



Children & Young People with Cerebral Palsy's experiences of adapted dynamic cycling - interview & diary findings



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Cardiff Pedal Power is a charity providing adapted cycles and cycling opportunities for all ages and abilities. This three year mixed methods study aims to investigate the effects of 6 sessions of adapted dynamic cycling (ADC) for children and young people with Cerebral Palsy (CP), who may have difficulty participating in leisure activities.

Background

Children and young people with Cerebral Palsy (CP) have limited opportunities for participation and there has been little research to explore this concept^{1,2}. The lack of participation in healthy leisure activities can impact on their long term health and well being. Adapted dynamic cycling (ADC) is one activity that enables them to participate in the community. A pilot research study is being carried out, investigating the effects of ADC for children and young people with CP. The aim of the study was to measure the effect of ADC on lower limb muscle strength and length and explore their cycling experiences.

Methods

Participants were recruited from the voluntary project, Pedal Power, by the physiotherapist employed for children and young people*. They were asked to take part in an interview about their cycling experiences, prior to starting the six sessions and again afterwards. They also kept a diary about these experiences. The children and young people had a variety of communication styles where communication aids, picture boards or symbols, as well as gestures and sign language, were used. This resulted in the 2 researchers adapting their communication style to mirror the needs of the individual. Interviews were conducted with children and young people and an accompanying adult.

Pictures were used to encourage a dialogue about cycling. Closed questions were developed with images of happy or sad faces to capture more feeling about the experiences when spoken language was not possible. Observation of their non verbal communication was essential. The data transcripts were verified by the accompanying adult and analysed using a template approach. The themes were sent back to the participants for comments.

The World Health Organisation International Classification of Functioning was used as a framework for data management (Figure 1)³.

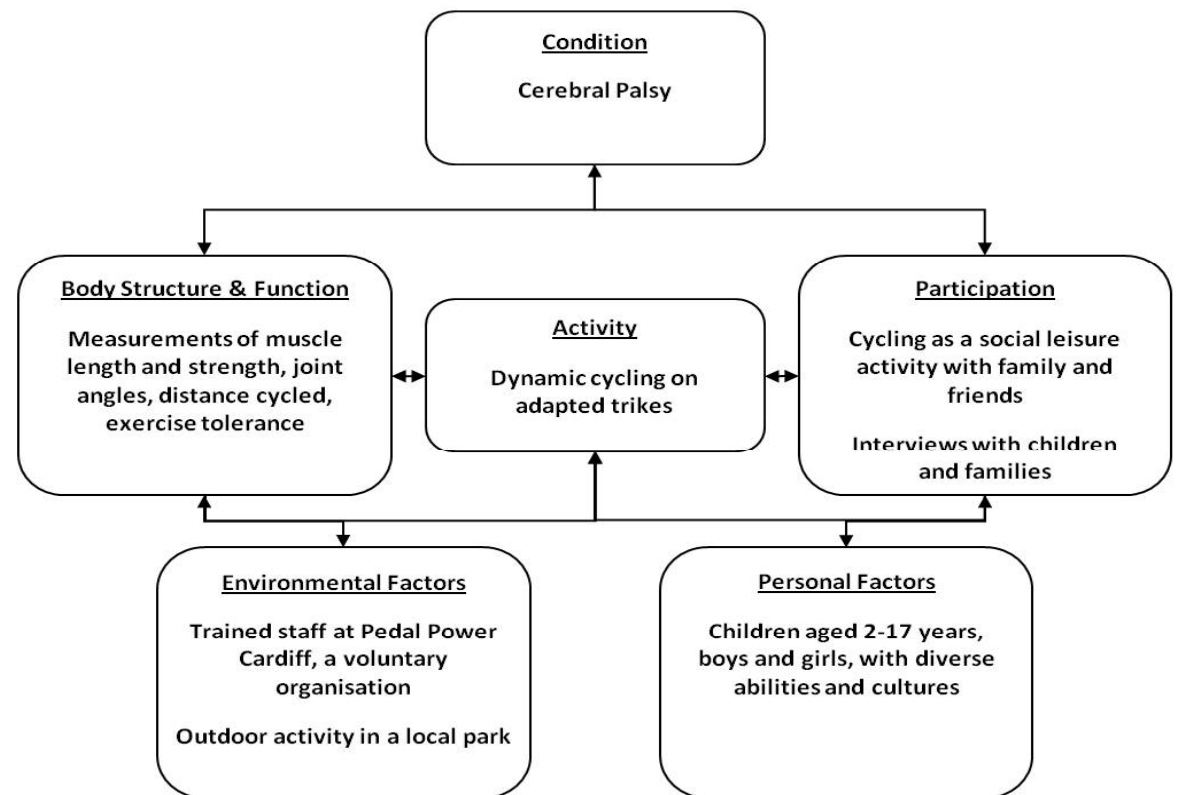
Results

Twenty six interviews and eight diaries were collected from seventeen children and young people aged between 2 and 17 years. The emergent themes are: firstly, the impact on the child and family providing them with an opportunity to join in a recreational activity together. Secondly, their future cycling aspirations, such as owning their own bike or going on a cycling holiday. Finally, the increase in social participation was evident from the new friends made and the independent cycling achieved. The children had enjoyed their adapted cycling experiences.

References

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Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning



Discussion

The experiences of ADC had increased the children and young people's leisure participation with family and friends. Some had made new friends, such as Diane (10 years/Hemiplegic) who drew the picture below. She had found ADC 'easier than walking'. Peter (7 years/Diplegic) had cycled on holiday and Becky (4years/Quadruplegic) aspired to do this in the future. Heather (7 years/Hemiplegic) aimed to cycle at the velodrome. Not all families owned their own adapted bike, some preferring to hire one from Pedal Power* due to the difficulties with transporting and storing such a large expensive item. Andrew (17 years Athetosis/Autism) progressed to going cycling with a carer: '...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...' The researchers considered they were able to represent the participants experiences even those without speech, whose 'smile' expressed their joy at cycling. The measurement data is being analysed before health benefits could be suggested, but there is a sense of 'well being' from this qualitative data.



Conclusion

The concept of participation requires deeper exploration for children and young people with CP⁴.

Implications

Policy makers and parents may find the information useful to enable the child with CP's participation.

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