

Young Carers in Norway: Children of patients with severe illness or substance use disorder, their caring activities and outcome.

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Design and sample

Design

- An explorative cross-sectional multicentre study.

Sample

- 246 children aged 8-17 years and their 238 parents
- Parents as patients in specialized health care services
- Severe physical illness (neurological disease or cancer)(n=135),
mental illness (n=75) or substance abuse (n=28)
- Recruited from five health trusts in Norway



Strength and limitations

- Almost no missing
- The use of well established questionnaires
- Extensive recruitment of three parental illness groups in health care services
- A sampling bias may have occurred:
 - Overall, the parents were highly educated with high income levels.



Sample differences across parental illness groups

- Physical ill parents (PI) had significantly higher levels of education and income, compared to mental ill (MI) and substance abuse parents (SA).
- MI parents had significantly higher income compared to SA parents.
- SA parents reported single-parent status significantly more frequently than the other two illness groups.
- MI parents reported significantly poorer mental health compared to those with PI and SA

Paper 1

Children with ill parents; Extent and Nature of caring activities

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Research questions:

1. What are the nature and extent of caring activities undertaken by children of severe ill parents?
2. Are there differences in the patterns of caring activities in relation to different types of parental illness?
3. Which factors are associated with the nature and extent of caring activities?



Main outcome measure

Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers

Dimensions	MACA-YC18 Joseph S, Becker S, Becker F, Regel S. Child Care Health Dev. 2009;35(4):510-20.	Never % (n)	Some of the time % (n)	A lot of the time % (n)
Domestic	1. Clean your own bedroom	9,3 (23)	54,1 (133)	36,6 (90)
	2. Clean other rooms	35,8 (88)	53,7 (132)	10,6 (26)
	3. Wash up dishes or put dishes in a dishwasher	13,0 (32)	51,6 (127)	35,4 (87)
Household	4. Decorate rooms	15,0 (37)	57,3 (141)	27,6 (68)
	5. Take responsibility for shopping for food	47,2 (116)	44,7 (110)	8,1 (20)
	6. Help with lifting or carrying heavy things	14,6 (36)	54,5 (134)	30,9 (78)
Financial/ Practical	7. Help with financial matters such as dealing with bills, banking money, collecting benefits	80,9 (199)	17,5 (43)	1,6 (4)
	8. Work part time to bring money in	85,5 (211)	11,8 (29)	2,4 (6)
	9. Interpret, sign or use another communication system for the person you care for	89,4 (220)	8,1 (20)	2,2 (6)
Siblings	16. Take brothers or sisters to school (N=221)	81,0 (179)	14,5 (32)	4,5 (10)
	17. Look after brothers or sisters whilst another adult is near by (N=221)	66,1 (146)	26,7 (59)	7,2 (16)
	18. Look after brothers or sisters on your own (N=221)	61,5 (136)	30,8 (68)	7,7 (17)

Multidimensional Assessment of Caring Activities (MACA-YC18)

Dimensions	The caring jobs I do	Never % (n)	Some of the time % (n)	A lot of the time % (n)
Intimate	10. Help the person you care for to dress or undress	85,0 (209)	12,2 (30)	2,8 (7)
	11. Help the person you care for to have a wash	91,5 (225)	7,7 (19)	0,8 (2)
	12. Help the person you care for to have a bath or shower	96,3 (237)	3,3 (8)	0,4 (1)
Emotional	13. Keep the person you care for company e.g. sitting with them, reading to them, talking to them	36,6 (90)	42,7 (105)	20,7 (51)
	14. Keep an eye on the person you care for to make sure they are alright	36,2 (89)	39,8 (98)	24,0 (59)
	15. Take the person you care for out e.g. for a walk or to see friends or relatives	69,1 (170)	28,5 (70)	2,4 (6)
Health MACA-YC42	24. Making sure that the one who is ill take their medicines	78,9 (194)	16,3 (40)	4,9 (12)
	41. Talking with officials doctor/benefits office about the person you care for	97,6 (240)	1,6 (4)	0,8 (2)
	26. Take someone you live with to the doctors or hospital	89,0 (219)	10,2 (25)	0,8 (2)

Results paper 1

Nature and extent of caring activities

The children reported:

- *Domestic activities and household tasks* were performed by the majority
 - *Financial and practical management* - more than one in ten
 - *Personal care for the ill parent* – more than one in ten
 - *Emotional care* for the ill parent - six in ten
 - *Sibling care* – provided by three in ten
 - *Health care* were performed by two in ten
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- Moderate extent of caring activities (total scores) were reported by more than two in ten
 - High or very high caring levels were reported by one in ten
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- More than one in ten reported caring for more than 10 hours a week on average.



Results paper 1

Nature and extent of caring activities

The parents reported:



- Increased caring activities among the children because of the parent's illness
- reported by more than two of ten parents
- one of ten reported that the child had helped them with personal care they usually would have done themselves.
- Six percent of the parents reported that the child did not have to do caring activities because health care or home based services performed these activities
- Six percent reported accesses to home based services

Results paper 1

Patterns of caring activities for different types of parental illness

- No significant differences between the parental illness types in the total extent of caring activities
- Children of parents with physical illness scored significantly higher on domestic activities and emotional care for their parent than children with parents with substance abuse
- 25 % of children of parents with mental illness and substance abuse reported more than 10 hours caring activities a week, compared to 4 % children of parents with physical illness



Results paper 1

Patterns of caring activities for different types of parental illness

Parents reports of:

- Increased caring activities by their children because of the parent's illness
 - 28 % of parents with physical illness
 - 21 % of parents with mental disorder
 - 3 % of parents with substance use disorder

- Helped with personal care the parent usually would have done themselves
 - 14 % of the parents with physical illness
 - 7 % of the parents with mental disorder
 - none of the parents with substance use disorder

- The child did not have to do caring activities because health care or home based services performed these activities
 - Only 9 % of parents with physical illness
 - 4 % of parents with mental disorder
 - none of the parents with substance abuse disorder

Results paper 1

Factors associated with nature of caring activities

Significantly associated factors:

Extent

- Higher external locus of control and better social skills among the children
- Poorer parental physical health

Domestic activities

- Being a girl, higher age and better social skills among the children

Household management

- Higher external locus of control and social skills among the children
- Poorer parental physical health

Personal care

- Younger age and higher external locus of control among the children

Emotional care

- Better social skills among the children
- Significantly less provided among children with parents with mental illness and substance abuse compared to children of parents with physical illness.

Financial and practical activities and sibling care - none significantly associated factors



Paper 2

Children with ill parents; Positive and Negative experiences of caring activities

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Research questions:

1. What are the positive and negative outcomes of caring activities undertaken by patient's children?
2. What are the differences in the patterns of positive and negative outcomes of caring activities between the types of parental illness?
3. Which factors are associated with positive and negative outcome of caring activities?



Results paper 2

Positive and negative outcomes of caring activities

The majority of the children reported positive outcome of caring activities

Because of caring activities they felt that;

- They were doing something good,
- Felt good about helping and liked who they were,
- They felt use full and that their parents were proud of them.
- Nine of ten felt closer to their family, felt good about them self's, and learned use full things because of caring activities.
- Eight of ten reported that caring activities made them better to cope with problems.

Almost half reported that they felt stressed because of caring activities

- Nearly four of ten reported that they had to do things that made them upset
- More than three of ten couldn't stop thinking about what they had to do.
- More than two of ten felt lonely, like they didn't matter, and had trouble staying awake.
- More than one of ten felt like running away, that they couldn't cope, were so sad that they couldn't handle it, and that life didn't seem worth living.

Differences in the patterns of positive and negative outcomes of caring activities between the types of parental illness

- No significant differences between the parental illness types in the children's experience of positive and negative outcome of caring activities

Factors associated with positive and negative outcome

Positive outcome

- Younger age and better social skills among the children
- Less household activities and personal care for the parents

Negative outcome

- Higher external locus of control and less social skills among the children
- Higher levels of financial and practical tasks, and personal care



Conclusion and implications



- A large portion of children of ill parents are performing various caring activities
- There were no significant differences in extent of caring activities or outcome between the types of parental illness

The factors significantly associated to increased caring activities were:

- Higher external locus of control and better social skills among the children
- Poorer parental physical health status

The factors significantly associated to negative outcome of caring activities were:

- Higher external locus of control and poorer social skills among the children
- Personal care

To prevent children to become “young carers” there is a need for interventions establishing informal care and increased access to flexible home-based services for parents and families adapted to the types of illness.

Thank you for the attention!

