




BMJ Open Patient and parent perspectives on transition from paediatric to adult healthcare in rheumatic diseases: an interview study

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ABSTRACT

Objectives To describe the experiences, priorities, and needs of patients with rheumatic disease and their parents during transition from paediatric to adult healthcare.

Setting Face-to-face and telephone semistructured interviews were conducted from December 2018 to September 2019 recruited from five hospital centres in Australia.

Participants Fourteen young people and 16 parents were interviewed. Young people were included if they were English speaking, aged 14–25 years, diagnosed with an inflammatory rheumatic disease (eg, juvenile idiopathic arthritis, juvenile dermatomyositis, systemic lupus erythematosus, panniculitis, familial Mediterranean fever) before 18 years of age. Young people were not included if they were diagnosed in the adult setting.

Results We identified four themes with respective subthemes: avoid repeat of past disruption (maintain disease stability, preserve adjusted personal goals, protect social inclusion); encounter a daunting adult environment (serious and sombre mood, discredited and isolated identity, fear of a rigid system); establish therapeutic alliances with adult rheumatology providers (relinquish a trusting relationship, seek person-focused care, redefine personal–professional boundaries, reassurance of alternative medical supports, transferred trust to adult doctor) and negotiate patient autonomy (confidence in formerly gained independence, alleviate burden on patients, mediate parental anxiety).

Conclusions During transition, patients want to maintain disease stability, develop a relationship with their adult provider centralised on personal goals and access support networks. Strategies to comprehensively communicate information between providers, support self-management, and negotiate individualised goals for independence during transition planning may improve satisfaction, and health and treatment outcomes.

BACKGROUND

Young people diagnosed during childhood with rheumatic disease have an increased risk of mortality and morbidities, including

Strengths and limitations of this study

- This study's design is a strength: using purposeful sampling provided a broad range of demographics, geographical regions, and experiences from before, during and after transfer.
- Thematic saturation was reached, which was also a strength of this study.
- Young people and their parents with a range of rheumatic diseases were interviewed, allowing for insight into a specialty where there is increasing interest and research in optimising transitional care for life-long disease that extends into adulthood.
- However, we were limited in our inclusion to English-speaking participants in Australia, which may limit the transferability.

early-onset cardiovascular disease, low bone mineral density and infertility compared with the general population.¹ Adolescents are at a greater risk of active disease flares and have higher rates of hospital readmissions.^{2,3} They report high levels of pain intensity, functional disability, and rates of psychiatric disorders such as depression and anxiety.^{4,5} Despite the ongoing impacts through to adulthood, up to half of patients who transition to adult care are lost to follow-up within 2 years after transfer.^{1,2}

Transitional care is the active, planned process of addressing medical, psychosocial, educational and vocational needs of young people preparing for the adult healthcare system.⁶ However, transition remains a clinical challenge because the specific requirements for adolescents and young adults may remain under-recognised, such as reported low confidence in self-advocacy and reluctance to leave trusted paediatric staff.^{7–9} Parental caregivers also have to adapt to

changes in the young people's needs for independence and autonomy.^{9 10} Unmet training needs in both paediatrics and adult specialists perpetuates the clinical challenge of transitional care.^{11 12} Forty-five per cent of adult rheumatologists reported no transitional care training in recent data from the USA.¹¹

The Bridges Transitions Framework assists individuals and organisations in managing change.¹³ The theory delineates between the term 'change', describing the event-based, external situation, and 'transition' considered as the individual's emotional or internal process in response to that change. The three phases of transition described were (1) endings—to identify what must be relinquished; (2) neutral-zone—the in-between period of accepting endings but discomfort with the new, possibly associated with confusion and distress; and (3) new beginnings—focus on the progress and growth towards new values or attitudes, but with possible underlying anxiety about regressing to past phases. Successful coping in the context of transitional care in rheumatology can therefore be facilitated by addressing each of these theoretical phases when targeting patient needs before, during and after the transfer of care.

Previous studies extensively examined the transition perspectives of young people, either in specific rheumatological diseases such as juvenile idiopathic arthritis (JIA)^{14–18} or a broad range of long-term physical or psychological health conditions.^{19–21} However, few studies focus on rheumatological diseases as a key area, in regard to the needs and perspectives of young people. Parent priorities described are similar across a range of health conditions; as needing clarification and support for their roles by transition services and feeling supported by well-coordinated communication between teams.^{22 23} Whether there are slight nuances in transition needs for parents of young people with rheumatological disease across the transfer continuum remains uncertain.^{14–18 24–27} This study aims to describe the experiences, priorities, and needs of young people with rheumatic disease and their primary carers on transition from paediatric to adult care. The insights gained will inform ways to optimise transition for improved patient and caregiver satisfaction, access to care and life-participation outcomes.

METHODS

We applied the Consolidated criteria for Reporting Qualitative research to report this study (see Research Checklist).²⁸

Participant selection and setting

Patients were eligible if they were English speaking, aged 14–25 years, diagnosed with an inflammatory rheumatic disease (eg, JIA, juvenile dermatomyositis, systemic lupus erythematosus (SLE), panniculitis, familial Mediterranean fever) before 18 years of age and their parents. Young people were included only if they had experience with paediatric rheumatology in the public or private setting

and were not included if they were diagnosed in the adult setting. Participants were purposively sampled to include a broad range of demographics including, age, sex and type of rheumatic disease.^{29 30} IJ recruited participants from patient databases of five centres (two paediatric and three adult hospitals) which encompass regional and metropolitan areas in New South Wales, Australia. One of the three adult hospitals had a dedicated age-based transition clinic. Participants were approached by their treating physicians and nurses and provided informed consent to be contacted by IJ via telephone.

Data collection

The question guide was semistructured and informed by a qualitative systematic review of patients' attitudes and experiences of transition in rheumatology³¹ and discussion among the research team (online supplemental file 1). Questions pursued areas relating to self-management, available and future support networks, current or recent experiences of transition and suggestions for improved transition. Interviews were initially conducted with two researchers present (IJ or DJT) to pilot the interview guide and train IJ (medical student) in interview techniques. DJT (PhD) had prior experience with qualitative research. The interview guide was subsequently revised to include further questions about medication adherence and residential location as a possible barrier.

IJ and DJT conducted face-to-face and telephone interviews from December 2018 to September 2019. Face-to-face interviews were conducted in the home, the clinic or the community (eg, library, café) based on the participant's preference. Before initiating each interview, IJ and DJT introduced their role in the study and the research aims to participants as there were no prior relationships established between the investigator and participants prior to study commencement. Written consent was then obtained from participants or their parents if the patient was under 16 years old. Young people and parents were interviewed separately with the exception of one interview conducted with both patient and guardian based on the participant's choice. Recruitment continued until data saturation, when few or no new concepts emerged was achieved.^{30 32} Field notes were not made and repeat interviews were not undertaken. Interviews were audio-recorded and transcribed verbatim by IJ and CT. The average interview time was 42 min and 36 min for patients and caregivers, respectively.

Analysis

The transcripts were imported into HyperRESEARCH V.4.0.3 (Researchware, USA) to facilitate coding and storage of data. IJ, DJT, AK, AT, CT and KM used thematic analysis to analyse the qualitative data, which is a method that is beneficial in clinical settings as it provides critical insight that is actionable for healthcare professionals.³⁰ Investigators IJ and DJT read and coded all transcripts line by line and conceptualised all sections to inductively identify and compare concepts relating to patient and

Table 1 Patient characteristics (n=14)

Patient characteristics	n (%)
Sex	
Male	6 (43)
Female	8 (57)
Age group (years)	
14–19	10 (71)
20–25	4 (29)
Age at disease diagnosis (years)	
0–5	5 (36)
6–10	4 (29)
11–15	5 (36)
Interview setting	
Home	10 (71)
Community (eg, café)	3 (21)
Clinic	1 (7)
Geographical location	
Rural	3 (21)
Metropolitan	11 (79)
Transition stage	
Pre-transition	2 (14)
During transition	3 (21)
Post-transition	7 (50)
Not followed up by rheumatology services	2 (14)
Rheumatological condition	
Juvenile idiopathic arthritis	8 (57)
Systemic lupus erythematosus	3 (21)
Familial Mediterranean fever	1 (7)
Panniculitis	1 (7)
Sterile multifocal osteomyelitis	1 (7)

parent perspectives on transition. They grouped similar and recurring concepts into themes and subthemes. The coding framework was discussed among members of the research team (IJ, DJT, AK, DS-G, GM, AT, KM) to ensure the full depth and breadth of data were reflected in the analysis. An analytical framework was developed through a process of analysis and comparisons of concepts to identify conceptual links to create a thematic schema.

Patient and public involvement

Patients assisted to recruit their parents and vice versa if patients were under 18 years old. Patients did not design, conduct, report or disseminate the study results and were therefore not included as authors.

RESULTS

In total, 14 young people and 16 parents participated. The participant characteristics are shown in [tables 1 and 2](#). The age of patients ranged from 15 to 23 years, with a

Table 2 Parent characteristics (n=16)

Parent characteristics	n (%)
Sex	
Male	4 (25)
Female	12 (75)
Age group (years)	
30–39	1 (6)
40–49	8 (50)
50–59	6 (38)
Not reported	1 (6)
Highest level of education	
University degree	6 (38)
Diploma/certificate	4 (25)
Secondary school	5 (31)
Not reported	1 (6)
Interview setting	
Home	12 (75)
Community (eg, café)	2 (12)
Clinic	1 (6)
Telephone	1 (6)

mean of 18.5 years (SD 2.1). Eight patients and 12 parents were women and 3 patients (21%) lived in rural areas. The participants had JIA (n=8), SLE (n=3), panniculitis (n=1), familial Mediterranean fever (n=1) and sterile multifocal osteomyelitis (n=1). The average age at diagnosis was 8 years and ranged from 2 to 15 years old. Two had not commenced the transition process, three were undergoing transition and seven had transferred to adult care. Two patients were lost to follow-up at specialty rheumatology services. All interviews were conducted face-to-face except for one that was conducted by telephone. Two participating parents were interviewed independently without participation of their child. Fourteen patients contacted did not participate due to family, work or other commitments, and the majority (71%) were 18 years or over.

We identified four themes: avoid repeat of past disruptions, encounter a daunting adult environment, establish therapeutic alliances with adult rheumatology providers and negotiate patient autonomy. The themes and subthemes are described below. Illustrative quotations are provided as online supplemental table. A thematic schema illustrating the conceptual relationships between themes is shown in [figure 1](#). The description of the themes in the following section applies to both patients and parents unless otherwise specified.

Avoid repeat of past disruptions

Maintain disease stability—patients experienced periods of medical instability during the initial stages of disease manifestation and diagnosis. Patients who had not commenced transition feared that clinicians in the

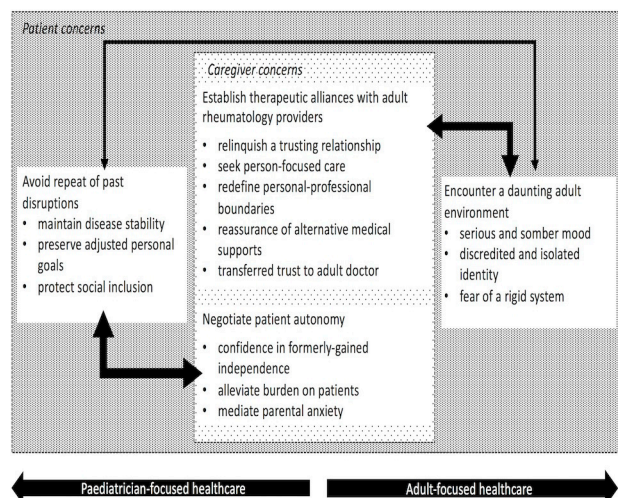


Figure 1 Thematic schema. Parents were concerned about the disease-related aspects of their child's transition. Parents sought to protect their child's social and personal goals by alleviating the disease burden, but simultaneously recognised more autonomy was needed as their child matured. While prior independence encouraged patients' preparedness to maintain disease stability through transition, they were apprehensive that personal goals would be protected. Hence, there was automatic trust in adult providers when transition decisions were led by their paediatrician. Young people and parents hoped to overcome the daunting adult environment by developing a relationship with adult rheumatologists before transfer. However, limited specialist access and adult system rigidities impeded the development of a professional, person-focused alliance.

adult setting would alter their management, which they expected could lead to a repeat of medical instabilities or increased risk of disease flares. During transition, some young adults were confronted by the realisation of long-term nature of their disease, as "[the doctors] always said I would grow out of my arthritis" and felt disconcerted about their 'reliance' on lifelong medications.

Preserve adjusted personal goals—before transition, symptoms of fatigue, low concentration, and absence from school or work impacted patients' ability to pursue educational or vocational goals successfully. This made them feel 'frustrated' and 'demolished'. Some patients reported being too 'overwhelmed' to continue pursuing 'dreams that (were) crushed'. Other participants learnt to accept the limitations on daily life imposed by their disease, found ways to 'manage and deal' with their bodies' constraints and thereafter, reshaped their ambitions. Patients valued transition timed during periods of disease and personal stability to avoid another disruption having readjusted their career ambitions.

Protect social inclusion—disease stability enabled young people to have 'more time to see friends'. Through transition, they valued support by friends who saw them 'as someone separate from (the disease)' and hence did not feel the need for patient support groups. Parents thought that friends enabled young participants 'to forget what (they were) going through'. However, patients

and parents in regional areas, as well as some younger adolescent participants, wanted support groups during transition. They perceived their friends could not 'really understand' them and reported being subtly excluded from social events because friends believed their disease was activity-limiting.

Encounter a daunting adult environment

Serious and sombre mood—the adult hospital was described as 'gloomy' and dismal, where the warmth and liveliness of the paediatric hospital enabled patients to feel "like I wasn't a patient". Participants perceived 'the white, the windows, people looking around' and physical 'maze'-like layout in adult hospitals to be 'stressful'. The quiet atmosphere and lack of ward activities to entertain patients meant that they had no distractions and felt 'put down' from dwelling on their disease symptoms.

Discredited and isolated identity—participants observed that clinicians in the adult healthcare setting were not as 'bubbly' or personable compared with clinicians in the paediatric hospital. In the adult hospital, some reported their 'invisible' symptoms, such as pain, were ignored by healthcare workers. Patients also experienced isolation when surrounded by elderly patients who appeared withdrawn and reluctant to talk with others. From clinicians, being asked about their medical history repeatedly made patients feel insignificant: "It'd be nice if the staff knew [my history] already, and they're just asking [me] to confirm." To protect young people from feeling isolated, some parents believed their involvement was more necessary in the adult environment where they thought patients received less attentive care than in paediatrics. Parents themselves reported feeling like 'outsider(s)' when they were unable to answer questions by adult clinicians who had higher expectations of parental disease knowledge.

Fear of a rigid system—young people anticipated that restricted doctor availability and reduced capacity to reschedule appointments in the adult system would limit their ability to adapt medical appointments around other life priorities. Around the time of transition, parents wanted to be informed beyond medical issues, such as specific requirements needed to attain financial government support, especially when young people were leaving home for tertiary study or vocation.

Establish therapeutic alliances with adult rheumatology providers

Relinquish a trusting relationship—young participants trusted their paediatric rheumatologist who they described as 'someone who knows you so well' ... and was like 'a second (parent)'. Patients reported their rheumatic condition was a source of insecurity and valued the comfort their paediatric rheumatologist provided them: "I'm quite a confident person but [my disease is] quite a vulnerable side." To leave the care of the paediatric rheumatology was one of the most 'upsetting' aspects of transition.

Seek person-focused care—young people reported feeling reassured when ‘important aspects of (their) life’ such as psychological and social concerns were addressed during consultations. They could ‘warm up faster’ to the adult rheumatologist if they demonstrated interest in personal goals. However, some young adults felt too intimidated to raise medical concerns because they perceived adult rheumatologists to be constantly ‘busy’. Given the invisibility of patients’ symptoms, such as pain, parents emphasised that clinicians should enquire specifically into patients’ well-being. They believed personal issues were often inter-related with presenting medical concerns: “You need a doctor that’s interested in the whole picture for [their background] to be helpful... to connect the dots to symptoms coming up” and therefore appreciated continuity of care that was whole person-focused, not just clinical.

Redefine personal–professional boundaries—participants struggled to redefine subtle social–professional boundaries with their adult rheumatologists such as the clinician’s flexibility to fill administrative forms between appointments, and leniency towards poor medication adherence. Parents and young people appreciated the accessibility of paediatric rheumatologists to promptly act during flares or answer questions by phone or email and were afraid they would not experience the same level of support from adult rheumatologists.

Reassurance of alternative medical supports—young adults felt ‘less trapped’ through transition when they had ongoing support from their paediatric rheumatologist and other familiar doctors. A meeting with the adult rheumatologist prior to transfer made transition less ‘daunting’ and less like ‘being thrown into fire’. Transition specialist nurses were also valued in preparing young people and parents for expectations of medication adherence, and expectations of the adult rheumatologist.

Transferred trust to adult doctor—participants were confident in their paediatrician’s choices to tailor individualised transition plans and therefore described an automatic confidence in their adult rheumatologist as: “[My paediatrician] would put me in good hands... with someone he knows I’d like.” They looked forward to developing a similarly trusting relationship with their new adult rheumatologist. A well-communicated transfer of medical and psychosocial history between rheumatologists hence provided major ‘security’ and ‘comfort’ for parents and young people.

Negotiate patient autonomy

Confidence in formerly gained independence—young people found transition was easy when they had developed independent self-care in the past. Previous experiences such as non-English or minimal English-speaking parents, previous changes in care providers or prior admission to adult wards required greater responsibility from patients to interpret medical information themselves. Some young people compared transition to ‘going from school to university’. They were not concerned with medication

adherence following transition and in fact, experienced more stress when they did not regularly take their medications. Parents believed that during the period of transition, their child increasingly matured and could react more negatively to parental advice, which they believed warranted less parental care. Parents expected their children to be more independent in medicine taking and honest when they felt unwell.

Alleviate burden on patient—parents believed they had a duty to protect their child from the burden of disease and found it difficult to ‘just walk away’ from involvement in their child’s care. Parents supported their child in other aspects of life such as transportation, housing and costs of treatment: “you might not pay the mortgage this week, but [they’ll] get [their] medications.” As such, parents continued to be invested in care, despite confidence in their child’s ability to manage their health. Some young people appreciated their parents’ presence during consultations as they believed they did not ‘fully understand’ their medical history and struggled with the increased need to ‘bring up (their) own concerns’.

Mediate parental anxiety—young people were acutely aware that their parents were anxious about their disease and believed that disease diagnoses and flares were ‘more stressful for their parents than it was for (themselves)’. Parents likewise expressed that their main concern was their child’s health, such as the inability to identify or predict flare severity and the long-term disease impacts on life expectancy. Hence, young participants, sensitive to their parental anxiety, desired either more or less autonomy during transition. Some patients reported more motivation to manage themselves independently and were less likely to disclose feeling unwell to prevent parental worries. Other patients felt obligated to forfeit their independence so that their parents could feel more reassured through continuing their caregiver role of their child.

DISCUSSION

Young people perceived that the transition process was an unstable period which could potentially jeopardise their disease stability and personal ambitions. Young people feared that their complex health information would not be comprehensively transferred or communicated between the paediatric and adult healthcare providers. Young people were concerned that adult healthcare providers would not discuss or consider their personal recreational and vocational goals. They perceived the adult healthcare system to be rigid and confronting, and were uncertain that the trust they had with their paediatrician to care for them as a whole person would be developed with their new adult rheumatologist. However, young people felt more confident to maintain their disease stability when they experienced prior independence and had other health professionals, such as their general practitioner, transition nurse or other specialists, available for support. To protect their child’s personal and social stability,

parents wanted to stay involved in their child's care after transition and help alleviate their disease burden. Some young people struggled with the tensions of desiring greater independence and enabling ongoing caregiver involvement to avoid additional parental worry.

There were some differences noted in patient perspectives based on geographical location and age. Young people and families who lived in non-metropolitan areas tended to feel isolated and expected that this could be addressed with the opportunity to join support groups during the transition period. Younger adolescents felt misunderstood and excluded by peers while young adults had been able to form strong relationships with friends, providing a feeling of acceptance and less need for social support groups. Our study included patients with different rheumatic diseases and we found that young people and parent perspectives of transition were consistent across different conditions.

Similar patient perspectives of transition are shown in studies in rheumatology and other life-long conditions such as diabetes mellitus and mental health disorders. It is well established that while young people with life-long conditions accept transition as an inevitable process, they report a hostile adult environment and distress in severing relationships with their trusted paediatric clinician, which are consistent with both our findings and the theoretical Bridges Transitions Framework.^{10 24 25 33–35} A recent systematic review noted that young people with diabetes mellitus expected their paediatrician to be a 'bridge' to their adult provider, to discuss expectations in the adult system and to guide them on how to ask questions to their new clinician without feeling like a burden.³⁴ We found that patients felt prepared for transition when they had experience in self-management prior to transition and could access other supportive health clinicians including primary care physicians, transition nurses and other specialists.

The need to balance autonomy and dependence on support from family has also been previously identified.³⁶ A study in the area of mental health services found that while patients perceived transition as a chance to gain greater independence from parents, they valued continued parental involvement as they lacked knowledge of their own disease diagnoses.³⁷ While this has also been recognised in rheumatology-specific conditions,^{24 33 38} our findings highlight some tensions. Young people were sensitive that their parents would be anxious if they were uninformed or uninvolved in their child's health. To protect and minimise parental stress, some young people wanted to involve parents in clinical appointments, despite having to forego some level of independence. Different degrees of autonomy sought by young people call for a negotiation in the strategies used to support independent self-management.

We included participants with a range of experiences of transition, and from regional and urban areas to strengthen our purposive sampling, despite relatively small subgroup numbers. We recruited participants until

data saturation was achieved and used investigator triangulation (IJ, DJT, AT) to ensure that the findings reflect the full range and depth of the data collected. Triangulation was performed throughout the duration of the study, which allowed for an inductive process of theme analysis and refinement to occur.

However, there are some potential limitations. Inclusion in this study required participants to be English speaking and in Australia, which may therefore limit the transferability of the findings beyond this setting. In addition, the majority of individuals who declined to participate were over 18 years of age, suggesting a possible selection bias. However, we note that similar themes in studies conducted in other populations and settings have been identified.^{10 24 25 33} The lack of patient involvement in the study design may limit the clinical relevance and transferability of these findings. However, this study was undertaken to inform a model of transitional care at a tertiary adult and children's hospital in Australia. Furthermore, different pathologies, disease severity and patient stages of transfer may limit the transferability of our findings to other settings, as varied clinical courses and disease manifestations may lead to differing perceptions of transitional support from patients and caregivers. Finally, structured parameters to measure patient outcomes such as the Visual Analogue Scale-global and Health Assessment Questionnaire (HAQ)/Childhood HAQ parameters were not collected during this study.

To improve transition, our findings suggest the need for paediatric rheumatologist-led planning; supporting a consistent management approach; ensuring that patients can readily access medical support from trusted healthcare workers such as primary care physicians, previous paediatric rheumatologists, outpatient rheumatology services and pharmacists when needed; addressing personal and social goals and expectations when building rapport. Given that young people have often built trust with their paediatric rheumatologist, we suggest that paediatricians support gradual transition by referring and introducing young people to the adult healthcare provider and discuss the differences in expectations in adult care with patients and families prior to meeting the adult provider. Maintaining a consistent approach to medical management (ie, avoiding changes to treatment) initially after transfer to adult healthcare may reduce the anxiety of parents regarding disease instability and increase young people's comfort in developing rapport with their adult rheumatologist. Age-specific transition clinics are consistently suggested to reduce the perceived differences between paediatric and adult care cultures for young people with life-long conditions.^{34 35}

Patient support groups have been previously shown to improve social well-being and optimism in transitioning patients.^{10 25 33 39–43} While patients in our study agreed that peer groups could be desirable in periods of disease instability or uncertain diagnoses, patients wanted to be more informed about medical support services (eg, general practitioners, allied health, transition nurses)

Box 1 Suggestions for caring for patients with rheumatological conditions transitioning to adult healthcare

Before transfer

- ▶ Discuss needs for autonomy with patients and caregivers early in the transition process.
- ▶ Discuss different expectations in the adult system with patients and families prior to meeting the adult provider.
- ▶ Promote paediatrician-led transition planning that involves referral and introductions to a trusted adult provider.

During transfer

- ▶ Group appointments with young people by age in adult centres.
- ▶ Seek more time during initial appointments to build rapport with patient by discussing personal and career goals prior to medical goals, in both paediatric and adult settings.
- ▶ If possible, avoid changing treatment initially after transfer.

After transfer and throughout transition

- ▶ Clarify and support individualised goals for self-management including access to care.
- ▶ Provide information on medical support services (eg, primary care physicians, allied health, transition nurses) available for patients and families.

and transition-related information sources they could access (eg, websites, apps). Training clinicians involved in the care of patients transitioning to adult rheumatology services is needed to ensure that their priorities and needs are met.³ This reflects findings from a Delphi study, conducted to develop a set of minimum training requirements for adult rheumatologists, which identified high priority areas for rapport building: training in issues unique to transition and adolescence, and relevant referral services that can be readily accessed by patients.^{44 45} Suggestions for caring for patients with rheumatological conditions undergoing transition are outlined in **box 1**, and are organised sequentially by stages of transfer as to reflect the continuum of phases in the Bridges Transitions Framework.

While patient perspectives are used to evaluate existing models of care,^{34 46} few inform the design of transition interventions.^{6 25 47 48} A transition model that is co-designed can help to ensure that the patient needs are considered and addressed.⁴⁸ For example, patient navigator programmes may have potential in the context of transition. Patient navigators are trained non-medical or medical personnel, who assist young people with life-long conditions through different care settings to understand clinical decisions and overcome barriers to access.⁴⁹ Studies suggest that navigator programmes may help to improve adherence to initial treatment, medical surveillance, quality of life and access to care as well as reduce drop-out rates from adult care.^{50–55}

High-quality evidence of the effectiveness of transition interventions is lacking and most trials in this area are underpowered and short term.⁵⁶ Further, intervention efforts have mainly targeted transition preparation more so than young people needs after the transfer to

adult care.⁵⁷ Trials involving transition coordinators have shown improvement in clinic attendance rates and reduced acute complications in patients with type 1 diabetes mellitus.^{34 58 59} Preliminary and single-centre evaluations have also been performed in rheumatology.^{55 60} We suggest that trials to evaluate models of care involving transition coordinators may be an area of future research.

CONCLUSIONS

Patients and parents perceive transition as a challenging and vulnerable period which may threaten medical, educational or psychosocial goals. Young people with rheumatological conditions in particular want stability, given the unpredictable disease activity. The unique set of patient symptoms can often be under-recognised in rheumatic diseases, heightening parental worries in being able to recognise flares, and inhibiting therapeutic alliances being formed with healthcare workers in the adult setting. Transition interventions that involve ongoing paediatrician support, negotiated autonomy in self-management including accessing care, and consistent management approaches between providers are needed, to improve life-participation and quality-of-life outcomes in young people with inflammatory rheumatic diseases.

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Contributors IJ was involved in the data collection and analysis, drafting and revision of the manuscript. GM, DS-G, FN, JC, SO, GH and AD substantially contributed to the conception and design as well as the manuscript revisions. CT,

AK, KM and SB analysed, interpreted the data and revised the manuscript. AT and DJT were involved in the conception, design, analysis, drafting and revision of the manuscript. All authors read and approved the final manuscript and agree to be accountable for all aspects of the work related to the accuracy and integrity.

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Data availability statement Data are available upon reasonable request. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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INTERVIEW GUIDE

Title

Optimising the transition from paediatric to adult healthcare of young people with rheumatic diseases: a qualitative study

Interview Plan

Introduction

- Explanation about the study, semi-structure interviews and informed voluntary consent
- Explanation that participants can stop the interview at any time without having to provide a reason.

Possible Interview Questions and Prompts

A semi-structured list of predominantly open ended and framed questions (17) will be used to focus the discussion, additionally prompts will be used to help stimulate the conversation.

Interview questions for adolescents and young adults with rheumatic disease.

1. General experiences of living with a rheumatic disease

- a. How did you feel when you were first told you have a rheumatic disease?
- b. How does living with a rheumatic disease impact your daily activities? (School/study, work life, relationships)
- c. Has your rheumatic disease changed how you feel about yourself? If so how?
- d. What's the hardest thing about having a rheumatic disease; how do you cope with these challenges?
- e. How do you think this rheumatic disease might impact your future?

2. Experiencing transition from paediatric to adult health care

- a. Have you discussed transition to adult healthcare with your doctor?
- b. What age were you when you discussed transition to adult healthcare with your doctor? When/ What age did you transfer to the adult clinic?
- c. What sorts of things did you discuss or ask your doctor about transitioning to adult healthcare?
- d. How did the process of transition begin? /What are the plans for your transition to adult healthcare? (Did you attend adolescent clinics in the adult hospital? Were you given a contact at the adult hospital? Did both an adult and paediatric doctor provide a consultation)
- e. Did you feel the plan was individualised/unique to your own situation?
- f. Did you find the paediatric and adult rheumatologist communicated well between each other and yourself?
- e. What aspects of transitional care are you most happy or satisfied with at the moment?
- f. What aspects of transitional care are you most unhappy or dissatisfied with?
- g. What sort of information and support did you receive when moving to the adult hospital?
- h. Pre-transition/During: What are you most worried about/ excited about for your transition?

3. Improving transition from paediatric to adult care

- a. How can doctors, nurses or other people working at the hospital or clinic provide better support for transition from paediatric to adult healthcare?

- b. What sort of information do you think should be available for young people moving to adult healthcare? How could it be given? (doctor, nurses, internet, phone apps, booklets)
- c. Other clinics take a slightly different approach. What are your thoughts on
 - adolescent clinics in adult hospital, adult and paediatric joining in the same consultation, a co-ordinator contact at the hospital

4. Self-management

- j. How confident do you feel about taking care of your own health and organising your clinical appointments? Why?
- k. What sort of things do you do to maintain your health? (*Medicine, diet, rest/activity*)

5. Social support (dealing with challenges of independence – work, school life, exams etc.)

- a. Do you feel you have someone who supports you? How do they help you? (organising appointments, driving you to appointments)
- b. How have your parents/guardian coped with your transition to adult healthcare?
- c. How do they let you gain independence in determining your healthcare?
- d. Who knows you have a rheumatic disease? (friends, relatives, school, work, etc...) How do they treat you?
- e. Do you know anyone else with a rheumatic disease? Are they a similar age? Are they also transitioning to adult healthcare?
- f. Have you joined a support group? Why/why not? (face to face, online)
- g. What sorts of initiatives, support, help is needed to improve the experiences of young people with rheumatic disease undergoing transition to adult healthcare?
- h. Have you ever found your location to be a barrier in accessing your healthcare?

4. Closing

- a. Is there anything else you would like add that you think might be useful for us to know?

Interview questions for parents and carers of young people with rheumatic disease

1. General experiences of caring for a young person with a rheumatic disease

- a. How did you feel when you were first told your child/dependent had a rheumatic disease?
- b. How does caring for a young person with a rheumatic disease impact your daily activities? (work, finances)
- c. How does caring for a young person with a rheumatic disease impact your relationships? (partner, other children, friends, work colleagues)
- d. Has caring for a young person with a rheumatic disease changed how you feel about yourself? If so how?
- e. How do you think caring for a young person with a rheumatic disease might impact your future?

2. Transition from paediatric to adult health care and self-management

- a. Have you discussed transition to adult healthcare with the doctor? How old was your child?
- b. What sorts of things did you discuss about transitioning to adult healthcare?
- c. What are the plans for transition to adult healthcare? (Are you taking a less active role in the care of your young person with a rheumatic disease? Are they attending an adolescent clinic in the adult hospital? Were you given a contact at the adult hospital? Did both an adult and paediatric doctor provide a consultation)
- d. How were you helping your young person through their transition?

- Are you participating in all the clinical appointments for your young person with a rheumatic disease?
- Are you organising the clinical appointments
- filling scripts?
- e. What aspects of transitional care are you most happy or satisfied with at the moment?
- f. What aspects of transitional care are you most unhappy or dissatisfied with?
- h. What sort of information and support did you receive when moving to the adult hospital?
- j. How confident do you feel about your young person taking care of their own health and organising their clinical appointments? Why?
- k. What sort of things do you do to help your young person maintain their health during this time? (*Medicine, diet, rest/activity*)
- l. What sort of things are you worried about for your young person moving to adult healthcare?
- m. What sort of things are you looking forward to?

3. Improving transition from paediatric to adult care

- a. How can doctors, nurses or other people working at the hospital or clinic provide better support for parents and caregivers for transition from paediatric to adult healthcare?
- b. What sort of information do you think should be available for parents and caregivers about transition to adult healthcare? How could it be given? (doctor, nurses, internet, phone apps, booklets)

4. Social support (dealing with challenges of your young persons new independence – work, school life, exams etc.)

- a. Do you feel you have someone who supports you? How do they help you? (emotional support, help finding further employment)
- b. How do you help your young person cope with the transition to adult healthcare?
- c. How are you letting them gain independence in their healthcare?
- d. Who knows your child has a rheumatic disease? (friends, relatives, school, work, etc...) How do they treat you?
- e. Do you know any other parents with a rheumatic disease?
- f. Have you joined a support group? Why/why not? (face to face, online)
- g. What sorts of initiatives, support, help is needed to improve the experiences of parents and caregivers of young people with rheumatic disease undergoing transition to adult healthcare?
- h. Did you receive much support financially? Have you had any troubles financially with your child's treatment?
- i. Have you ever found your location to be a barrier in accessing your child's care?

5. Closing

- a. Is there anything else you would like add that you think might be useful for us to know?

Supplementary Table

Theme/ Subtheme	Quotations	Participant Characteristics
Avoid repeat of past disruption		
Maintain disease stability	I've spent my life in hospital seeing doctors... I don't want to go through change of medications like in the past. I don't think my disease will [impact my future], but my medication will. That's what I'm worried about. There's always that concern in the back of your head. How is he going to be affected long term? is it going to come back? I'm hoping that they wouldn't change too much...sometimes I think they go in...fiddle with this and fiddle with that. [My daughter's] illness has been stable for so long. Let's not go changing stuff.	PM18 undergoing transition PM16 lost-to follow-up CM50s CF40s
Preserve adjusted personal goals	I was sitting there, and I was crying because [becoming a car mechanic] was something I really wanted to do. It was one of those dreams that was crushed. So, I'm doing my Bachelor of Business now and I want to in the future, open up a bookstore café... The thing now is with injections and the painkillers, I think I'll be okay There were some days where...I got so overwhelmed, stressed, especially when there's an emergency call and I have to see the doctor on my exam day at school. If [my son] doesn't look after himself, how can he do his dream? He has to look after himself first.	PF19 post-transition PF18 undergoing transition CM40s
Protect social inclusion	I think [my friends] see me as someone separate from that [the disease]. When they see me with it, they still see me. [Friends] don't really understand [my condition] to the extent that I would like... having someone your age trying to handle [the disease] with school, they would know what it's like to do that stuff too. If it [the support group] was somebody who I'd be friends with normally, I'd be friends with them anyway... People deal with [the condition] differently, especially a current disease like this. The locality where we are, it's very isolating. A few kids have a disability at school, but not the same as [my son]. I guess he struggles the most because you can't see it.	PM15 pre-transition PF16 during transition PM19 post-transition CF40s
Encounter a daunting adult environment		
Serious and sombre mood	You look at a children's hospital and it looks awesome, I was so scared that [the adult's] would be dark and gloomy. That's a big change, not having my parents with me all the time. But I think the biggest change is getting used to the environment.	PF20 post-transition PM18 undergoing transition
Discredited and isolated identity	I don't want [the medications] but if they're going to help me with the pain, I need them... Why do I have to prove that I'm sick when I've been in here for a couple of weeks? For me it's also about the people in the hospital and how they respect each other. When you have someone who is very uncomfortable and you have to talk to them for the rest of the day, you don't feel that connection. I think [the doctors] could explain things to me more because I don't know the questions to ask, really. Because I'm not educated enough.	PF19 post-transition PM18 undergoing transition CF50s

Fear of a rigid system	It was scary booking appointments. I was afraid of rescheduling... how? What would I say?	PF20 post-transition
	[The GP] was very reluctant to refer on. Then we got referred to an adult rheumatologist here [in this remote area], and they [said] straightaway 'this is out of my ballpark, I deal with adults'.	CF40s
	I had to take a lot of time off and [work] made it very hard for me, even though I had lots of letters from doctors. Then you're too scared to ever take any time off ever again.	CF40s
	I wasn't clear what the NDIS ¹ [National Disability Insurance Scheme] was, [the differences with] the disability payment... and Austudy ² . As a young adult choosing to move, my financial support can only go so far. I didn't know what options there were and how she fitted what criteria.	CF40s
Establish therapeutic alliances with adult rheumatology providers		
Relinquish a trusting relationship	I've had quite singular care by [my paediatrician]. Everything has always been, "I'll check with [my paediatrician]" ...so quite a big reception point. I'd go into surgery with other doctors and he's always stick his head in.	PF19 post-transition
	He goes through those important aspects of my life which makes me feel very comfortable that he understands what I'm going through, and willing to help me... He was like a second father.	PM18 undergoing transition
	We're going through an emotional time because I feel like he's part of my family, like he's an uncle to [my daughter]. He's taken time out that he hasn't been paid for to really take care of the kids.	CF40s
	[The paediatrician's] just like someone who knows you so well... I'm quite a confident person but it's quite a vulnerable side.	PF19 post-transition
Seek person-focused care	You're not dealing with just a doctor, it's a team here. [It's] good but there's a lot more people that have a say in what's going on.	PF19 post-transition
	Sometimes the doctors, just want to get things done and you don't really want to interrupt them. I do know [my daughter's] a bit hesitant and he's always busy when it comes to clinics...She just needs to assert herself and gets what she needs, because she doesn't look sick.	PF16 undergoing transition CF40s
Redefine personal-professional boundaries	It was very nerve wracking because... you don't know how close you are to your doctor that he's willing to let you slide in a few things, like if he needs to fill out this one form	PF20 post-transition
	I'll just email him [paediatrician] and I know he'll answer. I know that most doctors aren't like that.	CF40s
	I know how many patients doctors have. It's unrealistic to think that they'd know all [their patients] personally. I just hope he knows he's dealing with my most valuable possession.	CF40s
Reassurance of alternative	I didn't know everything that my mom knew [and] everything we needed to know. It was scarier than pressure.	PF19 post-transition

¹ NDIS is a national agency that assists people with intellectual, physical and psychosocial disability access mainstream, community and informal support and services to improve skills and independence, funded by the Australian and state and territory governments.

² Austudy Payment is a Commonwealth national government funded payment providing income support to students if aged over 25, studying full-time and under the income and asset limits.

medical supports	[The adult rheumatologists] show[ing] they support and still have connections with their paediatric doctor would help. To know that if you feel uncomfortable, you're not trapped here and still have contact with your paediatric doctor.	PF20 post-transition
Natural transfer of trust to adult doctor	I didn't know much about hospitals [so] I didn't really want to have the say. [My paediatrician would] put me in good hands, with someone that he'd trust and he knows I'd like. I just assumed it [my history] would all be passed on, it would all be understood. I'm pretty confident that [the paediatric rheumatologist] will refer [my daughter] to someone he obviously trusts, because he's shown nothing but care and compassion towards her. I expect him to pass her onto someone as good.	PF20 post-transition PF18 undergoing transition CF40s
Negotiate patient autonomy		
Confidence in formerly gained independence	The doctors aren't going to chase you up, just like going from school to university. That's why it was so easy for me. I did the transition two years ago. Every time we saw him, he'd come back to the [transition] topic so it wasn't a one-time thing. He'd always talk about transition, not just "today we talk, now we transition". [My daughter's] a very mature person to begin with. She pushes advice away quickly. I notice that if I try and advise her too much, she'll just get distant, so I don't do that.	PM19 post-transition PF20 post-transition CF40s
Alleviate burden on patient	I am still believing [my son] will be able to [look after] himself. But as a parent we can't just walk away, you know?... That's why I still monitor him, encourage and support him... That doesn't mean I'm not going to look after him at all You know how you feel and the other person doesn't, but as a parent I can't drop the ball... I feel so sorry for him, and I wish the pain was mine instead of his. I have struggled quite a lot asking for people to do stuff for me, that's always hard for me.	CM50s CF40s P16 undergoing transition
Mediate parental anxiety	The whole thing [condition] was more stressful for my parents that it was for me the entire time... I feel like he's super obsessed with doing stuff because he just wants me to not be sick. [My mother] looks strong but she's soft. That's why I try to stay as healthy as possible because if anything bad happens to me, she'd over-react and get really sad. My child's not going to turn out 100% and they're going to have all this weight on their shoulders for the rest of their lives, if not a shortened lifespan.	PM19 post-transition PF20 post-transition CF40s
Abbreviations: P, patient; C, parental caregiver; M, male; F, female.		