

Patients' attitudes and experiences of transition from paediatric to adult healthcare in rheumatology: a qualitative systematic review

Authors

Ayano Kelly^{1,2,3}, Fiona Niddrie⁴, David J Tunnicliffe^{3,5}, Andrea Matus Gonzalez³, Camilla Hanson^{3,5},
Ivy Jiang^{3,6}, Gabor Major^{4,7}, Davinder Singh-Grewal^{4,8,9,10,11}, Kathleen Tymms^{1,2,12}, Allison Tong^{3,5}

Authors affiliations

1. College of Health and Medicine, Australian National University, Canberra, ACT, Australia
2. Department of Rheumatology, The Canberra Hospital, Canberra, ACT, Australia
3. Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW, Australia
4. Department of Rheumatology, Bone and Joint Centre, Royal Newcastle Centre/John Hunter Hospital, Newcastle, NSW, Australia
5. Sydney School of Public Health, The University of Sydney, Sydney, NSW, Australia
6. School of Medicine, University of New South Wales, Randwick, NSW, Australia
7. School of Medicine and Public Health, University of Newcastle, Newcastle, NSW, Australia
8. Department of Rheumatology, The Children's Hospital at Westmead, Westmead, NSW, Australia
9. Discipline of Paediatrics and Child Health, The University of Sydney, Sydney, NSW, Australia
10. School of Maternal and Child Health, University of New South Wales, Randwick, NSW, Australia
11. Department of Rheumatology, Liverpool Hospital, Liverpool, NSW, Australia
12. Canberra Rheumatology, Canberra, ACT, Australia

Abstract

Objectives: We aimed to describe patients' attitudes and experiences of transition from paediatric to adult healthcare in rheumatology to inform patient-centred transitional care programs.

Methods: We searched MEDLINE, Embase, PsycINFO, CINAHL to August 2019 and used thematic synthesis to analyse the findings.

Results: From 26 studies involving 451 people with juvenile-onset rheumatic conditions we identified six themes: a sense of belonging (comfort in familiarity, connectedness in shared experiences, reassurance in being with others of a similar age, desire for normality and acceptance); preparedness for sudden changes (confidence through guided introductions to the adult environment, rapport from continuity of care, security in a reliable point of contact, minimising lifestyle disruptions); abandonment and fear of the unknown (abrupt and forced independence, ill-equipped to hand over medical information, shocked by meeting adults with visible damage and disability, vulnerability in the loss of privacy); anonymous and dismissed in adult care (deprived of human focus, sterile and uninviting environment, disregard of debilitating pain and fatigue); quest for autonomy (controlled and patronised in the paediatric environment, liberated from the authority of others, freedom to communicate openly); and tensions in parental involvement (overshadowed by parental presence, guilt of excluding parents, reluctant withdrawal of parental support).

Conclusion: Young people feel dismissed, abandoned, ill-prepared and out of control during transition. However, successful transition can be supported by preparing for changes, creating a sense of belonging and negotiating parental involvement and autonomy. Incorporating patient-identified priorities into transitional services may improve satisfaction and outcomes in young people with juvenile-onset rheumatic conditions.

Keywords

Transition to Adult Care

Transitional Care

Rheumatology

Qualitative research

Systematic review

Key messages

- Young people transitioning in rheumatology feel abandoned, dismissed and afraid amongst adults with visible disabilities.
- Gradual preparation for autonomy, psychosocial support and a sense of belonging can nurture successful transition.
- Qualitative evidence synthesis could further inform the provision of patient-centred transition services in rheumatology.

Introduction

Transition from paediatric to adult care is a complex process that presents multiple challenges for young people with juvenile-onset rheumatic diseases. These conditions often persist into adulthood, and include ongoing disease activity, comorbidities, burden of treatment and impaired psychosocial functioning (1-5). The transition period coincides with a vulnerable time in young peoples' lives when major biopsychosocial changes are occurring (6). Accordingly, transition is associated with discontinuity of care, medication non-adherence, increased hospital admissions, anxiety, depression and disease activity (5, 7-9).

Transition is defined as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems' (10). 'Transfer' is a single event, whereas transition is a process that continues even after transfer into adult care. The need for comprehensive transitional care support is recognised by national and international societies (11-14). However, the provision of transitional care in rheumatology remains suboptimal (15, 16) with limited evidence on the perspectives of young people regarding transition (17). In rheumatology, approximately half of patients are lost to follow up after transfer (7, 8, 18). Surveys amongst paediatric and adult rheumatology health practitioners identify issues in providing adequate transition support including low provider familiarity with transition resources and recommendations, inadequate training and limited clinic time (16, 19).

A synthesis of primary qualitative studies can offer broader understanding of young people's perspectives on transition across different contexts. The aim of this study was to describe patients' attitudes and experiences of transition from paediatric to adult care in rheumatology to inform patient-centred transition services.

Methods

We used the Enhancing Transparency of Reporting the Synthesis of Qualitative research (ENTREQ) framework for this study (20).

Selection criteria

Qualitative studies that reported the attitudes and experiences of patients (aged ≥ 10 years) with juvenile-onset rheumatic conditions (e.g. arthritis, connective tissue disease, vasculitis) of transition from paediatric to adult care were eligible. We excluded abstracts, non-primary research (e.g. reviews) and non-English language publications to avoid misinterpretation of linguistic nuances.

Data sources and searches

We searched MEDLINE, Embase, PsycINFO and CINAHL from database inception to 30th August 2019. The search strategy is provided (Table S1). We also searched Google Scholar and dissertation databases (Dart-Europe E-Theses Portal and ProQuest). AK and FN screened all titles and abstracts and reviewed potentially relevant full text articles.

Comprehensiveness of reporting

We evaluated the comprehensiveness of reporting using a modified version of the consolidated criteria for reporting qualitative health research framework (COREQ) (21). The criteria include items regarding researcher characteristics, participant selection, data collection, analysis and reporting. Each study was independently assessed by two reviewers (AK, FN, DT or CH). Discrepancies were resolved by discussion or a third reviewer if required (AT).

Synthesis of findings

We used thematic synthesis for data analysis (22). AK inductively identified concepts and discussed the preliminary coding framework with co-authors (AT/FN/DT/KT/GM). We imported all participant quotations and text from the results and discussion into HyperResearch (ResearchWare, INC 2015 version 4.0.1). AK performed line-by-line coding into themes and subthemes, refining and adding new concepts as they arose. AK/DT/CH/AT developed a thematic schema illustrating the conceptual links amongst themes.

Results

Literature search and study descriptions

From 2302 studies, we included 26 studies with 451 participants from 11 countries (Figure 1). The majority were female (n=315, 70%) and had juvenile idiopathic arthritis (JIA, n=302, 67%). The other conditions included were systemic lupus erythematosus (SLE), dermatomyositis, mixed connective tissue disease and scleroderma. Eight (31%) studies included adolescents (aged 10-18 years), four (15%) included young adults (aged 19-25 years), ten (38%) had both, and four (15%) did not specify participant age. Table 1 and Table S2 summarise the characteristics of included studies.

Comprehensiveness of reporting

Studies reported between 6 to 22 of the 26 items in the modified COREQ framework (Table 2). Data saturation was reported in 11 (42%) studies, investigator triangulation in 23 (88%) studies, and member

checking in 4 (15%) studies. Twelve studies (46%) provided broad and deep insights into patient perspectives of transitional care.

Synthesis

We identified six themes: a sense of belonging, preparedness for sudden changes, abandonment and fear of the unknown, anonymous and dismissed in adult care, quest for autonomy and tensions in parental involvement. The following section contains descriptions of each subtheme. Illustrative quotations (Table 3) and a thematic schema (Figure 2) are provided.

A sense of belonging

“He (paediatric specialist) was like another dad to me... And I knew that he wouldn’t do anything for me that he wouldn’t do for his own kid.” (33-year-old female with SLE) (33)

Comfort in familiarity: Some young people considered their paediatric rheumatologist to be as close as family, someone who knew their “whole life” history (31). They described paediatric wards as a “second home” (26) where they met friends and enjoyed social activities. They were upset about having to leave their trusted, supportive paediatric rheumatologist who respected their opinions through a well-established relationship. They felt reassured if their paediatrician was positive and confident that the adult service would provide high quality care.

Connectedness in shared experiences: Some young people felt like “the only person on earth” (29) with their condition. Adolescents craved connection, understanding and support and looked forward to meeting people with similar experiences at transition clinics or support groups organised by their healthcare providers. Self-management programs that included videos of adolescents with JIA from

different countries, or programs that included online discussion forums helped reduce isolation. Young people felt reassured by peer mentors (i.e. older patients) who gave them hope of being successful with further education and employment.

Reassurance in being with others of a similar age: Some older patients felt uncomfortable in a paediatric setting amongst “teddies and rattles and dolls” (27), and unable to be “grown up” in an environment designed for “babies and kids” (27, 37). However, they also felt misplaced in adult care amongst older adults and hoped to see young people in adolescent-focused clinics and wards.

Desire for normality and acceptance: Some people avoided taking medications in front of friends, worried about disclosing their illness, felt disappointed about missing out on social activities, and adolescents with SLE experienced being bullied because of the physical impacts of their condition and prednisone use. They lacked confidence in undertaking further education or seeking employment because of physical limitations and the experience of being discouraged by teachers, employers and careers advisers who they felt underestimated their potential. They wanted transition clinics to provide careers advice and advocacy at work or school. Adolescents wanted to know how to discuss their illness with friends and teachers, and young adults with their partners and employers. To protect their sense of normality, some avoided illness-related websites and support groups that had been suggested in transition programs. Some older patients avoided attending rheumatology clinics or taking medications when they felt well to forget about their illness.

Preparedness for sudden changes

“..when you’re jumping from pillar to post, like I was seen by six doctors in one year, then I just didn’t want to talk to them, but if you stay at the same doctor you tend to get a bit closer.” (Adolescent with JIA) (27)

Confidence through guided introductions to the adult environment: Young people appreciated being introduced to the adult healthcare team, clinic and ward prior to transfer through an information night, introductory folder/poster or an adult clinic visit with a nurse. They wanted to know the duration and frequency of consultations, medication and joint injection procedures including the use of sedation, changes in health insurance (some people in the United States lost health insurance coverage in adult care), service availability and access (e.g. hydrotherapy).

Rapport from continuity of care: Young people wanted to see the same adult rheumatologist and nurses to build a relationship with them. Having the flexibility to book extra consultations between appointments in adult care helped maintain continuity. During transition, young people wanted access to their paediatric rheumatologist for reassurance. They valued joint clinics with the paediatric and adult rheumatologist.

Security in a reliable point of contact: Some appreciated having a friendly transition co-ordinator, described as a “personal advisor” (47) who provided advice about alcohol, contraception, sports, self-image and medications. They preferred face-to-face contact which was more interactive and personal than written or online materials. The co-ordinator motivated confidence in self-management, helped build an immediate connection with the adult team, and reduced confusion about who to contact when in crisis.

Minimising lifestyle disruptions: Having to contend with an uncertain prognosis (e.g. disease flares, complications) and treatment burdens, adolescents’ (particularly those with SLE) wanted transition to be minimally intrusive and fit their preferences and lifestyle. They wanted flexible appointment times to reduce interruptions to school and work, and to attend family vacations and school events. They preferred receiving appointment reminders through text messaging, rather than calls or emails. Online

resources for self-management or to store and share health information with healthcare providers needed to be easy, fun and visually appealing.

Abandonment and fear of the unknown

“When I turned 18, I received a letter in the mailbox. It informed me that I was to report to a completely different hospital for my next check-up. And that was it... not even a single ‘good-bye’ from the doctor I had had for 10 years” (26-year-old female with JIA) (26)

Abrupt and forced independence: A sudden and unprepared transfer caused young people to feel abandoned, vulnerable, lost and alone in their new environment. They wished to be informed earlier about when transfer would occur, how long it would take, and to have a say in the timing. This provided a sense of control and ensured that transfer occurred when they were emotionally and physically stable and confident in their level of independence.

Ill-equipped to hand over medical information: Young people felt unable to handover medical information to new doctors, nurses and allied health professionals. Some relied on their parents to upkeep their health information and described themselves as being too “lazy” (42) to record and relay their medical history. Patients suggested having a written clinical summary, joint paediatric/adult clinics or providing them a copy of clinical notes. For some, poor coordination of information led to delays in transfer, cancelled appointments and discontinuation of care.

Shocked by meeting adults with visible damage and disability: People with JIA wanted to be warned about seeing older adults who had visible disabilities in adult outpatient waiting rooms. They were afraid that this was their inevitable fate. People with SLE were unsettled in sleeping alongside older

patients. Although at times, sharing an inpatient room with older adults enabled supportive relationships to form.

Vulnerability in the loss of privacy: Young people were afraid to communicate online with strangers or with healthcare providers through social media as they valued privacy. During transition, they preferred meeting peers face-to-face for support groups and to use secure, credible websites affiliated with medical institutions for online transition programs that involved communicating with their healthcare team.

Anonymous and dismissed in adult care

“Everybody was very friendly when I was a child... and suddenly I was treated as an adult... it felt a bit cold and rigid.” (Adolescent with JIA) (50)

Deprived of human focus: Young people felt like “objects on a conveyer belt” (26) in an adult clinic that was “business-like” (38) and rushed. They wanted to be supported in their daily lives, aspirations, and discuss the psychological, vocational, educational and social impacts of their disease. Although some enjoyed the efficiency of adult care, others felt the sole focus was on their joints and medications and perceived lower levels of empathy, expertise and resources.

Sterile and uninviting environment: The unwelcoming and impersonal atmosphere in the adult outpatient clinic contrasted the warm and friendly paediatric clinic. Adult services were difficult and cumbersome to navigate as they were spread over different locations. Unlike the paediatric inpatient ward which had social and leisure activities, “nothing happened” on the adult ward and young people felt lonely and anonymous (26).

Disregard of debilitating pain and fatigue: Young people experienced problems with not being taken seriously when they felt fatigue or pain by adult doctors. This reduced their self-confidence and made them question the validity of their own symptoms.

Quest for autonomy

“I enjoy it [the adult service] because now I can say what I want to say and what I think is important... It felt like you were grown up.” (18-year-old female with JIA) (37)

Controlled and patronised in the paediatric environment: Some young people felt that health professionals who knew them as children were unable to treat them as adults. People with SLE wanted a full explanation of their disease prognosis and treatment options to be involved in decision-making.

Liberated from the authority of others: Young people felt surprised and empowered by the freedom, responsibility and autonomy in adult care. They enjoyed being spoken to directly, making therapeutic decisions, and attending appointments alone or with their partners. Although some adolescents felt afraid and reluctant to move to adult care, after transition, some young adults felt the timing was appropriate and “no big deal” (38).

Freedom to communicate openly: Young people would seek opportunities to discuss sensitive issues with their providers without parental presence. This could include discussing medication non-adherence, relationships, alcohol, drugs and university life. They suggested having drop in clinics to be able to do this and appreciated doctors who asked parents to sit out of the consultation.

Tensions in parental involvement

“If [my parents] are there, [the consultant] just ignores me, talks to them and I just come out and don’t feel anything’s been achieved” (Adolescent with JIA) (27)

Overshadowed by parental presence: Patients, especially young adults, felt frustrated and undermined if the doctor relayed information about medications and tests only to their parents. Some chose to attend the clinic alone to force their doctor to speak with them directly. Young adults emphasised the importance of adolescents practicing attending clinics independently and learning about their treatments.

Guilt of excluding parents: Young people were unsure of how to tell their parents they no longer needed them in the clinic. Some felt obliged to invite their parents to their appointment if they had driven them. They were mindful of their parents’ struggles with relinquishing control and worried about hurting their feelings and appearing ungrateful of their support.

Reluctant withdrawal of parental support: Some young people were shocked and uncomfortable if parents were not allowed to attend appointments with them in the adult clinic, especially on their first visit. Parental presence helped them gain confidence in communication and build trust with their new provider. Parental support was particularly needed during medication changes, joint injections, or for people with SLE - when they felt “really, really sick” (32). Some patients completely depended on their parents for managing medications and health information.

Discussion

Some adolescents felt abandoned, disconnected and vulnerable in adult care. They were shocked to meet adults with visible damage and disabilities in waiting rooms. Some felt their debilitating symptoms were dismissed by their new clinician. A gradual introduction to the new system, including

thorough explanation of differences such as joint injection procedures, continuity of care and having access to a transition co-ordinator, helped them prepare for the major changes and skills needed for independence. The transition service needed be minimally disruptive, age-appropriate and address issues young people faced with their daily lives as they already had to contend with uncertain prognosis and treatment burdens and needed a sense of connection and belonging within and outside of their healthcare setting. Young people felt conflicted between wanting autonomy and negotiating changing relationships with their parents and clinicians.

We found some differences by country, rheumatological condition and age of participants. People in the US were concerned about changes to insurance, which impacted access to emergency care and medications in the adult setting. People with SLE indicated that the unpredictable disease course, burden of multiple medications and bullying at school disrupted daily living. They emphasised the need for transition services to provide better education about disease prognosis, involvement in treatment decision-making, advocacy and education at school, and parental presence in clinics when they were very unwell. People with JIA wanted to be warned about adults with visible damage and disability in waiting rooms. Adolescents expressed a greater need to meet people with similar experiences than young adults who had established peer support groups (25).

Young people with other chronic conditions, including diabetes, chronic kidney disease, HIV, congenital heart disease, sickle cell disease and cystic fibrosis have voiced similar perspectives and experiences of transition (51-53). The familiar and friendly paediatric services are in contrast to the impersonal and disease-focused adult service. They valued continuity of care with the adult physician, continued access to the paediatrician, peer support, transfer of health information and being given control of the timing of transfer. An observational study in young people with other chronic conditions found that their satisfaction with parental involvement, promotion of health self-efficacy, and meeting the adult team before transfer were transitional care features associated with improved outcomes (54).

Our findings also reflect and explain the role and impact of these factors in rheumatology. Concepts unique to rheumatology in this review included the need for information and parental support in adult care when joint injections are required, feeling confronted in seeing adults with frightening effects of their arthritis in waiting rooms, and feeling that symptoms of pain or fatigue were dismissed in adult care.

We used a sensitive search strategy, software to facilitate a systematic and auditable approach to analysis, and investigator triangulation to ensure that the findings reflect the full range and depth of data from the primary studies. However, there are some potential limitations. The majority of studies were from high-income countries with English-speaking participants. Most participants had either JIA or SLE. The transferability of the findings to other settings and populations that were not included is therefore uncertain.

Transition from paediatric to adult health services occurs in parallel to major physiological and psychosocial developmental changes. Accordingly, transition services need to be developmentally appropriate and support the unique needs of a population undergoing pubertal, social, vocational, emotional and cognitive transitions. To address this, guidelines have recommended optimal components of transitional care programmes (11-13). The European League Against Rheumatism (EULAR)/Paediatric Rheumatology European Society (PReS) developed 12 standards and recommendations for transitional care of young people with juvenile-onset rheumatic diseases. This includes high-quality, holistic, multidisciplinary care starting in early adolescence, transition co-ordinator, protocols and policies, efficient and direct communication, transfer documentation, an open electronic platform with transition resources, training for paediatric and adult healthcare professionals, secure funding and the need for further research to inform best practice (12). The World Health Organisation and GRADE (Grading of Recommendations, Assessment, Development and Evaluations – a framework for grading the quality of evidence for use in clinical practice guidelines) recommend

incorporating qualitative evidence synthesis to inform the values and preferences, acceptability, feasibility and equity of guideline recommendations (55-57). Incorporating findings from this qualitative systematic review could enhance future transition guidelines in rheumatology (Figure 3).

Some strategies highlighted in this review that are not addressed in current guidelines include: 1) Introduce – The paediatric rheumatologist introducing the adult healthcare team with confidence, 2) Inform - Providing comprehensive information on the differences in the adult setting (e.g. encountering adult patients with damage and disability in waiting rooms, joint injections procedures and changes in service availability such as hydrotherapy), 3) Empower - Providing guidance, training and opportunities to manage parental relationships and the ability to attend adult clinics independently, 4) Transfer – Allowing the timing of transfer to be flexible, patient-controlled and avoiding times of disease flares or medication changes and 5) Support – Advocacy at school and work to reduce bullying and discrimination.

Medication adherence is particularly challenging during transition. A survey of parents of older teenagers with juvenile myositis showed that only 51% were deemed responsible enough to take medications without being reminded (58). A cross-sectional survey of people aged 13-20 years with various rheumatic conditions showed only 54% reported full adherence to medications in the previous week (59). Our review showed that some young people continue to rely on their parents' reminders to take medications in adult care and may be more comfortable discussing non-adherence with clinicians without parental presence. They wanted to be more informed and involved in treatment decision-making and be presented with information about medications face-to-face. A brief transition programme for adolescents with JIA showed no effect on medication adherence (47). However, young people develop self-management skills with increasing age (58-60), and many continue to develop these skills after the age of 18 (61). Therefore, young people need to be supported in achieving mastery of self-management including medication management even beyond the age of transfer.

Transition to adult care in rheumatology is challenging for young people who feel suddenly abandoned, ill-prepared and fearful of the differences in adult-based healthcare that can be dismissive and impersonal. Creating an environment that promotes a sense of belonging, provides person-focussed and comprehensive care, and a gradual preparation for independence could enhance the young people's experience of transitional care and lead to better health-related outcomes into adulthood.

Acknowledgements

Funding

AT is supported by a National Health and Medical Research Council Fellowship (ID 1106716). The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Disclosure statement

All authors declare no conflicts of interest.

References

1. Hersh AO, Pang S, Curran ML, Milojevic DS, von Scheven E. The challenges of transferring chronic illness patients to adult care: reflections from pediatric and adult rheumatology at a US academic center. *Pediatr Rheumatol Online J* 2009;7:13.
2. Selvaag AM, Aulie HA, Lilleby V, Flato B. Disease progression into adulthood and predictors of long-term active disease in juvenile idiopathic arthritis. *Ann Rheum Dis* 2016;75:190-5.
3. Wipff J, Sparsa L, Lohse A, Quartier P, Kahan A, Deslandre CJ. Impact of juvenile idiopathic arthritis on quality of life during transition period at the era of biotherapies. *Joint Bone Spine* 2016;83:69-74.
4. Felsenstein S, Reiff AO, Ramanathan A. Transition of Care and Health-Related Outcomes in Pediatric-Onset Systemic Lupus Erythematosus. *Arthritis Care Res* 2015;67:1521-8.
5. Son MB, Sergeyenko Y, Guan H, Costenbader KH. Disease activity and transition outcomes in a childhood-onset systemic lupus erythematosus cohort. *Lupus* 2016;25:1431-9.
6. Christie D, Viner R. Adolescent development. *Bmj* 2005;330:301-4.
7. Hersh A, von Scheven E, Yelin E. Adult outcomes of childhood-onset rheumatic diseases. *Nat Rev Rheumatol* 2011;7:290-5.
8. Hazel E, Zhang X, Duffy CM, Campillo S. High rates of unsuccessful transfer to adult care among young adults with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2010;8:2.
9. Ting TV, Kudalkar D, Nelson S, Cortina S, Pendl J, Budhani S, et al. Usefulness of cellular text messaging for improving adherence among adolescents and young adults with systemic lupus erythematosus. *J Rheumatol* 2012;39:174-9.
10. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1993;14:570-6.

11. White PH, Cooley WC. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics* 2018 published on 22 October 2018. doi:10.1542/peds.2018-2587;142.
12. Foster HE, Minden K, Clemente D, Leon L, McDonagh JE, Kamphuis S, et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Ann Rheum Dis* 2017;76:639-46.
13. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003;33:309-11.
14. Clemente D, Leon L, Foster H, Minden K, Carmona L. Systematic review and critical appraisal of transitional care programmes in rheumatology. *Semin Arthritis Rheum* 2016;46:372-9.
15. Clemente D, Leon L, Foster H, Carmona L, Minden K. Transitional care for rheumatic conditions in Europe: current clinical practice and available resources. *Pediatr Rheumatol Online J* 2017;15:49.
16. Chira P, Ronis T, Ardoin S, White P. Transitioning youth with rheumatic conditions: perspectives of pediatric rheumatology providers in the United States and Canada. *J Rheumatol* 2014;41:768-79.
17. Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child Care Health Dev* 2007;33:368-79.
18. Jensen PT, Karnes J, Jones K, Lehman A, Rennebohm R, Higgins GC, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatr Rheumatol Online J* 2015;13:17.
19. McDonagh JE, Southwood TR, Shaw KL. Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology* 2004;43:737-43.
20. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181.

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-57.
22. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45.
23. Cruikshank M, Foster HE, Stewart J, Davidson JE, Rapley T. Transitional care in clinical networks for young people with juvenile idiopathic arthritis: current situation and challenges. *Clin Rheumatol* 2016;35:893-9.
24. Howland S, Fisher K. Looking through the patient lens - Improving best practice for young people with juvenile idiopathic arthritis transitioning into adult care. *Springerplus* 2015;4:111.
25. Knight A, Vickery M, Fiks AG, Barg FK. The illness experience of youth with lupus/mixed connective tissue disease: a mixed methods analysis of patient and parent perspectives. *Lupus* 2016;25:1028-39.
26. Ostlie IL, Dale O, Moller A. From childhood to adult life with juvenile idiopathic arthritis (JIA): a pilot study. *Disabil Rehabil* 2007;29:445-52.
27. Shaw KL, Southwood TR, McDonagh JE. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology* 2004;43:770-8.
28. Shaw K, Hackett J, Southwood T, McDonagh J. The prevocational and early employment needs of adolescents with juvenile idiopathic arthritis: the adolescent perspective. *Br J Occup Ther* 2006;69:98-105.
29. Stinson JN, Toomey PC, Stevens BJ, Kagan S, Duffy CM, Huber A, et al. Asking the experts: Exploring the self-management needs of adolescents with arthritis. *Arthritis Care Res* 2008;59:65-72.
30. Tong A, Jones J, Speerin R, Filocamo K, Chaitow J, Singh-Grewal D. Consumer perspectives on pediatric rheumatology care and service delivery: a qualitative study. *J Clin Rheumatol* 2013;19:234-40.

31. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev* 2008;34:557-63.
32. Tunnicliffe DJ, Singh-Grewal D, Chaitow J, Mackie F, Manolios N, Lin MW, et al. Lupus Means Sacrifices: Perspectives of Adolescents and Young Adults With Systemic Lupus Erythematosus. *Arthritis Care Res* 2016;68:828-37.
33. Wells C. Wellness in the Midst of Disease: A Narrative Analysis of Growing Up with Rheumatic Conditions [dissertation]. Minneapolis: University of Minnesota; 2015.
34. Cai RA, Chaplin H, Livermore P, Lee M, Sen D, Wedderburn LR, et al. Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR). *Pediatr Rheumatol Online J* 2019;17:23.
35. Hanghoj S, Boisen KA, Schmiegelow K, Holge-Hazelton B. Feasibility of a transition intervention aimed at adolescents with chronic illness. *Int J Adolesc Med Health* 2018;30:1-8.
36. Knudsen LR, de Thurah A, Bjerrum M. Transition from child to adult care in an outpatient clinic for adolescents with juvenile idiopathic arthritis: An inductive qualitative study. *Nurs Open* 2018;5:546-54.
37. Dickinson AR, Blamires J. Moving on: the experience of young people with juvenile idiopathic arthritis transferring from paediatric to adult services. *Neonatal Paediatr Child Health Nurs* 2013;16:2.
38. van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev* 2011;37:821-32.
39. Grande SW, Longacre MR, Palmblad K, Montan MV, Berquist RP, Hager A, et al. Empowering Young People Living With Juvenile Idiopathic Arthritis to Better Communicate With Families and Care Teams: Content Analysis of Semistructured Interviews. *JMIR Mhealth Uhealth* 2019;7:e10401.

40. Harry O, Crosby LE, Smith AW, Favier L, Aljaberi N, Ting TV, et al. Self-management and adherence in childhood-onset systemic lupus erythematosus: what are we missing? *Lupus* 2019;28:642-50.
41. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics* 2005;115:112-20.
42. Applebaum MA, Lawson EF, von Scheven E. Perception of transition readiness and preferences for use of technology in transition programs: teens' ideas for the future. *Int J Adolesc Med Health* 2013;25:119-25.
43. Stinson J, McGrath P, Hodnett E, Feldman B, Duffy C, Huber A, et al. Usability testing of an online self-management program for adolescents with juvenile idiopathic arthritis. *J Med Internet Res* 2010;12:e30.
44. O'Sullivan G, O'Higgins S, Caes L, Saetes S, McGuire BE, Stinson J. Self-management needs of Irish adolescents with Juvenile Idiopathic Arthritis (JIA): How can a Canadian web-based programme meet these needs? *Pediatr Rheumatol Online J* 2018;16:68.
45. Secor-Turner M, Scal P, Garwick A, Horvath K, Wells CK. Living with juvenile arthritis: adolescents' challenges and experiences. *J Pediatr Health Care* 2011;25:302-7.
46. Hilderson D, Eyckmans L, Van der Elst K, Westhovens R, Wouters C, Moons P. Transfer from paediatric rheumatology to the adult rheumatology setting: experiences and expectations of young adults with juvenile idiopathic arthritis. *Clin Rheumatol* 2013;32:575-83.
47. Hilderson D, Moons P, Van der Elst K, Luyckx K, Wouters C, Westhovens R. The clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: results of the DON'T RETARD project. *Rheumatology* 2016;55:133-42.
48. Wells G, Cranney A, Shea B, Tugwell P. Responsiveness of endpoints in osteoporosis clinical trials. *J Rheumatol* 1997;24:1230-3.
49. Dickinson D, Wilkie P, Harris M. Taking medicines: concordance is not compliance. *BMJ* 1999;319:787.

50. Raunsbaek Knudsen L, de Thurah A, Bjerrum M. Transition from child to adult care in an outpatient clinic for adolescents with juvenile idiopathic arthritis: An inductive qualitative study. *Nurs Open* 2018;5:546-54.
51. Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. *J Adolesc Health* 2011;48:429-40.
52. Fegran L, Hall EO, Uhrenfeldt L, Aagaard H, Ludvigsen MS. Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *Int J Nurs Stud* 2014;51:123-35.
53. Tong A, Wong G, Hodson E, Walker RG, Tjaden L, Craig JC. Adolescent views on transition in diabetes and nephrology. *Eur J Pediatr* 2013;172:293-304.
54. Colver A, McConachie H, Le Couteur A, Dovey-Pearce G, Mann KD, McDonagh JE, et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC medicine* 2018;16:111.
55. Downe S, Finlayson KW, Lawrie TA, Lewin SA, Glenton C, Rosenbaum S, et al. Qualitative Evidence Synthesis (QES) for Guidelines: Paper 1 - Using qualitative evidence synthesis to inform guideline scope and develop qualitative findings statements. *Health Res Policy Syst* 2019;17:76.
56. Glenton C, Lewin S, Lawrie TA, Barreix M, Downe S, Finlayson KW, et al. Qualitative Evidence Synthesis (QES) for Guidelines: Paper 3 - Using qualitative evidence syntheses to develop implementation considerations and inform implementation processes. *Health Res Policy Syst* 2019;17:74.
57. Lewin S, Glenton C, Lawrie TA, Downe S, Finlayson KW, Rosenbaum S, et al. Qualitative Evidence Synthesis (QES) for Guidelines: Paper 2 - Using qualitative evidence synthesis findings to inform evidence-to-decision frameworks and recommendations. *Health Res Policy Syst* 2019;17:75.

58. Katz JD, Mamyrova G, Agarwal S, Jones OY, Bollar H, Huber AM, et al. Parents' perception of self-advocacy of children with myositis: an anonymous online survey. *Pediatr Rheumatol Online J* 2011;9:10.
59. Lawson EF, Hersh AO, Applebaum MA, Yelin EH, Okumura MJ, von Scheven E. Self-management skills in adolescents with chronic rheumatic disease: A cross-sectional survey. *Pediatric rheumatology online journal* 2011;9:35.
60. Bingham CA, Scalzi L, Groh B, Boehmer S, Banks S. An assessment of variables affecting transition readiness in pediatric rheumatology patients. *Pediatric rheumatology online journal* 2015;13:42.
61. Stollon N, Zhong Y, Ferris M, Bhansali S, Pitts B, Rak E, et al. Chronological age when healthcare transition skills are mastered in adolescents/young adults with inflammatory bowel disease. *World journal of gastroenterology* 2017;23:3349-55.

Tables/figures

Table 1. Characteristics of included studies

Table 2. Modified consolidated criteria for reporting qualitative health research framework

Table 3. Illustrative quotations

Figure 1. Search results

Figure 2. Thematic schema

Young people could feel abandoned and afraid of the unknown adult health environment and dismissed in care that was impersonal. In contrast, those that were given graded preparation, psycho-social support and an opportunity to feel a sense of belonging had a successful transition experience. Young people must contend with the tensions surrounding parental and paediatric health professional involvement in their care whilst seeking increasing autonomy.

Figure 3. Patient-centred strategies for transitional care in rheumatology informed by qualitative evidence synthesis

Supplementary material

Table S1. Search strategy

Table S2. Characteristics of individual studies