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Children affected by rare disease and their families (CARE-FAM-NET)

Theoretical background

- Rare diseases as a group of diseases is defined by a low prevalence (<5:10000)
- In Germany, around 4 million children and adolescents may be affected by one of over 7000 rare diseases
- Exacting demands are imposed on affected families in terms of intensive disease management (1;2)
- Children and adolescents with a rare disease and their families are affected by a high physical and psychological burden (3)
- Parents of chronically ill children, especially mothers, are at high risk for clinical depression and anxiety (4;5)
- Children have an elevated risk for developing internalized and externalized behavioral and developmental disorders (6)

Objectives

- To close the existing gap in psychosocial health care of families with children with rare diseases
- To counteract psychological burdens and comorbidity
- To prevent and treat chronification of psychological symptoms and disorders
- To implement and transfer two psychosocial health care provisions for children affected by rare disease, their siblings and parents

CARE-FAM

- Family-based face-to-face intervention with 8 sessions over 6 months
- Based on principles of psychodynamic family therapy, development model, and analysis of requirements

WEP-CARE

- Online intervention for parents of affected children
- Based on principles of cognitive-behavioral writing therapy

Methods

Procedure

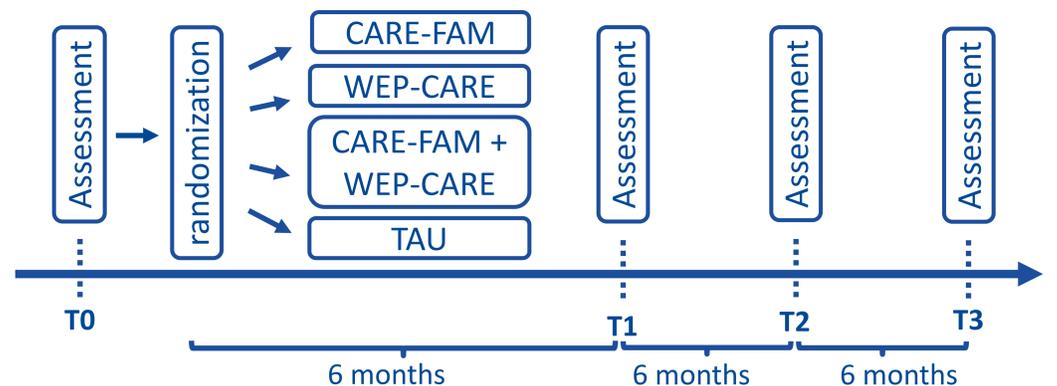
- Prospective, multi-center, randomized controlled study
- Accompanying evaluation by external institutions

Participants: N = 1000 families in 17 locations in Germany

Measures

- Primary outcome measures: psychological health of the children, siblings, and parents
- Secondary outcome measures: health-related quality of life, family relations, social support, disease management, health economics

Funding: Federal Joint Committee (7.6 million Euros)



Outlook

- Results from this project will be used to implement psychological health care provisions for affected families

Consortium partners

- Public relations (Christine Mundlos, Jörg Dirmaier)
- Forms of provision (Miriam Rassenhofer, Silke Wiegand-Grefe)
- Accompanying evaluation (Karl Wegscheider, Matthias Graf von der Schulenburg, Gerald Wilms, Monika Bullinger)
- 34 clinical partners at 17 locations in Germany
- Health insurance companies



References

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Disclosure statement: I have no potential conflicts of interest to report!