Supporting families with a child with Usher Syndrome

A psychoeducation program based on Self-Determination Theory

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Introduction

Parents of a child with Usher Syndrome may experience high levels of parental stress and psychosocial challenges, which can affect their ability to provide autonomy-supportive parenting. Children with Usher syndrome may face challenges related to changes in sensory abilities. Currently, no evidence-based psychoeducation program is available to support them.

Study 1:
Develop and evaluate a psychoeducation program for families with a child (0-18 years) with Usher Syndrome

Study 2:
Develop and evaluate a training program for care professionals providing the psychoeducation program

Interventions

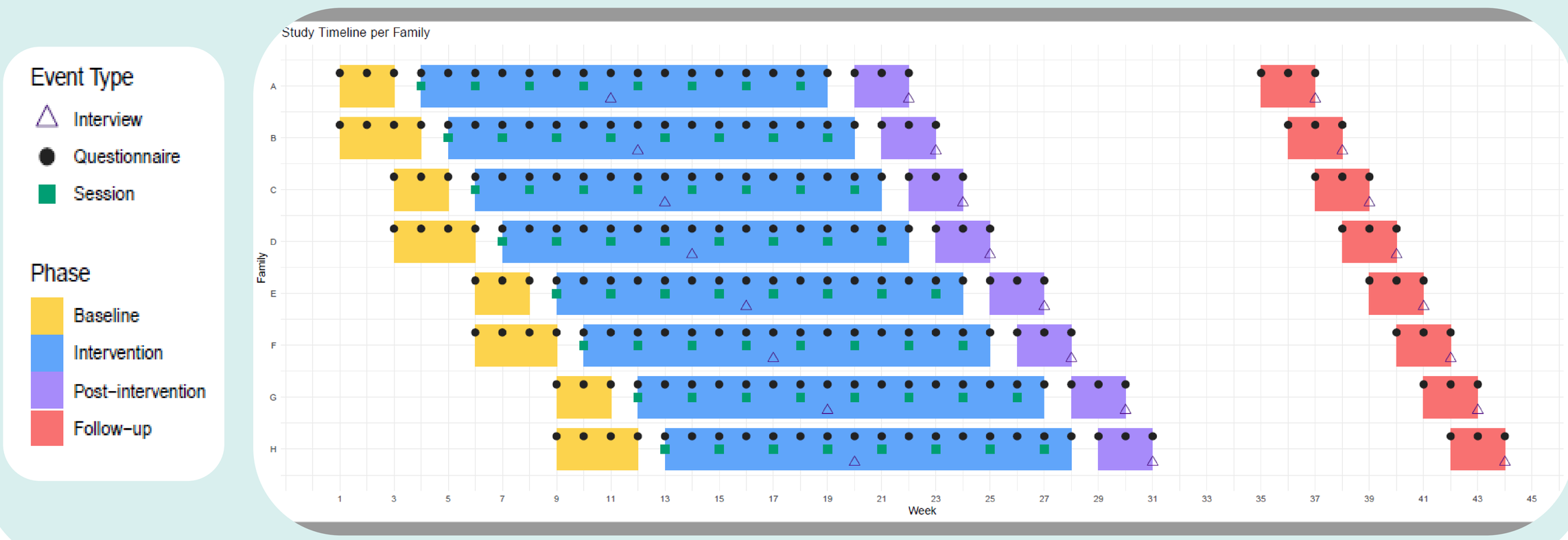
1. Family Psychoeducation Program

- Focus on family well-being, basic psychological need satisfaction, and autonomy-supportive parenting
- Based on Self-Determination Theory (SDT)
- Includes eight structured sessions with a trained care professional, supported by a treatment guide and practical handouts

2. Training Program for Care Professionals

- Three e-learning modules: 1) Usher syndrome, 2) Autonomy supportive practices, 3) Impact on life
- Four-hour in-class session to practice autonomy-supportive skills
- Follow-up sessions with experts by experience for reflection and learning

Methods



Participants

- 8 families with a child with Usher Syndrome (aged 1–17), from various regions in the Netherlands and Belgium.
- 15 parents, 1 child
- 11 care professionals

Expected outcomes

1. Insight into the effects of a family psychoeducation program for families with a child with Usher Syndrome
2. Insight into the effects of a training program for care professionals providing this type of care
3. An evidence-based psychoeducation that can be offered to parents in the Netherlands
4. Potential for international implementation, requiring only minor contextual and language adaptations



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Key references
Deci, E. L., & Ryan, R. M. (2000). The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior. Psychological Inquiry, 11(4), 227–268
Heppe, E., Knapen, V., Beijaard, I., Tham, G., Belt, E. & Damen, S. (2023). Eindverslag project Coping met Usher. Koninklijke Kentalis & Deelkracht.

www.deelkracht.nl