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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  
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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:

- 1) what are the experiences around parents' informal care activities and responsibilities
- 2) 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

- *The Meaning of Informal Care Responsibility*
- *The Social Organization of the Parent's World as Informal Careers in Form of Strategy Projects*
- *Adaption to the Caring Responsibility*





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# Experiences of informal care responsibility

## *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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# Experiences of informal care responsibility

## *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)*

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# Experiences of informal care responsibility

## *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*



## Experiences of informal care responsibility

### 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





## 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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## Experiences of informal care responsibility

### 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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## Experiences of informal care responsibility

### 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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## Experiences of informal care responsibility

*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.



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## ... 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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