or wouldn't be able to do something. The nature of JIA is that it's very unpredictable. One day I can keep up with the athletic students and the next I'm unable to walk and may need to use my wheelchair. This would mean that teachers would exclude me from certain activities, or sometimes tell me off for seemingly not trying hard enough, or not being able to complete an exercise when I did the week before/wanting to do an exercise when I couldn't the week before. (Ava)

Unfortunately for the participants in our study, and many other disabled pupils, there is research suggesting a relationship between a lack of knowledge of disability and negative attitudes towards disabled pupils (Beckett and Buckner, 2012), which may explain why 72% of participants had decided to only let a few of their closest friends know about their JIA. The disclosure of an invisible disability is a complex issue and very much a personal choice. While the reasons for not disclosing JIA were not teased out of the data that we generated, an unwillingness to disclose perhaps points towards an awareness among our participants that ableism pervades all social institutions and interactions (Goodley et al., 2019) and that it may result in them being judged negatively and having negative experiences of school and PE. To the best of our knowledge, no research has explored the disclosure of invisible disability among young people. Nonetheless, what we do know from research conducted with university students is that many decide not to disclose their invisible disability because of negative prior experiences of disclosure and fear of being stigmatised by staff and peers (Cinarbas and Hos, 2022).

For those participants in our research that had disclosed their disability, support from their friendship group was identified as being particularly helpful in PE:

> Friends would help or pick me for teams, whilst acknowledging my JIA and not pressuring me to 'win' or be as good as everyone else. (Nadia)

> Yes, those who are willing to stick up for you and position you in a less active roll (sic) in the team, but those who don't understand get angry that you aren't as good as they want you to be. (Erin)

It is important to note that the development of friendship groups and other positive peer interactions can have clear implications for feelings of belonging, acceptance, and value among the social group for disabled pupils (Spencer-Cavaliere and Watkinson, 2010). Hence, it is noteworthy that some, but not all, of the participants had those friendship groups to draw on as a support mechanism in PE. In this regard, Milner and Kelly (2009) highlight the importance of reciprocity among friends so that the relationship does not become hierarchical between disabled and non-disabled youth. Often, but not always, disabled youth occupy a position of lower social status when compared to non-disabled youth (Haegele and Maher, 2022), which is a clear indicator of ableism because it contributes towards the ranking and prioritisation of sentient life (Campbell, 2019).

Misunderstandings surrounding non-visible conditions are particularly prevalent when the person with the illness is younger (Ainsworth, 2018) and according to the participants there were misconceptions surrounding age and arthritis:

> …they [pupils] thought only old people have arthritis. (Ella)

> They [pupils] don't understand the pain you go through and think it's for old people. They just laugh or say it's only arthritis. (Nicole)

Tong et al. (2012) similarly found that many people did not recognise the seriousness of JIA and considered arthritis to be a condition which only older people experienced. This view aligns with an ableist perception that young mind-bodies (should) epitomise normative standards of health, vitality, and performativity (Campbell, 2019), while flawed or faulty mind-bodies are the reserve of so-called 'old' people. As such, many of the participants suggested the need to spread awareness of conditions such as JIA, in the hope that education would lead to better understanding amongst their peers:

> Having awareness that not all conditions are visible and just because someone looks fine and healthy, doesn't mean they are. There is a need for more empathy. (Sophia)

An increased awareness of disability can impact positively on attitudes towards disabled people and may go some way to disrupting and even dislodging ableism, especially when delivered from an anti-disablist perspective (Beckett and Buckner, 2012). However, this can depend on the ways and extent to which ableism has been internalised (Reeve, 2020); that is to say, how firmly embedded in an individual's habitus or personality structure (Elias, 1978) are ableist modes of thinking, doing, and being. In this regard, it is noteworthy that there is research questioning the ways and extent to which non-disabled people can ever develop the empathetic capacities (Coplan, 2011) required to cognitively and affectively imagine themselves (Cooper, 2011) as someone with JIA in order to 'understand' JIA, given that they have no lived nor embodied experience of it (Smith, 2008). Nonetheless, despite a seemingly widespread lack of knowledge and understanding about JIA, a small number of participants spoke positively about some of their teachers:

> I was also lucky enough to have one specific PE teacher who was pretty understanding and made the effort to listen to me and look up how my conditions affected me. She actually ended up enrolling me in the sports leaders programme…because she could see I was interested in sport and thought I'd be good at teaching others. (Ava)

It is crucial that teachers use their agency to actively resist ableist modes of thinking and doing by developing positive social relationships with (and, indeed, attitudes towards) disabled pupils as part of their attempt to foster feelings of belonging among disabled pupils in PE (Haegele and Maher, 2022). Moreover, it was encouraging to learn that some teachers were talking to pupils with JIA, given that these pupils have expert knowledge about JIA and teacher attempts at fostering inclusive PE environments (Maher and Haegele, 2022).

The negative judgements of others and peer bullying in PE

When questioned, participants expressed concerns about negative perceptions about their abilities in PE and the associated judgement made about their performance:

> I feel like I can't join in with stuff because I won't be as good because of my JIA – I fear that I'm being judged. (Jessica)

> I was so worried about being told off for underperforming compared to my peers. (Katie)

> It also affects my confidence because I might not be able to do things they [the teacher] ask. (Luis)

Tong et al.'s (2012) systematic review of qualitative studies that explored the experiences of children with JIA highlighted the worries some of the children had about their appearance and awkward movements, with the authors concluding that 'JIA disrupts a child's sense of normality and impairs their capacity for social participation' (p. 1392). Maher et al. (2023) and Lynch et al. (2023) have problematised the use of an ableist gaze to judge disabled pupils in this way because it is based on normative expectations about how mind-bodies should look, move, and learn, which can contribute to subordinating the abilities and achievements of those disabled people that do not conform to ableist expectations. This point is tied to neoliberal test-culture ideals and is contrary to research about the most effective ways to support learning and development, which emphasise more holistic views about abilities that incorporate social, affective, cognitive and physical domains, and tailoring expectations, pedagogy, and assessment to the needs and capabilities of pupils so that they can be stretched and challenged in ways suitable to them (Dinan-Thompson and Penney, 2015). We are especially concerned, as our readers should be, by the way our participants talk about their 'fear', 'worry', and lack of 'confidence' in PE. Whether it is perceptual or actual, our participants clearly believe that ableism permeates the ideologies, values, and practices of PE teachers, which is having a negative psycho-emotional impact on them.

According to our survey, 38% of participants did not enjoy PE because of their peers. The data similarly revealed that a number of participants had been mocked and abused by their peers as a direct result of their JIA:

> I am often laughed at in PE for not being able to keep up. (Ava)

> They [peers] get frustrated with me and some call me a cripple which upsets me (Jordan)

> Yes, I got called a cripple and was told I was ruining the lesson for everyone else because I was so slow. (Lily)

Interestingly, it seemed evident that for some participants their treatment by peers was tied to age:

> With age came more understanding, as it was definitely easier in my senior years of high school. Primary school was completely different, but again I think that had a lot to do with our age. Young

> children are ruthless and can be brutally honest and mean. I experienced a fair amount of bullying in primary school both in PE and in general, so I was definitely left out of PE activities more and was often laughed at for not being able to keep up. (Ava)

Bullying has been found to impact many disabled pupils in school (Dane-Staples et al., 2013). Tong et al. (2012) suggested that being misunderstood and discriminated against in school intensified pupils' feelings of stress, which may indicate why 38% of the participants suggested that they did not enjoy PE because of treatment by their peers. This finding is concerning because the bullying of disabled people in PE is said to lead to lower levels of physical activity outside of school (Dane-Staples et al., 2013). Furthermore, bullying, whether that be verbal, physical, or symbolic in nature, has been identified as a significant threat to interpersonal relationships and feelings of belonging among young people (Frederickson, 2010). It was clear from the testimonies of our participants that ableism, whether consciously or not, infiltrated the mode and mechanisms of interpersonal communication through the use of symbolically powerful language such as 'cripple' (Jordan). The use of such ableist language is, as is bullying, a chronic abuse of power and serves to (re)produce hierarchical relationships (Bourdieu, 1991) between disabled and non-disabled people. Consequently, research suggests that peer harassment and bullying have been associated with depression, and lower self-esteem, grade point average, and school attendance among young people (Crouch et al., 2014).

The (in)appropriateness of the PE curriculum

Only 15% of participants felt the PE curriculum was suitable for their needs. Activity (un)suitability was one of the most significant barriers to engagement in PE, with a need for 'more variety and less concentration on high impact sport' (Chloe) being a common remark. One participant outlined how the activity type would affect their participation:

> I'm not allowed to do contact sports… so if we were doing that for a term then I'd essentially have to sit out for the whole term instead of doing something I could do. (Ethan)

Seemingly, team games and contact sports, which dominate the PE curriculum in England (Griggs and Fleet, 2021), are an issue for many students with JIA and limit their involvement in PE lessons. Similarly, research by Sparkes et al. (2019), which centred the embodied PE experiences of a person with osteogenesis imperfecta (brittle bone disease), identified activities with a high degree of physicality and likelihood of bodies colliding as being indicative of ableist expectations of what the performative young corporeal body should be able to do and thus especially exclusionary for those physically disabled. Interestingly, research by Morley et al. (2021) suggested that teachers found team games and competitive sport especially difficult to plan and teach 'inclusively'. The findings from our research necessitate us to advocate for the use of curriculum activities that challenge and disrupt ableist corporeal performativity in PE through, for example, (more of) a focus on the individual, self-paced and self-regulated activities that Morley et al. (2021) recommended, which are often on the periphery of the PE curriculum. In this respect, survey responses from our research indicated the need for a wider repertoire of activities to be offered:

> Alternative PE, mindfulness, yoga, stretching, gentle exercise to support joints. (Joshua)

> Do less weight bearing exercise such as pilates, swimming or cycling. (Leah)

> If unable to do the structured class, there could be a strength and conditioning programme designed to improve my core strength. (Isabel)

> Climbing obstacles would be great and maybe some of my physiotherapy exercises could be included. (Jasmine)

There was also a suggestion, by participants, that disability sports should be included in the PE curriculum:

> I think maybe include some disability sports. (Emily)

> Do disabled sports such as goal ball. (Jacob)

> In one class, the teacher assigned us sit down volleyball, as a way for other people to understand a little. We should do more of that. (Emily)

While it is teachers who decide what the aim and purpose of using disability sports is, and thus the pedagogical approach underpinning them, empirical research suggests that disability sports can neutralise inherent power imbalances between disabled and non-disabled people and disrupt ableist perceptions of ability in PE by providing opportunities for disabled people to showcase their non-normative abilities to teachers and age-peers (Spencer-Cavaliere and Watkinson, 2010).

A number of participants suggested that they should be given ‘non-sporting or non-playing roles’ in order for them to be and feel included:

> Offering learning different roles such as referee etc. which may not be as physically challenging but offers a chance for everyone to feel involved. (Nadia)

> Being given tasks (like scoring, timing other students, setting up equipment) so I’m not just sat in the corner of the room. (Abby)

While we acknowledge the importance of inclusion being about how ‘included’ disabled pupils feel in the education and sporting spaces that they find themselves (Haegele and Maher, 2022), we caution against perpetuating an ableist mode of thinking and doing which relegates disabled pupils to passive roles in PE under the guise of inclusion because it may unintentionally cast them as, to use Fitzgerald’s (2005) term, ‘a spare piece of luggage’, and thus contribute to their marginalisation and subordination. Saying that, we do see wider educational value in disabled pupils taking on multiple roles and responsibilities in PE, as suggested by advocates of Sport Education (see, e.g. Siedentop et al., 2019), but this should be part of a carefully planned education unit, aligned to clear learning objectives that all pupils are set, rather than the consequence of a teacher’s inability to provide more active and meaningful experiences of PE for disabled pupils.

Interestingly, 67% of our respondents indicated that their teacher did not adapt their PE lessons to meet their needs. Participants suggested the following adaptations:

> Adapt sessions for those less mobile, like exercises that can be done in a chair or are lower impact. (Sara)

> Have differing ‘levels’ of activity, e.g. simpler exercises/skills, ranging to more competitive games so that there was something suitable for everyone. (Nadia)

> Potentially time to do physio programmes to one side instead of class activities so we could still get in our PE without just sitting out. (Ava)

The requirement to adapt learning activities to meet the needs of all pupils is outlined in the national curriculum statutory inclusion statement (DfE, 2013) and is widely considered indicative of 'inclusive pedagogies' (Vickerman and Maher, 2018). However, and while not wanting to undermine the views of the participants, we caution against activity adaptation being the default position of teachers because it can reinforce ableism by shedding light on perceived and actual differences between disabled and non-disabled pupils and consequently contribute towards the marginalisation of the former by the latter (Haegele et al., 2021). Accordingly, any decision to adapt learning activities in PE should be carefully considered and discussed with the disabled pupils because they are also 'expert knowers' because of their lived, embodied experiences of disability and the attempts of others to include them (Vickerman and Maher, 2018).

Concluding thoughts

In this paper, we sought to, for the first time in research, use an ableism-critical perspective to centre the experiences and amplify the voices of young people with JIA as a way of disrupting the ableism that permeates PE, schools, society and, for that matter, research. In doing so, it became apparent that pain, fatigue, and fear of injury shaped the ways in which the participants made sense of and constructed meaning about their experiences of PE. Our findings pointed towards the prevalence of an ableist, normative perception in PE that young bodies should be fit, healthy, and painless, rather than painful, faulty, and flawed (Sheppard, 2018). What we found about ableism, pain, fatigue, corporality, and youth in PE are perhaps our most novel findings because PE and sports scholars alike, ourselves included, have neglected to explore this important avenue of research. Based on what we found, it was clear that more needs to be done to increase teacher and peer knowledge and understanding of how pain, fatigue, and fear of injury influence the PE experiences of pupils with JIA because, at present, it seems that they are unaware. In this respect, there is scope to use, with their permission, the pain narratives that are lived, embodied, and told by young people as critically reflective tools to develop pre- and in-service teachers' knowledge. Moreover, where possible, teachers should gain more experience working with and teaching students who experience chronic pain because this 'contact' and 'exposure' has proven valuable to teachers when working with disabled young people generally (e.g. Coates et al., 2020).

There is a more general need to disrupt the ableist perceptions of ability that permeate all social institutions and spaces, including PE, because in this instance they contribute to casting pupils with JIA as being of inferior ability and consequently result in their marginalisation and even ostracisation. Perhaps more significantly, we found some evidence of ableist perceptions of ability being internalised – and thus psycho-emotional in nature – by some of our participants, manifesting in 'fear', 'worry', and a lack of 'confidence'. In this respect, we welcome holistic, multi-dimensional (rather than uni-dimensional) notions of ability, advocated by others, including Whitehead (2010), because they may contribute toward disrupting hierarchical ableist notions of corporeality and ability, whilst recognising the importance of pupils, including disabled pupils, learning, and developing holistically (Maher and Fitzgerald, 2022). Finally, there was strong evidence from the data that many of the participants had experienced bullying in PE because they did not conform to ableist expectations relating to how normative mind–body–selves should think, look, and move in PE. Ableist bullying, it is worth reiterating, is a chronic abuse of power and serves to (re) produce hierarchical ableist relationships between disabled and non-disabled people. At the same time, the friendship groups that the participants had developed served as an important support mechanism. Therefore, we agree with Haegele and Maher (2022) that schools and teachers need to do more to foster positive relationships between pupils with JIA and their peers because this contributes towards greater feelings of belonging for the former.

To end, initial teacher education and continued professional development are often identified as ideal (cultural) mechanisms for increasing knowledge, skills, and experience about disability and inclusion (Coates et al., 2020). While we want to advocate for anti-ableist perspectives underpinning PE teacher education, we know that ableism is deeply embedded in all ideologies, values, discourses, and practices (Campbell, 2019) that shape the culture of schools and PE (Maher et al., 2023). Therefore, focusing on teacher education alone is not enough. Instead, a more strategic and all-encompassing multi-stakeholder approach is needed to disrupt ableism by cultivating an anti-ableist culture in schools through policy, curriculum, pedagogy, and assessments, much like what critical race scholars and activists are trying to do vis-à-vis anti-racism. We know that we ask a lot, but it is what is required.

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