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Resilience in children and families when a parent has cancer – an intervention study

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What is a family with a parent with cancer?



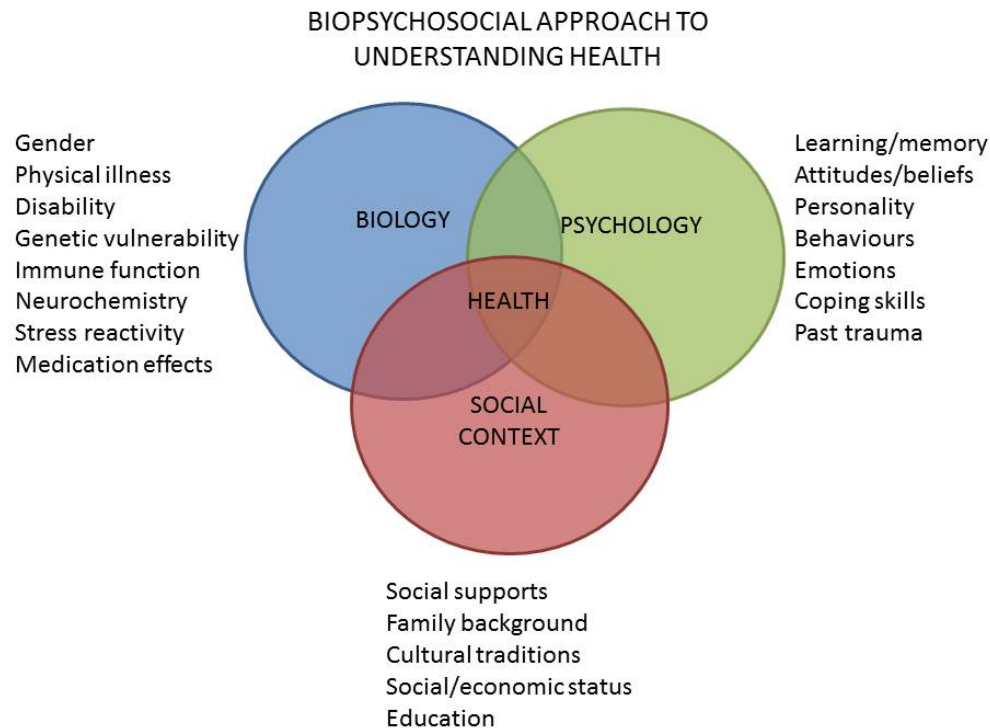


Background

- 20 % of new cancer patients have minor children
- Their children have increased risk of emotional and behavioral problems – and more contacts with psychiatric services
- The parents worry seriously about their children's needs
- Parenting concerns are associated with more depressive symptoms in the parent
- Family functioning is of major impact in child adjustment to parental cancer
- Approximately 7 children/GP in Denmark live with parental cancer
- Only 10 % of children with parental cancer receive formalized support



Health and wellbeing in 7-15years old children when a parent has cancer – a mixed methods study



| Familie ID | children | | Patient parent | Diagnosis/ year | Partner participating |
|------------|----------------|-----------------|----------------|------------------------|-----------------------|
| | Boys/age years | Girls/age years | | | |
| F1 | 14 | | Mother | Breast cancer/2008 | + |
| F2 | | 15 | Mother | Breast cancer 2007 | - |
| F3 | 7, 13 | 11 | Farther | Intestinal cancer/2012 | + |
| F4 | | 12 | Mother | Breast cancer/2009 | + |
| F5 | 9 | 13 | Mother | Ovarian cancer/2012 | + |
| F6 | 7 | 15, 9 | Mother | Breast cancer/2008 | + |
| F7 | 10, 12 | | Mother | Breast cancer/2014 | + |
| F8 | 8 | | Mother | Breast cancer /2012 | - |
| F9 | | 8, 10 | Farther | Testicular cancer/2014 | - |
| F10 | 8, 14 | 0 | Mother | Breast cancer/2012 | - |
| F11 | 6 | 9 | Farther | Brain tumor/2015 | + |



Results - parents

- Parents wanted their children to participate for the ‘wrong’ reasons
- Parents worried how their children were doing, and what they were thinking?
- Parents often did not know how to cope with their children’s feelings
- The GP (and other health staff) was only consulted very sporadically and often not at all
- School teachers very rarely contacted the parents
- Support groups and child psychologist was stigmatising to some parents



Results children

- Children very often did not talk to any other adults than their parents about the cancer
- Children often hid the disease from their friends
- Children lacked strategies to cope with negative feelings
- Children had often seen their GP with symptoms they worried whether it could be cancer
- Children wanted to be 'normal'

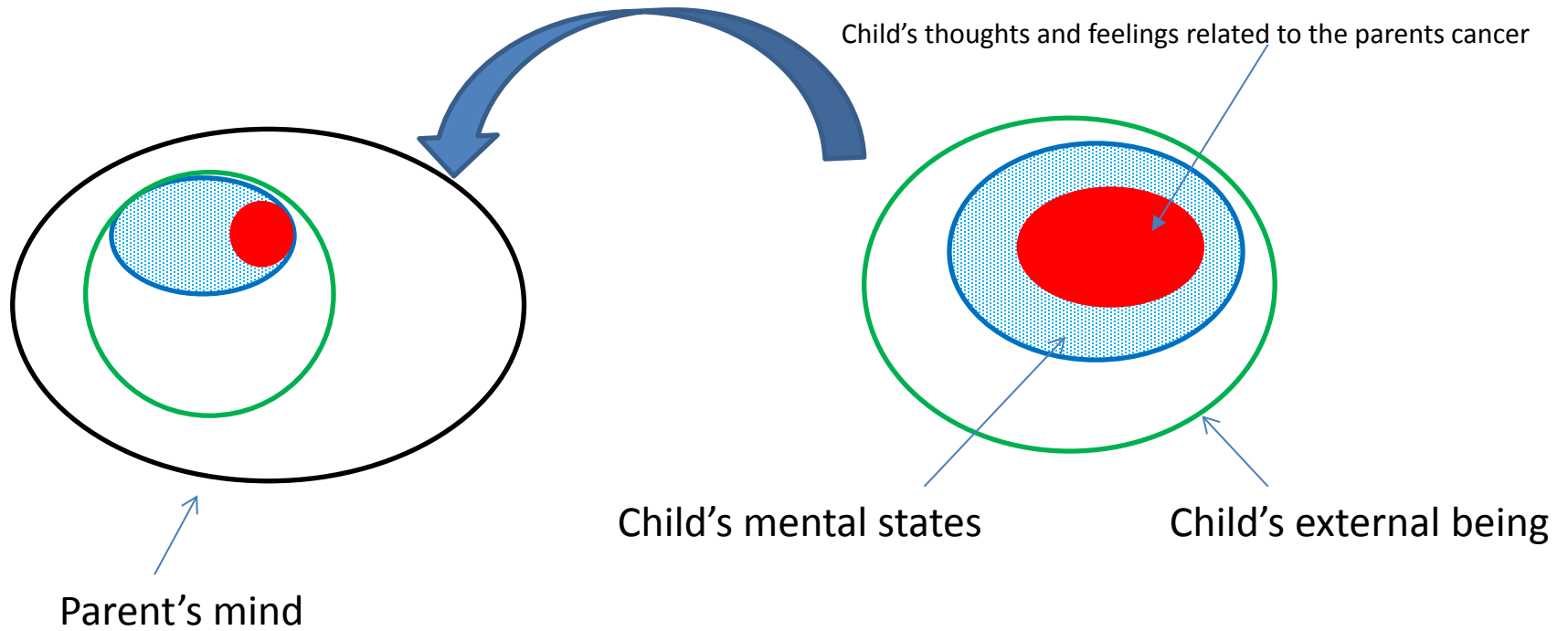
Conclusion – how is my child doing?

- It is very difficult – even to parents -to evaluate whether a child needs support or not
- Parents and children need ‘a safe space’ – a way to talk about the disease and their thoughts and emotions
- Children also have a ‘normal life’ beside the cancer – this may hide their difficulties
- Parents lack support and knowledge in communicating and supporting their children

A mentalization perspective

- *Mentalization is the mental processes by which an individual implicitly and explicitly interprets the actions of himself and others as meaningful on the basis of intentional mental states such as personal desires, needs, feelings, beliefs and reasons. (Bateman & Fonagy 2004).*
- *‘Seeing yourself from the outside and others from the inside’ (skårderud)*

Parental perception of child's mental state



Mentalization and resilience is closely connected

- *'it is difficult to know, but we will do whatever we can to prevent her from cutting herself when she gets older.... (father with cancer about his 12 year old daughter).'*
- Resilience is defined as 'successful adaptation to adversity including two components: successful recovery from adversity and sustainability in relation to life challenges

Resilience in families

- 1) belief systems
- 2) organisational patterns
- 3) communication
 - (Walsh 2003)



Resilience intervention in families with parental cancer.

- Aim with the study:
‘to examine the acceptability and feasibility of a mentalization-based web-program on resilience in children and parents in a pilot study’

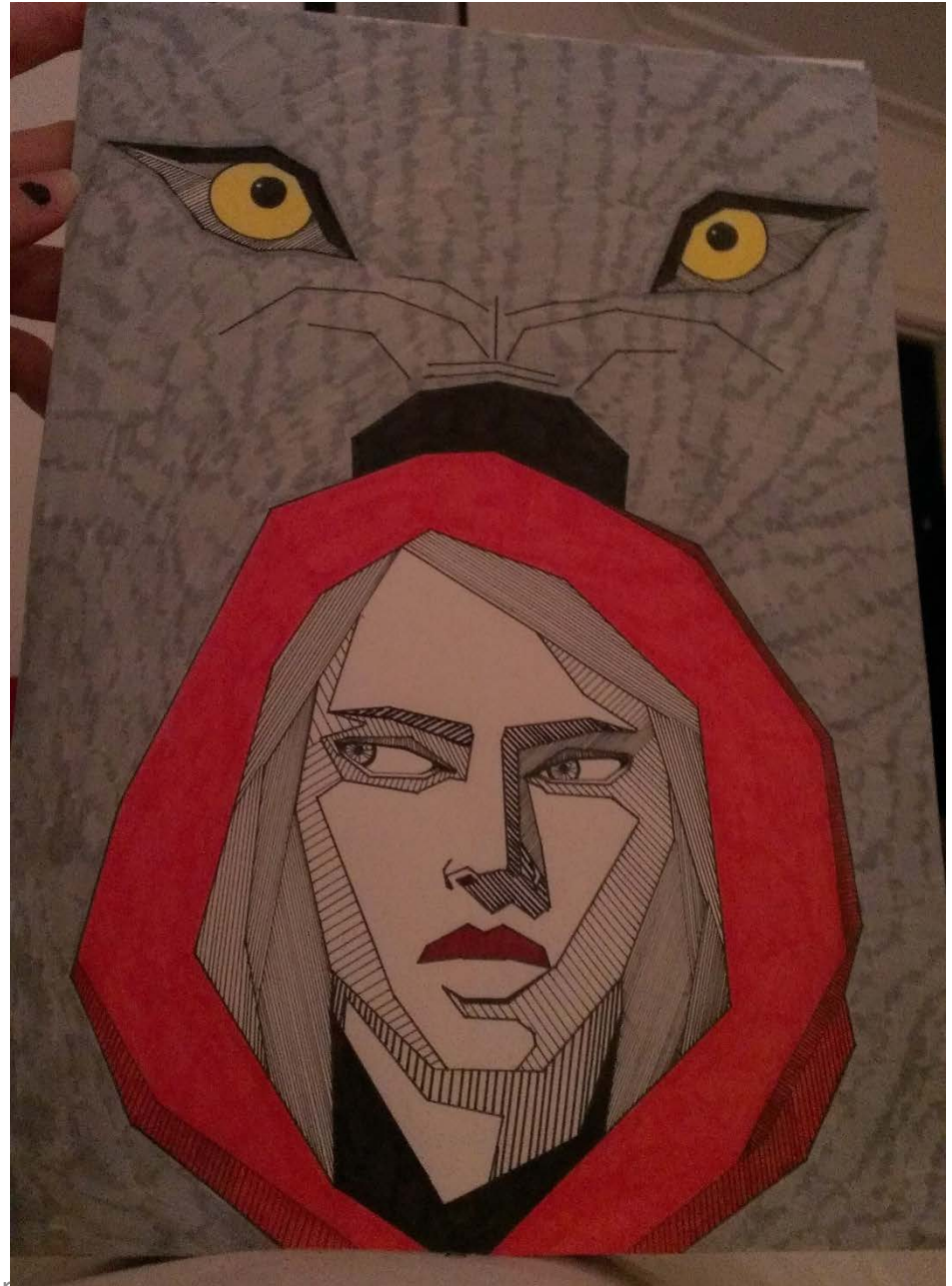
Me and my thoughts.....

- "I am sad" vs. "I feel sad" (Daniel Siegel)



Thoughts and feelings are “tools for life”. It’s easier to use a tool when you know something about how it works. (resilience.org)

FEAR MAKES THE WOLF LOOK BIGGER



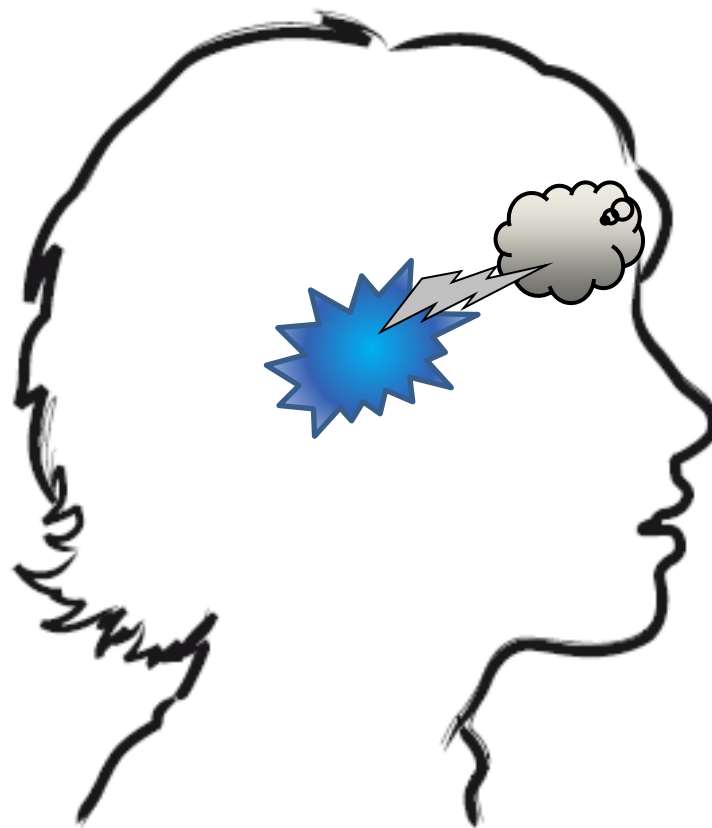
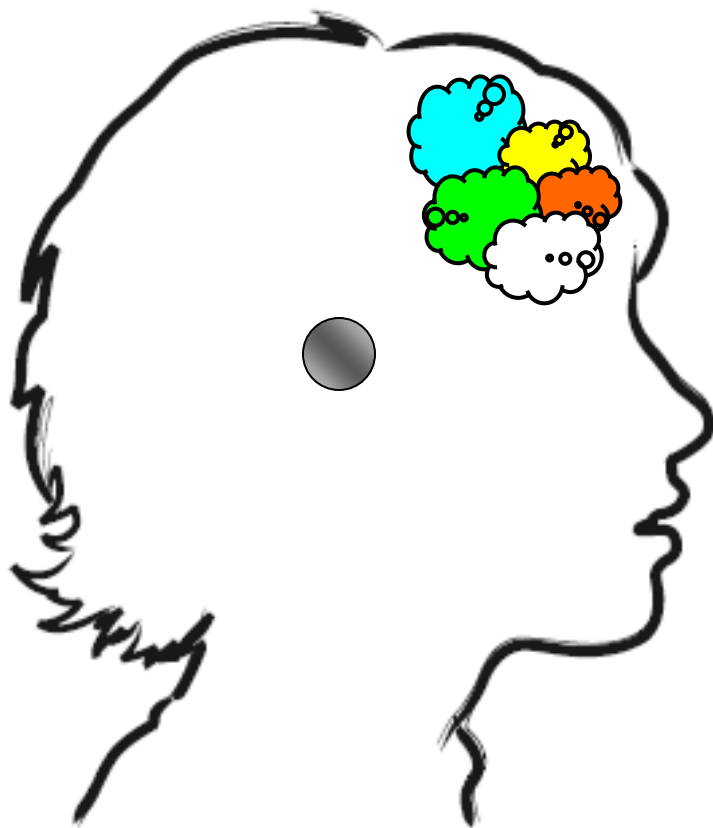
Principles behind the intervention

- Based on a web-based resilience program for families and children - <http://robusthed.dk/en/>
- Available to all families with interest – not only families or children with 'special needs'
- Free of costs to the family
- A minimum of training of training of professionals and parents
- Develops resources inside the family – supports parents in supporting their children

Aim with the intervention.

- Increased mentalization skills in all family members
- Increase resilience in all family members – especially the children
- To reduce the short and longterm effects of parental cancer in the children (health, anxiety/somatisering, internalisation and school performance).

The thinking brain and the alarm center



House of thoughts

| I fear my mother will die | Am I good enough in school? | When should I cry and when should I stop crying? |
|--|---------------------------------------|--|
| what can I do when I get a quarrel with my friend? | I am proud that my aunt is an actress | I like doing karate |
| I look forward to christmas | It is good that the medicine works | I love my mum and dad |

Girl, nine years, mother with chronic cancer

Design of pilot study

- Modification of the RP based on interview results
- Inclusion of five-eight families with parental cancer > six months, children 7-15 years.
- Group introduction to mentalization and resilience theory and to the content and use of the Resilience Program
- Continuously email based supervision and feed-back as requested by the parents
- Follow-up after three months in focusgroups with the parents and individual interviews with children
- Testing out quantitative measures

Evaluation of intervention – pilot study

- Focus group interviews with the parents before and after the intervention
- Video recordings of the introduction session with the parents
- Recording of additional contacts in the intervention period
- Questionnaires to all participants before and after the intervention about; family functioning, psycho-somatic symptoms, anxiety and depression, parenting, quality of life, resilience and mentalisation

Outcome measures of the evaluation

- Increased mentalisation in the family
- Improved family communication about thoughts and emotions
- Increased knowledge of self-regulation of emotions and feelings
- Decreased signs of depression, anxiety and somatic symptoms
- Families' evaluation of the intervention

This is work in progress..

- Thank you for your attention

