

Mothers of children aged 6 - 12 years with cerebral palsy or autism: How much time is required for caregiving?



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Aims

How much time do mothers of children aged 6-12 years with cerebral palsy or autism spend caring for their children?

Does this differ from the time required to care for children without disability?

Aims (cont.)

Is there a relationship between time required for care-giving activities and the mental health of mothers?

Background

Overall value of caring activities is greater than the total value of government expenditure on welfare services

(AIHW, 2003, Arno et al 1999)

Participants

- Identified from the SA Cerebral Palsy Register and Novita Children's Services
- Registered with Autism SA
- Children without disability attending one of three schools in South Australia

Number of Participants

Cerebral Palsy 107

Autism 162

Control 140

GMFC Scores (n=107)

Level	Percentage
1	39%
2	23%
3	9%
4	10%
5	18%

Center for Epidemiologic Studies Depression Scale (CES-D)

- 20 items
- Scores range from 0-60
- Assess previous week
- Higher scores indicate more problems

General Health Questionnaire (GHQ)

- 30 items
- Scores range 0-30
- Assess previous four weeks
- Higher scores indicate more problems

Percent of Mothers with Mental Health Problems

	CP	AUTISM	CONTROL
GHQ Scale	34%	56%	28%
CES-D Scale	19%	36%	7%

Daily Activity Diary

- What was your main activity?
- Was the activity done for the child?
- What else were you doing?
- Intensity of support for child?
- Who was with you?

Intensity of Support

- 1 Low**
Low-level supervision & sleep periods
- 2 Moderate**
Medium level supervision. Occasional intervention required. Child cooperative
- 3 High**
Close supervision and frequent intervention. Child uncooperative
- 4 Intense**
Very close supervision and continuous intervention. Child cannot complete activity without assistance

Diary Example

Time	WHAT WAS YOUR MAIN ACTIVITY?	FOR CHILD IN STUDY?	WHAT ELSE WERE YOU DOING?	LEVEL OF INTENSITY?	WHO WAS WITH YOU?
6:00	Sleep	No		1	Family
.05	Sleep	No		1	↓
.10	Sleep	No		1	↓
.15	Georgia is awake	Yes	Getting up	3	Nana & Pop
.20	↓	Yes	↓	3	↓
.25	Out of bed and on the move	Yes	Getting dressed	3	↓

Days Completed

	CP	AUTISM	CONTROL
Weekdays	82%	74%	85%
Weekends	18%	26%	15%

How much caregiving time do mothers of children with cerebral palsy or autism spend with their children?

Time spent in activities for child

	CP	AUTISM	CONTROL
Weekday (hh:mm)	5:53	6:02	4:47
Weekend (hh:mm)	9:11	7:02	5:41

Time spent at each level of support intensity

	CP	AUTISM	CONTROL
Intense	1:18	0:48	0:12
High/ Moderate	2:27	3:15	2:07
Low	2:19	1:52	2:06

Primary Activity Descriptions

- **Physical Care:**

Dressing, waking up, putting to sleep, cleaning teeth, bathing, brushing hair, first aid, or supervision of these activities

- **Teach/Help/Reprimand:**

Helping child to do things or showing them how, helping with homework, directions about household chores, and settling disputes

Time spent on child care activities

	CP	AUTISM	CONTROL
Physical Care	1:41	1:10	0:23
Teaching/Helping /Reprimanding	0:28	0:50	0:34

Is there a relationship
between caregiving time
and maternal mental
health?

Regression Coefficients* for Physical Care Time

Scale	CP	AUTISM	CONTROL
GHQ	1.21	1.08	2.24
CES-D	1.69	1.84	3.69

*expressed as unit change per hour

Regression Coefficients* for Teach, Help & Reprimand Time

Scale	CP	AUTISM	CONTROL
GHQ	0.05	2.95	0.53
CES-D	1.36	3.41	-0.09

*expressed as unit change per hour

Quotes from Carers

"I hurt my back on the 15th of January. Life still has to go on. No time to rest. S still needs everything done for him and no one else is home to do it. My husband has to work and that's just life. S is getting bigger and heavier and I know when we get older we will suffer physically for it"

- mother of 11 year old boy CP.

Quotes from Carers

"T requires 24hr assistance to do nearly everything. He is however able to drink from a cup with a straw by himself and is able to slowly finger feed himself if the food is suitable for this. T permanently wears nappies and these need changing several times a day. He wakes often during the night because he tries to roll over onto his side and becomes stuck. We need to get up at night to settle him on his side...A lot of the time I feel tired."

-mother of 16 year old boy with CP.

Conclusions

- Large amount of time required to care for children with CP and Autism
- Between 4X and 6X as much time spent caring at the highest level of intensity

Conclusions

- Significant relationship between maternal mental health problems and
 - physical care time for children with CP
 - teaching, helping and reprimanding time for children with Autism

THANK YOU