

'Dragons and Couch potatoes'

Meanings of participation using metaphors from children and young people with cerebral palsy(EACD 2017)

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Introduction

A recent critique of the WHO-ICF model has proposed health as the ability to 'adapt and self-manage', suggesting that coping strategies and participation are more important than a full restoration of health (Huber et al, 2011). Children with cerebral palsy (CP) mature into adulthood living with their long term condition and it is proposed that participation in recreational activities can have both physical and emotional well-being benefits (Imms et al 2016). Whilst some do participate, it is not yet fully known why some choose not to participate.

Patient and Methods

Two pre-pilot cases are presented as part of a PhD 'VOCAL' study exploring the lived experiences of children and young people with CP. Creative methods were used for them to tell their stories in 2 interviews, 3 months apart. A diary of recreational activities was kept in the intervening period. This included creating a digital story, using hand puppets, figure characters in a sandbox and observations of a super triathlon. Data were transcribed verbatim and analysed using an interpretative phenomenological approach (Smith et al, 2013).

Results

Two female participants (pseudonyms), 'Becky' aged 9 and 'Katie' 21 years, took part over a 12 week period in 2015. Each interview utilised storytelling about their experiences. Diary entries included some photographs. Becky, describes neurosurgery that changed her capabilities, enabling her to walk with her friends, improving her social opportunities. Katie, described herself previously as inactive before she was given the opportunity, aged 19 years, to try Race Running (Picture 1).



Picture 1: Race Runners (<https://www.racerunningdragons.org/>)

References:

- Huber et al (2011) Health How should we define it? *British Medical Journal* 343 (d4163)
Imms et al (2016) 'Participation': A systematic review of language, definitions and constructs used in intervention research with children with disabilities. *DMCN* 58 29-38
Smith JA et al (2013) *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage publications



Picture 2: Interview 1 Becky



Picture 3: Interview 2 Becky

Themes which emerged included enriched perspectives of the emotional impact of living with CP and metaphors to enhance our understanding of their Lifeworld experiences. The **Dragon** was used as a metaphor for spasticity in Becky's story who had now '**flighted away**' - see pictures 2 and 3 from interview 1 and interview 2 where the Dragon has gone from her story. Becky enjoys horse riding, swimming, playing the violin, reading as well as doing her treadmill, stretching and fitness training. The observation of the super triathlon demonstrated her increased motivation to walk 400 metres when cheered along by an enthusiastic crowd.

Katie had discovered Race Running and described herself as changing from a '**couch potato**' to a young adult who trains 15 hours a week. Katie did not like swimming but had previously ridden a trike. The effort of walking limited her concentration '*...what I can't do is think coherently when I walk, but I can when I Race Run..*'. This new found confidence influenced Katie's choices: '*...as soon as I started sport ...not even any races, as soon as I started working out.....it made me embrace the abilities I had and created new abilities- not necessarily physical...in University, I went for the president of the faculty position. I was so much more happy within myself.....*'. Both participants demonstrated the adaptation, resilience and self determination learnt from their recreational opportunities. These findings support the health and well-being benefits of participation in recreational activities.

Conclusion

Further doctoral data will increase this knowledge by capturing children and young people with CP's own 'voices' about what is meaningful to their quality of life. The Chartered Society of Physiotherapy is part funding this part time PhD.

This work will be published as a chapter in August 2017 in this forthcoming book:

