

Support groups for children and youngsters living with a parent with dementia



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The Danish Alzheimer's Association

"Every Child has the Right to..." conference in Malmö
May 30, 2017 - 11.30-13.00 (108)

Disposition

- Dementia and young carers
- "Time to be young" - a pilot project
- Knowledge about children and youngsters living with a parent with dementia
- Midterm evaluation results

Dementia and young carers

An overlooked group

- In society in general
- The families tend to isolate themselves the first years
- Youngsters not living at home
- Parents downplays the illness

... That yet exist!

- Aprox. 3.000 patients are under the age of 65 years in Denmark
- Changing family patterns
- No official numbers or means of registrating the exact number
- Estimation: 3.000-6.000 children and youths under the age of 30 years in Denmark

... So far they have been no specific help/support for this

Knowledge about children and youngsters as caregivers

- Children, youngsters and dementia is an overlooked field of research
- Research so far is primarily qualitative studies focusing on how the everyday life of the child is affected
- No evidence based research



Grief

Loneliness

Responsibilities

Time to be young - The project

Aim of the project

To generate knowledge and experience on establishing support groups for children and youngsters with a parent with dementia

The vision

Building on this experience more support groups will be established in different regions of Denmark



3 support groups established

- 2 group facilitators
- 6-9 participants
- 16-29 year
- Different dementia illnesses
- 11 group meetings over 1,5 year
- 2 weekendcamps

Purpose of the support groups

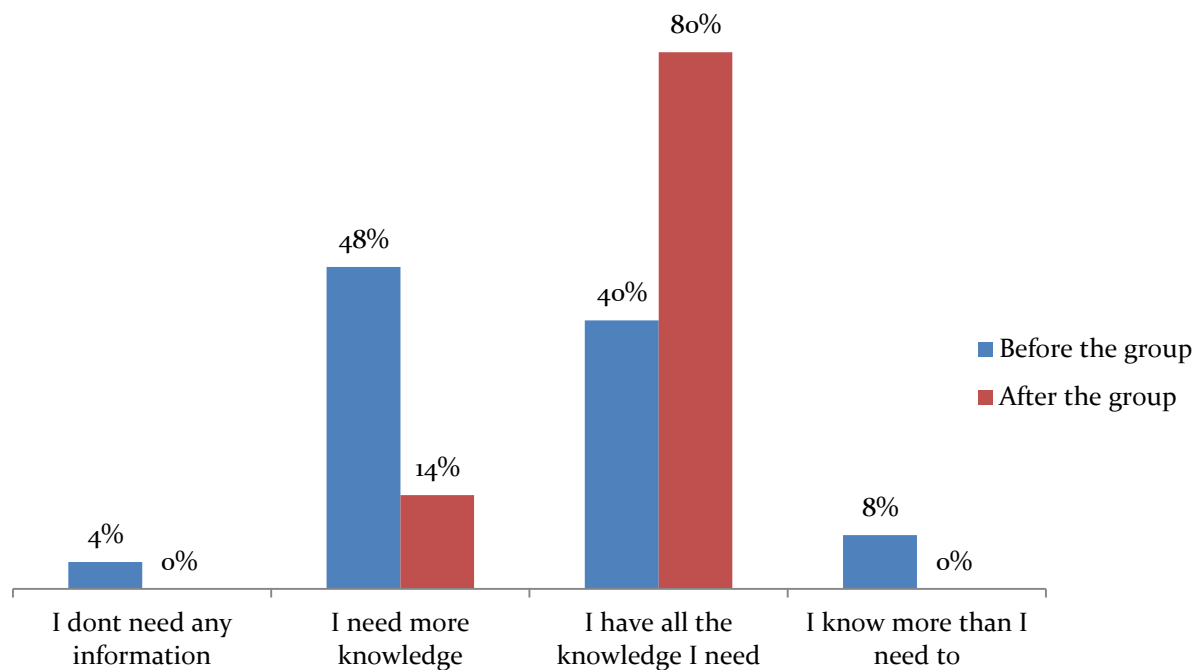
- To not be alone, but part of a community of likeminded
- Seeing one's own situation in the meeting with others
- Coping with the changed every-day situation
- Support to hold on to one's own life



*I rarely feel lonesome now,
because I know that I have the
group, if I need to talk*

More knowledge

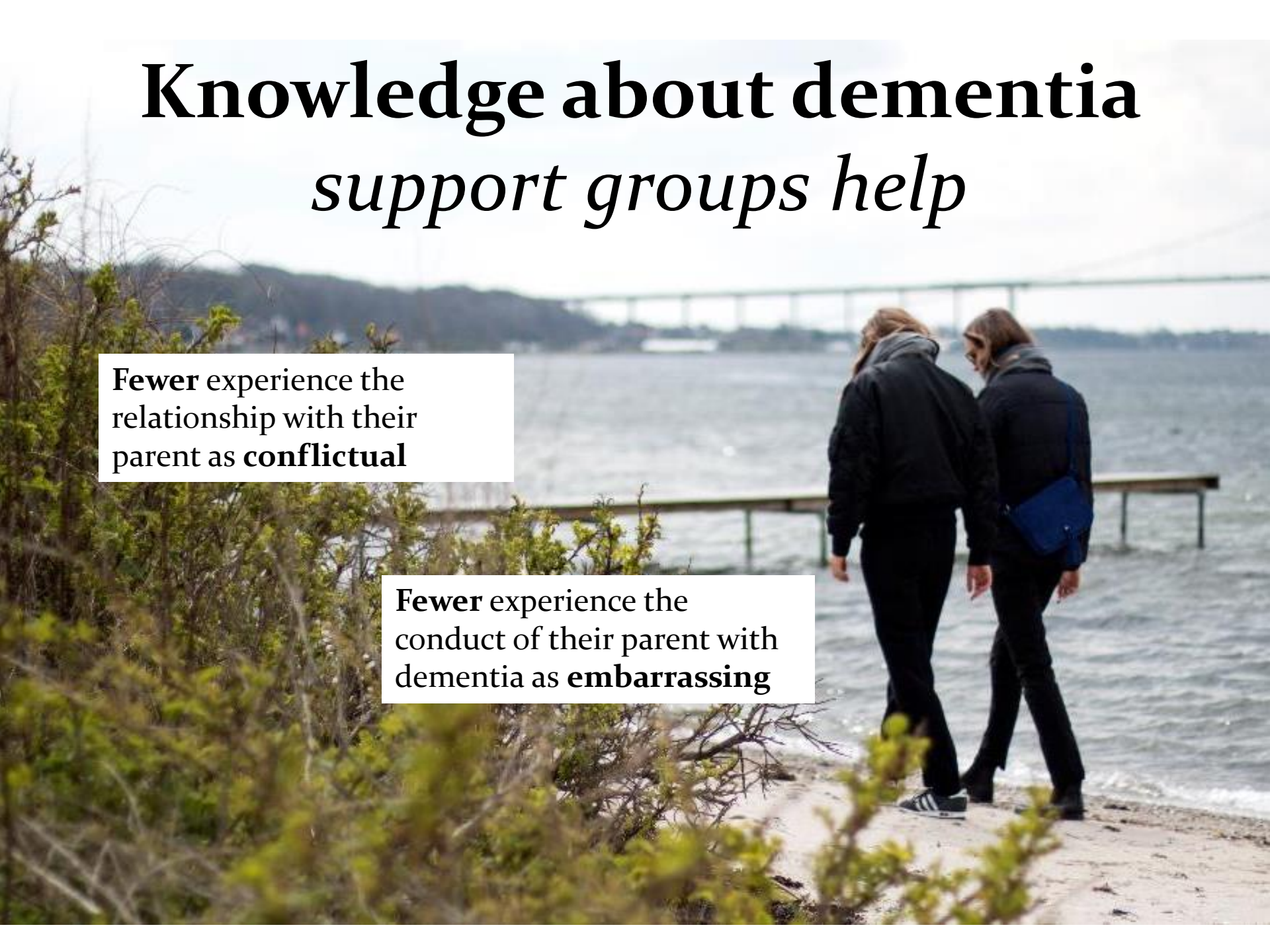
Do you feel, that you have enough knowledge about your parent's dementia illness?



Knowledge about dementia *support groups help*

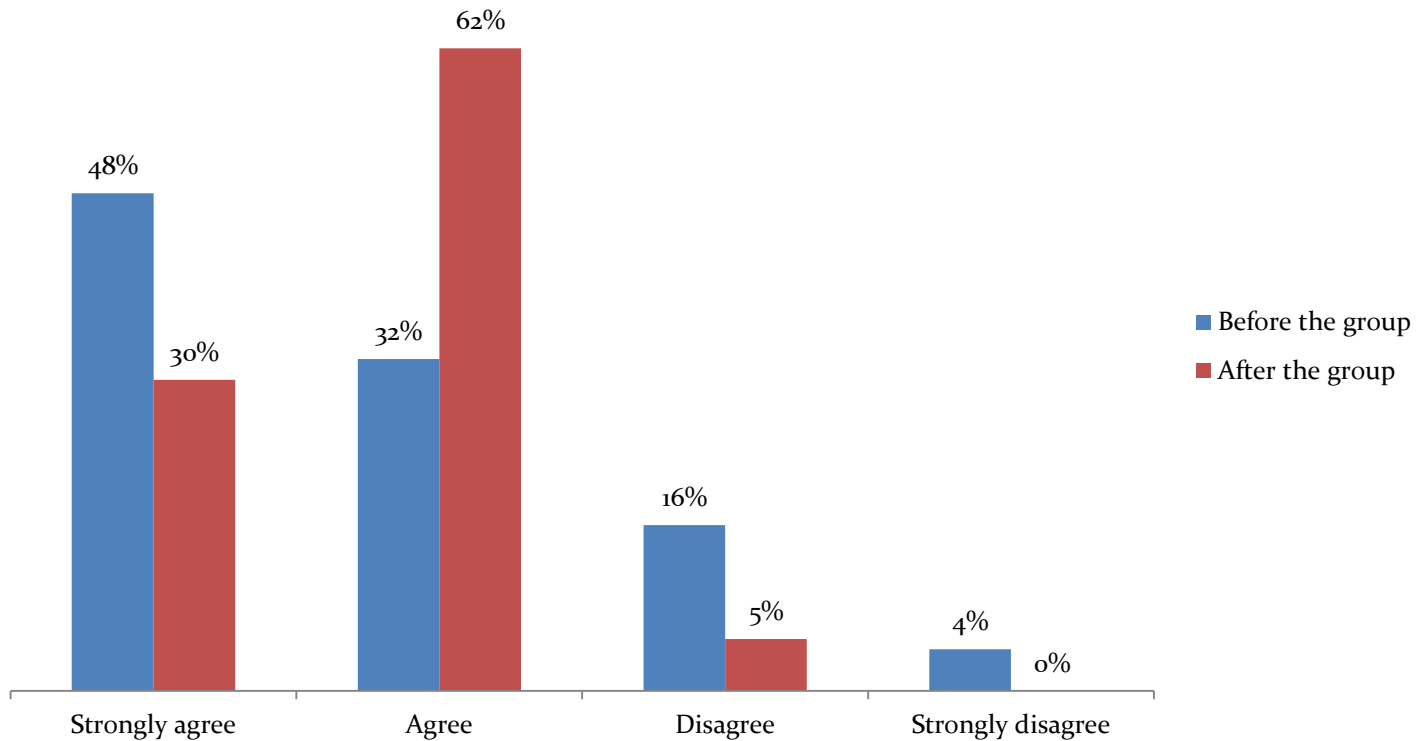
Fewer experience the relationship with their parent as **conflictual**

Fewer experience the conduct of their parent with dementia as **embarrassing**



To prioritize oneself

When my parents need me, I set aside my own needs in order to be available for them





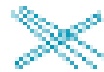
”After I started in the project I dare to open more up in regards of my feelings about my mother’s disease. I have now opened up to the persons I feel that I might in the future need in order to talk to once in a while. I feel that I have developed a lot.”

On a final note



Thank you for listening
and a special thanks to

VELUX FONDEN



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