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Parents' experiences of caring responsibility for their adult child with schizophrenia

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Research Article



Parents' Experiences of Caring Responsibility for Their Adult Child with Schizophrenia (2016),

Ann Blomgren Mannerheim, Ulla Hellström Muhli, Eleni Siouta

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The starting position

 Family members have taken over from the formal healthcare system significant responsibility for the care of persons with a mental disability and illness.

Questions:

- what are the experiences around parents' informal care activities and responsibilities
- how do parents construct and manage their caring responsibility and
- 3) with what consequences?

Knowledge contribution:

the individual's experienced meaning of his or her life situation





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Background

- The psychiatry reform in Sweden
- The parents have a significant responsibility for the care of their adult child with schizophrenia
- The informal caregiving role puts a burden on the parents





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Aim

To describe and analyze the experiences of parents' informal care responsibility





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Method

- Qualitative interviews
- 16 hours of recorded material
- Eight parents
 - both men and women aged 52-63 years
 - all members of the interest group "Interest Association for Schizophrenia"
- Analysis with a Hermeneutical model of interpretation



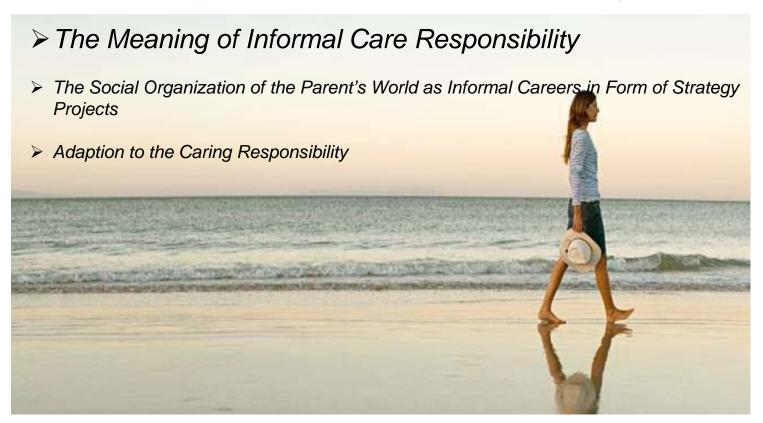


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Findings

Experiences of informal care responsibility







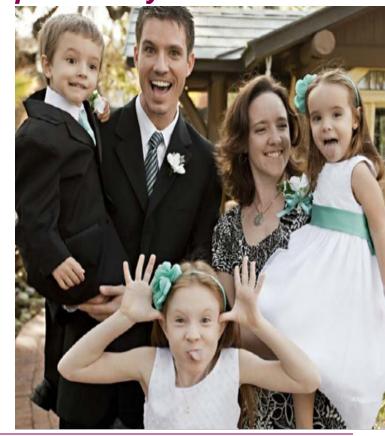
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The Meaning of Informal Care Responsibility

To experience one's selves

AS A GOOD AND
RESPONSIBLE PARENT
WITH
COMPETENCE WHO
CARE ABOUT THE WHOLE
FAMILY







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The Meaning of Informal Care Responsibility

"I think I feel good, I feel myself quite happy, sleep well at night even though I have a big workload, now I have a full-time job, plus I take care of my dad who is 90 years plus I have xx (her son) to think about and I'm single, so it is much that lies on me". (Informant)



The Social Organization of the Parent's World as Informal Careers in Form of Strategy Projects

Strategy projects providing room for own growth and develop

Strategies such as:

- parental projects
- work related projects
- recreational projects





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Repertoires of controlling the life situation on the one hand, and feelings of being out of control, on the other

"The strength to fight. . .but it's not always that I have the strength to do that, sometimes I fall down and then I'll lie down for a couple of days and then I'll get up again . . .

"now have they fucking done that again, now damn, I say to myself, and then I start over again, and then I fall down again", ...

"and sometimes I feel that I give up—now I'll take all my sleeping pills, now to hell with this, but I don't, ... But I feel like that sometimes". (Informant)







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Experiences of informal care responsibility Adaption to the caring responsibility

- Uncertainty facing all the unknowns
- Positive events that made life worth living
- Perception of health and activity
- Negative circumstances that made life difficult to live





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Experiences of informal care responsibility Adaption to the Caring Responsibility

Uncertainty facing all the unknowns

 "Nobody saw me, no one told me anything.. The painting by Munch; The Scream of Angst, I was like that painting!"

- A mother from the study







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Experiences of informal care responsibility Adaption to the Caring Responsibility

Examples of negative circumstances that made life difficult to live

"When xx got sick, my husband became really hateful to me and even overheated my children, I have never before felt me so hated, it was as if his aggressions went over to my daughter and she, like throwing arrows on me, I have Never felt so bad, it felt terribly hard and unfair. "

(Informant)

/.../

"My parner, she chose to move abroad because of the disease and my old dad just thought it was strange,... and my former wife... and I have not had so easy to agree,... so it has been inadequate with support." (Informant)





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Examples of negative circumstances that made life difficult to live

 Attitudes from the formal health care and society



"I felt useless and the health care staff just like questioned what kind of mom I had been " (Informant)





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Examples of negative circumstances that made life difficult to live

Perception of health and activity



"So I've thrown my ears again so I will not hear that much, otherwise I start to freeze my head, get a headache and I start to feel bad Physically, I am in very bad condition". (Informant)





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Adaption to the Caring Responsibility
Positive events that made life worth living

- Maintain one's work
- Maintain leisure and social networking
- Have a good relationship with the formal care and society



"The work became something to lean against, I just fled to work for It was important to me to go to work every day before then I switched off everything else "(Informant)





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Discussion

So, what constitutes being a good parent and what are the consequences? *Inwardly* – Outwardly?

Parents compromise between elements of struggle, cooperation, avoidance, and adaptation in their interaction with the world outside, as well as with the world inside themselves.







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Need for support

"Now I'm not getting more, when I feel so stressed, I'm done ... so I think now that I have to go to the psychiatric emergency care"

(Informant)







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Conclusions and practical considerations

- It is crucial for healthcare professionals to be aware
 of parents' perspectives as being responsible for informal
 care so as to be able to support care services for parents.
- There is a need for an in-depth debate about professional psychiatric care's responsibility to support the relatives who are informal carers of psychiatric patients.
- It is most important to establish a policy for how psychiatric care is to be divided between the formal and informal care givers.







... What can we learn from this?

- At the individual level we can learn that the parent has his/her own needs
- At group level, we can learn that parents with informal care responsibilities need support

 At the level of society we can learn the importance of visualizing needs that must result in social course of actions for informal care givers





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Thank You!

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