‘Qualitative Research: Children’s Perspectives, Cerebral Palsy'

4th Baltic and North Sea Conference on Physical and Rehabilitation Medicine,
Riga, Latvia
Dawn Pickering, Physiotherapist,
Senior Lecturer,
18th September 2015
Objectives

• Data from 2 different studies with be used to show the additional value of qualitative data:

• 1. ‘Pedal Power’- 35 children and young people with Cerebral Palsy: Interviews + diary.

Lack of participation opportunities for CP Fowler et al, 2009; Fauconnier et al, 2009; McConachie et al, 2006; Mihaylovat et al 2004

Choice of activities limited - requires some adaptation and support

- Physiotherapy clinical practice with Cerebral Palsy (CP) - team approach.
Context for 3 year study: Cardiff (2009-2012)
Research question: Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels and quality of life in children with Cerebral Palsy.

Quality of life aims:

1. To find out about their experiences of adapted dynamic cycling/physical activities.
2. To introduce a non cycling group to information about adapted dynamic cycling, to explore if this is something they would consider for the future.
2 groups of children and youth with CP

- Adapted dynamic cycling
- 17 recruited from Pedal Power (travelled up to 50 miles to access this hire facility)

- Non cycling group – weren’t currently participating in adapted dynamic cycling
- 18 recruited from NHS and voluntary organisations
Interview schedule

Cycling group: First interview at beginning. Diary kept about their cycling experiences (only 8 returned).
Second interview after 6 sessions of cycling (not all were able to achieve 2 interviews)

Non cycling group: Information given about adapted cycling in their area (limited for children) at first measurement session.
Diary kept about physical activities (14 returned).
One interview at second measurement session 6 weeks later.
Children's Rights approach

- To enable their ‘voice’ to be heard

  - United Nations Convention on the Rights of the Child: Articles 12, 23 and 31:
    - All children have the right to say what they think
    - If disabled to have support to lead full and independent lives
    - to relax and play and to join in a wide range of activities (UNCRC, 1989)

  - Hart’s participation ladder (Hart, 1992)
• ‘Unhurried listening’

Attempted to use creative methods such as stickers/drawing/ink pad printing/game card matching, but several children had limited cognitive and manipulative Skills. Photographs were used but Many children were unable to take these themselves.
Puppets

• We used a glove puppet to engage the child in measurement and also when doing the interview—non verbal children responded well to the puppet.
Story telling/ Peppa pig goes cycling
• Different contexts for cycling were presented to the children in picture format to explore where they might like to cycle in the future:
  – Park in a City
  – Countryside
  – Seaside
  – With family and friends
Results: 35 recruited: Voices from 32 children and youth with Cerebral Palsy

43 Interviews
15 carried out own interview
10 Joined in with parent
7 Parent/carer reported

22 Diaries
4 self reported
3 mixed
15 parents completed
[ photographs included]

A5 Diaries set the interview agenda
• Interview
“...at the caravan park it was much easier than walking ...I cycled quickly with my friends and we chased each other on bikes and went to buy sweets at the village shop...we cycled on our own without Mum and Dad to the ‘lagoon’[see drawing]...when I don’t have my bike I tag along with others for a while..ponder my thoughts... get bored... in the city there aren’t enough safe places to cycle but at the caravan its easier to get around- it’s a clever ,clever invention whoever invented it I want to thank them.....”

• Diary drawing

Diane was 10, GMFCS II and has Diplegia
May is GMFCS II and has underdeveloped organs, dystonia and hemiplegia due to prematurity and having a stroke.
Interview:
Int: … So assuming you pass your cycling proficiency test, what do you hope to do with your cycling?
May: …to get better and better at it.
Int: Where would you like to go with your bike?
May: H Forest
Int: Have you been there already?
May: Yeah but I had to go on a ‘stupid tandem’ because my teacher kind of forced me…another Dad pedalled..
Mum: …It was sort of an ice cream basket on the back..
Int: So you didn’t do any pedalling at all?
May: No which was really, really, really disappointing…cos all my other friends were like riding a bike and I was lonely….
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…This year we cycled from Bristol towards Windsor because we could hire the special trike….I think completely independently he cycled not far off 40 miles…”

“I did cycling and it was wicked!”

Peter aged 7 years Diplegia, High tone, GMFCS I
How children’s voices changed our view - ‘Wheel of participation’ Pickering et al, 2015

Social model
Children’s illustrated story book 2015

- Story inspired by the 35 children who took part
- Illustrated by Hannah Pickering
2. Proposed Doctoral study: 2015 onwards

- Individual study- more in depth qualitative.

- Interpretative Phenomenological Analysis: Human lived experience
  3 components
  - 1. Phenomena-show/reason – both perceptual and analytical
  - 2. Hermeneutic- interpretation- sense making process. non-linear
  - 3. Idiographic- particular- single case analysis provides insight–series of cases.

Explores embodied, cognitive, affective and existential- double hermeneutic-explores empathy/ suspicion. Use of metaphors by participants.
2. Proposed Doctoral study Title: ‘VOCAL’

- Beyond Physiotherapy: 
  Voices of children and young people with cerebral palsy and their carers about ‘Participation’ in recreational activities.
• What is the ‘Lifeworld’ and the views of Children and Young People with Cerebral Palsy (C & YP) and their carers about ‘Participation’ in recreational activities?
Methods

• 2 interviews 12 weeks apart:

• 1st interview structured around the 6 themed ‘F’ words: Fun, Fitness, Family, Friends, Function and Future in relation to recreational activities

• 2nd interview makes reference to the diary entries.

• Diary of Recreational Activities kept for 12 weeks.
Pilot 2 case studies (pseudonyms)

- Girl aged 9 years: ‘Becky Lamb’
  Attends mainstream primary school, lives with both parents and younger brother.
  Prior research relationship since 2009: (6 years)

- Young adult female aged 21 years: ‘Katie Tate’
  University Student, lives away from home.
  Met at a children’s physiotherapy conference November 2014.
  Telephone interviews.
• Descriptive: describes what participant said.

• Conceptual: engages at a more interrogative and conceptual level. Interpretative.

• Linguistic: focusses on the specific use of language by the participant, sometimes metaphors used.
Digital story 2014

- https://www.youtube.com/watch?v=2jYXHdMoEgg
1: Becky Lamb - Digital Story 2014 (in press, Pickering and Anstey)

Metaphor: Dragon for Spasticity
‘The dragon story is about Dr Park...he did an operation on the boy......and it made the fires...that made my legs to cross, it flighted it away…’
BL speaks to father who arrives at the end of the interview and sees the sandbox:

‘That's me. I’m the smiley one in the pink dress.’
Sandbox (Mannay, 2015)
Interview 2
‘...the medal with the orange ribbon was for the Super Tri I did in March...it’s got one star, two stars, three stars, four stars, five stars, six stars, seven stars....I’m a winner...

Int: What did you have to do?
.....Three things...swimming, riding my bike and walking 100 miles

Diary entry week 7
Ben helps me I wolk for 400M with my frame....I did two lengths (swimming) bye my own.....Ida came two help riding by bike I did two times round the cycle track.....the end of my Triathlon everyone cheers for me!....I had a medl and a bag with a egg water stickus....’
Dragon – gone
‘..outside of university…I don’t have a job…so outside of that I do mainly sporting activities: mainly working out which is part of my role as a development trainer, it varies from week to week but I do 15 hours of physical activity a week, I do cycling on a trike and also stretching and then also strength and conditioning.’

INT: So, has this always been your experience that you do 15 hours per week?

‘No….I was never an active person….. I was what I would describe as a ‘couch potato’ all the way up until 19 years of age and I’m 21 now. I was very sedentary, and I hated working out..’

INT: What was it that changed your experience?
• ‘It was an introduction to a cerebral palsy specific sport called RaceRunning… it was just so freeing, even though I looked ridiculous, despite everything it was just amazing! …… My activities were very short and staggered, I would never really raise my heart rate or get into an easy motor pattern. …. Gravity and my CP is what made my walking pattern so disjointed- the need to stay upright against gravity with muscles which co-contract at the faintest hint that I might fall. So at first the RaceRunner gave me the experience of what walking must be like without cerebral palsy- using motor patterns which come naturally and easily……. Of course, I understand that some people truly cannot use the RaceRunner or can but won’t enjoy it or it is too much hassle to get one. You can get the mentality of sport even if you aren’t doing exercise, I mean people who play Boccia in their electric wheelchairs, that does not necessarily have a health effect but it does help mentally in the same way as RaceRunning.'
Race Running
...So you go (Race Running on a University Running track) and it's so beautiful, fresh air, you get to obviously run and because - obviously every movement, even driving, is very much concentrating, trying to do it right, not to fall over and then you get on to RaceRunner and you don't have - you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. *What I can't do is think coherently when I walk, but I can when I Race Run.*

Obviously loads of people, able-bodied people talk about how much they can think when they run and it's beautiful and they become more creative, so it might be something to do with that but I'm not sure......
What have I learnt so far?

• Both participants described the activities they consider fun, they have self awareness about the importance of their own fitness levels.

• It is important to address capacity building as this has an impact on their functional levels determining choices of recreational activity and can affect their concentration, mental and emotional well-being due to fatigue and pain levels.

• The future is unclear as the present NHS seeks to accommodate for the diverse needs of a developing child and young person with cerebral palsy. It is clear that opportunities to participate in RA builds self awareness, confidence and self esteem. New literature is suggesting Freedom and Fulfilment are also important. Further research is need to hear more ‘voices’ of disabled children and youth to understand their Lifeworld.
Dawn Pickering,
PhD candidate,
Senior Lecturer,
Physiotherapy,
School of Healthcare Sciences;
Cardiff University,
Wales, United Kingdom
pickeringdm@cf.ac.uk