

The experience of play for 6-12 year olds with high levels of physical disability due to Cerebral Palsy: An Interpretative Phenomenological Analysis

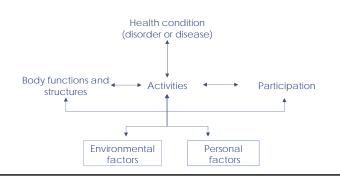
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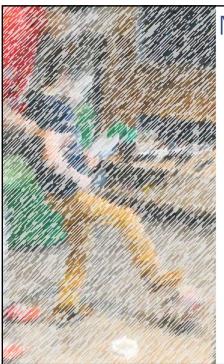
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Literature review

- Play defined by Freedom, Choice and Control (Bundy 2012)
- Primary occupation (Chiarello et al. 2006).
- Every child has a right to play (UNICEF, article 31).
- ICF (World Health Organisation, 2007)





Motivation for further research

- Children with disabilities are reported to play less than their typically developing peers (Whittingham et al. 2010, Chiarello et al. 2006)
- Young people with physical disabilities reported play to include: interactive play, onlooker play; play alone; and play with adult (Tamm & Skar 2000)
- Interviews with parents suggest that children with CP may engage in play: vicariously, through communication, through therapy. (Graham et al. 2015)
- Engagement despite limited performance (Polatakjo et al. 2007).

Methodology

Ontology-Minimal Hermeneutic realist

- One reality in the world but this is understood and it's nature is recognised within individual contexts. (Heidegger's perspective of reality as described by Larkin et al. 2006).
- The study findings will represent children's perspectives of the reality of play for them.

Epistemology-Social Constructionism

- Knowledge is constructed and influenced by society and our interactions with others (Crotty 2003). The focus is on the *person-in-context* (Larkin et al. 2006).
- Within this study an understanding of the meaning of play for children with Cerebral Palsy will be constructed through the participants account and interaction with the researcher within their own context.

Theoretical perspective-interpretation of the meaning of a phenomenon (Finlay & Ballinger 2006).

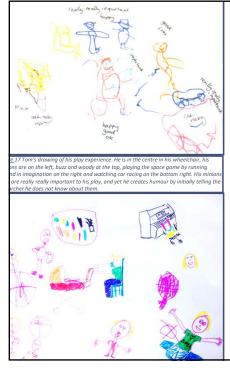
This study will present interpretations of the meaning of play to each of the research participants.

Interpretative Phenomenological Analysis (IPA) aims to understand and interpret the meaning of a lived experience of a particular phenomena (Smith & Osborne 2015).

This study aims to understand the meaning of the experience of play for 6-12 year olds with high levels of disability due to Cerebral Palsy.

In-depth semi structured interviews were used to explore the experience of play for children with Cerebral Palsy.

Visual methods such as the use of video recordings of the children playing, photos and favourite toys were used to elicit greater in depth discussion.

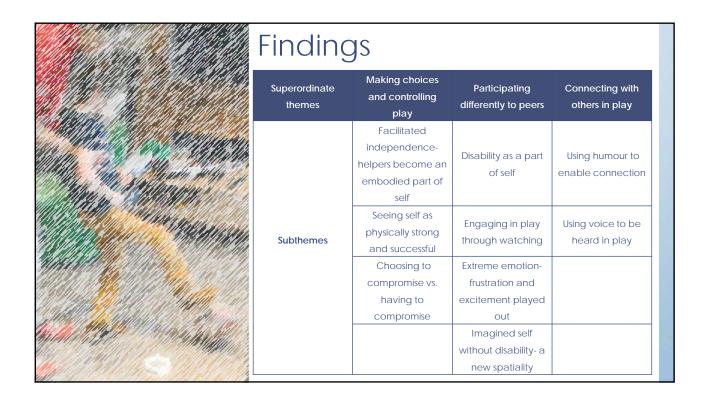


Method

- 3 semi-structured interviews per child
- Visual methods- videoing play, creating drawings
- · Video recorded and transcribed

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Pseuc	donym	Daniel	Abi	Lucy	Jess	Ben	Tom
Child	d Age	9	11	8	8	8	6
Cerebr	type of ral Palsy CP)	Dystonic quadriplegia	Dystonic, athetoid quadriplegia	Spastic Quadriplegia	Spastic Quadriplegia with dystonia	Spastic Quadriplegia	Dyskinetic quadriplegia
Child So	chooling	Mainstream, 50hrs support per week	Mainstream with 1:1 support	Specialist provision for physically disabled children	Mainstream with 1:1 support	Mainstream with 1:1 support	Mainstream with 1:1 support
GM	IFCS	IV	V	IV	IV	IV-V	V
MA	ACS	IV	V	III	III	IV	IV
CF	CS	II	II	II	I I	- II	II
Num	ber of	11	4	1	1	1	1
sibl	ings						
No	otes	Sibling not always at home. Communicates with eye gaze and verbally.	Bilateral hearing loss. Verbal communication. Siblings no longer at home.	Developed speech in the last 3 years, communicates verbally.	Identical twin of sister who does not have CP. Communicates verbally.	Verbal communication	Communicates through eye gaze and choice making. Sibling no longer at home.





Making choices and controlling play

- Facilitated independencehelpers become an embodied part of self
- Seeing self as physically strong and successful
- Choosing to compromise vs. having to compromise

Vista play

N-ok so who helps you roll the dice?

A- I do it on my own, do you remember, shut the box. (indicating back to game where Abi rolled the dice), like that, rolling the dice.

N- Rolling the dice like that, but in shut the box I had, I was holding your

A- oh yeah

N- but I was just, I was just helping?

A-Yeah

Abi, Interview 3

Being strong and successful

N-What else did you do for your celebration?

B- slide along the floor

N- how do you do that?

B- so you bend down, bend in the middle and then you Slide (emphasis and shout) along!

N- wow

B- you kind of break your knees though

N- oh do you, and who normally does the sliding?

B- Mummy!

N- so does mummy normally help you slide?

B- yep and I do it too

N- and what are you thinking in your head when you're sliding?

B- I'm going to win the world cup

Ben, Interview 3



Participating differently to peers

- Engaging in play through watching
- · Disability as a part of self
- Extreme emotion- frustration and excitement played out
- Imagined self without a disability- a new spatiality

N- so what imaginary game are you and Josie playing in this picture?

J- We're playing a game where we're friends from work and we go off on a girls night and it's all really fun

N- and what do you do on your girls night?

J- so we go to a pizza hut and then we go to the swimming pool and then we play in the swimming pool for ages and then we go home N- great, what do you like to play best in swimming pool?

J- Probably games where my Dad is the mermaid king and my mum is the mermaid queen and we are the mermaid princesses N- ah huh

J- that's probably my favourite game

N- that sounds really fun. And then what do you do in those games?

J-um, I kind of do this thing where I have to find, we have to dive down to our grotto kind of things and it's really fun. Jess, Interview 2

N- so if you do swimming then it's different to if you do swimming with Daddy?

J- yes because when I do swimming with Daddy I'm in a different pool and I can just swim freely. But the reason why I have armbands is because I, that means that I can have more freedom with my swimming whereas if I don't have it I have to have someone in front of me.

N- ok, so if you have armbands does it make it feel more like play

J- yeah so I can just swim around on my own

N- cool, so what do you play?

J- so we play that mermaid game, remember, and um, that's all we play really

N- ok so does he, does Daddy chase you?

J- no neve

N- so what happens in that game?

J- so mummy's the Queen, Daddy's the King and me and Josie are the princesses and Josie is just a mermaid who gets trapped and I see her and I free her and she becomes my friend and she becomes another, one of us, so it's really fun.

Jess. Interview 3



Connecting with others in play

- Using humour to enable connection
- Using voice to be heard in play

Humour in play

[watching video]

T- [vocalising and then squeals/ laughs]

N- [laughing] what happened! Did something go wrong or was it something else?

T- [chooses- 'something went wrong']

N- something went wrong! And you're doing lots of laughing, did that feel funny?

T- [looks- 'yes']

N- so do sometimes things go wrong when we're playing?

T- [looks- 'yes']

N- and is it part of playing or not part of playing?

T- [chooses- 'part of playing']

N- and is it sometimes what makes it funny or is that not right?

T- [chooses- 'they're sometimes what makes it funny']

Tom, Interview 3

Children with high levels of physical disability experienced a fluctuation in their lifeworld between their disabled and imagined self.

- Further exploration of the experience of being with a physical disability is needed.
- The concept of a fluctuating lifeworld, particularly the presence of an imagined self needs to be explored for adolescents and adults with high levels of physical disability.

Children with high levels of physical disability embody their wheelchair and equipment so it becomes a part of themselves in play.

- The importance of early mobility in enabling children to develop an embodied sense of self needs further exploration.
- Further research about the importance of wheelchairs and equipment to individuals who have had disabilities from birth is needed.

Children with high levels of physical disability are able to participate in play through watching, commenting and teaching.

- Exploration of experiences of participating in play through watching for children with both physical and communication difficulties is needed.
- Specific studies focusing on ways children participate through watching are needed. Studies should address the activation of mirror neurons and the tension between watching as participation and watching which is tokenistic.

Children with high levels of physical disability experience extreme emotions such as excitement and frustration in their play • Further research needs to address whether experiencing extreme emotion in play is unique to children with high levels of disability. This could explore the role of emotion in adjusting to the experience of disability.

Children with high levels of physical disability experience participation through 'vista play' an embodiment of their helper.

- •The concept of embodying another person needs to be further explored for both children with physical disabilities and other individual-carer dyads in order to understand the impact of this upon participation.
- Exploration of vista play for typically developing children.
- The importance of vista play for children with high levels of physical disability needs to be further explored in terms of its prevelance and commonality.

Children with high levels of physical disability experience a greater sense of belonging in play than their social world may anticipate.

- Further research should explore the experiences of isolation for children with disabilities in comparison to their typical developing peers.
- Research is needed to explore the impact of a helper supporting a child with disabilities on the participation of their typically developing peers.



Conclusions

- Children with high levels of physical disability experienced vista play
- Children with high levels of physical disability embodied both their helpers and equipment in play
- Children with high levels of physical disability demonstrated a tension in their lifeworlds which is seen in the way they experience play.
- Children participated in play differently to their typically developing peers and could participate through watching.



Questions?



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