

Socialisation in families with mentally ill parents: Children's perspective on illness related burden and the need of health promoting interventions

Prof. Dr. Ullrich Bauer Miriam Schmuhl, MPH

ISAPP, 14th - 18th September 2011, Berlin



Background – what is the problem?

In Germany

- Altogether about 3 million children with merially ill parents (about 270.000 children living together with a schizophrenically diseased parent and about 1.230.000 with an affectively diseased parent unit)
- Up to 70% of the children with mental parents inherit the parental disease
- Health risks are up to ten times higher than in a reference group with healthy parents

(Bebbington 2000, Lenz 2005, Wittchen & Jacobi 2005, Mattejat 2008)



Background – what is the problem?

So....



What is happening in these families?

Background

Aetiology is multifactorial

•Personality traits

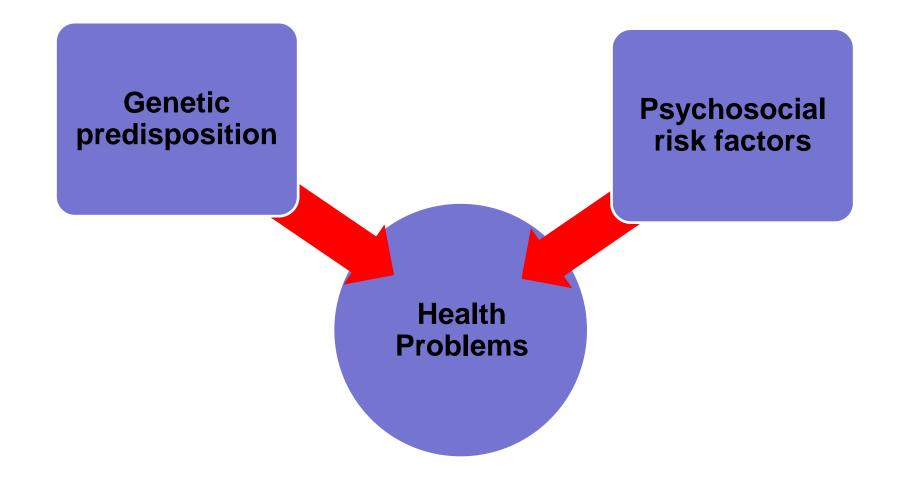
•Toxins

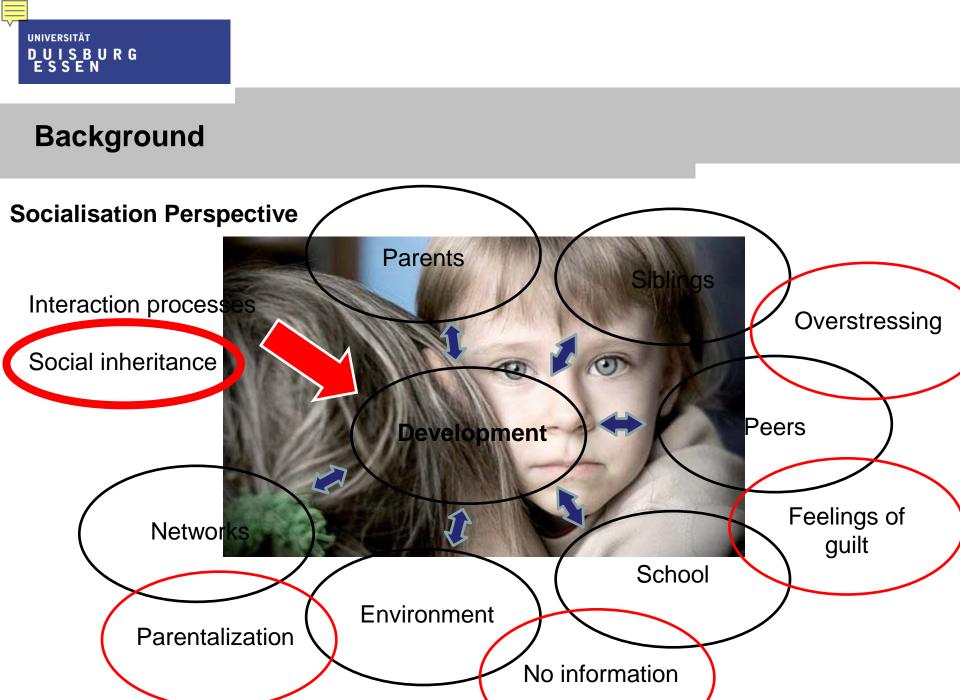
•Genetic disorders

•Psychosocial risk factors



Background







Preventive research project "Kanu – Gemeinsam weiterkommen"

- Aim to reduce the children's burdens and to support the capabilities within families
- Founded by Federal Ministry of Education and Research (BMBF)
- Project duration is October 2008 June 2012



Preventive research project "Kanu – Gemeinsam weiterkommen"

Two steps in research

- 1. Qualitative Study
- Identify the burdens within families

2. Quantitative Study

 Development, implementation and evaluation of an intervention for parents who suffer from depression or schizophrenia and for their children aged 6 to 14 years



Qualitative study

- October 2008 December 2009
- Parents who suffered from depression or schizophrenia and their children aged 6 to 14 years were interviewed
- Aim of the qualitative study was to identify the burdens within families with a mentally ill parent and their need for support
- The findings were used to develop the following intervention (Step 2)



Sample and data analysis

	Participants	female	male	Depression	Schizophrenia
Parents	22	18	4	15	7
children	23	13	10	-	-

 \rightarrow The data analysis followed the methodology of Grounded Theory



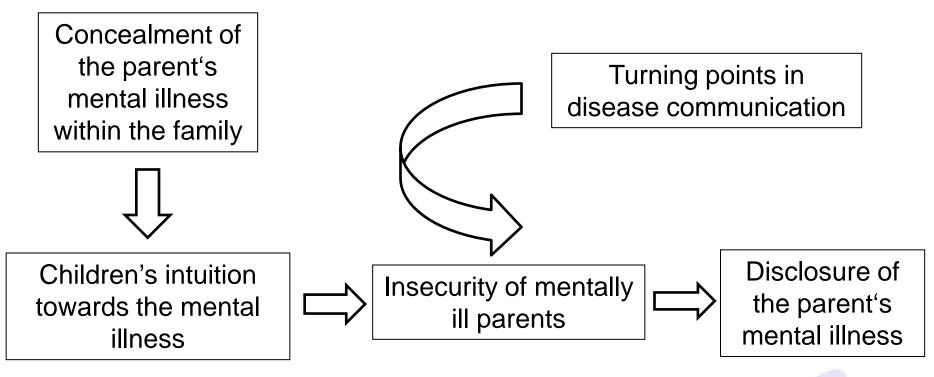
- Mental illness and its symptoms often remain undiscovered for years
- In most cases a flash point leads to a breakdown
- The admittance in the psychiatric care system occurs suddenly

Self-stigmatisation and a lack of information leads to the concealment of a mental illness



- The parent's main reasons for concealment:
- to protect their children from their mental illness
 to prevent a negative influence on the children's development
- " My son has to grow up without a mother and I am afraid that it is too much for him, when he also experiences the burdens caused by my mental illness (...). That's why I take so much care that he won't notice my disease. I try so hard, (...) because he is very important to me." (Quotation of a Turkish father suffering from depression)

- The parent's main reasons for concealment:
- feelings of guilt and shame
- difficulties to find an explanation that is suitable for children
- to avoid that their social environment will know about their disease







Findings: Burdens experienced from the children's perspective

- Fear of the parental mental illness
- Feelings of guilt
- Reduction of friends/ social isolation
- Communicative isolation
- Takeover of the parent's responsibility

UNIVERSITÄT DUISBURG ESSEN

Findings: Burdens experienced from the children's perspective

"The time when my mom went to the clinic was sometimes exhausting for me. When she wasn't home I had to take over the mother's role (...) and made dinner for my siblings.

"You have an older brother, haven't you?"

"Yes, but he doesn't do much. Most of the time he stays in his room (...), I think he isn't interested."

(Quotation of a 12-year-old daughter of a mother who suffers from depression)



Conclusion

- Further research should investigate how the parent's ability for disease communication can be influenced (e.g. economic, social and cultural capital)
- Preventive programs have to include offers which will improve illness communication within families by providing age-adjusted information for children and by improving the parent's communicative skills



Gemeinsam weiterkommen