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Foot care needs for children and young people with intellectual and developmental disabilities

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Accessible Summary

- We asked parents of children with intellectual and developmental disabilities to complete a survey to help us understand more about the foot problems their children have experienced.
- Parents told us that foot problems were common in their children, 75% of the parents raised this as a concern. Less than half of the parents felt confident with managing these problems. Buying shoes was considered difficult.
- The results from this survey tell us that foot problems in children and young people with intellectual and developmental disabilities are a concern. It is important to ensure that children have access to foot care services.

Abstract

Background: Foot problems have been reported to be a very common health issue in adults with intellectual disabilities; foot problems in children and young people are, however, poorly understood. The aim of this study was to explore foot care needs of children and young people with intellectual and developmental disability.

Methods: An exploratory, cross-sectional online survey was undertaken across a four-month period. A purposive snowball sampling approach was adopted. The survey tool was piloted before launch and comprised three sections. The first section elicited information relating to parent/caregiver status, diagnosis, secondary diagnoses and age of child/young person. The second domain explored foot care and sought to obtain information about foot problems, access to health services and existing knowledge about foot health. The third domain focussed on footwear. Ethical approval was granted from the host institution, and all participants provided electronic consent before completing the survey.

Results: Data were collected from 49 parents/parental caregivers reporting on behalf of their children (mean age 7 years of age; SD 4.5 years of age). Parents reported foot problems to be very common (75%), and pes planus was the most frequent concern (51%). Twenty-four parents reported difficulties with finding shoes (48%). A mismatch between foot shape and the shoe (30%) or complications with orthotic devices (14%) within the shoe were highlighted.

Conclusion: The results demonstrated that the burden of foot problems in children and young people with intellectual and developmental disabilities is considerable. The findings highlight the importance of access to foot care services for these children.

1. INTRODUCTION

Healthcare needs in children and young people with intellectual and developmental disabilities are higher than the general population (Robertson, Roberts, Emerson, Turner, & Greig, 2011) and include many secondary comorbidities such as obesity, diabetes and musculoskeletal problems (Rimmer & Yamaki, 2006; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010). The foot and ankle is a common site for musculoskeletal complications in children (Fuglkjær, Dissing, & Hestbæk, 2017); these are often debilitating (Foley & Killeen, 2019) and can have significant impact on quality of life (Roux et al., 2005) and participation (Morris, Liabo, Wright, & Fitzpatrick, 2007). Foot and ankle problems result in additional health burden for children, their families and health service providers, and early intervention to support children to live healthy, active lives is essential (Roth-Isigkeit, Thyen, Stöven, Schwarzenberger, & Schmucker, 2005). This is particularly important for children with intellectual and developmental disabilities where the pattern of healthcare needs is more variable than the wider population (Cooper et al., 2015) and health inequalities remain common (Emerson, 2011).

Foot health is an important determinant of health and social mobility (Courtenay & Murray, 2015), and timely access to foot care services for children and young people is key to the early detection and management of foot complications (Foley & Killeen, 2019). Musculoskeletal problems in children with developmental and intellectual disabilities are common and include structural foot problems (Concolino, Pasquzzi, Capalbo, Sinopoli, & Strisciuglio, 2006; Foley & Killeen, 2019; Mik, Gholve, Scher, Widmann, & Green, 2008; Roizen, 2002), joint dysfunction (Galli, Rigoldi, Brunner, Virji-Babul, & Giorgio, 2008; Galli, Rigoldi, Mainardi, et al., 2008) and changes in foot shape (Church et al., 2017) and position (Galli et al., 2014). The pathways to musculoskeletal foot problems are complex and multifactorial, exacerbated by factors such as motor impairment (Cleaver, Hunter, & Ouellette-Kuntz, 2009), fixed deformities and contractures due to spasticity (Church et al., 2017), secondary issues such as obesity-related fatigue and muscle deconditioning (Rimmer et al., 2010), as well as individual factors such as pain experience(s) (Dubois, Capdevila, Bringuier, & Pry, 2010). The functional effects of foot problems are equally complex with gait changes (Galli et al., 2014) resulting in complex biomechanical movement characteristics which requires careful consideration during clinical consultation. Footwear has an important role in supporting the foot during weight-bearing; yet, findings suggest that footwear problems are a frequent concern in children (Kennedy, McGinley, Paterson, Ryan, & Carroll, 2018; Lim et al., 2015; Morrison, Price, McClymont, & Nester, 2018; Prasher, Robinson, Krishnan, & Chung, 1995). Poor footwear fit can affect gait and balance (Kennedy et al., 2018; Wegener, Hunt, Vanwanseele, Burns, & Smith, 2011) and has been reported to be associated with increased levels of foot-specific disability in children with Down syndrome (Lim et al., 2015) and reduced physical activity levels (Shields et al., 2017).

A better understanding of the musculoskeletal and biomechanical challenges in children and young people with intellectual and developmental disabilities could help identify the burden of these problems, and help understand their effects on activity and participation. Greater awareness of the foot problems across the lifespan is needed as good foot health and appropriate footwear choices are integral to enabling children and young people to participate in their communities (Ervin, Hennen, Merrick, & Morad, 2014). Despite the importance of these issues, work beyond the Down syndrome population is limited and a broader understanding of foot problems in children and young people is needed to inform preventative strategies and to reduce the progression of complications into adulthood. The aim of this study was to explore parent-reported foot care and footwear characteristics in children and young people with intellectual disabilities. This work sought to understand more about the issues that parents consider to be important as they are closely involved in managing their children's health and well-being. It is anticipated that this work will help health professionals target foot-health promotion strategies to raise awareness and better respond to the needs of children and young people with intellectual and developmental disabilities.

2. METHODS

2.1 Design

An exploratory, cross-sectional, UK-based online survey was undertaken across a four-month period from July to November 2017. The survey was adopted as the preferred data collection instrument in order to offer a flexible approach to data collection. This helped facilitate a broad reach of respondents across the UK and to help offer a real-world perspective on this issue (Kelley, Clark, Brown, & Sitzia, 2003). A purposive snowball sampling approach was adopted in which we sought to recruit parents/parental caregivers of children and young people with an established diagnosis of intellectual or developmental disability.

2.2 Survey Development

The survey was initially drafted by a group of BSc (Hons) Podiatry students under the supervision of the lead author. It was then reviewed and piloted with a group of 10 parents and further refined in response to their feedback. This second iteration of the survey was reviewed, readability and accessibility of the language assessed, and content agreed by all the co-authors to ensure relevance and clarity.

The survey comprised of three sections. The first section was used to profile the survey respondents and elicited information relating to parent/caregiver status, diagnosis of disability, secondary diagnoses and age of child/young person. The second section explored experiences of foot care and asked respondents to report on the typical foot problems they had experienced, whether they had accessed health professionals to seek advice and who these health professionals were, what advice they had been given and how confident they were about their existing understanding about foot care/foot health. The third section focussed on footwear and asked respondents to identify the types of shoes their child typically wears, where they buy their shoes, what advice they had been given about footwear purchasing and what they understand about appropriate footwear choices.

The survey was administered using online surveys. All participants read an overview of the project via the online information sheet and consented to participation via a consent statement embedded within the survey. Participants who did not agree to consent were not able to progress with completing the survey.

2.3. Participant recruitment

This survey sought to explore the views and experiences of foot care needs in children with intellectual and developmental disabilities through recruitment of UK-based parents/parental caregivers. To enable UK-wide participation, dissemination of the survey was conducted via online social media platforms. This included targeted Twitter™ activity to intellectual disability associations, as well as promotion of the survey to local intellectual disability schools. Parents/parental caregivers of children and young people who were without a formal diagnosis of intellectual disability were also eligible to complete the survey.

Prior to launching the survey, ethical approval was granted from the School of Health Sciences Ethics Review Panel. The survey was anonymous (unless parents submitted their email address and requested feedback on the results) and self-administered. UK status was self-reported when completing the consent statement.

The survey comprised a mixture of open and closed questions, as well as dichotomous, nominal and ordinal questions. Where participants were invited to respond to a fixed question and, where appropriate, an “other” category was included, and participants were invited to provide a narrative answer. Where possible, open-ended questions were coded back into existing categories. Coding of

the data into new categories was undertaken when the data could not be coded back to the existing categories. Coding of the narrative data was undertaken by the lead author (SM). Data were exported from online surveys, and initial cleaning of the data was undertaken using Microsoft™ Excel. Descriptive analysis was then undertaken with frequency and percentage data being reported.

3. RESULTS

Complete data were collected from 49 separate respondents. Two participants were excluded, due to not meeting the inclusion criteria ($n = 1$) or incomplete data ($n = 1$). Forty-five of these reported to be parents and four reported to be a parental caregiver/other. All respondents confirmed a diagnosis of intellectual and developmental disability. Twenty-nine of the children were male, 19 were female and one did not disclose the sex of their child. The mean age of the children was 7 years of age ($SD: 4.5$ years; range from 1 to 18 years). Eighteen of the children had a diagnosis of Down syndrome, and eight had a rarer chromosomal deletion (e.g., Potocki–Lupski syndrome or unknown deletion). Five did not offer a formal diagnosis. Seventeen had a developmental disability (e.g., autism), and one child had cerebral palsy. Nineteen parents reported additional secondary diagnoses which included developmental delay, hearing impairment, sensory processing dysfunction and visual impairment. Eleven respondents reported their child's intellectual disability as severe and 13 as moderate.

3.1 Foot care

Foot problems were highlighted in 75% ($n = 37$) of the respondents of the survey. Flat feet (pes planus) were the most common foot-related issue with 51% of respondents highlighting this as a concern. Joint hypermobility was also reported to be common with 35% of respondents reporting this as a problem. Skin and nail complaints were mentioned in 10% of the respondents. 57% ($n = 28$) of the sample reported receiving foot care advice for their child. Of those reporting foot problems, this increased to 75%. Foot care advice tended to focus on orthotic intervention (60%) and often occurred in conjunction with footwear advice (e.g., specialist footwear), which was mentioned in 53% of cases ($n = 26$). 8% ($n = 4$) reported advice on exercise intervention, and 1 respondent highlighted advice on skin or nail care. Of the sample, 85% ($n = 42$) reported that they inspected their children's feet and 26% undertook this daily. Less than half of the parents (48%) reported confidence in knowing how to manage their children's feet if they developed problems. 87% ($n = 43$) confirmed that they would seek advice from a health professional but online resources, shoe shops and family members were also cited as resources for advice.

Of those reporting that their child had encountered foot problems, several health professionals were accessed to seek support for advice and management of foot-related problems, and this included physiotherapists, GP and podiatrists. In 53% of the responses, parents/parental caregivers reported accessing physiotherapy services for foot care. Podiatry was mentioned in 43% of the cases and the GP in 40% of the cases. One respondent reported that their child had not been seen by a health professional regarding their foot care needs.

3.2 Footwear

Difficulties with finding suitable footwear were reported by 48% of the respondents. Reasons for this were varied but a mismatch between the child's foot shape (e.g., too narrow, too wide) and the shoes that were available on the high street was an issue for 28% of the respondents ($n = 14$). Fourteen per cent ($n = 7$) reported problems with finding shoes that accommodated orthotic devices, for example foot–ankle orthoses. One respondent highlighted that sensory processing dysfunction made footwear fitting a challenge. Footwear choices varied but were commonly trainers (38%), boots (32%), orthopaedic footwear (8%), school-type shoes (8%) or others such as croc- or converse-type shoes (8%). 73% of respondents preferred footwear with Velcro; 14% preferred footwear with laces and

12% had no preference. 55% of the respondents did not know what features made a good shoe. 44% of the respondents reported receiving footwear advice which was delivered from a range of health professional (i.e., podiatrists, physiotherapists and orthotists), as well as staff working in shoe shops. Two respondents had footwear provided for their children but the majority (95%) accessed high street (including supermarkets) and online retailers to buy shoes for their children. 68% respondents reported getting their children's feet measured.

4. DISCUSSION

The purpose of this study was to advance understanding of the range of foot problems experienced by children and young people with intellectual and developmental disabilities. This work has described the common foot care issues experienced in children and young people and demonstrated that a high proportion of those were affected by foot problems. This finding was similar to a previous study in a cohort of adults with intellectual disabilities (Lennox, Nadkarni, Moffat, & Robertson, 2003) where foot problems were reported to be the most common health issue in this cohort. These data also echo recent work which has highlighted musculoskeletal problems to be common in children with Down syndrome, specifically foot-related complications (Foley & Killeen, 2019). The findings from our study confirmed that parents were accessing healthcare services for their children and that parents were regularly monitoring their children's feet. It was reassuring that 85% of the respondents were undertaking regular inspections of their children's feet as this is an important preventative strategy for identifying foot problems early and preventing longer-term issue complications.

Health professionals were cited as a common source of advice with 87% of respondents reporting that they would seek advice from health professionals when needed. The common clinical issues reported in this study included flat feet and joint hypermobility, both of which have been related to recurrent lower limb and foot arthralgia (Murray, 2006), proximal joint problems (Kothari, Dixon, Stebbins, Zavatsky, & Theologis, 2016) and reduced quality of life (Kothari, Dixon, Stebbins, Zavatsky, & Theologis, 2015; Kothari, Stebbins, Zavatsky, & Theologis, 2014). Respondents reported accessing foot care advice via the internet, shoe shops and family members. This finding reflects the evolution of health information seeking (Powell & Clarke, 2002; Tonsaker, Bartlett, & Trpkov, 2014) with the Internet emerging as a key resource for parents. The data suggest that better strategies might be needed to ensure that accurate information is available across different media platforms to support parents' knowledge and understanding of common foot problems. Of our sample, 57% reported that they had received foot care advice; yet, fewer than 50% of our respondents reported that they were confident in knowing how to manage their children's feet problems. Health education and access to specialist foot care services are clearly important, and this study adds to existing concerns about footwear (Farndon, Robinson, Nicholls, & Vernon, 2016) and highlights the need for carefully directed education which involves parents/parental caregivers and their children. Given the health burden faced by this population, it is important that children have access to health professionals that understand the complex pathways to the types of foot problems reported in this study. It is clear that more evidence is needed to understand the functional effects of the foot problems reported and further work is required to understand what interventions are needed to mitigate against these issues. The availability and provision of appropriate and affordable foot care services are a concern (Hart, 2015) and it is important that services are responsive to the needs of children, as well as being adaptable to the different models of care. Family carers and other stakeholders (such as school staff) would benefit from understanding more about the typical foot care needs in children with disabilities and health promotion activities could be a positive approach to raising awareness about these needs, as well as promoting preventative strategies.

Problems with footwear were common with 48% of the respondents reporting difficulties when buying high street footwear. A mismatch between foot shape (possibly due to deformity or changes

with foot position) and the suitability and availability of shoes on the high street was the most common reason for this concern. Respondents reported difficulties with standard footwear accommodating orthotic devices (e.g., ankle-foot orthoses) leading to poorly fitting shoes. Appropriate footwear choices through the lifespan are important to protect the feet as well as provide support for the body during functional activities (Morrison et al., 2018), and these data add to an existing concern. Previous work in a sample of 50 children with Down syndrome identified that poorly fitting footwear was a source of pain and associated with increased levels of foot-specific disability (Lim et al., 2015) and reduced physical activity levels (Shields et al., 2017). Poorly fitting footwear has also been implicated in the development of mechanical skin injury (e.g., blisters, and callus) and nail complications (Jenkins, Cooper, O'Connor, Watanabe, & Wills, 2011). These data highlight the importance of easily accessible and specific footwear guidance which helps parents to understand the common features of shoes and to recognise what is important to inform their decision-making.

Understanding the features that make an appropriate shoe is important, and this must be communicated to parents in a manner that they understand. 44% of the respondents reported receiving footwear advice but 55% ($n = 27$) of respondents were not aware of features that made a good shoe. We identified that parents were typically seeking guidance about footwear from physiotherapists and GP, and the data suggest that there is a need to ensure consistency of information across all stakeholders (including footwear retailers). There is a shift in how people are buying shoes with a greater number of outlets (e.g., supermarkets) and online retailers offering greater purchasing convenience. As identified in the survey, foot problems were common in children and young people and the appropriate support (particularly where devices such as foot or ankle-foot orthoses are being worn) is needed. Findings from a recent narrative review called for greater emphasis on both footwear fitting education and the provision of shoes that accommodate the variation in foot morphology amongst the population (Buldt & Menz, 2018). This appears to be particularly important in these children and young people where typical retail footwear may not meet their needs.

Although these data highlight some clear concerns about foot care for children and young people, the findings must be interpreted in relation to the limitations of the study. The decision to undertake an online survey offered several benefits but does also compromise the depth of the data we were able to capture, as well as the level of analysis that can be undertaken on this. We did not record the sex of the parent/parental caregiver respondents, and this impacts the broader interpretation of the findings. It must also be acknowledged that the response rate was small and is a potential source of responder bias. The findings reflect the views of respondents that we were able to capture via social media channels and online media, and we acknowledge that this offers a limited perspective of the view of parents/parental caregivers and may offer a skewed perspective of the needs that these children have. This also highlights the limitation with our parent-reported data. It is difficult to determine the true burden of the issues reported, and a larger prevalence study based on the clinical assessment of foot care issues is needed to bolster the validity of the findings reported. Further consideration of the functional effects of foot care problems in children with intellectual and developmental disabilities is essential to inform service delivery and ensure that services are responsive to the breadth of care needs that these children have. Further work will also help inform the development of clinical guidelines to help set standards of care for these children.

5. CONCLUSION

The results from this survey demonstrated that foot problems in children and young people with intellectual and developmental disabilities were considerable. The data offered a snapshot of the concerns that parents encounter, and the findings highlight the importance of access to foot care services for these children and young people. These findings highlight that health professionals

working with children and young people with intellectual and developmental disabilities should be aware that foot problems are common and ensure that these issues are explored during consultations. Coupled with this, there is an ongoing need to offer tailored foot care and footwear education that is targeted at the common problems encountered in this population. Footwear fit and suitability were important issues and highlight the need for greater consideration of these issues, from both clinical and footwear industries. Findings from this study can inform further work to capture the prevalence of foot problems in this population and understand more about the functional impact of the problems reported in this study.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the lead author (Stewart C Morrison) upon reasonable request.

DECLARATIONS

The authors have no declarations of interest.

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