CONTEXTUAL ANALYSIS OF A TRANSITION MODEL FROM PEDIATRIC TO ADULT RHEUMATOLOGY

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Background

Pediatric rheumatic diseases (**PRDs**) are among the most common **chronic illnesses** during childhood[1]

About **3000** children and adolescents are diagnosed with a PRD in Switzerland[2]

Up to 50% of patients with PRDs need further medical care into adulthood[2]
=> Access to structured transitional care (**TC**) is crucial

Current TC practice in **Swiss rheumatology** is not uniform **=>** Rheumatology clinics do not follow European TC guidelines[3]

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 unit)
- 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 with a PRD, parents, and HCPs at collaborating units of two Swiss university clinics, and involved stakeholders
- **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. Informal conversations with all interviewees.
- **Data Analysis:** Braun and Clarke's six phased thematic analysis

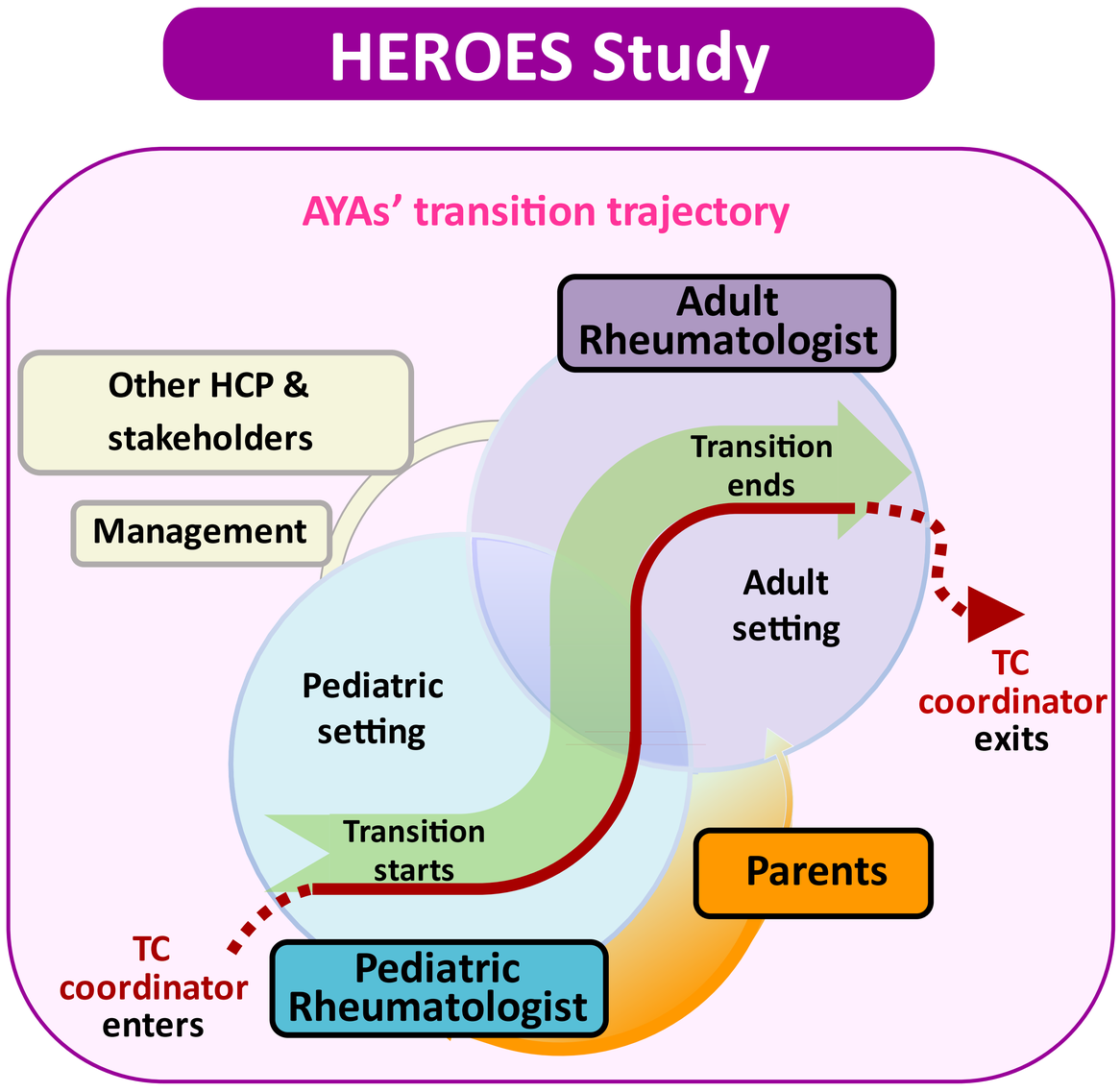
Results

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 unmeet needs

- Financial constraints (e.g., funding, billing system)
- 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 trans-disciplinary research is the basis to understand the needs of all parties involved and to thus implement an optimal TC process

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Contact

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