

Childhood Disability: Interpretative Phenomenological Analysis to explore their 'Lifeworld' and views about Participation in recreational activities.

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Background

The complexity of a disabled childhood has been described as a hybrid experience which is not yet fully understood. 'Participation' in health has been based upon the World Health Organisation's International Classification of Functioning 'involvement in life situations'^{1,2}. Physiotherapists have been criticised for not demonstrating an increase in this domain from their interventions. However, in the social science literature, participation is based upon children's rights³. Kellet⁴ defines participation as the 'Act of doing and being involved' where both voice and agency play a role in influencing change. Here, children and youth are valued as social actors and agents of change in their own right which demands their voice be heard. Carpenter and McConkey⁵ have suggested it is the healthcare professionals 'moral imperative' to listen to the disabled child's voice. King⁶ suggests the way forward in research should explore the social aspects of participation, including their 'lived experiences' which has limited studies to date in this field of childhood disability⁷.

Objective

The purpose of this PhD study 'VOCAL' is to explore the 'Lifeworld' and views of children and youth with Cerebral Palsy (CP), about what participation in recreational activities means to them.

Methodology

Qualitative: 2 Interviews were carried out before and after a diary of recreational activities was completed over 12 weeks. The interviews were based upon 6 'F' words: family, function, friends, fitness, future and fun⁸. Participatory methods were developed using puppetry and 'sandboxing'. Interpretative Phenomenological Analysis (IPA) was carried out on 2 case studies where descriptive, conceptual and linguistic components were analysed^{9,10}.

Ethical Approval

Cardiff University's School of Healthcare Sciences granted ethical approval in Oct 2014.

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Pilot Data Results

Two female participants '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.



Picture 1: Interview 1 Becky



Picture 2: Interview 2 Becky

Results and Discussion

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 images in 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 all her treadmill, stretching and fitness training. 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 demonstrate resilience and self determination learnt from their recreational opportunities.

Conclusion/Implications for Practice

More data is needed to fully appreciate the 'Lifeworld' of a child or young person with CP, participating in recreational activities. Insights gained are enabling the voices of disabled children and young people to be heard. However, more data will be collected to achieve saturation, before it can be considered if physiotherapy practice could change to include participation outcomes.