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Supportive seating and wheelchairs: what is important to young people?

Final report

Summary

This qualitative study explored young wheelchair users' views on their postural seating and wheelchair equipment. Face-to-face interviews were carried out with fourteen young people (aged 11 to 19 years) who had cerebral palsy or a similar non-progressive condition. Their physical difficulties were classified at level IV or V on the Gross Motor Function Classification System (Palisano et al 1997). Participants had the cognitive and communication skills necessary to take part in an interview (at least National Curriculum Level 2 in English Attainment Target 1: Speaking and Listening (Dept for Education 2012), with augmentative and alternative communication (AAC) methods being used where necessary. The postural seating included at least pelvic and thoracic support on a manual or powered wheelchair base. A thematic analysis of the data was carried out. Eight themes were identified in the data, with independence, comfort and postural issues being referred to most frequently and by the greatest number of participants. An additional five aspects of the equipment were reported to be important by individual participants.

Background to the study

In 2009, the researcher was involved in a qualitative study entitled "Wheelchair seating equipment for children: parents'/carers' views and experiences" (Taylor and Porter 2009). The study explored what made children's wheelchair seating more or less useable within everyday family life and identified aspects of the equipment that were important for families. It was not possible to include the young wheelchair users themselves in the study because the methodology was not appropriate to the age and developmental level of the children. However, as the study progressed, the need to seek the views of young wheelchair users themselves was raised by several participants and became a priority for future research.

Wheelchair seating

There are a large number of children and young people in the UK who have been provided with wheelchair seating equipment and the provision of this equipment is costly to the NHS (Audit Commission, 2000). It is believed that this wheelchair seating can increase comfort and ability and reduce the deterioration of deformity in children with cerebral palsy and similar neurological conditions (Audit Commission 2000, Pountney et al 2004, Porter & Schindler 2008).

Use of the seating

An important consideration is whether the equipment provided by wheelchair services meets the users’ needs and is actually used. If there is a benefit from using posturally supportive seating in a wheelchair, then this will not be realised if the seat is not used. Several studies indicate that assistive technology, including wheelchair equipment, often does not get used by the people for whom it is provided (Philips and Zhao 1993; Riemer−Reiss and Wacker 2000). Hocking (1999), Wielandt and Strong (2000) and Wessels et al (2003) reviewed the literature and documented some possible reasons for this. Riemer−Reiss and Wacker (2000) and Hocking (1999) conclude that greater user involvement is required in future research, to explore the relationship fully between user and equipment.

Previous work on the views of parents/carers, young people and therapists

Some studies have included investigation into the views of parents/carers about some equipment. Wiart et al (2004) sought mothers’ perceptions of their children’s equipment, looking specifically at powered mobility. Marshall and Goldbart (2008) carried out a study in which they interviewed parents regarding the use of Augmentative and Alternative Communication equipment and Gibson et al (2010) investigated factors influencing carers’ use of postural management equipment used by children with cerebral palsy. Some studies (Pain et al 2000; McDonald et al 2003 and 2007; Shahid 2004) have looked specifically at children’s seating equipment and the views of parents/carers and therapists have comprised an element of their studies. The studies have identified that there is often a difference between the opinions of the parents/carers and the therapists on what aspects of the equipment are important. Cox (2003) carried out a review of the wheelchair needs for children and young people and attempted to gain the views of children and their parents, but the questionnaire response rate was very low and the results were not presented. Hallett and Roberts (2010) investigated older children’s perception of powered mobility but a review of the literature identified no published studies focusing on young wheelchair user’s views on supportive wheelchair seating.

Relevance of the study

Government initiatives such as Every Disabled Child Matters (2006) and Aiming High for Disabled Children (2007) have placed the needs of disabled children and young people high on the political agenda, with the aim of making improvements to the provision of disabled children's equipment across social care, health and education and to understanding unmet need. In 2009, the Healthy Lives, Brighter Futures strategy committed funding to Primary Care Trusts to deliver the Aiming High for Disabled Children initiative in partnership with local authorities. This funding was expected to go to 4 key areas, one of which is children’s wheelchairs (Department for Children, Schools and Families 2010). The Department of Health (2010) published an independent consultant’s report, which notes that the commissioning and provision of children’s equipment remains poor in many areas. Within this context, research focusing on the views of young wheelchair users is highly relevant. The findings of this study may be useful to service providers as they attempt to improve their services to meet the requirements of current political initiatives and to use any additional funding to best meet the needs of their users.

The study

Objectives

- To provide young wheelchair users who need seating that provides postural support with an opportunity to report freely on what aspects of their seating and wheelchair equipment are important to them.
- To use young wheelchair users' views to inform the practice of those working in services that provide wheelchair and seating equipment and also those who design, manufacture and sell it.

Method

This qualitative study used a constructivist approach, informed by phenomenology, in that it was designed to investigate the lived experiences of the participants, whilst recognizing that the reality of a situation depends on their individual perceptions, interpretations and environment (Guba 1990). Data collection was via face-to-face semi-structured interviews. Students at Treloar School in Hampshire were involved in the planning of the study and contributed to the development of the interview schedule.

The study was reviewed and approved by Oxford Brookes University Research Ethics Committee (study reference 110527). All participants gave consent to be interviewed, for the interview to be audio-recorded and for anonymous quotes to be used in any presentation of the findings. For participants under the age of sixteen, the consent of their parent or guardian was also sought.

Inclusion criteria

Young wheelchair users who:

- were aged 11 to 19 years (inclusive).
- had cerebral palsy or a similar non-progressive condition and classified at level IV or V on the Gross Motor Function Classification System.
- used posturally supportive seating (including at least pelvic and thoracic support) on a manual or powered base.
- had sufficient cognitive and communication ability to take part in an interview (at least National Curriculum Level 2 in English Attainment Target 1: Speaking and Listening) using augmentative and alternative communication (AAC) methods if necessary.

Recruitment

Educational establishments were approached for the recruitment of participants. This included specialist schools and colleges known to the researcher and additional establishments identified through an internet search.

Fourteen educational establishments were contacted:

- Ten specialist residential schools/colleges
- One mainstream local education authority (LEA) school with a specialist unit for young people who have a physical impairment
- Three LEA special schools

Participants were recruited from five establishments (two specialist residential schools, one specialist residential college, one local education authority (LEA) special school and one mainstream LEA school). They were located in Wiltshire, Hampshire, Gloucestershire, Bedfordshire and West Midlands.

Fourteen participants were recruited:

- Nine male, aged 12 – 19 years (average 15.3 years)
- Five female, aged 12 -16 years (average 14.6 years)
- Twelve had cerebral palsy (CP), one had an inherited metabolic disorder and one had dwarfism with compounding difficulties.
- Twelve participants used powered wheelchairs. Ten of these were competent drivers using a standard joystick. Two were developing their driving skills using a switch ‘click to go’ system, under supervision
- Two participants used manual wheelchairs, one self-propelled and one attendant controlled.

Interviews

All participants took part in a face-to-face interview. Eight participants were interviewed individually, while six chose to be interviewed with a peer. A teaching assistant was present at seven interviews to support communication but took no part in the interviews.

Ten participants used speech. This varied in clarity so the young people were supported by a helper where necessary. Three participants used voice output communication aids (one direct access, one eye-gaze controlled, one switch controlled) and one participant used a symbol-based communication book. The interviews were audio-recorded and transcribed by an experienced transcriber.

Results

Eight themes were identified in the data. An additional five aspects of the equipment were reported to be important by individual participants.

Theme 1: Independence

a. powered v manual wheelchair

Thirteen young people spoke about the issue of a manual versus a powered wheelchair base. Those using powered wheelchairs highly valued the independence it gave them and spoke about how important this is to them. Two young people reported that they choose to use their manual wheelchair sometimes because driving is tiring for them. One participant preferred using their manual chair because they didn't feel confident in their driving. Two participants using a switch 'click to go' system were only driving when supervised but valued the independence this gave them.

Nine participants reported that, although they preferred using their powered wheelchair, there were times when it was not possible and it was necessary to use their manual base. The following reasons were given:

- when out shopping (lots of steps, space available)
- when wet and muddy (so not able to take powered chair inside)
- holidays (transport, unfamiliar environment)
- when powered chair breaks down
- carer's choice
- transport (no wheelchair-accessible vehicle available)

"My parents don't have a wheelchair accessible car so if we go out I have to take my manual, which is a blow"

Two participants used the word 'hate' when referring to their manual wheelchair and expressed frustration at having to use it.

b. control of wheelchair functions

Two participants suggested they would like more independent control over additional aspects of their wheelchair and seating (engagement and disengagement of the motor, thoracic supports, tilt mechanism on manual base). The reasons given for wanting this additional independent control was that they had had experiences where carer's had not got things right for the participants and they found it difficult to communicate their precise needs.

Theme 2: Comfort

Thirteen participants reported that 'comfort' was important, with two linking it to their ability to carry out their everyday activities.
"I like to feel comfortable, otherwise you don't function properly"
"It's difficult to concentrate if you're not comfortable"

Eight participants spoke about comfort generally, while others identified particular aspects of their wheelchair and seating within which comfort is important:

- **headrest**
  Seven mentioned the importance of getting their head support right. Two related this to how it affects their ability to concentrate and function within their daily living tasks and one related it directly to their happiness. Two recognised the importance for travelling and two spoke about the importance of good head support in relation to the prevention of neck problems

- **Cushion**
  Three related comfort to their cushion; two generally and the other one in relation to pressure problems and leg position.

- **Tilt**
  Three talked about the importance of the tilt facility for their comfort.

- **Temperature**
  Two reported they got uncomfortably hot in their wheelchairs and would like to find some way of alleviating this. One identified that the problem was their hoist sling, which they have to sit in all the time. They reported that this was the thing they would most like to change about their seating.

- **Lap-strap / harness**
  One participant reported that his lap-strap and harness caused discomfort and identified this as the main thing he would change about his wheelchair if he could.

- **Pommel**
  One reported the importance of the pommel in relation to keeping their leg position right and their hips comfortable.

- **Thoracic supports**
  One identified their thoracic supports as being the main thing they would change about their wheelchair if they could. They suggested that they would be more comfortable if the supports were ‘bigger’.

- **Suspension**
  One spoke about how important the suspension on the wheelchair is to comfort and the need to get it just right (*“not too boingy!”*)

Theme 3: Posture

Seven participants referred to how important their seating is for their posture. Their comments regarding posture were closely related to comfort, but they showed great awareness of their postural needs. Four reported problems with their back and three had problems with their hips and commented on how important they felt their seating was in preventing further difficulties in the future

- **Change of position / other equipment**
  When talking about comfort and posture, four participants spoke about the importance of having changes of position throughout their day.

- **Positioning by others**
  Two participants spoke of their dependence on other people for getting their seating position in their wheelchair correct and how important it is to them that this is done correctly.

Theme 4: Function

Six participants spoke of how important their seating and wheelchair was to their function within daily activities.

"It (wheelchair) is my legs"
"I can't really concentrate on things if I'm not in the right position in my chair"

One participant commented on the need for good positioning on their wheelchair of their voice output communication aid.

Two participants spoke in terms of their wheelchair and seating being a general help to them:
"Helps me at home and school"
"It's (seating) very important to me really because it's made my life change a lot"

Theme 5: Aesthetics

Aesthetic aspects of the seating and wheelchair were mentioned by five participants.

One male participant wanted his wheelchair to be "more funky". When asked what that meant, he described many customisations he would like to make.

One mentioned not liking the headrest he had to have for travelling (***"it's a bit clumsy really I think"***) and was dissatisfied with an addition to his arm-rest.

Three female participants mentioned the importance of having a choice of colour
"I was looking to get a wheelchair colour that will go with everything I wear"

Two participants (one male and one female) spoke about how they thought the aesthetics of their wheelchair affected the perception of other people.
“It does bother me what other people think because I just want to be as normal as them really”
“I want people to look at me, not my chair”

Theme 6: Reliability and maintenance of equipment

Five participants spoke about issues relating to on-going maintenance of their equipment:

- three spoke of the importance of quick repair if their wheelchair breaks down
- one mentioned the importance of charging their powered wheelchair
- one mentioned that they felt regular reviews by the wheelchair service were important and said they would like regular maintenance checks
- one mentioned frustration at the need for weekly washing of the seat covers on their Matrix seating (to keep their shape and prevent pressure problems)
- one reported that their ‘click to go’ wheelchair control was not accurate. It veered off to left when should be going straight and no-one seemed to be doing anything about it

Four of these five participants expressed frustration of their dependence on others to carry out these maintenance tasks. Three of the five spoke of experiences where their powered wheelchair had been out of action and expressed how important it is to them that:

a) problems are sorted out quickly
b) they have a back-up wheelchair available

Theme 7: Size and weight of wheelchair

Four participants reported that the size of their wheelchair was important. Two issues were raised with regard to this. One was the size of the wheelchair in relation to living space and transport. For example, one participant couldn’t use their powered wheelchair around the house due to space restrictions. The other issue raised was participants’ ability to be independent in driving their chairs. They commented that they had trouble manoeuvring their large powered chair through doorways and felt it would be easier with a less bulky chair. One participant expressed a wish that light-weight powered wheelchair could be developed so that they could take them on holidays.

Theme 8: Height adjustability

Height adjustability was mentioned by three participants. One had this facility on their wheelchair and reported how important it was to their independence. Two others mentioned it as something they had seen on other people's wheelchairs and would like on theirs.

Other aspects identified as important to individual participants

Ease of movement and driving
One participant commented on the importance of their manual wheelchair being easy for a parent/carer to push. Another commented on the difference between two powered chairs they had had and the difference in ease of driving. They were unable to identify the reason for the difference.

Being safe
When talking about why thoracic supports and knee blocks were important, one participant using a voice output communication aid said ***"they make safe".***

Position of lights
One participant reported that their lights were continually being damaged and felt they could have been placed in a better, safer position on their powered base.

Speed
One participant spoke of how quickly their powered wheelchair could go and how important that was to them (they went on to tell that, although they were told not to travel at full speed around school, they still did!).

Wheel guards
One participant spoke of the importance of their wheel guards in preventing their hands getting injured by the wheels.

Conclusion

The researcher was impressed by the willingness of all the participants to speak with great insight about their seating and wheelchairs. It was not easy for some to make their views known but they appreciated the opportunity to be involved in the study. However, it had been hoped, prior to data collection, that the interviews would produce richer data about the participants' experiences than turned out to be the case. It proved difficult to encourage the participants to expand on the issues they raised and they generally seemed to lack the confidence to speak assertively about their needs and opinions. This, perhaps, was to be expected, given the age of the participants and the fact that they were talking to an unfamiliar person. However, it does raise the question of how able young people feel to contribute to discussions about their seating and wheelchair with those working within the wheelchair services. It could be suggested that this difficulty is compounded in those who have some level of communication difficulty. It suggests that those working in the wheelchair services need to carefully consider how best to meaningfully engage young people in the process of their seating and wheelchair provision.

It is possible that an alternative data collection method (e.g. focus groups) might have enabled students to speak more freely and may have resulted in richer data. Focus groups were considered during the planning of the study but the experience of meeting with a group of six students in the planning stages indicated that group situations may be intimidating for more reserved individuals and discussion can be dominated by those who are able to speak confidently. The quieter students in the group suggested that interviews with one other peer would be preferable.

The study inclusion criteria meant that all the participants had significant physical difficulties. It is therefore, maybe not too surprising that comfort turned out to be one of the strongest themes within the data. There was no suggestion by any of the participants that their postural seating was not highly valued or not used. However, when asked it there was anything they would change about their existing equipment if they could, eight of the fourteen participants identified something they would change. Five were completely happy with their existing equipment.

Thirteen of the fourteen participants spoke of the importance of independence. However, an issue that featured in several of the themes was how many important aspects of successful use of seating and wheelchairs were dependent on other people. This dependence on others was reported in regard to:

- achieving a good sitting position
- benefitting from changes of position throughout the day
- maintenance of the equipment
- whether their powered or manual wheelchair was used
- correct use of postural supports
- appropriate use of wheelchair facilities such as tilt

This highlights the importance of parent/carer involvement in the process of seating and wheelchair provision and of ensuring everyone involved in a young person’s care has the best possible understanding of the needs of the young people and of their equipment.

Analysis of the data identified a large range of seating and wheelchair characteristics that were reported to be important by the participants. Some were reported by many and it could be suggested that they might be representative of the wider population who have similar postural needs. Others were smaller issues reported by single individuals. However, even these are important in highlighting to people working in the wheelchair and specialist seating services how seemingly insignificant issues can have a considerably impact on the life of an individual.

It is acknowledged that wheelchair and seating services do make every effort to meet the needs of their clients. However, in busy clinics, the need to engage young people in the process and encourage them to offer their opinions should not be overlooked.

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Acknowledgements

The researcher would like to thank:

- PMG research sub-committee for funding this study
- Staff and students at Treloar School, Hampshire for their involvement in the planning and preparation of the study
- The fourteen participants and staff members at their educational establishments for organising the interviews
- Oxford Brookes University for employment for the period of the study
- Professor Helen Dawes at Oxford Brookes for supervising the study
- Dr David Porter for his involvement in the planning and preparation of the study and his support throughout

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18.10.12