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Between Support, Responsibility and Letting Go – Parents' Perspectives on Transition in Rheumatology

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Background

Up to 50% of children with pediatric rheumatic disease require medical care into adulthood.[1]

Transition from caring pediatric care to self-reliant adult care occurs during adolescence, a challenging and vulnerable phase of life.[2]

During childhood, parents play a central role in adolescents' disease and care management, taking on considerable responsibility.[3]

As the transition begins, this role gradually changes. Parents now take on a more advisory role instead of a leading role, which can be challenging.[4]

Objectives

Research Gap

- Despite recognition of parental support during transition, parents' perspective is still under-researched, particularly for rheumatic diseases.
- A deeper understanding of parental challenges is pivotal to provide valuable insights into their support needs during transition as well as possibilities to optimize transitional care.

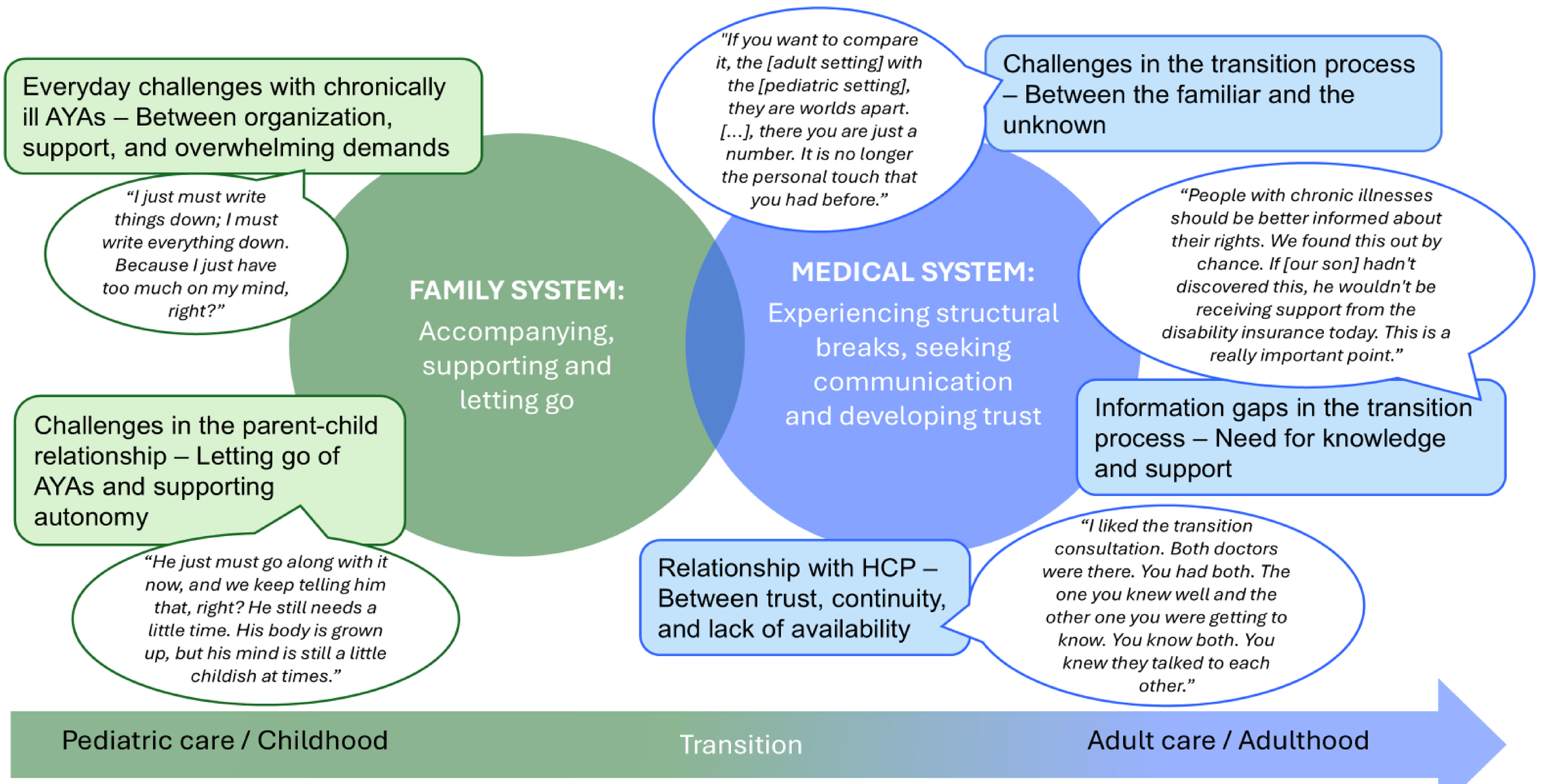
Research Aim

- To explore the **experiences and needs of parents** of AYAs (adolescents and young adults) with a rheumatic disease **during transition process** from pediatric to adult medicine.
- To describe **the practical implementation** of the transition process in four different centers in Switzerland.

Methods

- **Methodology:** Rapid ethnographic methods, including semi-structured interviews with parents (N=8), non-participant observations in rheumatology (transition) consultations (N=11) and informal conversations with healthcare professionals (HCP) and families.
- **Participants and Settings:** Parents of AYAs, aged 16-24 years, in different phases of the transition process in two pediatric and two adult rheumatology centers in Switzerland.
- **Data Analysis**: Braun and Clarke's six phased reflexive thematic analysis.

Identified Themes and Subthemes



Conclusion

Parents need support in dealing with their AYA's disease-related challenges and want comprehensive information and active involvement in their care – throughout the entire transition process. HCPs are required to meet these needs **through proactive, structured communication and participatory collaboration**.

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Contact

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