




17th Annual SASRO Meeting
4-6 July 2013 Davos



When parents have cancer: what are the risk factors for child maladjustment and how can we promote individual and familial resilience?


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Noemie, 13 years

What has changed for you and how do you deal with changes?

I am more sad and thoughtful, mostly when I am away from home, for example when I spend the night at my friend's place. I am then worried, how they are doing at home. When I'm at home and I am sad, I spend more time in my room; I don't want my parents to be more stressed than they already are. But, in general that's not very helpful, I hang around in a bad mood. When I am feeling sad it helps sometimes to talk to my friends. Or I distract myself, I go swimming or to my workout. Sometimes I simply think of something positive, for example our last holidays.




Nicole, 44 years

What has changed and what was important to be able to deal with changes?

There has been a clear change in responsibilities and roles. At the beginning this was quite challenging and needed a good exchange with my husband. My husband was more involved in taking care of the children and the household. He did not want more help from the outside than a cleaning woman.

It was difficult to juggle my own needs and the needs of the children. I learned to give my friends a chance to help. To accept help was difficult at the beginning but I wouldn't have made it without.




Katharina, 41 years

How do you describe good and bad days:

Bad days are days when my husband is suffering from pain or is anxious. I then try to encourage him, to make him feel better and to distract him and the kids (talking about something nice, cooking together etc.).

For me it is challenging to deal with my own irritability and bad moods. Also, the load of responsibility at times puts a big pressure on me.

Good days are days, when we talk about normal things, like children sorrows and nice things, politics. (When we are able) ... to consciously perceive the small moments of togetherness: now we are here and we are all alive.





Psycho-Oncology
Psycho-Oncology 19: 1013-1025 (2010)
Published online 14 December 2009 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.158

Review Article
Review of the literature on the effects of caring for a patient with cancer

Una Stenberg^{1,2*}, Cornelia M. Ruland^{1,3} and Christine Miskowski⁴

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⁴Department of Psychological Nursing, University of California, San Francisco, CA, USA


➤ More than 200 problems and challenges identified (emotional, physical, social problems)

Positive emotional aspects for families with parental cancer

- Appreciation of being together
- Experience of own strengths and potency, increase of independence
- Strengthening and intensification of family cohesion
- Revision of values
- Sense of relatedness
- Positive sense of doing something good and meaningful
- Improvement of self-esteem
- Increase in mutual respect

➔ chance of growth at the level of the individual, the couple and the family



Stenberg et al., 2010, Psychooncology

Prevalence of psychological maladaptation to cancer

- **Patients** (depression, anxiety and adjustment-disorders, reported by metaanalyses) 32%^{1,2}
- **Partners** : ca. 10%, at subclinical level ca. 30%²
- **Children**: twice as often with signs of psychological maladaptation (ca.34%), mostly internalizing behavior, somatization, anxious-depressive symptoms⁴
 - Higher vulnerability of small children and teenage girls
 - Teenager report on more problems in self-reports than parents report
 - Patient parent experiences child more strained than healthy parent

¹Singer et al., 2009, Annals of Oncology
²Mitchell et al., 2011, Lancet Oncology
³Welling et al., 2012, Psychother Psych Med
⁴Visser et al., 2005, Psychooncology

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Hilfen für Kinder Krebskranker Eltern

Deutsche Krebshilfe HELFEN FÜR KINDER, KREBSKRANKER ELTERN

11-17 year old girls and boys exceeding clinical cut-offs for depression:

Time Point	Gender	Observed (%)	Not Observed (%)
t1	Mädchen	65.3	34.7
	Jungen	78.8	21.2
t2	Mädchen	61.5	38.5
	Jungen	70.7	29.3
t3	Mädchen	55.8	44.2
	Jungen	84.6	15.4

t1: up to 6 months after dx (n=110)
t2: 6 months after t1 (n=80)
t3: 12 months after t1 (n=85)

Brahler (2012) Fachtagung 5. Oktober, Familien mit chronischen Belastungen

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Frequency and efficacy of adolescents' coping strategies.

Coping strategy	Frequency ^a		Efficacy ^b	
	%	N	%	N
Active problem solving	57	122	47	101
Distraction	54	116	34	72
Acceptance	53	113	23	50
Wishful thinking	53	113	21	45
Seeking social support	43	91	48	102
Emotional regulation	41	88	43	91
Cognitive restructuring	40	85	38	82
Social withdrawal	39	84	19	41
Self-criticism	32	68	22	48
Blaming others	27	58	21	45
Emotional expression	22	46	24	52

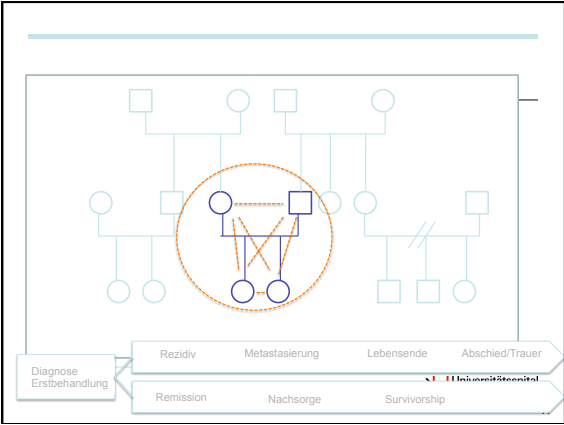
Note: Coping strategies are categorized as problem-focused (PF) vs. emotion-focused (EF) and approach-oriented (APO) vs. avoidance-oriented (AVO).
^a Proportion of the most often used coping strategies.
^b Proportion of coping strategies rated as effective.

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Krattenmacher et al. / Journal of Psychosomatic Research 74 (2013) 252–259

RISK FACTORS FOR PSYCHOLOGICAL MALADJUSTMENT AND RESILIENCE OF FAMILY MEMBERS

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Predictors of maladjustment in partners

- Younger age
- Low SES
- Work outside of home
- Low self-esteem and self-efficacy
- Isolation
- Higher age, low level of education
- Preexisting relationship problems
- Stronger neglect
- Ambiguity and lack of clarity of partner expectations
- Few opportunities for open communication
- Partners need of emotional support
- Low psychological functioning of partner

Appraisal, Coping, pre-existing psychological problems

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Risk factors for child maladaptation: **Moderators**

- Age, sex
 - Higher risk for younger children and teenage girls
- Development phase
- Personality
 - Early attachment and stress reactivity
- Family system
 - Higher risk for single parent families
- Low SES
- Stressors and critical life events in history
 - Trauma history, developmental disorders

Visser, A., et al., The impact of parental cancer on children and the family: a review of the literature. Cancer Treat Rev, 2004, 30(8): p. 683-94.
 Watson, M., et al., Factors associated with emotional and behavioural problems among school age children of breast cancer patients. Br J Cancer, 2006, 94(1): p. 43-50.

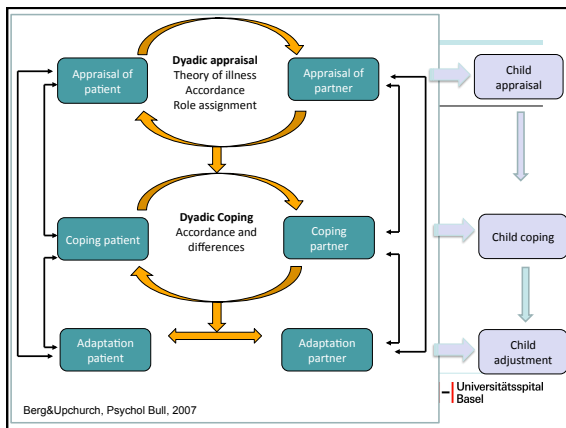
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Mediators influencing the response of the family and the child to parental cancer

- **Family functioning**
 - Lack of coping behavior at the level of the family
 - Absence of open and affective communication
 - Too little or too much cohesion and flexibility
 - Low involvement in extra-familial activities
- **Parental factors**
 - Higher psychological distress in patient or both parents
 - *Quality of relationship: communication problems, conflict, criticizing behavior*
 - Low parental *concurrency* in theory of illness and expectations

Visser, A., et al., The impact of parental cancer on children and the family: a review of the literature. Cancer Treat Rev, 2004, 30(8): p. 683-94.
 Watson, M., et al., Factors associated with emotional and behavioural problems among school age children of breast cancer patients. Br J Cancer, 2006, 94(1): p. 43-50.
 Krattnermacher et al. (2012), Journal of Psychosomatic Research 72 (2012) 344–356

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Key process of family resilience

Appraisal in family	<ul style="list-style-type: none"> - Finding meaning in challenging life circumstances - Optimistic attitudes - Spirituality
Structural and organizational patterns	<ul style="list-style-type: none"> - Flexibility of family structures (e.g. co-parental relationships) - Bonding and connectedness (e.g. mutual support, collaboration and commitment, respect of needs, differences and limits of each family member) - Social resources
Communication and problem solving	<ul style="list-style-type: none"> - Communication which promotes clarity - Expression of emotions - Shared problem solving

Walsh, 2003

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How can family resilience be promoted?

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Nationales Krebsprogramm für die Schweiz

2011–2015

«Nationale **Standards und Leitlinien zur psychosozialen Versorgung** von Krebskranken und ihren **Angehörigen** sind erarbeitet. Dies betrifft auch krebserkrankte Kinder und Kinder von an Krebs erkrankten Familienmitgliedern»

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Elements of effective intervention programs	
Education and communication patterns	Conveyance of communication: how to talk to children about cancer Facilitating age appropriate appraisal and understanding of the illness Promoting of the understanding of the child's responses
normalisation	Secure environment Expression of emotions Emotional support Strengthening of everyday life and finding new routines
Activation of resources, promotion of coping behavior	Strengthening of parent-child-relation Consolidation of parental competence Facilitating family coping behavior and conveying active coping strategies

Psycho-Oncology
 Psycho-Oncology 19: 453–461 (2010)
 Published online 11 August 2009 in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/pon.1620

Review

A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer

Mika Niemelä^{1,2*}, Heliina Hakko² and Sami Räsänen²
¹Department of Psychology, University of Gävle, Finland
²Department of Paediatric, Gävle University Hospital, Finland

- 11 interventions, 6 family-based, 5 peer-group interventions
- The majority of the participants including the children had a positive attitude to the interventions
- Children, parents and health professionals reported positive impacts of intervention on children's and parents' psychosocial well-being
- Conclusions: methodological limitations → there is a need for evidence-based good-quality research utilizing structured evaluation methods (including controlled study designs and long-term follow-ups)

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Psychosoziale Versorgung von Kindern mit einem an Krebs erkrankten Elternteil – Eine Bestandsaufnahme spezifischer Versorgungsangebote in Deutschland
 Psychosocial Care of Children with a Parent having Cancer – An Appraisal of Specific Care Services in Germany

- Identification of 29 psychosocial, family specific offers
- Setting:
 - single and group format for children and parents
 - Family counseling
 - Counseling of third parties (teachers, nurse)
 - Home visits
 - Experience oriented offers
 - Weekend offers (families, children)
 - Online counseling (email, chat)
 - Telephone counseling
 - Couple counseling
- different concepts

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 Ernst JC et al. Psychosoziale Versorgung von Kindern ... Psychother Psych Med 2011; 61: 426-434

But...

- „The primary response is of great interest, but this doesn't reflect in case numbers.“
- „The enthusiasm about the availability of the programm is big, the realization however is difficult. This correlation is very poor.“


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 Ernst JC et al. Psychosoziale Versorgung von Kindern ... Psychother Psych Med 2011; 61: 426-434

Possibly because...

- „My husband came once with me to the psychologist. It was to decide at what age to tell our girls that I have a gen mutation. Otherwise he did not feel like seeing a professional to discuss our topics.“
- „He searched the internet and even chatted for a while in a forum but did not talk much with his friends about it.“
- „I would be reluctant to drag my family to the psychologist. Only if the problems were really big and unsolvable for us.“
- „It's not easy to organize all five of us for a family appointment, especially during the school year“

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www.kankerspoken.nl



- Analysis of 158 forum discussions over 3 months
- average age 15.3 years, 80% female
- participation in 4 to 5 forum discussions on average
- Main activities on the website:
 - sharing personal experience
 - providing encouragement/support
 - providing and seeking information or advice
 - seeking contact outside of the website
- Results content analysis: children are faced with emotional problems and experience a lack of understanding and communication in their direct environment

Giesbers et al., Psychooncology, 2010
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→ How to

- Reach boys / males
- Promote adjustment on individual *and* systemic level
- Overcome known barriers (geographical, shame, organizational etc.)

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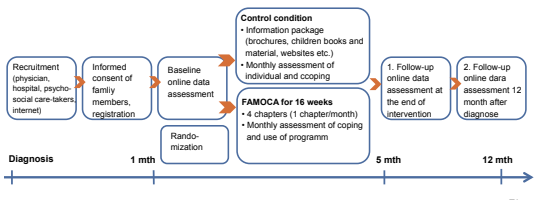
FAMOCA Web-based family counseling for families with parental cancer
 A randomized controlled intervention study
 Alder, J., Roth, B., Gaab, J., Wössmer, B., Rochlitz, C.



Universitätsspital Basel KREBSFORSCHUNG SCHWEIZ PSYCHIATRIE BASELSTADT

Study design

- „Multicentric“, randomised, controlled
- Families with first time parental cancer diagnosis, up to 1 month after diagnosis
- children: 3 to 18 yrs, living with single or both parents
- N = 90 families
- 3 measurement



Timeline: Diagnosis (0 mth) → 1 mth (Recruitment, informed consent, baseline assessment, randomization) → 5 mth (FAMOCA for 16 weeks, control condition, 1st follow-up) → 12 mth (2nd follow-up)

Research questions

- Primary outcome: child adjustment
- Secondary outcomes:
 - adjustment at the level of the parent, the couple and the family
 - Change of communication and affective involvement within the family
 - Study of predictors of families, who benefit from the intervention and families who need further/ no support

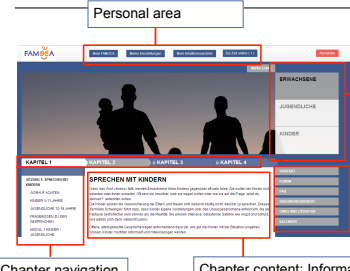
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FAMOCA: Online-Program

Chapter 1	Chapter 2	Chapter 3	Chapter 4
Talking about cancer	Adjustment to changes in family	Dealing with emotions	Looking back and ahead
aim: <ul style="list-style-type: none"> • Open, age-appropriate communication, • Knowledge and understanding on illness and treatment • Establishing support network 	aim: <ul style="list-style-type: none"> • Balance between flexibility and stability • Mutual support and autonomy • Coping with good and bad days • Establishing cancer-free zones • Problem solving strategies 	aim: <ul style="list-style-type: none"> • Understanding emotions and improving their expression • Fostering coping behavior • Respecting differences and limits • Strengthening relationship 	aim: <ul style="list-style-type: none"> • Developing a common story • Identifying challenges • Validating developmental steps • Promoting common development

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Building up of website



- 3 separate areas password protected
- Open children area
- Comparable building up of areas

Open area: Access to forum and email contact with psychooncologists for parents, adolescents and children

Chapter content: Information, «work sheets», Audio / Video

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Teenagers (12 to 18 years)

Comics-accompanying figure

Access to children area

Interaction with program

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Teenagers: chapter 1

Information

- Information on cancer and treatments as text and video
- How to communicate effectively

Try out and experience

- Quiz on cancer
- Collecting questions
- Identify person of trust

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Teenagers: chapter 2

To cope with family daily life

Information

- Responsibility vs autonomy
- Own physical symptoms and stress
- Changes in friendships

Try out and experience

- Activities for good and bad days
- Audio relaxation stories

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Teenagers: chapter 3

Dealing with emotions

Information

- Understanding emotions

Try out and experience

- Trying out coping behavior:
 - Talking about feelings
 - Mindfulness (audio)
 - Songs and Songtexts
 - Managing difficult situations

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Teenagers: chapter 4

Looking back and ahead

Information and trying out:

- Understanding illness as part of the family's story
- Identify accomplished milestones since diagnosis
- Recognize own development
- Prepare Feedbacks for parents

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Teenagers: open area

Diary in blogform with „assignments“ for each chapter

Forum (supported by Famoca-team)

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Children (3 to 11 years)

Change of cover picture: children drawings of their family

Accompanying figure: dragon fly

Simple navigation

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Illustrated story: to read, look at, listen to and to color



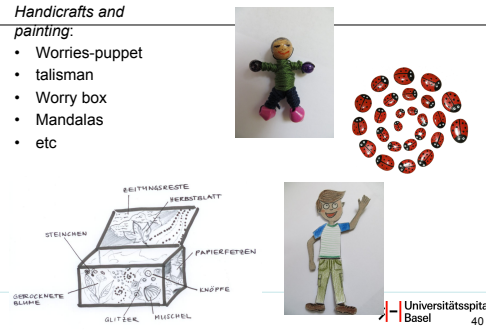
Experience and try out

- Quiz on cancer
- Active games
- Audio fantasy to relax
- Emoticons to choose
- Funny videos
- Collection of children jokes
- Story of fairy who collects wishes

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Handicrafts and painting:

- Worries-puppet
- talisman
- Worry box
- Mandalas
- etc



Diary: consolidation of chapter content

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Possible benefit

- For all family members
- Low threshold
- Independence of time and place
- Cost efficient
- Schliesst Versorgungslücke in der Schweiz
- Kontakt zu Fachpersonen möglich → Risikofamilien frühzeitig ansprechbar

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- Master students: V. Ehrbar, A. Stauffer, M. Kaufmann,
- IT: Jürg Langhard, Greenbanana GmbH



Web-based family counseling for families with parental cancer
 A randomized controlled intervention study
 Alder, J., Roth, B., Gaab, J., Wössmer, B., Rochlitz, C.

Pilot study starting next week
 Main study start end of august 2013

Thank you for your
 attention

www.famoca.ch

www.famoca.ch

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