

A CONTEXTUAL ANALYSIS OF A SWISS TRANSITION MODEL FROM PEDIATRIC TO ADULT RHEUMATOLOGY

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Background

Pediatric rheumatologic diseases (**PRDs**) are among the most common **chronic illnesses** during childhood¹

About **3000** children and adolescents are diagnosed with a PRD in Switzerland²

Up to 50% of patients with PRDs need further medical care into adulthood²
=> Access to structured transitional care (**TC**) is crucial

Current TC practice in **Swiss rheumatology** is not uniform
=> Rheumatology clinics do not follow European TC guidelines³

Objectives

Research Gap

- The contextual factors influencing as well as the perspectives of all parties involved in TC - including adolescents and young adults (**AYAs**) and parents - have not been assessed in Switzerland
- The challenges faced by healthcare professionals (**HCP**) involved in TC are not defined

Research Aim

- To understand the experiences, barriers, and unmet needs of all parties involved related to current TC practices in two collaborating Swiss university clinics (pediatric and adult rheumatology units)
- To transfer these insights to a Swiss-wide research project aiming to develop and implement an optimal TC process in all Swiss rheumatology clinics

Methods

- **Sample & Setting:** AYAs receiving rheumatological care, parents, HCP, and involved stakeholders at two collaborating Swiss university clinics
- **Data Collection:** Rapid ethnographic methods, including observations during transition consultations and semi-structured interviews with 6 AYAs, 4 parents, 3 HCPs, 4 clinical leadership representatives, and 4 stakeholders
- **Data Analysis:** Braun and Clarke's six phased thematic analysis

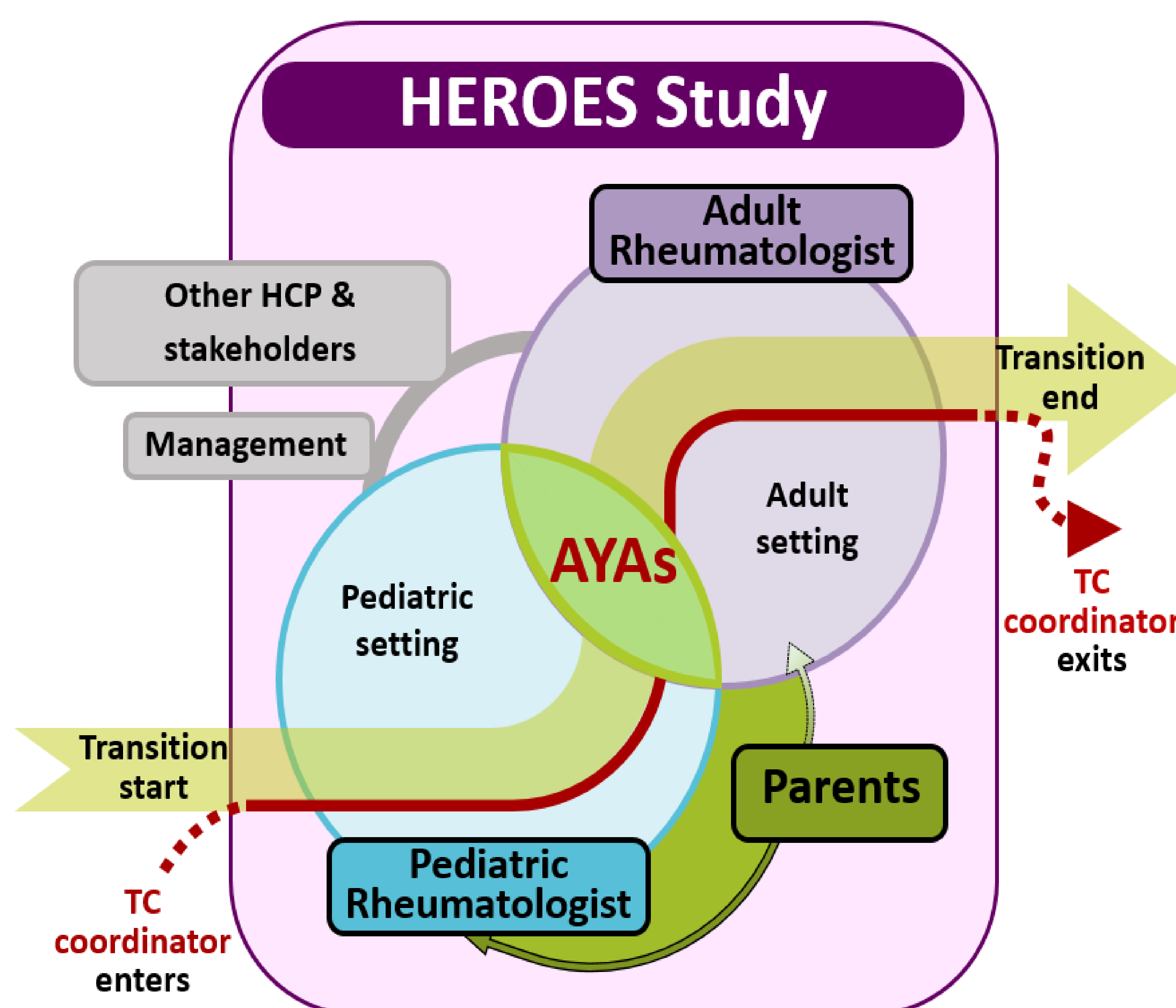
Results

Transition coordinator as stable anchor

- Provides continuity of care during the entire transition process
- Prepares AYAs to self-manage the treatment of their disease
- Is easily accessible to AYAs and their parents for medical and non-medical advice as well as to HCPs

TC team skills & expertise

- Good cooperation with external services and institutions (e.g., social services, pediatrician/general practitioner, insurance companies, schools)
- Excellent trans-disciplinary collaboration within TC team



Barriers and unmet needs

- Financial constraints (e.g., billing)
- Knowledge gaps about TC and the undefined role of the transition coordinator
- Structural challenges (e.g., time for consultations)
- Training opportunities

Experiences of AYAs and parents with TC

- Visible evolution of TC over time/since introduction
- Arriving in adult care can be a shock
- Parents feel it is not their place to express their concerns during consultations
- AYAs need specific care geared towards their needs

Conclusion

Multi-perspective, multi-site, and transdisciplinary research is the basis to understand the needs of all parties involved and to thus implement an optimal TC process

Funding



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1. Gillispie et al. (2018). Pediatric rheumatology curriculum for the pediatrics resident: a case-based approach to learning. *MedEdPORTAL*

2. Roethlisberger et al. (2015). Pediatric Rheumatology in Switzerland. *Paediatrica*

3. Berben et al. (2021). Current practice of transitional care for adolescents and young adults in Swiss paediatric and adult rheumatology centres. *Swiss Medical Weekly*

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