Daily Living Transactions: How children and carers work together to complete daily routines when the child has cerebral palsy

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Introduction

Children with cerebral palsy (CP) at Gross Motor Function Classification System (GMFCS) IV and V use wheelchairs as their primary form of mobility [1] and are likely to require assistance from a carer to complete daily routines [2]. Achievement of daily routines occurs as a transaction between the child, carer and in context [3]. While goals for intervention will be individual for each family, building the capacity of children and carers within the context of daily routines is likely to be highly beneficial.

Aim

This research explored how children with CP functioning at GMFCS levels IV and V work together with their carers to complete daily routines. We also investigated the child-related actions that were useful in daily routines. Our purpose is to inform goal setting and intervention planning for children and carers.

Methods

This was phase two of an explanatory sequential mixed methods study. Non-ambulant children (GMFCS IV and V) aged 5-18 years and their carers were recruited from the Victorian Cerebral Palsy Register. Five child/carer pairs were filmed in their homes completing daily routines, and participated in video-elicited interviews. The thematic analysis of the interviews examined what happened and the child related actions that occurred during daily routines. Further exploration of how to build capacity in the transactions between child and carer was undertaken.

Results

Participants

Child age range 8-18 years; GMFCS IV n=3; female n=3. Carer age range 33-54 years; mothers n=4, father n=1.

Core Findings

Findings from the interviews highlighted how carers and children worked together during routines. Themes were derived describing how families negotiate a busy life, and the child, carer and contextual factors that influence routines and that change on a daily basis. The findings are synthesised and summarised in the CAR framework described below.

The Child Active Routines (CAR) Framework.

1. The racing car: Carers and children achieved routines in the quickest and easiest way to be efficient as possible in a busy life.
   “We have to find the...straightest line to achieve what we need to do in a day.” (Carer of 10 year old)
2. The tractor: Disruptors occurred during the task that made daily routines slow and hard work.
   “I can just look at you and know that your muscles are behaving badly...you will say I don’t really feel what my legs are really hurting, my body is being tricky, and can you help me.”
   (Carer to 16 year old)
3. The Sports Utility Vehicle (SUV): There were some days and times that carers and children had time to negotiate opportunities for learning, adapting for change, and skill development.
   “On weekends and holidays and times when her dystonia is better controlled, then we do stop and take the time to allow her to do more.” (Carer of 16 year old)

Conclusions

Understanding carer child transactions in daily routines can help guide practical learning for carers and children

Children with significant impairments can contribute to some daily routines with support

The CAR framework may aid communication between children, carers and clinicians about when and how children can contribute and learn skills in daily life

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References