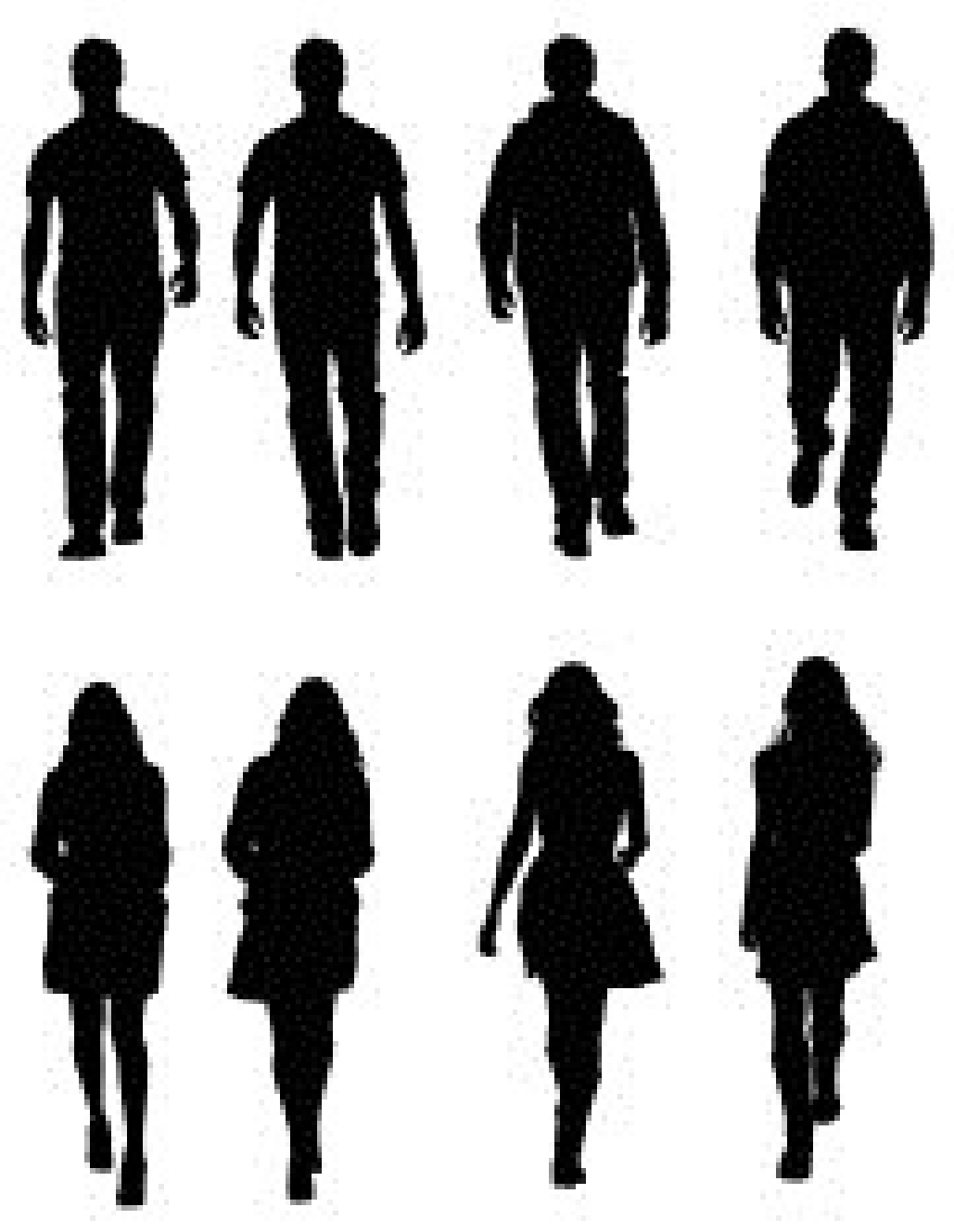


A qualitative investigation into living with Developmental Coordination Disorder as a young adult

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Background & method



Developmental Coordination Disorder (DCD) is a neurodevelopmental condition affecting motor coordination that impacts on everyday activities and continues into adulthood (APA, 2013). Previous studies have focused on the presentation and experience within children. There is limited knowledge about the experience of adults with motor coordination difficulties.

Building on the limited knowledge, the study sought to extend the understanding of how DCD presents in young adults (18—25 years), the perception of difficulties arising from this and how these difficulties affect the decisions and life-choices of young adults with DCD.

Participants: Five participants; one young adult and four parents of young adults (19-25 years) participated in the study.

Method: Semi-structured narrative-episodic interviews (Flick, 2009), lasting between 32 & 69 minutes enabled participants to recount their experience of living with DCD. Interviews were audio-recorded and transcribed, with participants invited to review transcripts prior to inductive thematic analysis (Braun & Clark, 2006).

Findings

Findings suggest that young adults face a range of difficulties as they move from adolescence towards adulthood.

These difficulties present across multiple domains and inhibit life choices.

Difficulties with motor coordination persist:

- Fine and gross motor difficulties were frequently mentioned, and despite the persistence of difficulties, participants did not feel this fully represented the experience of living with DCD
- Motor difficulties impact on many activities of daily life; ***“personal hygiene can be really hard if you can’t manipulate your hands”***
- Learning new skills often brings new difficulties; ***“he managed to learn to ride a bike, but he isn’t road safe, because he can’t look over his shoulder without falling off”***

Difficulties with planning and organisation

- Young adults found planning and being organised difficult; ***“I’m still late a couple of times a week because I’m so poorly organised”***
- Remembering to do things was problematic; ***“I’ve run out of toothpaste because I’ve forgotten to buy it”, “will she remember this critical appointment with the doctor?”***
- Financial management was difficult; predicting expenditure, physically withdrawing cash from cashpoints, and getting into arrears.
- Participants lived chaotic lifestyles, with one parent recalling taking her son back to university ***“and getting all the way to the house before he realised he had forgotten his key”***

Sensory, physical and health problems

- Other difficulties, such as a ***“dulled sense of feeling”*** also impact on the daily lives of young adults
- Young adults had sensory difficulties towards temperature, being ***“unable to tell if something is too hot”***, also sensitivity towards certain fabrics
- Poor bladder control and needing ***“the toilet all the time, ... every hour, on the hour”*** was also attributed to DCD.
- Young adults also experienced disrupted sleep patterns; ***“waking about ten or twelve times a night”***, and that young adults need a ***“huge amount of sleep”, “by 9 o’clock-ish, he is pretty shattered”***

The importance of support

- Multiple support networks assist young adults in their daily lives
- Parental support to prepare for university, financial support and assisting with resolving problems.
- Education/work support with mentoring, modelling social scenario’s, support with interviews by having a copy of the interview questions to help ***“remember what the question was”***
- Support from partners for financial matters, walking ***“I usually hold my girlfriends hand to keep me in a straight line”***, home chores and creating social networks

Discussion

- The findings concur with previous empirical evidence that motor difficulties persist into adulthood. Young adults face additional constraints which impact life choices. These constraints may be ameliorated by external resources, such as support networks, technology and the development of coping strategies.
- Positive social interaction was important to young adults, but without knowledge of what life might be like without DCD, participants were unable to express how much more important these interactions were.
- The concept of marginal gains (Sugden, 2014) may highlight the importance of small, positive changes which when combined can make significant difference to an individual.
- The findings suggest that motor difficulties are less of a concern to young adults and that they face additional difficulties, which may be further impacted by sensory, physical and health difficulties.
- The study highlights the importance of understanding the wider implications of DCD in order to help in the planning of appropriate support, developing effective interventions and appropriate tools for diagnosis and screening of motor coordination difficulties in adults.

References

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