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AN EXPLORATION OF COMFORT AND DISCOMFORT AMONGST CHILDREN AND YOUNG PEOPLE WITH INTELLECTUAL DIFFICULTIES WHO DEPEND ON POSTURAL MANAGEMENT EQUIPMENT

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Acepted for Publication

ABSTRACT

Abstract

Background

The natural response to the intrusive bodily sensation is positional change. This study explored how children and young people (CYP) with intellectual disabilities had their comfort needs met when using adaptive positioning equipment.

Methods

Thirteen qualitative case studies were undertaken. A parent, a teacher/key worker and a therapist for each CYP were interviewed, and daily routines were observed, with selective video recording. Single case and cross case analyses were undertaken.

Results

Attentive caregivers read the behavioural expressions of the CYP and responded reassuringly, safeguarding them from discomforting experiences. Threats to comfort include the restrictive nature of some equipment accessories, positioning errors and procedural stretching.

Conclusions

The same item of equipment can be both comfortable and uncomfortable. Given the social and interactional world in which the CYP live and learn, it is others who must accept responsibility for ensuring their optimal level of comfort.

Introduction

The advent of adaptive seating in the twentieth century was a response to and catalyst for social change, enabling children, young people (CYP) and adults with physical and intellectual disabilities (ID) to leave the confines of institutional life and access the wider community (Watson &Woods 2005). Adaptive seating can potentially enhance an individual's learning and life experiences by enabling practical access to transportation, variable environments and interpersonal communicative opportunities. A later focus on positions other than seating arose to address the distorting effects of gravity on body shape, and CYP are now using a variety of sitting, standing and lying devices (Hill *et al*. 2009; Pountney *et al*. 2009; Hill & Goldsmith 2009; Gericke 2006). The influence of positioning on function is addressed in evaluative studies of adaptive equipment with some positive outcomes emerging from literature syntheses, although statements about the imprecision of included studies, lack of appropriate outcomes and the heterogeneity of user populations included remain prominent features (Ryan 2012).

Comfort is of major importance for users of adaptive equipment, as some spend several hours in one position (Goldsmith & Goldsmith 2007; McDonald & Surtees 2007; Telfer *et al*. 2010). Individuals with communicative capacity can evaluate equipment comfort; they express views and experiences, use visual analogue scales, pain diagrams or the Wheelchair Seating Discomfort Assessment Tool (WcS-DAT) (Crane *et al*. 2005; Bergstrom & Samuelsson 2006). Users incapable of using language, who remain dependent on others to gauge their need for positional change, are not indifferent to pain and discomfort which could arise from a pre-existing health condition, procedural activities or the equipment they use on a daily basis (Dubois *et al*. 2010; Tupper & von Baeyer 2010; Parkinson *et al*. 2010; Carter *et al*. 2002).

Positioning discomfort first presents itself as an unconscious desire to change body posture, which diminishes when the individual is able to initiate a change of posture. The discomfort increases across time, and may be associated with one or more factors such as instability, sliding, excessive heat build-up, stiffness, excessive localized soreness or pain, spasticity, or stretch. It may be specific in location

or generalized (Frank *et al*. 2012; Gibson & Frank 2005; Geyer *et al*. 2003), and possibly worsened by the distorting effects of gravity on body shape (Hill & Goldsmith 2010).

Comfort as an explicit outcome of adaptive positioning technology is consistently rated as important by parents, therapists and teachers (Washington *et al*. 2002; Fradet *et al*. 2011), but rarely examined in isolation (Roxborough 1995; McDonald *et al*. 2004). Equipment evaluations sometimes include a targeted question on the topic of comfort, particularly if it is a carer reported objective prior to the intervention (Neilson *et al*. 2001). A survey of parents and therapists of fifty-nine children with multiple and complex needs investigated opinions about individual seating systems; one question asked participants to rate the child's comfort, and another question asked about discomfort (McDonald *et al*. 2004). The findings, which might relate to the amount of time spent with the child, or parents' confidence in communicating with their children, reveal parents were confident that they knew when their child was comfortable and were accordingly consistent with their responses; therapists, however, were less consistent.

Contemporary adaptive equipment designs should enhance comfort but functional use could be compromised if intrusive positioning discomforts exist; such a negative event could affect an individual's quality of life. The overall purpose of the current study was to extend understanding of how CYP with physical disabilities and ID, who own the experience but do not use language, have their comfort needs met when using adaptive positioning equipment. For these individuals, interpersonal relationships are important as they help maintain a connection between the person, their social world and their personhood (Hogg 2007). Significant others become their communicative partners yet the experience of using equipment belongs to them, and their expressive behaviours must form and inform contextual decisions made by others about comfort/discomfort. The concept of person-centred practice and the professional postural management experience of the first author were motivating factors in the development of the current research. The starting point was the formulation of three exploratory questions:

1. how does the CYP communicate an experience allied to positional comfort or discomfort?
2. how do others in the social life world of the CYP interpret comfort and discomfort?

3. and, what factors contribute to an experience of equipment comfort/discomfort?

Methods

Design

The study used qualitative case study design; an approach that allows cases to be explored over time and place through detailed, in depth data collection involving multiple sources of information rich in context (Creswell 2007). Sampling was nearly inseparable from conceptualisation of design as the 'case' evolved, with its own unique pre-designed 'case' framework. None of the current authors had previous associations with the study sites. Throughout, an audit trail documenting decisions and activities was used alongside 'reflexive accounting' (Creswell & Miller 2000).

Participants

Using intermediaries, thirteen index cases (CYP who used adaptive positioning equipment) were recruited from three sites providing specialist education for those with severe and profound ID. The purposive sampling was also sequential as other specified participants were essential to each 'case' (a child/young person, his or her parent/s, a teacher/key support worker, and a therapist). The three sites allowed for maximum variation, representation of diverse cases and multiple perspectives (Creswell 2007). Some characteristics of the CYP are presented in Table 1, but to preserve anonymity identifying data are not defined for each case. Five index cases were receiving primary education in a special needs school (ages 4-11), two pre-school children commenced full time education at the same primary school during the course of the study, four were receiving secondary education (ages 11-19) at a different school, and two young adults attended a day service centre. Nine CYP functioned pre-linguistically, not using symbols in the interactive opportunities that took place. Seven CYP had cerebral palsy (CP), and five a diagnosis of chromosomal or syndrome cause origin. Whilst not all the CYP had CP, assessment using the gross motor function classification system (Palisano *et al*. 2008), found that eleven scored a functional level V and two level IV, thus indicating a need for postural management (Gericke 2006). Collectively, the equipment used included moulded, matrix and various types of postural support modular/adjustable seating (all with a tilt-in space-chassis), supine and prone standers, and sleep systems. The CYP often had a second seat for home, and some a third for transportation. All CYP lived in their family home.

Ethics

Ethical approval was obtained from a university Research Ethics Committee, the National Research Ethics Service, the National Patient Safety Agency and an NHS Trust Research and Development department. Parental permission, which included informed consent, was obtained, and assent from the CYP using interpersonal practices (Lambert & Glacken 2011). Written informed consent was obtained for all adult participants within each bounded case, following approved permission to access school and day centre premises, undertake field work, and access education, health and social care staff. Due to the overt nature of school-based/day centre fieldwork, open discussion with staff was used to ensure that data collected remained anonymous and non-attributable outside the organisations involved.

Data collection

Different levels of data sources and methods were used explicitly for the purpose of triangulation (Flick 2009). Semi-structured, open ended interviews were conducted by the first author with the parents, teachers, therapists and key support staff, using an interview schedule. Parent interviews took place in the family home, each lasting 50-130 minutes. A convenient location in school or day centre was used for the other interviews; these were conducted either at the beginning or end of the working day each lasting 30-60 minutes. At the end of each interview participants were asked to complete a checklist of behaviours, extracted from the Non-Communicating Children's Pain Checklist (Breau *et al.* 2002), allowing them to comment on differences between pain and discomfort. The first author observed the school or day centre routines of each CYP for one full day, using observational grids and field notes to document equipment usage, posture, salient contextual influences, situational events, transfers, communicative interactions, facial expressions, vocalizations, and limb movements. The video recording of each CYP took place on a separate day using a small, portable, digital hand held recording camcorder. A fully charged battery pack allows 80-90 minutes continuous recording time and two were available; however, the recording was discretionary not continuous due to ethical, privacy and contextual factors. Consensus was achieved via member checking of interview data and video streams of behavioural expressions.

Analysis

As the cases and research questions were defined in advance, with assumption that in the different case groups different understandings would be found, a thematic analysis developed by Flick (2009 pp.318-323) and suitable for case study research provided the framework. This approach generates thematic domains and categories for the single case first. Following cross-check of the categories, a thematic structure evolves which create the framework for subsequent case analyses, allowing for comparison and interpretation beyond the single case. This approach was chosen as the procedures followed remain sensitive and open to the specifics of individual cases and the social group with regard to the issue under study (Flick 2009).

Data management

All interviews were transcribed verbatim. The video images were converted to MPEG file format for playback, ethnographic content analysis and textual transcription (Grbich, 2007). Timelines produced from observation data displayed the length of time a position was adopted, core curriculum activity/personal hygiene/breaks and equipment usage, alongside noteworthy behavioural change. Case vignettes were produced, embedding data from different sources (observation and video), alongside the different sets of interview data (parent, therapist, teacher/keyworker) (Flick 2009). The computer assisted qualitative data analysis software programme NVivo version 7 (QSR 2006) enhanced storage and retrieval of the data.

Analytic stages

For each case, NVivo coding was used to label the data; some codes were apriori, linked to the research questions, for example, 'facial expression', others inductive, for example 'distraction'. This was followed by a synthesis of the codes labelled and allied to a 'behavioural expression' (interview transcripts and observations) with the behavioural checklists. Next, coded extracts of similar characteristics were brought together using NVivo's hierarchical tree branching structure, whereby a parent code may have one or two child codes, which may themselves be children to other codes (Gibbs 2002). One branching tree structure was immediately explicit as a potential thematic grouping, 'behavioural expressions' as this had a direct link to the first research question. Except for one other overarching theme linked to 'causes', the remaining data configurations at this stage were less explanatory, particularly the group of sub-categories grouped under 'contextual use/non-use of

equipment'. This prompted review of the coded contextual events, case vignettes and code definitions. Accordingly, there was reorganisation of this and other family trees. For example, the shaded parent codes in Table 2 subdivided from the group and merged with another as these were 'interactions' in response to observed behavioural change, not just description of the event/equipment.

With guidance from Flick (2009 p.230) further endorsement of meaning in relation to comfort/discomfort was achieved by cross-check of the categories, the use of strategic questioning and the formulation of a visual model. The outcome was a thematic structure (Fig.1) developed for the first case and continually assessed for all further cases.

Comfort/discomfort were the phenomena of interest, but the focus being the CYP's means of communicating this experience (behavioural expression), or another type of experience. Alongside interpretation of the behavioural expressions, the significant others had an influential role, accordingly gauging need and instigating use/non-use of the equipment. Therefore, a second thematic grouping was created from the data sub-categories 'interactional strategies' and 'interpersonal factors'. Circumstances (physical and contextual) leading to the consequence comfort/discomfort formed the third thematic grouping.

Results

The results are organised to illustrate the across-case findings that advance the three exploratory questions. The first theme gives focus to the behavioural expressions of the CYP and addresses question one regarding communication of the comfort/discomfort experience, but in reality they were interpreted by the significant others (including the researcher). Retaining a focus on the CYP owning the experience and their behavioural expressions, the theme evolved as a composite to address the first two exploratory questions. The dependency of the CYP meant they did not use equipment without help and the second theme presents findings with supplementary focus on the significant others. The final theme links directly to the third question, addressing factors contributing to an experience of equipment comfort/discomfort. Case pseudonyms are used and ellipses (…) indicate the material has been edited for brevity.

Communication of a comfort/discomfort experience

Based on the researcher's observations in the classroom (hereafter referred to as observation) and participant descriptions, the findings describe the CYP's non-verbal behaviours and expressions. All case participants reported on features exhibited which enabled them to detect expressive differences. Facial and vocal expressions were predominant for most of the CYP, although for Susan, right arm movement appeared more expressive. Table 3 contrasts the behaviours for Susan and Ellie, the shaded rows represent responsiveness to unpleasant situations.

The participants described behaviours using significant events involving equipment. Phillip's keyworker said '…because after 10 minutes you can see his face change, he doesn't want to be on it [tilt table]. He is obviously uncomfortable', another mother said:

> …it is moulded to fit her shape, you have to have her exactly in the exact position or she is uncomfortable. I know a few times she has come back from school and she has been a tiny bit out and she has cried all the way home (Nicola's mother).

> He kind of moans a bit to start with and his feet move a little bit because he finds it difficult, he can't really move his legs but he can move his feet; you can see his boots moving a bit as if to say 'I'm uncomfortable but I can't do it myself'. (Aiden's teacher)

In addition to positioning comfort/discomfort the participants also reported these behavioural expressions of affect being used to determine somatic and visceral acute pain status, emotions/ distress, constipation/flatus/cramp, boredom, fatigue, as well as the CYP's response to pleasurable comforting events. Affirmation of the categorical nature of the behaviours was perceived possible for some individuals.

> I never thought we would know what he wanted or anything but he can tell us … we have learnt his different whines. There's a whine when he's like bored and there's a whine when he's generally upset, and then he has like his proper crying. (Dominic's mother)

Other participants explaining that if certain behaviours were extreme it meant something more serious.

> …one night she was hysterical…she was flitching and jumping…we ended up taking her to hospital … and the pain, you could see she was in pain, pain, the expressions, the clinging to you as if to say. 'You've got to do something', because she obviously can't tell us what it is'. So yes, you can tell the difference between discomforts in the seating to pain. She's very good at showing the difference. (Ellie's mother)

However, a teacher who had known the pupil in her class for approximately 6 months explained the difficulty when attempting to attribute a cause when a similar behaviour could map on to a range of issues.

> …it is quite hard to distinguish because I think is it whether he is poorly or got a pain or whether he is uncomfortable or whether he is just being a little bit naughty for want of a better word. It is sometimes quite hard, and it takes a long time to get to know. (Brendan's teacher)

Whether discomfort from equipment was present sometimes remained unclear. Struggling with interpretation, the significant others used a process of elimination and sometimes team effort was necessary. Susan's father said 'If she is uncomfortable, you go through a list. Is she sitting comfortable where she is, is it her bowels? You just have to guess yourself, take her upstairs check her pad'. In school, 'because if she cries and they can't find out what's wrong they'll bring her along and see if I can find out'(Nicola's therapist).

In comparison, the findings revealed times when the CYP were content, happy and responsive to everyday activity.

> She is more focused. When she's sitting in her school chair and she's got her tray in front of her, she's looking at me, she's giving me a whole load of eye contact, she's smiling, she's giggling, there's a tray so we can put things on, we can interact with her and kind of she's right in front of me and I'm right in front of her but when she's on the floor she shuffles away (Elizabeth's teacher)

Contribution of significant others to the experience

Parents experienced equipment use in the context of family life. Conversely the teachers, therapists and support workers used equipment in the context of their professional activity, often in busy educational environments, where therapy-identified goals for postural management were in place alongside curriculum content and care plans. The second theme illustrates how daily routines, judgments made by significant others regarding equipment and their attentive responsiveness may affect the CYP's experience of the equipment.

The time charts revealed typical days with regard to equipment use at school/day centre, with the positional changes facilitated by significant others more varied for the younger children. Ellie's chart revealed she experienced eleven transfers and four different items of postural management equipment during the school day, and for one hour was free from all equipment spending time in a sensory

learning room. In contrast, Susan's day only involved two different types of the same item of postural management equipment (seating) but she was still involved in seven transfers, and spent time out on a floor mat. In all cases obligatory care acts relating to personal hygiene also involved re-positioning. Other equipment--free curricula activities included hydrotherapy, rebound therapy, physical education and physiotherapy. Some days the CYP spent more time in their wheeled seating experiencing life outside of the school/day centre.

> In terms of the equipment time wise, he will be in his [adapted] buggy for about half an hour for transport, he will sit in his school seat for another 45 minutes, and then unless something else happens to him he will be taken out and may-be lie prone and then he will go back in his seat for lunch, and then he will come out of his chair for something. Unless he is out on the bus for a full day, then he will spend a little bit longer in his buggy (Aiden's therapist).

> I think from a teaching point of view…, in your planning etc. you do think about how long the children are sitting, to make sure there are opportunities. I wish we could do more. I wish I could say he is out every morning, every afternoon but I can't because I know that is not the case but I can honestly say he is out every day. He loves to be out I think it must feel very restricted. (Stephen's teacher)

Used less frequently but still involving a transfer in and out of equipment, a standing frame/tilt table was used by ten of the CYP, with seven standing for approximately 30 minutes, three to five times per week at the school /day centre. Again this varied, with teachers reporting 'sometimes 45 minutes based on length of assembly' (Elizabeth), 'the therapist aims for an hour' (Peter), 'but on another day might only be 5 minutes' (Aiden), 'he sometimes does not tolerate it due to pressure on his gastrostomy peg (Dominic).

Parental obligations and routines varied across the cases. However, emerging from the parental narratives was a son or daughter's entitlement to freedom from school/day centre exertions whilst at home. Parental actions were not always spontaneous; rather they had become routine family practices, which saw a number of the CYP using the sofa, the floor, supportive arm chairs or even bed on their return from the school/day centre.

> Probably take him out of his chair. Lift him on the floor. He has been in a chair all day at school. That journey on the bus home is quite a long time - just stuck there squashed in that chair. (Aiden's mother)

> Really, the most comfortable position is when she is lying down, but, it is obviously not the most ideal position; that is why she has this chair now. I think

> that when she comes in from school she wants to get a lie down, her brace off and things… because she usually is quite tired.(Nicola's mother).
>
> She sits on the floor. The chair; we don't leave her in the wheelchair all day. I don't like it, her legs swell up, cause she's not moving around enough. I prefer her on the floor so she can just move around (Jenny's mother).

The findings illustrate the impact of distress on the parents and others. Distress was not ignored. One mother (Dominic's) said, 'I can sleep if he is still laughing but I can't when he's whining or crying I've got to be there'. Age was no barrier, with all parents regularly attending to their offspring's needs during the night. One mother explained how they still go to their daughter about three times a night if awakened suddenly or usually in response to a groan. She said, 'If Vikki has never moved for a while I've got to turn her'; a need which sometimes, but not exclusively, related to positioning discomfort. One father (Susan's) said, 'Being a parent you know the signs straight away, you know something needs to be done.' Another mother said:

> It's hard, it's really hard to see your child so upset knowing that they're [professionals] telling you it's going to help them in the long run but you don't see any of those good side effects, you don't see them for quite some time to be truthful. So you're being told to persevere, ignore the crying because that's just for... or you know, 'I'll cry and my mam will stop' … and it was really hard and these equipments didn't look nice, it looked like torture equipment and you don't want your kids in stuff like that…I hated her in it, absolutely hated her being in that. (Ellie's mother)

This caring ethic was not exclusive to parents. Significant others strived to fulfil professional aims but also demonstrated an empathetic awareness of and sensitivity towards the CYPs' likes and dislikes. They were aware of the distress some items of equipment used to address therapy goals could evoke, regularly removing the CYP from the equipment in cases of uncertainty or perceived distress. This practice was observed; a strategy, irrespective of cause, which gave opportunity for repositioning and possible relief from any discomfort. One participant said:

> I mean she has come in first thing in the morning…really upset and we just have to get her out of her chair straight away. I think it's because, I hope it's because she knows she can trust us knowing how she's feeling if something wasn't right, it could be her hip in her chair,… on her leg or something like that anything. We just try to get her out the chair as quickly as possible… I couldn't personally leave her for longer than that or tell her it's alright'. (Nicola's teaching support worker)

Factors influencing comfort/discomfort

This theme considers factors perceived to be a source of equipment discomfort, and those that portray functional well-being, expectantly trusting that the CYP were comfortable. Irrespective of practicality aesthetics was used to appraise equipment, words such as, 'comfortable', 'relaxing' or 'comfy' used to describe equipment that was pleasing on the eye.

> He hasn't really got a comfy chair or anything, where he could just sit and be a bit comfier, he always seems to be strapped and all stuck in and I just think he looks very tight stuck in, and even on his stander he has to be strapped in (Aiden's mother).

Visually, if the CYP appeared excessively restricted in the equipment this was a concern for the parents; the words 'straight jacket', 'fixed', 'torture chair' and 'squashed' used to describe some items. One mother explained:

> She just hated the straps and being put into that position and stuck in it'…'the equipment now is more padded and it's more comfortable, she still doesn't want to be in them. (Ellie's mother).

The parents were aware of their son or daughter's likes and dislikes, and if a particular accessory was viewed as restrictive, its use was modified. Although all the CYP demonstrated atypical movement patterns; some moved too much, others too little. One parent insisted their daughter (Elizabeth) who moved excessively didn't like being 'tied' in the chair; they removed everything except the lap belt and allowed her to move within the chair. Her behaviour they suggest changed following removal of this restriction. Her mother said, 'She had a real paddy, tears, red face. And then we took it off we had smiles'. Her father added, 'She just doesn't like been tied in'. The educational teams described the benefits, but still offered views of a similar nature. Elizabeth's teacher said, 'She had a lap belt, a chest strap, a waistcoat and jacket, and she had knee blocks…' and I thought she was 'so uncomfortable'. Foot straps were often mentioned, alongside indications that they themselves would not like their feet strapped. One parent said, 'Her feet are strapped; don't like that either but I think, my opinion, she switches off because she's restricted' (Hannah). Safety always took precedence.

> He used to get quite upset at school when they used to fix his feet down and I asked them not to do that, but having said all that the footplate he can get his feet down the back because he likes to sit with his feet vertically down and because he is getting so tall now his feet drag along the pavement, so we might have to get some straps put on. (Stephen's mother)

In contrast, Phillip's family viewed the accessories differently, 'its like putting your clothes on' They described the benefits and recognised the progress he had made over the years, no longer requiring a seating system with extensive head support. His mother said, 'he doesn't get distressed or he wouldn't have been in it, there was no way we were just going to leave him to slump'.

The behavioural response to stretch particularly in preparation for standing was reported and endorsed through observation. Nonetheless, staff appeared to anticipate the response, distraction temporarily appeared to overcome stretch discomfort. One physiotherapist said:

> He always complains. We're not, or we presume we are not hurting him, because once the task is done, he forgets about it. So we presume it doesn't actually hurt; he just doesn't like the initial stretch, but once we've got him there he usually accommodates to it. (Peter's physiotherapist)

Parents also spoke about this distraction at home. Ellie's mother said, 'You couldn't just sort of stick her there and think oh well she's sat in the seat, she would be quite happy, that just didn't work.' A video observation of Phillip revealed changed facial expression when left unattended on the tilt table. His trunk posture suffered a slump to the left. Reinforcing engagement with an adult during the activity brought displays of happiness back to his face, and a willingness to continue with the activity. Brendan's therapist said, 'He gets bored very quickly if he is not stimulated, gets fed up and then starts to whinge and cry and will then try and make something happen'. Equipment tolerance she believed was manageable as confirmed by his teacher. School assembly was another distraction; as analysis of data for the first case progressed, it was rewarding to see the data triangulating. Both the teacher and therapist spoke of Elizabeth's enjoyment of standing in school assembly. In the primary school, it was observed that assembly was the time most of the children used a standing frame. The assembly itself was a fusion of music, laughter, noise and the sound of children orienting well within this environment.

If personalised equipment is not used as intended the consequence may be a positioning error, and these were reported as causing discomfort. One mother said:

> …or she's uncomfortable and I know a few times she's come back from school and she hasn't been, she might have been a tiny bit out and she's crying all the way home ...I can feel the hip bone sticking on the side of the chair. She shuffles around and you can see her trying to get the hip comfortable cause of her hip,

> obviously I am not saying it causes her a lot of trouble but she has to get it into this comfortable position. (Nicola's mother)

Therapists were eager to achieve positioning preciseness to avoid discomfort.

> Yes if he is in his seat properly, he will tolerate it, if he has not been put in properly and his bottom is not right back and his pelvis is forward then he will not tolerate it past about 20 minutes… he will moan and groan until somebody comes to sort him out. (Peter's physiotherapist)

Prolonged use of equipment without respite was rarely identified as a cause for concern in this study. Embedded routines and vigilance by significant others had in most of the cases reduced the risk of these susceptible CYP developing pressure sores because of sustained positioning. Although, one pressure sore was attributed to prolonged positioning and lack of backrest contouring following the receipt of a new chair. Vikki's mother intuitively knew something was different due to Vikki's unusual unhappiness and facial expression.

Fatigue, however, was reported, with several parents judging their son/ daughter to be tired at the end of the learning day, wanting some freedom and relaxation for them in the home. Some had spent up to an hour in transit. Janet's mother said, 'As much as you would want her to have equipment and physio, it's nice to have that little break away from all that chore. It is hard work'.

In contrast, the findings abound with example of distress-free, purposeful use of equipment which may give others increasing confidence that a state of ease, and thereby comfort is achievable.

> In his school chair because he is upright. He is fastened in so he's nice and safe but he's fastened in so that he's in an upright position and he's got a tray and his hands rest on the tray and it kind of pushes his head up. When he hasn't got his tray on, because sometimes he doesn't need his tray, his arms are then on his knees and his head goes down so you can't get as much interaction, but when he's in his school chair, he's got his tray on, he's more upright, we get a lot more out of him(Aiden's teacher).

A teaching assistant said of one child, 'He loved his chair… it was his comfort zone' (Peter). Another teacher said, 'Complaints are with standing' and that 'she becomes uncooperative if she does not want to stand', her wheeled seating is different, 'she never complains and don't feel she is uncomfortable' (Janet). In the busy communal areas of the school/day centre, adaptive equipment provided a safe microenvironment for the CYP, with wheeled equipment allowing access to outdoor play areas, circle

time registration, school assemblies and a means of regularly experience life outside the special school/day centre.

Discussion

As the CYP could not express comfort/discomfort using language, much uncertainty will remain. Nonetheless, the first research question brought the CYP's expressive behaviours to the fore of this exploration. Predominantly facial and vocal expressions were used to interpret their responsiveness to equipment. Whilst feasible to suggest these behaviours were dependable responses to a known stimulus/experience they were not exclusive to equipment use. For example, there was alignment to pain, and of the expressive behaviours to the descriptors found within the pain screening tools (Breau *et al*. 2002). This fuels discussion as the reliability of others using affective behaviour as an indicator of the emotions of people with severe or profound ID has been questioned (Vos *et al*. 2013).

Pain is evaluated in this population of CYP (Dubois *et al*. 2010; Parkinson *et al*. 2010; Stevens *et al*. 2007). A systematic review of 27 studies, mostly focussing on acute pain in clinical settings, concluded that the more common behavioural pain indicators were facial activity, non-verbal vocal expression, motor activity and social emotional indicators (deKnegt *et al.* 2013). These authors, however, identified as a limitation the difficulty of discriminating pain from other causes, such as fear and anxiety. Beyond the boundary of acute pain assessment in clinical settings, other researchers have studied facial expression and idiosyncratic behaviours in persons with ID. Regnard *et al*. (2007) developed the DisDAT scale for adults with learning and severe communication difficulties as their earlier research found that caregivers could not always distinguish the source of distress. Equipment discomfort is an added challenge,, and a reason why some of the significant others felt the need to use additional clues. Behavioural observations have been validated with physiological measures (Vos *et al*. 2010), with findings reinforcing the perceptive judgements made by others about the emotional responses of people with severe or profound ID to everyday positive and negative stimuli**.** Although in the hectic, constantly changing classroom and day centre environments, teamwork and additional contextual cues were drawn on rather than physiological measures in the face of uncertainty.

Furthermore this ramification may also concern any evaluation of comfort, which may be a distinct concept in its own right, not simply the absence of discomfort (Branton 1966; Helander & Zhang 1997).

In contrast the findings reveal that the CYP habitually communicated contrasting behaviours, akin to contentment or happiness. This could be an indication that no physical discomforts are present and the CYP are indeed feeling safe, secure, functioning well within their equipment and experiencing comfort. Positive association with functional well-being , illustrated in the findings and reported in previous studies, between the use of certain items of equipment and meaningful positive impact on the individual would suggest this could be the case (Ryan *et al*. 2014; Ryan 2012; Ostensjo *et al*. 2005, Ryan *et al*. 2009). An observational coding scale of affective behaviours, including those akin to happiness, was validated for people with severe or profound ID (Petry & Maes 2006), and their concurrent findings imply sounds and facial expressions could portray pleasure and displeasure and positive and negative moods. This gives support to the current findings as all participants felt they could distinguish some expressive differences.

Understanding the comfort/discomfort needs of CYP who are unable to use language is complicated. Whilst data illustrating behavioural interpretations helped address the second research question, a sizeable influence must also be the significant others as the dependency of the CYP means they do not use the equipment without help. They function in a social world; the teachers, therapists and support staff have daily responsibilities, individual roles, each with their own respective attributes. Current findings imply that some postural re-positioning occurs throughout the day. This suggests relief from any positioning discomfort, if present, may follow. This finding is not contradictory. Hutton & Coxon (2011) found that school personnel try to implement postural management or repositioning programmes in spite of the barriers, while Telfer *et al.* (2010) estimated the average time spent by teaching staff members transferring children to and from their seating systems during the course of a day to be 1 hour 3 minutes. For CYP, it is conceivable that these organisational solutions promote comforting experiences.

A humanistic, holistic perspective on comfort accepts that in complex situations others must meet unmet needs for an individual's comfort (Kolcaba 2001). Due to prior witnessing of particular distressing events, some involving equipment, all significant others, including the therapists, were prepared to remove the CYP from the equipment, even temporarily, to eliminate this as a source of distress. The trusting relationships in evidence, the care handling and the communicative interactions taking place imply genuine commitment to caring about the CYP, which Hogg (2007) would propose is an assertion of personhood in a social context. Removing of the equipment may interfere with developed postural management plans and daily routines; nonetheless, these individuals who made the decisions possessed everyday lived experience of supporting the CYP. They do not have embodied knowledge of the distressing events but their response to the adverse behavioural expressions of the CYP may be empathetic, derived from close association (Craig *et al*. 2010; d'Agincourt-Canning, 2005). For humans, empathy depends upon features of an incoming stimulus, observer knowledge and disposition (Goubert *et al*. 2005). Combined with an ability to make reasoned judgments, this may aid insight into the thoughts and feelings of others (Craig *et al*. 2010; Campbell-Yeo *et al*. 2008). In the context of a CYP experiencing discomfort, significant others have the capacity to perceive the embodied experience of those in their care, and make decisions on that basis. Thoughtful responses can produce a substantial increase in the level of happiness of persons with ID (Singh *et al*. 2004). These caring acts suggest a postive diffference is made to the whole CYP's sense of comfort.

The third question addressed intent to explore factors contributing to an experience of equipment comfort/discomfort. In vulnerable CYP unrelieved mechanical loading of the tissues, particularly over bony prominences can cause detrimental physiological effect and result in tissue breakdown (Haalboom 2005). This damaging trigger already influences practice and the low reporting of pressure sores in the current study suggests the repositioning programmes were effective in reducing this risk. Well-designed equipment helps reduce the magnitude of tissue loading (Ding *et al*. 2008), yet the physical precursors described in the findings, for example a positioning error, may still provoke microcirculatory and neural responses in the tissues of sufficient intensity to cause discomfort. Some design accessories apply mechanical forces to the musculoskeletal tissues. Stretch also induces a

number of physiological processes including transient viscoelastic deformation and neural responses, sufficient to cause discomfort in individuals without ID (Folpp *et al*. 2006). Furthermore, users with communicative capacity have reported intrusive unpleasant body sensations, akin to a discomfort experience, from equipment (Crane *et al*. 2005; Bergstrom & Samuelsson 2006).

Visual appearance of the equipment had influence on the decisions made about its comfort /discomfort, findings supported by research from the field of ergonomics. A series of studies involving office workers revealed that users could distinguish between parameters that related comfort to a sense of well being and aesthetics more than longer-term ergonomic features, and discomfort to biomechanics and fatigue factors not ergonomic features (Helander 2003; Helander & Zhang 1997). Biomechanical fatigue, due to the passage of time accumulated during the day, could account for the tiredness/fatigue experienced by the CYP on their arrival home. Postural management equipment is personalised to the individual but irrespective of design the bodies of the CYP will remain subject to atypical stresses due to their diminished postural control. This type of fatigue is a reduced ability of the muscles to produce force or power during a task, and if the degree of weakening is not profound, masking of the fatigue is possible (Dobkin 2008). This appears unlikely for the CYP in the current study due to their much diminished control of posture and movements.

Parents of children with an ID experience high levels of stress, but research suggests they employ various strategies to adapt to the demands posed by counterbalancing the many competing and contradictory forces in their lives (Hassall *et al*. 2005; Maul & Singer 2009). In these studies postural management was not singled out as a separate source of parental stress, owing to possible sampling differences or its classification under 'care giving demands'. Nonetheless, equipment avoidance may be a way of coping with time consuming or emotionally distressing tasks, as Henderson *et al. (*2008*)* found that over one hour of a parent's time per day is taken up transferring their son and daughter from seating systems. The CYP and their families need support to live fulfilling lives; perceived discomfort could negatively affect parental levels of stress. An investigation into parental burden and the use of night orthoses in children with CP supports this view (Mol *et al*. 2012). Findings implied the use of night orthoses did not increase sleep disturbance, and that parental burden was experienced

less when parents were extraverted and emotionally stable. This highlights an important issue for professionals looking to build relationships with the family, whilst promoting the benefits of postural management.

In conclusion, a wheelchair, an adapted seat, a standing frame or sleep system are technologically and scientifically designed items for physical positioning, and there are high expectations that all types are both aesthetically pleasing and comfortable. The essence /consequence of meeting these needs are represented, diagrammatically in Fig. 2. A CYP may be experiencing discomfort if physical clues are present and his/her behaviours imply unhappiness, especially if change occurs following removal from the equipment. In contrast, if the position achieved is visually pleasing, environmental/interpersonal opportunities appropriately facilitated and observed behaviours suggest contentment, perhaps comfort can be assumed. Nonetheless, vigilance will always be required in the absence of physical clues and, or the presence of behavioural distress? The question of whether equipment related discomforts can be minimised and comfort achieved hinges on the CYP's requirement for a communicative partner and thoughtful person-centred acts from those who possess the capacity to influence positioning practices. The impact of context aptly helps explain why CYP can be both comfortable and uncomfortable in the same item of equipment.

Strengths and limitation of the study

In reality, the irreducible subjective experiences of the CYP with ID could only be illustrated in this small scale study. Context dependent findings linked comfort/discomfort to equipment but these were not easy to separate out from other aspects of care management. Nonetheless, the study was situated where the CYP live and learn, environments full of influences. The qualitative pre-designed case studies gave structure to a research design known for its flexibility. The small sample allowed perspectives to be examined; whilst not allowing for generalisation some transferability to other users of adaptive equipment may be possible. However, by integrating the illustrative findings with key empirical and theoretical works the contextual findings become more dependable.

Implications for practice and research

Whilst using adaptive equipment the CYP in this study could be at ease, appearing comfortable, thus enabling access to peers, the learning environment, social interactions, school assembly and play areas. Yet threats to comfort existed, and as those with an ID may not have the capacity to understand the reasoning which underpins equipment use the implications for practice occur around planning, inter-personal collaboration and regular review of recorded contextual observations involving equipment. Ensuring comfort is maximised and discomfort minimised requires the authentic presence of someone who cares about their wellbeing, is attentive to their communicative attempts and instructed to use the equipment as intended. In educational settings for those with ID, collaborative teams facilitate learning and communication; promote function and participation, with therapists initiating equipment provision where necessary to achieve these outcomes. The catalyst for enhancement and greater understanding will emerge from combined effort, learning from each other and with parents to develop postural management programmes. Staff resources in special education may preclude the use of time-consuming checklists, but pictures of a CYP's ideal postural position within the equipment, combined with an individualised scale of affective behaviours which represent his/her pain/discomfort/distress indicators and his/her content/happy/engaged indicators may further understanding of individual comfort needs. As comfort may be more than just the absence of pain/discomfort the well-being of those with ID using contemporary adaptive equipment warrants further investigation using validated observational instruments which can detect pain/ discomfort and expression of emotions. Finally, parents are generally supportive of professionals using the equipment to achieve both health and educationally related goals but they also desire periods of relaxation for their children with time out of restrictive equipment. This may be an important area for future research, potentially of a participatory collaborative nature with parents, as this would be in keeping with family/person centred models of practice.

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