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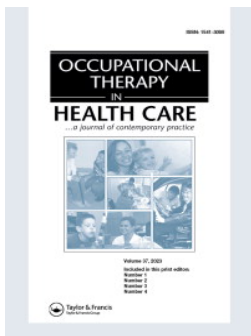
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The Experience of Living through the Transition from Adolescence to Adulthood for Young People with Cerebral Palsy

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ABSTRACT

This study explored the lived experience of transition from adolescence to adulthood for young people with cerebral palsy to inform occupational therapy practitioners as to what might promote positive life opportunities. A phenomenological methodology was used with six participants, aged 18 to 25 years with cerebral palsy. The findings are presented in the form of hermeneutic stories and three themes: *The storm of uncertainty; time, space and the body, Capsizing in a world of others* and *Securing anchorage; being heard and understood*. Recommendations include service integration across health, social care and education based on partnership and provision of coordinators.

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Disability; growing up; hermeneutics; phenomenology; young people

Introduction

It is important to understand what life is like for those living with cerebral palsy as this is one of the largest groups of people living with disability (Usuba et al., 2015), and is the most common major disabling disorder of childhood affecting individuals throughout the whole of life (Rosenbaum et al., 2007; Westbom et al., 2011). Life expectancy for children with cerebral palsy is increasing, with 90% reaching adulthood, and 80% living to over 30 years (Hemming et al., 2006; Oskoui, 2012; Strauss et al., 2008). Substantial research highlights the gap between children's and adult services and the traumatic experiences for young people and their families (Berg Kelly, 2011; Gorter et al., 2011; Hamdani et al., 2011; Kingsnorth et al., 2011). No studies explore this issue in the United Kingdom (UK) yet the need to improve transition arrangements for young people with disabilities has been encouraged since the beginning of the century (Department of Health, 2001; National Institute for Health & Care Excellence, 2016).

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Transitioning to adulthood can relate to the ages of 16-21 years (Bagatell et al., 2017) or sometimes 18-25 years (Carroll, 2015). Arnett (2015) describes these years as an 'emerging adulthood' when young people examine their relationships, education, occupations and where they might live as adults. As suggested by Ridosh et al. (2011), the transition is the developmental period when adolescents become young adults while increasing self-management of their condition and independence. In a previous review we found that adolescents living with cerebral palsy are ill-prepared for transition to adult life, they want to be informed and empowered, and there is much to learn about living through the body and how we might understand vulnerability (Boyle et al., 2022). By living through the body we mean the sensory and perceptual existence in terms of time and space, the potential and limitations of the body, and the human relations we all experience. Our review highlighted evidence as to the experience of living with cerebral palsy and the transition from adolescence to adulthood from studies outside of the UK (Canada, USA, Sweden) and with participants with substantially varying levels of disability from mild to severe (Boyle et al., 2022). Other studies highlight the gap between children's and adult services, the traumatic experiences for young people living with cerebral palsy and their families, and the worry for parents with many young people finding this period stressful (Berg Kelly, 2011; Gorter et al., 2011; Hamdani et al., 2011; Kingsnorth et al., 2011; Van Staa et al., 2011; Watson et al., 2011).

According to Pountney et al. (2004) movement and biomechanics are interrelated and therapeutic interventions for young people with cerebral palsy have often been designed to promote normal motor control, improve practical ability and reduce the progression of deformity. It is likely that the use of postural support and wheelchairs contributes toward management of deformity and improvement of quality of life (Ryan, 2016; Ryan et al., 2009; Ryan et al., 2014). The Gross Motor Function Classification System (GMFCS) (Palisano et al., 2007) is commonly used to classify levels of motor function between levels I to V, with V being the most severe. Regarding young people with cerebral palsy and a GMFCS level of IV or V, Orlin et al. (2010) found that low participation in physical activities has implications for health. This life, as a young person reliant on specialist equipment, fostered our curiosity as to their sense of belonging as wheelchair users, and our understanding of being human in such circumstances.

It is the everyday lived experience of this group, that is young people living with a high level of disability, as they become adults that is the focus of this study. There are no studies exploring this transition from a phenomenological perspective in the UK, and few that explore the lived experience of those with severe disability. Thus, the aim of this study was

to explore the lived experience of transition from adolescence to adulthood for young people living with cerebral palsy to inform occupational therapy practitioners as to what might promote positive life opportunities. The research question was *what is the lived experience of transition from adolescence to adulthood for young people with cerebral palsy?*

Method

Design

The research used a hermeneutic phenomenological methodology drawing upon Heidegger (1973) and Van Manen (1997), and hermeneutic stories according to Crowther et al. (2017). According to Van Manen (2017) good phenomenology adheres to sound philosophical principles understanding phenomenology as both descriptive and hermeneutic. Ethical approval was secured from the University of Brighton to ensure confidentiality and anonymity with written consent provided by each participant.

Public involvement

A public involvement group consisting of people living with cerebral palsy and family members ensured a high level of inclusivity as encouraged by the National Institute for Health Research (National Institute for Health Research, 2023). Recruitment to this advisory group was mainly through local advertisements and also following a presentation of the study background at a conference (Boyle, 2016). Although there is limited research about the use of public involvement in research design, the benefits seem to include development of user-friendly information and appropriate recruitment strategies (Brett et al., 2014). Our group included five young people living with cerebral palsy aged 20-26 years, a couple in their early thirties, and some family members. Harries et al. (2020) encourage occupational therapy researchers to embrace public involvement in a truly people-centred way with reflection as to how feedback from a broad range of people is sourced and used. Spending time with these provided access to their expertise, influencing the study design. Communication with members was helpful to explore aspects of the design including suggestions regarding the written account, the participant information sheet, and how to carry out the interviews. We do not claim this study is user-led, emancipatory or participatory, but has successfully involved a variety of stakeholders from an early stage to inform the design. Consultation with people living with cerebral palsy, and those involved with supporting them, to inform the design was highly valued and is recognized as good research practice (Harries et al., 2020; National Institute for Health Research, 2023).

Table 1. Participant and interview details.

| Pseudonym | Gender | Age | Interview venue | Interview duration (minutes) |
|-----------|--------|-----|-----------------|------------------------------|
| Theo | M | 24 | Work | 65 |
| Aisha | F | 24 | Home | 65 |
| Hasan | M | 25 | Home | 68 |
| Maria | F | 18 | University | 55 |
| Helen | F | 24 | Home | 67 |
| John | M | 19 | Home | 55 |

Participants

The inclusion criteria consisted of those diagnosed with cerebral palsy in childhood, permanent wheelchair users, aged between 18-25 years, able to use a physical or electronic document to write, understand and answer questions in English and provide consent. Six participants were recruited, all had a form of spastic quadriplegic cerebral palsy and were permanent wheelchair users, some had a mild speech impediment, but all were cognitively able to communicate verbally and provide consent. The ethnicity of the participants included people with a white-British, white-European, middle-eastern and Asian heritage. Participants lived across England and Wales in urban and rural areas, all had received substantial health, social care and education services including occupational therapy, [Table 1](#) provides further information including pseudonyms used. Participants were recruited via voluntary sector organizations and the university website, this attracted some press attention which helped to promote the research (Ryan, 2017; *The OT Magazine*, 2018). According to Finlay (2011) large sample sizes are not necessary for phenomenological research. Recruitment did not guarantee representation of young people in terms of class, gender and ethnicity, however, the study never intended to recruit a sample from which generalizable findings would result. Rather, we wanted to generate sensitive findings from those with direct lived experience of the phenomenon to provide new insight, crucial in phenomenological research (Finlay, 2011; Van Manen, 1997).

Procedure

Similar to Shakespeare et al. (2018), we recognized the limited voice of young people in the literature and concluded two rounds of data generation were warranted to explore experience first-hand. Participants were therefore requested to complete a written account followed by one interview. All participants were able to complete the written account using a computer. This form of data triangulation was beneficial for those living with a high level of disability to express themselves and can be helpful to deepen understanding of human experience (Mason, 2017; Silverman,

2013). While not necessarily leading to a single truth, the textual and dialogical methods facilitated the co-generation of rich data with young, severely disabled people.

A simple form for the written account was used with the following prompt statement - *I invite you to use the space below to write about your experience. You can write as much or as little as you like but I would encourage you to think deeply about your experience of growing up and maturing during your teenage years to now. I am interested in everything about your life and I would encourage you to write with as much detail as possible.* The interviews were carried out by the first author using unstructured, open-ended questions such as ‘*What was it like growing up with cerebral palsy as a teenager?*’ and ‘*Can you tell me more about becoming and adult during these years?*’ in a way that encouraged discussion.

Phenomenological research requires an understanding of the researchers’ position and pre-understandings to enhance rigor and we brought to the study many assumptions including our view that all of us are part of a world within which we are deeply connected with others, our own body, shared spaces, time, and relations—an existentialist position in-keeping with Heidegger (1973) and Van Manen (1997). It is important to understand and recognize such assumptions in order to trust the way in which research is carried out and enhance confidence in the findings.

Heidegger (1973) understood the social world in which we live in terms of *Dasein*, or *being-in-the-world*, a view of human beings engaged within a world of people, relationships and things that brings about meaning. With this in mind close attention was paid to each text *via* the writing of concrete accounts, reflection on hermeneutic stories and finally eidetic themes. The method allowed for a hermeneutic circle of understanding *via* a series of analysis tables, initially to provide exploratory comments alongside each text which gradually developed to link with sub-themes and themes, these were then finalized in relation to the existential modalities (spatiality, corporeality, temporality, relationality) as understood by Van Manen (1997). The use of these tables was not in a systematic way but rather as a place to store and view text where much was written and rewritten, reflected upon, and reviewed. This allowed for an increasingly sensitive, wondering writing experience, reflecting Adams’s (2010: 2) view of phenomenology as “a writing project not unlike that of poetry”.

Data analysis

Data analysis was carried out by the first author who, as an experienced occupational therapist with an interest in seating and the environment, brought to the study many assumptions. These were explored in a reflective journal and discussed with the other authors facilitating a critical

consideration of early interpretations and judgements. As such, reflection as to the first author's position was crucial to bring about an open mind and a phenomenological attitude.

Interpretations were sent to each participant for comment, this form of participant validation, and investigator triangulation, has been argued as adding credibility to research, but should not be confused with member checking which some critique for expecting too much from participants who cannot break away from the natural attitude (Finlay, 2011). Excerpts of the hermeneutic stories are provided below with some participant quotes, followed by the themes, with [Table 2](#) providing additional quotes.

Findings

Hermeneutic stories

Theo

Theo was 24 years old and in full-time employment, he lived with his parents in a large city but had lived away from the family during his teenage years in a residential college.

Theo experienced substantial difference positioning him in a world where he was never the same as those around him. Being different remained with him as he matured, pushing him to the fringe of social spaces. This perception of others came with implications as to how accepted he felt.

...I want a good standard of living that's the main thing, I know a lot of my friends now, a couple of them feel quite isolated in where they live, and I knew if I wasn't careful that could happen to me, the system sees you as a tick box sometimes and that happened to me when I first left college and just wanted a job, any old job, just to get out and do something, but obviously because of my condition I am often written-off. I went to the job centre and they said why do you want a job you are written-off for life and don't have to work if you don't want to, so and I said oh I want to work and they were really surprised by that, really, really surprised...

To live with others where there was bemusement dampened ambition replaced instead with tension. There were new relationships which brought satisfaction—being physically and emotionally close to other young people which was desired. Satisfaction was experienced particularly while meaningfully doing something that was important, with others where there was difference, but also some degree of sameness.

New relations provoked Theo's willingness to engage more with the world around him, especially as this came with excitement about what might be possible. However, the perception of others remained all

Table 2. Themes with supporting quotes.

| Themes | Supporting quotes |
|---|--|
| Theme 1 The storm of uncertainty; time, space and the body | <p>I use my wheelchair all the time, I've never not used a wheelchair so it's kind of you but I feel like it's kind of frustrating at times, you know going to pubs and whenever I wanted to hang out, to hang out with some of my mates, there was only a few select houses I could go....and so most of the time we'd have to come to mine, or there's only a few pubs that I need to know beforehand that I can go to (Maria).</p> <p>I could not go out because, like with a manual wheelchair and the streets are not like very level, I lived in the countryside so had it pretty bad back then, thankfully not now, but I used to have a pretty bad life, I remember seeing my siblings going out, I felt that right to do the same but I couldn't quite do it and it was pretty hard (Maria).</p> <p>It was hard because at 13 you thinking what is happening to me, why, why are these things happening, you think it's your fault, but you've got to remember at the same time, that this is a condition that is never going to go away no matter how hard you try (Helen).</p> <p>It just felt like you were, you are, being stripped of you what know it's like, the only way I can describe it if you like, is when you are stripping wallpaper off, and you and every strip is down here, and it's very different and I think young people should have more of a say in what they want, because, because this is a thing that will stay with you forever, and does define you, and does change you as a person, I don't think it changed me but I think as you get older it does definitely change your outlook, cos you think ah well when you go to those tricky interviews, you think why, but then obviously you know, look at what you can put yourself through, and I think that's the best way to look at it, try and focus the positives if you will, rather than the negatives, but I think, erm I think, just to be treated as a statistic, is just, I think, the whole system with regards to finding access to work, finding access to different areas that you never ever knew about, and then having to suddenly strip yourself and prove that you can do these different things I think is just wrong (Helen).</p> <p>I think I got to a position where I just accept things and accepting my disability. I think I have in the past pushed myself too hard, well it more clicked, I think oh well I can't really do that, and I don't need to do that. I look at what I can do rather than what I can't do. But then I think everyone goes through that, but because of my disability I think it's almost kind of threefold, the amount you think about it as you kind of compare yourself with your peers, which is a silly thing but everyone does it I know it's just one of those things, I've kind of got oh yeah limitations in things and that but it doesn't have to hold you back it can push you forward in a way, because you want to learn what you can do not what you can't do (John).</p> |
| Theme 2 Capsizing in a world of others | <p>At the end of the day, what people see is, what I figured out is people see my disability first, rather than my personality and that's been a pain, cos I'm in a wheelchair, but I have the mind of a human being, and that's what, because, I think it's really cos of society and education (Hasan).</p> <p>When I was younger I saw myself as extremely disabled and I didn't want to be seen like that, cos you, I felt especially like when I was younger I would sometimes scare kids and when they saw you struggling to do stuff, or your hand shaking a bit they would judge you and I never wanted to go out, I was seen as really disabled and I think I had quite a lot of self-esteem issues (Maria).</p> <p>The system let me down in a way, I mean I know it's a cliché but it's true, it's true, this does happen and it happened to me (Theo).</p> <p>I think the whole growing up process is brutal because you know there's so many different thresholds that are being used, throughout your childhood and throughout your adolescence and I think, to get, to cut those relationships away, especially when they have built that rapport with you and with your family and they know you so well, I think it's cruel, I think it's very cruel society that we are living in now unfortunately, I think it's only until this point you realise how cruel it actually is, but I think it depends on your attitude as well and the support network you've got around you, but I found it particularly difficult within the social services aspect because when you are in paediatric social services you are given a certain pot of money and then that is yours to do whatever you want with, but when you are in adult services it is a completely different ball game, completely different ball game, and ... but it just makes me laugh as well really, cos I think well hold on a minute, none of my circumstances has changed – none – but then they don't look at your previous records or your history like and therefore you get asked questions over and over again, I think why the hell am I having to prove myself, why am I having to prove that I have a condition that will stay with me forever (Helen).</p> |

(Continued)

Table 2. Continued.

| Themes | Supporting quotes |
|---|---|
| <p>Theme 3 Securing anchorage; being heard and understood</p> | <p>I did wheelchair basketball for a bit right up to recently, from about 14 to recently. That was really nice as everyone was still quite active although disabled so I felt I could relate to a lot to people there which I didn't really have at college. I think it was no one judging that was the main thing at basketball, it's just a sport so you go and play. It wasn't about being disabled, you know everyone just played. Whether you are disabled or not, there was no patronising, the kids are just treated as kids (John).</p> <p>When it came to the consultants side of things, most of the times I was literally left out, I wasn't involved most of the times, they were speaking to my mum not me, and I'm like, I'm here I'm the guy that needs the help, how does my mum know most of these things, so it was quite difficult but to be seen and believed, generally we are literally left to the side, and it's anything we do is just left aside (Hasan).</p> <p>It's like fighting a battle that you think people aren't listening, I think everyone should listen, you shouldn't be afraid to say something, it's not just what they say. I didn't feel afraid but I felt that they were taking advantage of me, but I am a bright person, take me for what I am. To be honest I don't think half the people knew me, like didn't know me and I think it was really bad because, this is where the problem starts, because if they don't know you that's, they assume something that's not true. It made me feel like, am I being taken advantage of, am I being taken seriously, or am I being deceived (Aisha).</p> <p>With my siblings it has been the greatest thing that has happened to me, cos I feel that if I didn't have siblings then life would be harder with socialising with people outside of the school, would be so hard to develop social skills without my siblings who have always treated me just like a sibling and not just disabled (Maria).</p> <p>Parents play a big part in any kid's life, not just a disabled person, but yeah my parents always want the best for me, if they see that I want to achieve something they don't get in the way or anything, they don't say 'oh it's too hard for you' or like anything like that, they say 'you can do it, you can do it', believe in yourself and do the best you can (Theo).</p> |

pervasive. To be let down was shocking and became the norm, to be seen as 'useless' was worse and shook his footing in the world.

...and they weren't really helpful at all, they were very lackadaisical about it. I think because the boxes were all ticked so they thought why are we helping him, it's not going to help our numbers, that was really quite disheartening to see.

Aisha

Aisha was 24 years old and lived with her parents in a remote, rural region, she had never lived away from the family, but had attended college.

For Aisha, the transition years were a time of aspiration and expectation for greater independence. She needed to be strong, and heard, and related to the world with her own view as to her rights. School was unsettling as basic needs were unmet and her experience of support from others was based on inequality¹ leading to a marginalized existence.

...I can't basically speak to them, and I know they don't want me there, I know I had a hard time but I wanted to stick with it, see how it goes, but like a few months and I'm fighting a battle, but they are not teaching what I need, I didn't get what I wanted and they found me probably, they probably found me quite a difficult person because I was the first wheelchair person there ... and the battle was so immense...

Becoming an adult required a strengthening of disposition to assert her place in the world, which was experienced as lonely and exhausting. Aisha saw herself as like others, with an expectation that professionals would act in her best interests. Failure from others was surprising which became the norm.

...they think if they say move on you should be grateful, they didn't think of what you really need to do to move on. People like us need to know how to move on, it's all well and good saying words but there is no action...

Those with authority had low expectations, shaking her grounding in the world. When support was provided, she was helped to become more determined, but without this she would question her existence bringing about despair and relations with those in authority built on hostility, pushing her toward a marginalized and disempowered existence.

Hasan

Hasan was 25 years old and lived alone in his own home, a ground floor adapted flat in a large city with his mother nearby, he was not employed but was a keen gamer, social media enthusiast and active athlete.

For Hasan, the transition to adulthood was a negative existence in terms of relations with others and use of the body. He knew little about what to expect, feeling fortunate to receive the little he did. Adolescence was a period of strained relationships, being bullied, and not heard or cared for sufficiently. He saw the world as hostile, subject to the influence of others.

...people see my disability first rather than my personality and that's been a pain cos I'm in a wheelchair but I have the mind of a human being...

Hassan experienced tension with those in authority contributing toward his anxiety as he inhabited a disempowered place with relations with others coming from a position of misunderstanding. Hasan lived with distance from others as he saw himself as singled out for being different, yet there was always a desire for social connection.

Others did not altogether see beyond Hasan's disability, neglecting the person within, this distance from others was alienating leading to suspicion from and toward others. A continual concern, as to how others understood and related to him, caused distress resulting in relations that lacked depth, as stated in this quote.

...when you are about 15 you start to think for yourself, so I don't really think there should be a limit that when you are 18 you are allowed to speak. It's not right cos at the end of the day when you are 11 to 18 you literally speak for yourself, yeah you can speak to your mum you can consult with your mum but it's our body at the end of the day, our parents can't make a decision on our body...

Maria

Maria was 18 years old and a full-time student, she lived with her mother and siblings in a medium-sized city.

Maria's story comes with positivity and excitement, there is optimism as she enters adulthood but also a desire for more. Recognizing herself as living with disability required a coming to terms with her position in the world. To be disabled for a long time was simply not being able to walk, but her existence in her body that differed so much from others that it was one of continual dissonance making her question what might be possible.

...like I mentioned in the written account I feel like when I was younger I thought it was not being able to walk but then when I was a bit more conscious about my life, I thought I realised, it was also about the way I moved, the way I talked, and I feel like these last few years it's been way harder than I thought it would be, you know with my speech and stuff, but you know I mean, I'm definitely like you know,

how sometimes you get people say like, oh it must have been easy for you cos you were born that way, I know in a way that's kind of true, but you know there's always been a struggle for me...

Maria saw herself as different but was also excited to live with others. This was a period of continual challenge as to how others understood her, as well as the relationships she desired. It was not entirely negative, as there was opportunity and friendships which provided opportunities to socialize. However, a search for meaning came with a greater recognition of the limitations of her body which increasingly informed how she understood herself.

...when you are disabled, you don't realise, you think you are an introvert, and your life becomes small...I don't think you realise how important social relationships are, meaning if you don't even realise it, I had to come to terms with this and how others think that's just the way you are, you generally feel that you don't want to socialise...I didn't want to come across as just a disabled person and I'm an introvert, and I don't really talk that much, so I think it didn't really help me to develop a whole certain side of my personality...

Helen

Helen was 24 years old, in part-time employment, she lived in her own home in a small industrial town with her parents nearby.

There was a feeling of contentment as a child and early adolescence for Helen when she felt safe, but this began to be lost during the transition years. She experienced her body changing in a world that was changing too and with this came uncertainty. She was seen primarily by others as disabled first which brought a sense of injustice.

...sometimes they forget that you have your own voice, they forget that you're there, they just think that you're in the shadow and you can't say what equipment works and what doesn't work, well you can, well I used to say to my physiotherapist, when I got older I used to say well you know basically this piece of equipment is not helping me because I'm either sitting wrong or there's something wrong with it and they always used to just dismiss it...

This was a period when Helen would question her body as there were inevitable changes and limitations that she sensed and understood as real. Her existence was entwined with that of her parents which brought contentment together with fear for the future. Living with parental comfort was reliable but experienced as a time when her body was changing, and some form of independence beckoned. She found herself questioning her abilities and sensed low expectations from others deepening her sense of injustice. Being a teenager with a disability and having to rely on others

was accepted but there was an unsettling strangeness experienced in relation to how she fitted into a world that could be neglectful.

...and I'd be like I'm, I'm telling you this is the problem, this is the problem, and you know there were some of them were understanding but some of them were like why is she not using it, well I used to say it's not gonna benefit me, it's not gonna benefit me in the long run, because you know they used to bring out walkers and standing frames and things like that and I used to, I used to do it, I used to comply with it, but then think why, cos it's not gonna let me, I'm not gonna walk, I would rather use my voice and use the communication that I have now, that I've been equipped with...

John

John was 19 years old and a full-time student, he lived at university and only with his parents during the holidays in a small seaside town.

Positive life opportunities were desired yet John found himself with unequal relationships with others. His relationships were changing making him feel more part of the adult world. This was especially true with those in authority, where there was a recognition that John was no longer a child. John entered adulthood with excitement, and some confidence that his place as a young man living with a disability would be accepted. John saw himself as a young man, different to others, but with an eagerness grounding him in the world that made him feel secure.

...I definitely went through a phase where I just didn't want to associate myself with other disabled kids...You kind of go through the process of asking yourself why should I compare myself with them, you almost get a weird feeling of I'm better than them. It's a weird thing as disability is different for everyone and comparing disability is kind of ridiculous as it affects people so differently...

John experienced unsettledness too, questioning his existence and why his place in the world was not like others. There was a growing sense of injustice and some innocence in his view which was becoming harsher as he matured.

...I didn't really feel ok about being me – which is a really odd thing to say but I think it's just because especially with my disability, especially with CP because you can either have it very extreme or it can be very mild, and I guess I kind of have the more extreme side of it, I think it was more difficult for me socially because I felt slightly awkward because I didn't really fit in with the other disabled kids because I was kind of...I remember the college were not good as they kind of put all the disabled kids into one pot...

This positioning of John, outside of the world of others, influenced his relationship with his family where he had always found warmth. There was a judgemental way in which he looked at the world around him, what others were doing, and his own position pushing him further away from others to an increasingly uncomfortable place.

Themes

Theme 1 the storm of uncertainty; time, space and the body

This theme illuminates living through the body in terms of time and space, and the relationship experienced with the body aligning with Van Manen (1997) understanding of spatiality, corporeality, and temporality. There is concern about being ready for the adult world as a wheelchair user which necessitates interaction with services for support. This does not always provide the opportunities that are yearned for and there is reliance on others. Relationships with services are unreliable limiting access to desired, shared spaces which frustrates opportunity. The life-world is one of insecurity bringing deep uncertainty. When there is participation with respect and dignity there is greater meaning, security, and joy.

There is comfort too when in the company of people like themselves, during these moments there is a harmony, sharing of difference and understanding of the body. Transitioning in a body that is changing highlighted a deeply felt difference to others which is unavoidable. Participants could not help but compare their lives with others living with disability, this could be inspirational but made them more aware of their bodies, their lives and position in the world which was experienced with harshness due to judgment from others. This period came with apprehension as there was a looking forward to what life may offer, and a sense of excitement for independence.

Theme 2 capsizing in a world of others

This theme relates to being the focus of attention and Van Manen (1997) understanding of relationality and corporeality as judgment by others can never be avoided and recognition of living a life under the scrutiny of others. This is lived with unavoidable distress as disability is seen first prevailing all else. The lifeworld can be described as a lived awkwardness, as the world is unsettling, for which the young people are ill-prepared. There is harshness experienced as the young person matures and the lack of understanding from others is dehumanizing. The way in which the young people are seen positions them on the outside, feeling capsized, uncomfortable and unsafe.

The perception of others influences how well understood young people feel about themselves and their relationships. Becoming an adult means to be seen as potentially nonproductive, when actually the young people see themselves as able and have ambition like other young people. Becoming an adult means living with a struggle to be recognized as more than a disabled person, but as wholly human with desires like anyone else. To

be able to be seen by others as someone who is changing, maturing and growing becomes a constant worry.

Their place in the world is built upon the focus of the visible disability and relations with others. The young people saw themselves as being part of a world with other disabled people, and that engaging in a struggle for their rights was worthy. Being part of this endeavor, to be assertive, brought feelings of being alive, with a desire to achieve, and to share in happiness and pride, but there was constant frustration too.

The transition to adulthood was a time of excitement and a desire to break away from family, but also a period of struggle as the influence of others was formidable. This was an unsettling period as there was a harshness in relationships with others as they entered adulthood. This was experienced with an abruptness in terms of relations with both children's and adult services across health, social care and education. Engagement with disjointed services was experienced as unwelcoming and chaotic yet could not be avoided. The young people found themselves distressed, immersed within a disappointing culture of low expectations.

Theme 3 securing anchorage; being heard and understood

The voice of the young people is understood as small contrasting with an inner voice desperate to be heard accompanied with a skepticism as to who might be listening aligning with Van Manen (1997) understanding of relationality and corporeality. There is tension when adjusting to adulthood, living with insecurity and a struggle to find one's voice. It became easier to accept failure, and instead of achieving, to become less than successful was seductive. As the young people passed through these years an inner strength increased leading to a greater sense of self-worth. This provided meaning but was not recognized by others, increasing marginalization. In contrast, when there was a sense of meaningful participation, contentment with others seeing beyond disability was realized.

Transitioning to adulthood means being surrounded by people who do not always believe in you. This can be a battle-like experience, but there is anticipation at what might be possible, when greater respect might be gained. The lifeworld involves substantial change, with relationships that were somewhat cold and distanced. The value of being disabled and finding a place that offers contentment cannot be guaranteed, which may be unsettling, compounded by mistrust of others. The lifeworld then is characterized as one of being misunderstood with uneasy, unequal relationships.

Living in a world that does not listen means the voice of the young people with disabilities is not heard and life is unfulfilling. There is deception, a battle to be heard, and a relationship with others that comes from

a position of conflict. This is experienced as unfair and there remains a lack of trust. For the young people, their place within the family was central but with maturity the potential for greater independence becomes alluring. Although there is a lifeworld that is warmly lived within the security that comes with family, there is a sense of dread as the future is uncertain and unpredictable.

Discussion

This study aimed to explore the lived experience of transition from adolescence to adulthood for young people living with cerebral palsy to inform as to what might promote positive life opportunities. The young people seem to live a life where parental struggle is the norm which becomes increasingly uncomfortable for the young people as they mature. The parental role is more than advocacy, and is seen by the young people as possessing an ever-present combative responsibility with health, social care and education services, a theme that is common in the literature (Björquist et al., 2015; Blacher et al., 2010; Darrah et al., 2010).

In the UK, the Children & Families Act, 2014 brought in measures endeavoring to support young people to make use of comprehensive education, health and care (EHC) plans. These aimed to provide a legal safeguard to ensure coordinated support across health, social care and education for young people up to the age of 25 years resulting in a smoother transition into adulthood (Robinson et al., 2018). EHC plans were hoped to provide a legislated integrated process relating to this period for young people living with disabilities (Robinson et al., 2018). However, this was not the experience for the participants in the current study where it seems resources were not made available and responsibilities of service providers across these services were avoided, supporting the findings of Robinson et al. (2018). An effective joined-up way of working between health, social care and education requires young people to be placed at the center with service providers having high expectations for employment, independence and community participation (Robinson et al., 2018). The argument for increased coordination between children's and adult services across health, social care and education is therefore strong.

Occupational therapy practitioners understand that it is the *doing* in life that defines humans as occupational beings (Kielhofner, 2008). With this in mind, occupational therapists commonly draw upon Townsend and Wilcock (2004) understanding of occupational rights including the right to experience occupation as meaningful, to develop through participation in occupations for health and social inclusion, and to exert autonomy *via* a choice of occupations. When considering the findings these seem to be absent leading to a lived experience consisting of occupational injustice,

deprivation, marginalization and alienation as understood by Christiansen and Townsend (2010). Existence for the young people in the current study appears to position them in a world which is experienced with ambiguity, and the role of those in positions of authority are experienced as overwhelming in determining many aspects of the young people's lives.

It seems the lifeworld includes a being-in-the-world with limited opportunities, although there is perplexity as to why this is so and a desire to be better informed, reflecting the findings of Freeman et al. (2018) and Carroll (2015). This is more than simply being poorly informed, but might relate to social exclusion, as the nature of being-in-the-world for the young people seems to be one of a normalcy that differs to others. Greater opportunity for socialization might address a social void which, in terms of relationships and intimacy, seems to be present for all, reflecting previous studies (Bagatell et al., 2017; Björquist et al., 2015; Freeman et al., 2018). Bagatell et al. (2017) findings are helpful in this regard as there seems to be something relating to frustration experienced with services. The young people's being-in-the-world might be best described as forever on the outside implying that services might be failing, that professionals need to listen more, and service development is necessary to encourage integration across health, social care and education.

Arnett (2015) explored what he referred to as a theory of emerging adulthood where young people in this age range are neither adolescents or adults but as something in-between. This supports Björquist et al. (2015: 258) call for a flexible, "stepping-stone" approach where family members, or others close to the young people, are available during the initial period after leaving the family home. This group it seems are likely to benefit from more time for developmentally appropriate support to adjust to adult life.

The findings encourage a broader understanding of disability, as suggested by Shakespeare (2020), and collaborative, integrated services across the 16–29 age range are more likely to provide services resulting in better outcomes (Morris et al., 2015). To integrate health, social care and education services across the adolescence to adulthood period catering for all needs is therefore recommended. To ensure collaborative working between services provision of coordinators linked to each young person is also recommended. There is demand from young people for greater independence without a complete break from parents, and service development to work with the whole family whilst supporting independence is recommended also.

Through greater partnership, youth-centred services are more likely to evolve responding to what matters for young people. To invest in new, youth-centred, rights-based transition services provided by well trained professionals with an understanding of disability as a human rights and equality issue is encouraged. Further research relating to relationships and

judgment by others built upon involvement of young people is recommended also to enhance understanding and wellbeing for this group.

Limitations

The participants lived across a large geographical region, as such the six participants may have experienced services that differed substantially. Similarly, the findings are limited to residents of the UK only and living with one condition, cerebral palsy. Recruitment was challenging and there is a strong argument to think creatively to increase recruitment. Overall, the public involvement dimension is a significant strength which ensured rich, contextual data crucial for phenomenological enquiry (Finlay, 2011; Van Manen, 1997).

Conclusion

This study explored the phenomenon of transitioning from adolescence to adulthood for young people with cerebral palsy in the UK. Insight is provided *via* revelation of being-in-the-world with others, being judged, the perception of others, and a desire to be understood and dwell in a safer world implying that services might be failing and professionals need to listen more. Recommendations are for service integration to be prioritized followed by provision of coordinators, to work effectively with families whilst preparing for independence, and to invest in strengths-based services based on partnership. Further research built upon involvement of young people is recommended to enhance understanding and wellbeing.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.

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