Living with Cerebral Palsy: A Journey to Self-Awarness and Understanding

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What Do We Know?

- Fatigue, pain and joint deformities as the top three CP-related impairments in adulthood that can interfere with activities of daily life.[1]
- The purpose of this study was to have a client-centered account of fatigue and pain that is experienced by adolescents and young adults living with cerebral palsy (CP).
- It is important to understand the experience of fatigue, and its relation to pain and physical activity, in early adolescence through to young adulthood as a result of growth of the individual and the negotiation of new body management techniques, as well as to identify factors that shape the experience of living with CP.

What Did We Do?

- Ten individuals aged 14-25 years were interviewed about their bodily experience of living with CP.
- During the interview participants were asked to describe a typical day, a day in which they experienced fatigue and/or pain and more general questions about living in a body with CP.
- Line-by-line coding was used to identify relevant text, after which a thematic analysis was conducted, both within and across transcripts to understand the lived meaning of the experience.

What Did We Find?

Participants	n=10
Age (years)	19.2 (2.49) Range= 15-24
Distribution of Involvement	Diplegia n=8 Triplegia n=1 Quadriplegia n=1
GMFCS Level	Level I n=1 Level II n=6 Level III n=3
CFCS Level	Level I n=9 Level II n=1
Sex	Female n=4 Male n=6
Educational or Employment Status	Unemployed n=1 Full-time Student n=9

Table 1 – Participant Characteristics

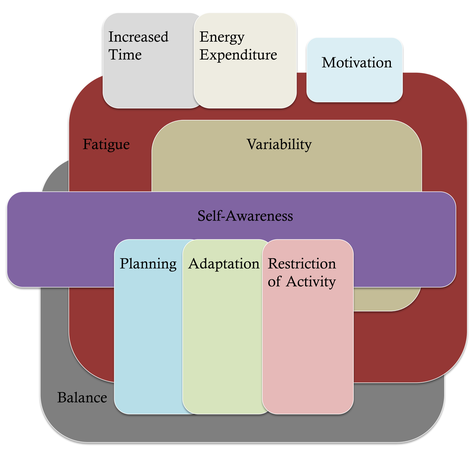

Figure 1 – Major Themes Identified

"So even though, like my energy level and balance is…is…well I wouldn't say my balance is worse, but my energy level is definitely lower, my pain threshold is a little lower, recovery time is a little lower….but I have more of an awareness now, so it kinda balances each other out, 'cause now I know what not to do, how not to step, how to kinda plan a route…and the route can be you know, if there are many obstacles, I'm like how am I going to get around them without falling over or kicking something over? So that…it's kinda more of a preplanning and an awareness of my own ability in conjunction with each other to get from point A to point B without falling over." – Goofy

"So I think, especially in my case, you know, wanting to do all these sports and wanting to be physically active, knowing that I'm going to tire out quicker sort of almost hinders me to do those things. So I think that could be one of the most worrying symptoms, to me, at least. Just because there is that fear that if I do get so fearful of just tiring out, tiring out and tiring out, that I eventually just abandon the whole idea entirely and then become sedentary, which I know is not going to help me at all." – Mickey Mouse

"I think it…I think I wouldn't be as tired [if I had more of a routine], and maybe would be more active. I find that even…like, I just…I think it has, over the years I think I kind of…I kind of decreased…I'm not as healthy as I maybe used to be." – Ariel.

"You know, kids with CP or any kind of physical disability I guess would be…you know, we all…kinda want independence, we all kinda wanna, you know, be able to do our own thing and…find a way to get things done and…I find, like…a lot of it comes down to, you know, adaptability and there's always a way to do something I think it just…like you can't really do it, you know, in the typical way, the way people are used to doing it." – Wade Wilson

"Well, I'll have good days and bad CP days, and on bad CP days I will try and not walk as much because usually my muscles are really tight and it's just impossible to actually get my feet to move the way I want them to. I'll drag them more which means I trip over my shoes more and then I fall more and then…I don't know, it's just a snowball of bad stuff." – Jasmine.

"I notice I have more trouble with my balance just because it's a longer walk and I find myself getting tired easily just because that…just because of how long it takes me to get back up and going back home with my family. It takes a lot of energy to get up [from a fall] than it does to get down." – Travis.

"As far as just day to day, like…like going out and…like play, like…I know it's different with my age now too, but yeah I used to go out in the winter time and, say go tobogganing or something but I wouldn't even try to attempt that anymore. I was a lot lighter and my Dad could carry me around a lot more when I was smaller, but, to do all that by myself it would be just too physically tiring, and I just couldn't…I couldn't do it unless…like, I'd be done for the day after an hour of doing that kind of thing." – Chris Bosh

Conclusions and Future Directions

- Fatigue is a major concern for many individuals living with CP. It is also clear that the experience of living with CP is complicated and multifaceted.
- In order to manage fatigue experienced on a daily basis, some individuals in this study found methods to adapt or alter their activities, while other participants had not yet reached this point on their journey to self-awareness.
- When preparing for transition from pediatric care, service providers typically encourage youth with CP to learn to manage their own health care needs.[3] Self-awareness of their bodies and the impact of fatigue should be fostered by service providers and included in clinical conversations about managing their health care needs for the present and the future.

References

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