Participation in adapted dynamic cycling (ADC) - experiences of children and young people with cerebral palsy: a work in progress

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Dawn Pickering, Karen Visser, Lyn Horrocks and Gabriela Todd
Background

- Pedal Power, Cardiff
  (www.cardiffpedalpower.org)
- Cerebral Palsy
- Participation- ICF (WHO, 2001)
- Literature around cerebral palsy, fitness and participation (Fowler et al, 2009; Fauconnier et al, 2009; Mihaylovat et al 2004)
Ethics of research with children with a disability


Rights of children to participate:

*Article 31*: ‘children have a right to relax, play and join in a wide range of activities’

*Article 23*: ‘children with a disability should have special care and support so they can lead full and independent lives’
Objectives

To measure the effects of participation in Adapted Dynamic Cycling (ADC) at a voluntary organisation cycle hire facility

Outcomes:

- Lower limb muscle strength, length and quality of life (QoL)
Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning

- **Condition**: Cerebral Palsy

- **Body Structure & Function**: Measurements of muscle length and strength, joint angles, distance cycled, exercise tolerance

- **Activity**: Dynamic cycling on adapted trikes

- **Participation**: Cycling as a social leisure activity with family and friends; Interviews with children and families

- **Environmental Factors**: Trained staff at Pedal Power Cardiff, a voluntary organisation; Outdoor activity in a local park

- **Personal Factors**: Children aged 2-17 years, boys and girls, with diverse abilities and cultures
Picture of Cycle Path

Pedal Power Cycle Map of Pontcanna Fields and Bute Park

- Taff Trail
- Walk over footbridge
- Hailey Pk 3km
- Tongwynlais 7km
- North Rd
- Cardiff Castle
- Cafe
- Toilets
- Cricket Ground
- Caravan site
- Warning! Steep or slippery slope
  Change gear in advance and use breaks
- Green Route 2km
- Pink Route 4km
- Taff Trail to Cardiff Bay 3km
Physical Measurements
Results- demographics

- n= 17: 7 males, 10 females
- Aged 2-17 years
- 8 Quadraplegia, 8 diplegia, 1 hemiplegia

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Results- inferential statistics

9 complete data sets: (4 boys & 5 girls):
Non-parametric: Wilcoxon Ranks Sign Test
Significant Quadriceps changes: (R) p=0.018; (L) p=0.021
Non-significant Hamstring changes: (R) p=0.065; (L) p=0.069

Means: 16 RQ (A), 13 RQ (B), 16 LQ(A), 14 LQ(B),
16 RH(A), 13 RH(B), 16 LH(A), 13LH(B)

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<th>Means</th>
<th>Quadriceps (R)</th>
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<td>Before</td>
<td>39.60 N</td>
<td>33.41 N</td>
<td>33.77 N</td>
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<td>After</td>
<td>51.88 N</td>
<td>47.99 N</td>
<td>38.97 N</td>
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Significant (L) Quadriceps changes: p=0.05
Non-significant (R) Quadriceps & Hamstring changes: (R) Q p= 0.38
(R) H p=0.35; (L) H p=0.43
Results - qualitative data

- **Interviews** carried out at beginning and end of 6 cycle sessions by 2 researchers
- 26 interviews and 8 **diaries** (some were lost or not completed)
- 6 of the children used additional forms of communication than verbal; requiring adaptation of the questions and the use of pictures
Thematic analysis

Pickering et al, 2012b

Figure 2 Themes

Key:
Clear boxes are topics being explored
Shaded boxes show emerging themes

Child with CP

Pedal Power Cardiff

Aspirations

Parents/Carers/School staff

Interview and diary data

IMPACT ON CHILD AND FAMILY

Cycling skills

Developments over time

Social Participation Health Benefits Other skills

Enriched environments

Other physical activities

Measurement data

Facilitators

Barriers

Adapted Dynamic Cycling

Technical setup of bike

Staff + volunteers

Environment
Peter’s Mum: ‘The physio put him on the TomCat 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’
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 (10 years, Diplegia) who completed the diary by herself and drew this picture.
Limitations

Practical limitations:

- Rigour: Standardisation of intervention
- Weather
- Cycle computer and monitors
- Intervention – only 6 sessions
- Diaries
Implications for clinical practice

- **Community facility** in an appropriate area-
  - Access to a grass roots cycling area
- **Policy makers** to consider adapted cycle hire within a 50 mile radius
- **Strengthening** through cycling through participation - maintaining
- No change in popliteal angle
- **Quality of life** - Children and families enjoyed the participation
Conclusions

- The children who took part in adapted cycling enjoyed this experience and it improved their sense of well being and had a positive effect on muscle strength.

- Policy makers should consider adapted cycle hire in their region.

- Physiotherapists and other Healthcare professionals can carry out creative research to hear the voice of children and young people with CP.
Acknowledgements

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- Bike-shed staff and volunteers
- BBC Children in Need
- Jenx Ltd
- NHS physiotherapists in England and Wales who helped us recruit to control group (yet to be reported)
- Polar
References


References

- Pickering D. et al (2012b) Adapted Bikes- what children and young people with cerebral palsy told us about their participation in adapted dynamic cycling *Disability and Rehabilitation: Assistive Technology*, Early Online 1-8 © Informa UK,Ltd
THANK YOU FOR LISTENING

ANY QUESTIONS?