



‘Every picture tells a story’

Interviews with children with cerebral palsy about adapted cycling

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Pedal Power Research Study



- 3 year study looking at the effects of adapted dynamic cycling for children with Cerebral Palsy (CP)
- Mixed methods – quantitative measuring muscle strength and knee joint angles
- Qualitative interviews and diaries
- Cycling(hired bike)/ Control (not yet cycling) group
- Video from BBC ‘Children in Need’ 2010



Research question



Pedal Power

Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy?

How did children with Cerebral Palsy find the experience of Adapted Dynamic Cycling with “Pedal Power”?

Would they consider participating in the future? (control group)

Cerebral Palsy

Rosenbaum et al 2006

- *‘a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems’ (pg 9)*

Clinical experience



- The 4 researchers were all physiotherapists who had worked with children with CP - Clinical experience and literature shows that there are limited opportunities for children with CP to participate in physical activities

(McConachie et al, 2006)

Cycling is one activity than can be adapted

- The 2 interviewers had not previously carried out research with children

(Fleming and Boeck, 2012)

Research team



Dawn
Pickering



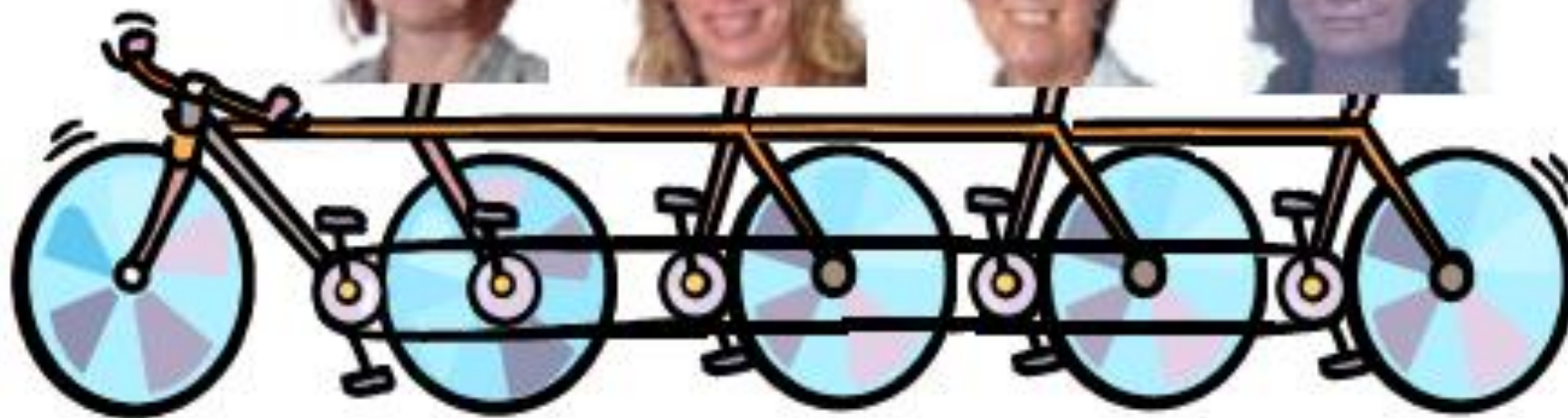
Karen
Visser



Lyn
Horrocks



Gabriela
Todd



Limited literature base



- Connors and Stalker (2003) interviewed disabled children and their siblings to obtain their view and experiences
- The whole family were invited to participate including siblings, however they interviewed the child, siblings and parents both separately and together
- Due to the variation of the presentation of CP we considered this too difficult for novice researchers- we needed a person to help facilitate communication (Morris, 1998)

Challenges of interviewing children with CP



- Age range between 2 – 17 years
- Some children fully conversant
- Some children use augmentative forms of communication- eye pointing/signing/ gesture
- Some children use alternate forms of communication- communication boards
- Some children use PECS- picture recognition to make choices

Interviewing children with a disability



Consent issues to interview children with a disability under 16 years alone:

- Parents act as gatekeepers
- Children may disengage with the interview
- How do we obtain the child's voice?
 - To gain their consent/assent to participate?
(Morris, 1998)
 - To obtain their views?
(Renold et al, 2008)

Question design



- Activity Scale for Kids (ASK) (Plint et al, 2003) – questionnaire
 - Used themes from ASK for 4 pilot interviews about capacity and performance
- Iterative – questions developed more about cycling rather than capabilities

Mosaic Methods

Clark and Moss (2001)

- Attempted to use creative methods such as stickers/ drawing / ink pad printing/ game card matching, but several children had limited cognitive and manipulative skills
- Age appropriate creative methods to engage the child eg puppetry

Physical measurements



Methods



- Semi Structured Interviews took place following the first measurement session and the commencement of cycling and again after the 6th session (2 interviews per child)
- Recorded with a Dictaphone
- Diary kept of cycling experiences- used as a prompt for 2nd interview in cycling group (only 1 interview in control group)

Researcher's interview style



Booth and Booth,(1996), Minkes et al, (1994)

- Need to build up the relationship
- Assume they can understand
- Creative Guesswork
- Unorthodox methods- needs more thought and to be flexible and creative- 'Self Developing' (trial and error)

Interview Questions



- Semi Structured style –
 - Tell me about the cycling you have done at Pedal Power?
 - What colour is the bike? Helmet?
 - Who else has gone with you?
 - How far have you cycled?
 - What do you hope to achieve from cycling?

Languages spoken



- Languages spoken by the families Welsh, Urdu and English
- Interviews carried out in English
- Interpreters used where necessary
- Always an adult present who was familiar with the child and their communication style

Adaptation of interview questions

- Style for children needed to be more direct not open ended (Booth and Booth, 1996)
- Closed questions when vocabulary limited so the child could answer yes/no with gesture or nod/shake
- Made it hard to allow the child to lead the interview- more directed by interviewers

Use of pictures

- Different laminated pictures of cycling were used to engage with and generate a response from the child.
- Happy/ sad faces were used for children to point to if they were not able to vocalise their response- this could be finger/hand pointing or eye pointing

Pictures



Children were asked how cycling made them feel

Happy/Like



Sad/Don't Like



Pictures



Some children had drawn pictures in their diaries and stuck photographs in which were used in when a second interview took place



Data management



- Transcripts typed up and sent back to participants for verification
- Data managed with NVIVO⁹
- Analysis by Themes using InspirationTM mind mapping- 2 researchers

Results

- 17 children in the cycling group and 18 in the control group who have not yet cycled.
- Results here only cover 17 in the cycling group and the first 8 children in control group (25 all together)
- 34 interviews and 16 diaries
- 10/25 (40%) children used additional forms of communication than verbal

Trustworthiness

- Stiles(1999) suggests that:

'investigators use their imperfect empathic understanding of participants inner experiences'

'interpretations are tentative and bound by context'

Themes Pickering et al, 2012



- Learning a new skill- cycling
- Impact on wider family and friends
- Social participation
- Future aspirations

Peter: I did cyclingit was wicked !



- **Peter's Mum:**
'Gabriela put him on the Tom Cat trike, strapped his feet in and it was the first time ever he pedalled and he couldn't stop it. Everybody got so emotional, fantastic. It just shows if you've got the tools for the job, the right equipment, you can do it'

Learning a new skill



Int: Did you like the cycling?

Katie: Yeah

INT: Did you?Tell me what was good about it then ?.....

Mum: Was it because it was you went very, very slowly?

Katie: No [shakes head]

Mum: Did you go very, very fast?

Katie: Yeah!.....

Mum: Do you like going fast?

*Katie: **Yeah!** [really enthusiastic here]*

INT: Brilliant!Why do you like going fast?

[Katie puts her thumb up, smiling]

INT: Was it good? Is it, yeah?....What do you enjoy about it?

[Katie lifts her thumb up and down]

Katie (Aged 10, Ataxia)

Gesture

- Use of gesture as a way of expressing- should I have mirrored this and not asked the open questions?
- Use of Katie's Mum who was engaged in the interview was very helpful, however did I get to Katie's truth?

Impact on wider family

- Andrews muscle strength had increased by 100% and he progressed to going cycling with a support worker rather than just his Dad during the 6 sessions:
‘...we cycle in the park and I go down the slope...and then I change it.... you know... I put into 3 (gears) and it makes me fast...’

Andrew (17 years Athetosis/Autism)

Other family participation

- Emily's (4 years, ataxia) Grandma went cycling for the first time and Husain's (10 years, Hemiplegic) Mother from an African country.
- *“we went on a picnic and we explored and we went to look for the ‘Gruffalo’ ...”*
{Emily used playing at making a picnic during the interview with a toy bike}

Pictures of cycling- Control group

Int: Ok you wouldn't like to do that, let's see if we can find somewhere that you might like to go...those people are out in the countryside with their Mum and Dad, {No11}, is that somewhere you might like to go?

Suarez: (shakes head), no

Int: Ok what about that one its more in the wider countryside {No12}, do you think you might like to go cycling in the wider countryside?

Suarez: Nods and smiles

Suarez aged 8 years, quadriplegic, quiet, dysarthric speech

Timothy Aged 5 years, Hemiplegia and limited spoken vocabulary

Timothy was more interested in the happy /sad faces than the pictures of cycling

Social participation



“I: So, what’s it like if you haven’t got a bike when you are with your friends at the caravan?”

Diane: I normally tag along, walk for a while, ponder my thoughts, get bored.... The bike’s great, easier to get around than walking. Clever, clever invention whoever invented it I want to thank them....”

Diane (10years, Hemiplegia)

Future aspirations

Father of Katie: *“I think also you know, in the long term, it's access to a leisure opportunity.....But like, one not just leisure as in a pastime, but one which strengthens and improves her health and also her general bodily functions, and the co-ordination, the sense of braking, the sense of taking care. She's usually so dependent, so she can experience a sense of danger, you know ?”*

Results so far

- The 17 children who took part in cycling enjoyed this experience and it improved their sense of well being.
- Further analysis of the control group is needed to validate the muscle strength and length measures before health benefits can be confirmed.

Reflection

Style of questioning for some children needed to be more direct not open ended to provide closed choices.

Researchers developed more confidence in managing the different communication styles by combining their clinical experience with their research development.
(Fleming and Boeck, 2012)

Picture of the context



Where next

- Complete full analysis
- Publish full results
- ? Develop larger study with children with a range of disabilities

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