



Miscellaneous

Systematic literature review informing the EULAR points to consider for patient education in physical activity and self-management of pain during transitional care

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ABSTRACT

Objectives: To synthesise existing evidence on transitional care programmes for young people with juvenile-onset rheumatic and musculoskeletal diseases (jRMDs), focusing on their structure and implementation, the qualitative experiences and perceptions of those involved, and the quantitative outcomes associated with these programmes. Together with additional information, these insights have informed the European Alliance of Associations for Rheumatology (EULAR) Points to Consider for patient education in physical activity and self-management of pain in jRMDs during transitional care.

Methods: A systematic literature review was conducted with a broadened scope beyond patient education in physical activity and self-management of pain to provide a comprehensive overview of transitional care in rheumatology, aiming to optimise current strategies, support evidence-based approaches, and identify areas for clinical improvement. The search was conducted in PubMed and the Cochrane Library from inception until November 1, 2023. Descriptive, qualitative, and quantitative studies were included. Two researchers independently conducted the search, screening, data extraction, and quality assessment.

Results: From 31 studies, we identified 18 transitional care programmes with key approaches, including individualised and developmentally appropriate plans that often integrate educational strategies. These programmes, which generally aim to increase readiness to transfer, health-related quality of life, and continuity of care, frequently involved multidisciplinary teams and early intervention strategies. Young people with jRMDs and their families reported satisfaction with these transitional care experiences, particularly valuing early self-management support. While these programmes showed potential in promoting positive health outcomes and clinical practices, quantitative evidence supporting their effectiveness is limited, with few experimental studies confirming consistent benefits.

Conclusions: This systematic review highlights the diverse yet fragmented approaches in transitional care for jRMDs, emphasising the need for stronger quantitative evidence. Thus, it is important to conduct further experimental research to optimise existing programmes or develop new ones, ultimately contributing to a smoother transition to adult care and improved long-term outcomes.

INTRODUCTION

The core aims of transitional care are to assist in continuing to adult treatment and to improve physical, psychological, social, vocational, and illness-related outcomes of young people with juvenile-onset rheumatic and musculoskeletal diseases (jRMDs) [1]. Transitional care relies on 3 principles: (1) preparing young people and families for independent disease management and readiness to transfer from paediatric to adult care; (2) providing information and resources to enhance health- and disease-related knowledge, health literacy (ie, person's ability to find, understand, and use health-related information when making health-related decisions) [2], and self-management skills; and (3) offering individualised support through attentive, developmentally appropriate care according to the individual needs, preferences, and resources of young people with jRMDs [1,3,4]. Importantly, transitional care constitutes an opportunity to build attitudes, skills, and behaviours in childhood, adolescence, and young adulthood that likely provide valuable long-term benefits later in life [5].

The establishment of the Got Transition programme [6] (endorsed by the American College of Rheumatology) and the

launch of the 2017 European Alliance of Associations for Rheumatology /Paediatric Rheumatology European Society (EULAR/PReS) general standards and recommendations in transitional care for young people with jRMDs [1] have been key-works in this field. Based on this foundational framework, new programmes have been developed and implemented, leading to new evidence that requires revision [7–9]. For example, a number of transitional care programmes [7,8] have been designed regarding the Six Core Elements of Health Care Transition designed by the Got Transition Framework [10], incorporating educational interventions that address topics such as understanding the transition policy and creating a plan of care. These programmes guide young people with jRMDs through structured conversations with patients, families, and healthcare providers to foster autonomy and self-management skills and prepare them for the transition adult care [8]. Although some of the existing EULAR recommendations address important aspects of transitional care (eg, patient education [11], physical activity [12], and self-management of pain [13]), they were not specifically designed for young people with jRMDs. This limits their applicability in transitional care, which requires specialised considerations to accommodate the developmental needs of these

WHAT IS ALREADY KNOWN ON THIS TOPIC

- The launch of the 2017 European Alliance of Associations for Rheumatology /Paediatric Rheumatology European Society (EULAR/PReS) European Alliance of Associations for Rheumatology (EULAR)/Paediatric Rheumatology European Society (PReS) standards and recommendations was a major step towards providing general guidance in transitional care for young people with juvenile-onset rheumatic and musculoskeletal diseases (jRMDs).
- The effectiveness and experiences of available transitional care programmes require revision to increase evidence-based knowledge and improve practice, outcomes, and implementation.
- There is a lack of consensus on best practices for transitional care programmes in rheumatology.

WHAT THIS STUDY ADDS

- While young people with jRMDs and their families generally express satisfaction with transitional care practices, they highlight the need for more personalised approaches that integrate their unique needs, preferences, and resources.
- The evidence base for transitional care in rheumatology from experimental quantitative studies remains limited.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- This review informs the EULAR Points to Consider for the patient education on physical activity and self-management of pain in jRMDs during transitional care.
- This task force encourages appropriate randomised controlled trials to evaluate existing patient education programmes focused on physical activity and self-management of pain during transitional care. If necessary, these programmes should be optimised or new ones developed.
- This task force highlights the importance of improving accessibility to transitional care by addressing barriers, especially for underrepresented groups with limited healthcare access, to ensure inclusivity and equal support in managing jRMDs.

young individuals (eg, avoid parental overprotection) [14–16]. The present systematic literature review aims to synthesise existing evidence on transitional care programmes for young people with jRMDs, focusing on their structure and implementation, the qualitative experiences and perceptions of those involved, and the quantitative outcomes associated with these programmes. These insights have informed the EULAR Points to Consider (PtC) for patient education in physical activity and self-management of pain in jRMDs during transitional care [17].

METHODS

Eligibility criteria and literature search

The steering group of the taskforce designed, registered, and conducted a systematic review according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses [18] and the Cochrane Collaboration guidelines [19] (PROSPERO No: CRD42023481386). Three questions were formulated to synthesise evidence on practices, experiences, and outcomes in transitional care programmes for young people with jRMDs as well as their relatives, rheumatologists, and Health Professionals in Rheumatology (HPRs). These questions focus on understanding transitional care programmes in rheumatology for young

people with jRMDs, their families, and healthcare providers. The first question, ‘How are transitional care programmes structured and implemented in rheumatology?’, explores how these programmes are implemented by rheumatologists and HPRs, as well as the content provided. The second question, ‘What are the experiences and perceptions of young people with jRMDs, families, and healthcare providers involved in transitional care programmes?’, aims to capture the experiences, perceptions, and barriers faced by these groups. The third question, ‘What are the benefits of transitional care interventions for young people with jRMDs and their families?’, examines different outcomes, such as continuity of care, self-efficacy, disease-specific knowledge, and readiness to transfer to adult care.

The eligibility criteria of studies were determined according to the PICOS (Population, Intervention, Comparators, Outcomes, Study design) approach (Table 1).

Preparatory material for the initial planning meeting of the task force was developed based on a systematic literature review of PubMed and the Cochrane Library performed on October 1, 2021. To include an update on the results, we conducted this systematic literature review again on November 1, 2023. The search strategy consisted of a combination of relevant keyword variations in free terms, presented in Supplemental Table S1. Using a snowball technique, we included additional studies by performing backward (by checking reference lists) and forward (by checking citations) searches of the works included in the present review.

Study selection, data extraction, and quality assessment

The search was conducted by 2 researchers independently (JCI and RPM). Screening, data extraction, risk of bias and quality of evidence assessment were conducted by 2 researchers independently (JCI and RPM). Discrepancies were discussed for consensus or solved with a third researcher (FEL) if necessary. Eligibility criteria were applied to titles and abstracts (first-stage screening) and full texts of the remaining studies (second-stage screening). Risk of bias was assessed by the Clinical Appraisal Skills Programme for qualitative research [20]. For quantitative research, we used Cochrane risk of bias tool for randomised controlled trials (RCTs) [21], the Quality In Prognosis Studies tool for observational studies [22], and the Appraisal tool for cross-sectional studies [23].

RESULTS

The results of the search for this systematic review are shown in Figure 1. From 1600 studies, 98 were selected for full-text review, and 31 were included in this systematic review. For question 1, we identified 18 transitional care programmes (17 structured plans for young people with jRMDs and 1 for their parents) (Table 2) [24–49]. For questions 2 and 3, we found 25 studies. Of them, 2 were mixed-methods designs (ie, cross-sectional plus qualitative study) [7,49], 6 were qualitative [28,37,41,43,44,48], and 17 were quantitative. Specifically, among the quantitative studies, there were 5 intervention studies (1 RCT [42], 1 clinical trial protocol [50], and 3 quasi-experimental studies [16,38,40]), 5 cohort studies [8,30,32,33,47], 1 retrospective study [31], and 6 cross-sectional studies [24,29,39,45,46,51] (Table 3). The methodological quality is presented in Supplemental Tables S2–S5.

Table 1
Eligibility criteria of studies were determined according to PICOS (Population, Intervention, Comparators, Outcomes, Study design)

Clinical question	P	I	C	O	S
How are transitional care programmes in rheumatology structured and implemented?	Young people with jRMDs, their family and healthcare providers involved	Structured transitional care programmes	N/A	N/A	- Qualitative studies - Quantitative studies - Clinical trials protocol
What are the experiences and perceptions of young people with jRMDs, families, and health professionals involved in transitional care programmes?	Young people with jRMDs, their family or healthcare providers involved	Structured transitional care programmes	N/A	- Experiences - Perceptions - Barriers/facilitators	- Qualitative studies - Quantitative studies - Clinical trials protocol
What are the benefits provided by transitional care interventions in rheumatology for young people with jRMDs and their families?	Young people with jRMDs, their family and/or healthcare providers involved	Structured transitional care programmes	- Follow-up changes - Control group, - Other strategy - No comparator	- Continuity of treatment - Fatigue - Functional status - Knowledge - HRQoL - Pain management - Physical activity - Psychosocial health - Readiness to transfer - Self-management skills - Sexual health, - Vocation	- Qualitative studies - Quantitative studies - Clinical trials protocol

HRQoL, health-related quality of life; jRMD, juvenile-onset rheumatic and musculoskeletal disease; N/A, not applicable.

Question 1. How are transitional care programmes in rheumatology structured and implemented?

Common elements across the majority of transitional care programmes included: (1) the formulation of a specific written individual transition plan; (2) adopting a patient-centred, shared decision-making approach; (3) providing developmentally appropriate care; (4) initiating the process early; (5) involving a multidisciplinary team; and (6) offering educational resources. Multidisciplinary teams usually involved paediatric and adult rheumatologists and nurses [24,25,34,39,42–44,51,52] with most programmes including HPRs such as physiotherapists [24,25,34,35,39,44,51], social workers [24,25,35,38,52], or occupational therapists [24,25,34]. Seven programmes included a coordinator [25,30,35,36,38,44,52]. Two studies included psychologists [35,52], and another study involved sexual/vocational counsellors [25].

Some programmes were structured in developmentally appropriate phases, with specific shared goals and contents adapted to young people’s readiness and age [7,44,53]. Tools and formats of delivery vary in transitional care, and their effectiveness remains unclear. In addition to face-to-face consultations, most of the programmes also included telehealth (websites [7,30,35,36,41,43,53], web-based educational programmes [40–42], videos [36,42,43], and e-consulting [43]) and paper-based information (flyers [30,35,36], handbook [30,38], toolkit [7], or filofax [30]) with telephone [7,30,35,36,38] and e-mail [7,35] follow-up. One programme organised informal activities with peers, including meetings, workshops, and lectures [36].

Common self-management learning contents provided were disease management [7,25,35,36,38,42,44,51,52], education [7,24,25,30,34,35,38,42,44,50], social relationships [25,30,34,35,36], sexual health [24,25,30,34,38,42,52], disease-specific knowledge [25,30,35,36,42,52], physical activity

(including sports and exercise) [30,36,38,42], risk-taking behaviours [24,25,34,38,52], independent living and self-advocacy [24,25,30,38,52], diet [30,38,42,52], and psychosocial health [30,38,42,52], fatigue [36,42], financial counselling [24,25], communication skills [25,42], home/parental issues [30,34], self-confidence/body image [30,36], dental health [30], cybersafety [30], suicide [34,52], spirituality [34], cooking [36], disabilities [36], and pain management [42]. Contents for rheumatologists and HPRs were included in only 1 programme [30], addressing adolescent development, communication, and adolescent-friendly resources. Last, despite the essential role played by family and peers in transitional care in facilitating the transfer of responsibilities to young people [1,3], not all the programmes included dedicated resources for relatives [25,30,34,44] and peer support [7,24,30,36,43].

Question 2. What are the experiences and perceptions of young people with jRMDs, families, and healthcare providers involved in transitional care programmes?

In general, young people with jRMDs and their families were satisfied with the transitional care programmes [33,38–40,45]. They appreciated receiving early psychosocial, nonpharmacological interventions with the transition coordination to express their intimate concerns (ie, sports, school, friends, medication, body image, alcohol use, and contraception) [16]. Importantly, young people appealed for better understanding and integration of their individual needs, preferences, and resources during transitional care [28,37,43]. Parental education was valued by young people with jRMDs to gradually take over responsibility for their care [48]. Likewise, parents stated they would not give responsibility to their children without the programme assistance and admitted their overprotectiveness was due to lack of knowledge [16]. Both youth and parents recognised the role of

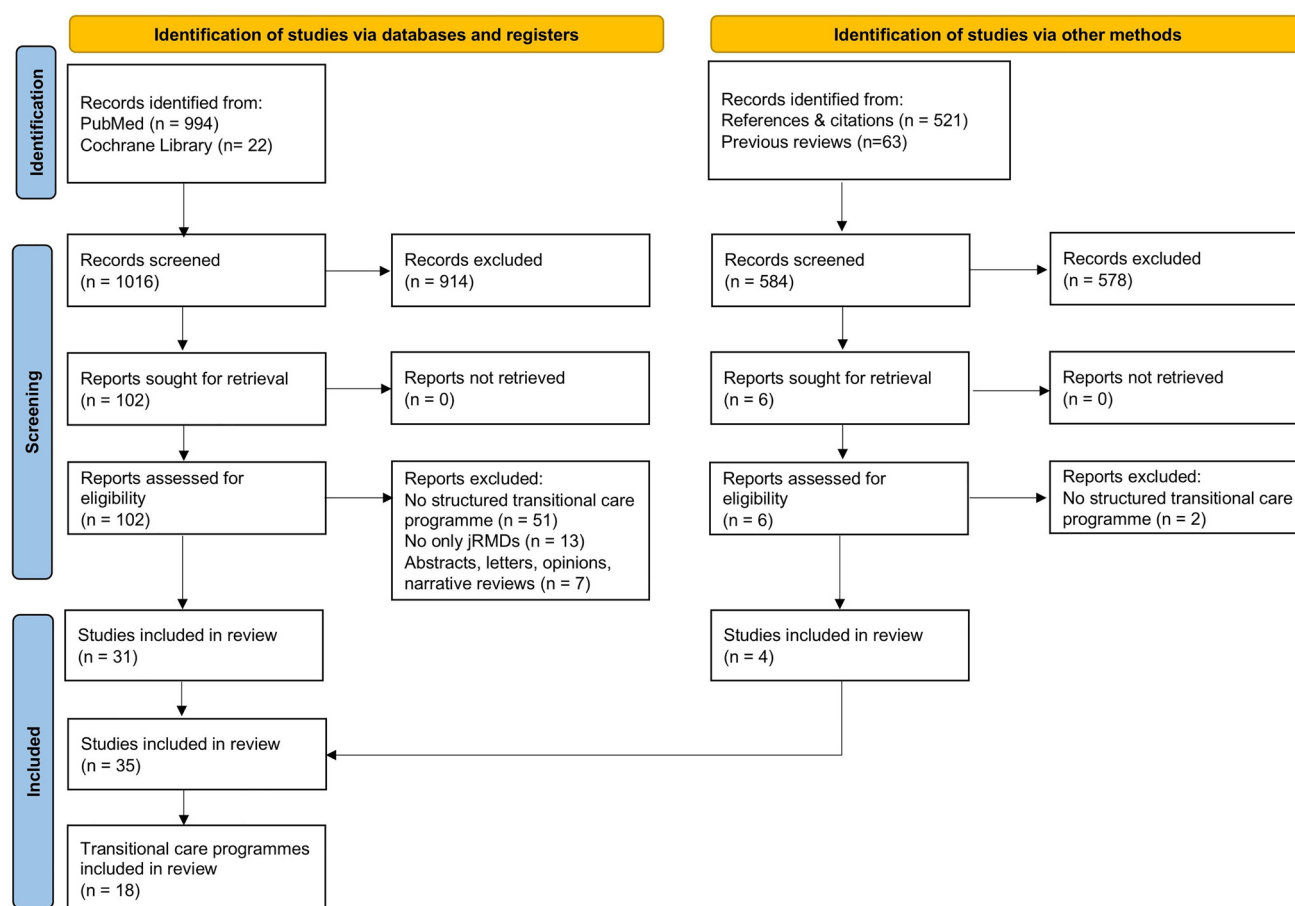


Figure 1. Flow chart of the study selection and inclusion process. jRMD, juvenile-onset rheumatic and musculoskeletal disease.

peer support to improve confrontation, identification, and fellowship [16].

Preliminary surveys and focused group discussions were used to guide the development of the transitional care programmes according to the experiences and expectations of young people with jRMDs [29,37,44,48]. This information served to identify missing topics during consultations [44] and the importance of gradual education, parental involvement, and adapted healthcare settings to match their expectations [37]. There is evidence reporting positive feedback on the access to the transition plan via website, the timeline learning steps, and the decision-making worksheet and emphasised the benefits of addressing mental health. In addition, young people valued self-management learning experiences outside the clinic (camps or conferences) and raised concerns on how to integrate the skills developed through the programmes in their daily routine [48].

The implementation of transitional care may improve the clinical practices and transfer administrative process through better documentation of transitional issues and higher multi-disciplinary involvement [31]. However, reports on diet and home exercise remained poorly documented even after starting the programme [31]. Reported barriers to implementation included inadequate resources, coordination, and lack of specific training for rheumatologists and HPRs [29]. This is in line with the experience of rheumatologists and HPRs in having a lack of skills and self-confidence when dealing with young people with jRMDs [30]. The adoption of a structured transitional programme appeared to be manageable and was generally viewed positively, as it could contribute to

improved organisation, efficiency, follow-up care, structured communication, and availability of helpful resources [7]. Because each clinical setting may have unique needs and barriers to start implementing a transitional care practice, programmes should be flexible (eg, creating generic, but customisable, resources) and start the process with small changes [4,7].

Question 3. What are the benefits provided by transitional care interventions in rheumatology for young people with jRMDs and their families?

Transitional care programmes may have benefits in enhancing continuity of care [8,24,38,39,45] and may improve health-related aspects (ie, health-related quality of life, pain, and functional status) [32,33]. Some findings suggest that these programmes may enhance self-efficacy skills [45], vocational plans [32], disease-specific knowledge [32], and readiness to transfer to adult care [47]. In addition, 2 interventions found positive results on familiar relationships (ie, better parenting climate, autonomy support, reduction in parental control, and worry) [16] and possible improvements in parental knowledge and health-related quality of life [32]. Nevertheless, the knowledge and readiness acquired differed between programmes; some found difficulties with healthcare insurance, financial support, and decision-making autonomy about their care [47], while others reported issues with travel, booking appointments, or getting prescriptions [46]. These findings highlight the importance of effective communication

Table 2

Structure and contents of transitional care programmes in rheumatology

Programme	Studies	Age	Educational contents	Tools	Health care providers involved
Rheumatology transition programme	Rettig and Athreya, 1991 [24]	17-19	Vocational and financial counselling, alcohol education, birth control, parental independence. Parental education. Peer support.	Not reported	Paediatric rheumatologist, adult rheumatologist, social worker, nurse, internist rheumatologist, physical therapist, occupational therapist
Vancouver Young Adults with Rheumatic Diseases (YARD) clinic	Tucker and Cabral, 2005 [25]	14-18	Developmentally appropriate. Individualised plans. Education and self-management skills (disease, medications, skills in communication, educational/vocational career, finances/healthcare coverage, independent living, relationships outside the family, sexual health, risk-taking behaviours, family problems). Parental education.	Not reported	Coordinator, paediatric rheumatologist, adult rheumatology, nurse, social worker, physiotherapy, occupational therapy, vocational and sexual counselling services
Calgary Young Adults with Rheumatic Diseases (YARD) clinic	Miettunen, 2008 [26] Guelber, 2008 [27]	14-25	Developmentally appropriate. Individualised plans. Education and self-management skills (illness management, coverage, school, career counselling, personalised fitness programme).	Not reported	Coordinator (nurse), paediatric rheumatologist, adult rheumatology, nurse, physiotherapist, and social worker
Growing up and moving on	Shaw et al, 2004 [28,29] McDonagh, 2006 [30] Robertson et al, 2006 [31] McDonagh et al, 2007 [32] Shaw et al, 2007 [33]	11-17	Developmentally appropriate. Individualised plans. Education and self-management skills (disease, psychosocial health, social issues, parental issues, education and vocation, sexual health, self-confidence, body image, diet, dental health, exercise, cybersafety, independent living). Parental education. Peer support.	Websites Filofax Handbook Phone calls Flyers Templates	Coordinator, consultant rheumatologist
MAGICC (Moving on in Adolescence, Growing up In Collaboration and Coping)	Tattersall, 2012 [34]	10-25	Developmentally appropriate. Individualised plans. Education and self-management skills (HEADDSS schema: home, education/employment, activities outside school and home, drugs, sexual health, suicide, spirituality). Parental education.	Not reported	Paediatric rheumatologist, adult rheumatologist, nurse, physiotherapist, occupational therapist
Berlin Transitions Program	Minden et al, 2014 [35]	16-20	Developmentally appropriate. Individualised plans. Joint consultations. Education and self-management skills (disease, health disease management, future plans and prospects, social environment, attitude and readiness for transition).	Websites Flyers Phone calls e-mails	Coordinator, paediatric rheumatologist, internal rheumatologist, physiotherapists, psychologists, social workers
Don't Retard	Hilderson et al, 2013 [36,37] Hilderson et al, 2016 [16]	14-16	Individualised plans. Education and self-management skills (disease, medication management and adherence, exercise, cooking, fatigue, school, friends, self-image, social issues, disabilities). Parental education. Peer support.	Websites Booklet DVD Phone calls Workshops Lectures	Coordinator, paediatric rheumatologist
Nationwide Children's Hospital	Jensen et al, 2015 [38]	15-26	Individualised plans. Education and self-management skills (medical management, occupation, hobbies, relationships).	Phone calls Workbook	Coordinator (social worker), paediatric rheumatologist, adult rheumatologist

(continued)

Table 2 (Continued)

Programme	Studies	Age	Educational contents	Tools	Health care providers involved
IWK Health Centre Pediatric Rheumatology Transition Clinic	Stringer et al, 2015 [39]	14–16	Individualised plans. Education and self-management skills (medical management and psychosocial health).	Not reported	Paediatric rheumatologist, adult rheumatologist, nurse, paediatric physiotherapist
Challenge your arthritis	Ammerlaan et al, 2014 [40] Ammerlaan et al, 2015 [41] Ammerlaan et al, 2017 [42]	16–25	Web-based educational programme. Education and self-management skills (disease, pain, fatigue, sport and exercise, nutrition, intimacy, communication skills at school or work).	e-Health News Videos Homework Games Chats	Paediatric rheumatologist, adult rheumatologist, nurse, peer trainers
University Medical Center Utrecht	Ammerlaan et al, 2017 [43]	16–25	Individualised plans. Education and self-management (5 themes: treatment and medication; physical exercise, holidays, alcohol and drugs; relations, sexuality and pregnancy; dealing with pain, fatigue and emotions; study and work). Peer support.	Website Videos Stories Online consulting	Paediatric rheumatologist, adult rheumatologist, nurse
Clinical transition pathway for adolescents in Netherlands	Walter et al, 2017 [44] Walter et al, 2018 [45]	12–18	Individualised plans. Joint consultations. Education and self-management (medical care, psychosocial and vocational needs). Parental education.	Not reported	Coordinator (paediatric rheumatology nurse and adult rheumatologist), paediatric rheumatologist, adult rheumatology nurse, physiotherapists
McMaster Rheumatology Transition Clinic	McColl et al, 2021 [46]	14–17	Not reported	Not reported	Not reported
Got Transition	Overbury et al, 2021 [8] Teh et al, 2022 [47] Cox et al, 2023 [7] Carandang et al, 2022 [48] Chang et al, 2023 [49]	14–27	Education and self-management (Got Toolkit: self-care skills, education and resources, readiness). Parental education. Peer support.	Websites Phone calls e-mails	Paediatric rheumatologist, adult rheumatologist, nurse ^a , child life specialist ^a , physiotherapist ^a
ParTnerSTEPS (Parents in Transition—a Nurse-led Support and Transfer Educational Program)	Thomsen et al, 2022 [9]	Parents	Educational contents (adolescent's life with a chronic condition, independence, need for parents' support and expectations/emotions regarding the transfer, what to expect in adult care).	Websites Scripts	Paediatric rheumatologist, adult rheumatologist, nurse
TRACER (Transition to Adulthood Through Coaching and Empowerment)	Batthish, 2022 [50]	16–18	8-mo coaching intervention. Education and self-management (self-advocacy, medication management, general health, lifestyle issues, education/vocation, psychological and social well-being).	Not reported	Clinical psychologist
TTP (Tuebingen Transition Program)	Boeker et al, 2022 [51]	13–Not reported maximum age	Self-management, disease knowledge, reflection of the individual progress, and topics particularly relevant to adolescents (not specified). Parental involvement at the end of each visit.	Visits	Paediatric rheumatologist, adult rheumatologist, psychosocial team, physiotherapist, teachers
TCARD (Transition Clinic for Adolescents with Rheumatic Diseases)	García-Rodríguez et al, 2023 [52]	16–18	Self-management, knowledge and literacy, mental health (psychiatric disorders, drugs, suicide risk, education/vocation, sexual behaviour), nutrition, sports and physical activities, and rehabilitation.	Workshops Activities Counselling	Paediatric rheumatologist, adult rheumatologists, nutritionist, physical medicine and rehabilitation specialists, medical specialist in adolescent psychiatry, clinical psychologist, nurse, social worker

^a Varied between studies/among countries.

and positive patient-provider relationships to identify individuals' needs, preferences, and resources to offer tailored contents during transitional care. Telehealth and e-consultation may play a role in better communication [41]. Ongoing clinical trials may provide new insights on the effectiveness of a face-to-face, coaching transition intervention (psychologist-driven) [50].

DISCUSSION

The present systematic review, informing the EULAR PtC for patient education in physical activity and self-management of pain in jRMDs during transitional care [17], aimed to synthesise existing evidence on transitional care programmes for young people with jRMDs, focusing on their structure and implementation,

Table 3
Studies characteristics examining transitional care programmes in rheumatology

Studies	Design	Population	Comparator	Main outcomes (instruments) and results	Risk of bias
Rettig and Athreya, 1991 [24]	Cross-sectional	36 (jRMDs) Aged 17-19 y UK	N/A	Continuity to adult care (%) ^a	High
Shaw et al, 2004 [29]	Cross-sectional	478 (HPRs) UK	N/A	Resources to be important: self-medication teaching packages and social skills training ^b Barriers for implementation: inadequate resources, coordination, and training ^b	Medium
Shaw et al, 2004 [28]	Qualitative	30 (JIA) Aged 13-30 y 23 (parents) UK	N/A	Young people with JIA and their parents call for developmentally appropriate care that address physical, social, psychological, and vocational issues	Medium
McDonagh et al, 2006 [30]	Cohort	194 (JIA) Aged 11, 14, 17 y 185 (parents) UK	Follow-up (6 months)	Acceptability ^a Educational resources usability ^a	Medium
Robertson et al, 2006 [31]	Retrospective	8 (centres) UK	Follow-up (12-24 months)	Documentation: Transitional issues (HEADS) ↑ ^c Transitional readiness (ad hoc) ↑ ^c Parental needs (ad hoc) ↑ ^c MDT involvement (ad hoc) ↑	High
Shaw et al, 2007 [33] McDonagh et al, 2007 [32]	Cohort	308 (JIA) Aged 11, 14, 17 y 67% women 303 (parents) UK	Follow-up (12 months)	Young people with JIA: Satisfaction (Mind the Gap) ↑ ^c Health-related quality of life (JAQQ) ↑ ^c Arthritis-related knowledge (ad hoc) ↑ ^c Vocational plans (ad hoc) ↑ ^c Independent health behaviours (ad hoc) ↑ Parents: Satisfaction (Mind the Gap) ↑ ^c Arthritis-related knowledge (ad hoc) ↑ ^c	Low
Hilderson et al, 2013 [37]	Qualitative	11 (JIA) Aged 18-30 y 73% women	N/A	Experiences and expectations ^b 3 main themes emerged: preparation, parental involvement, and an adapted setting for the late-adolescent or early adult	Medium
Ammerlaan et al, 2014 [40]	Quasi-experimental	19 (JIA: 42%) Aged 16-25 y Netherlands	10 post intervention (1 month) Comparators: 9 face-to-face intervention	Technology acceptance (TAM) ^a High adherence and interaction ^a Perceived usefulness (0-10 Likert) ↔ Perceived user acceptance (0-10 Likert) ↑ Goals achievement ↔	High
Hilderson et al, 2015 [16]	Quasi-experimental	23 (JIA) Aged 14-16 y 74% women 23 (parents) UK	Follow-up (6-11 months)	Young people with JIA: Psychosocial health (PedsQL) ↑ ^d Physical health (PedsQL) ↑ Pain and hurt (PedsQL) ↔ Communication (PedsQL) ↑ Daily activities (PedsQL) ↑ Health-related quality of life (VAS) ↑ Fatigue (MFI-20) ↓ Motivation (MFI-20) ↑ Parents: Worry (PedsQL) ↓ ^d Behavioural control (PRS-YSR) ↓ ^d Autonomy support (PVF) ↓ Promotion of independence ↓ Pain and hurt (PedsQL) ↔ Psychological control (PRS-YSR) ↓ Psychosocial health ↓ Physical health (PedsQL) ↓ Daily activities (PedsQL) ↑ Communication (PedsQL) ↓	Low

(continued)

Table 3 (Continued)

Studies	Design	Population	Comparator	Main outcomes (instruments) and results	Risk of bias
Jensen et al, 2015 [38]	Quasi-experimental	210 (JIA: 52%, SLE: 26%) Aged 15-26 y 79% women USA	Follow-up (6-8 months) Comparator: 26 controls	Continuity to adult care (%) ↑ ^c Satisfaction (5-50 Likert) ^a	Medium
Stringer et al, 2015 [39]	Cross-sectional	51 (JIA: 82%) Aged 15-17 y 78% women Canada	27 Follow-up (adult care) Comparator: 13 no follow-up	Satisfaction (VAS) ↑ Disease control at transfer (ad hoc) ↔ Functional capacity (HAQ) ↔ Health-related quality of life (SF-36) ↓	Medium
Ammerlaan et al, 2015 [41]	Qualitative	13 (JIA: 42%) Aged 16-25 y Netherlands	N/A	High acceptability and feasibility for an online educational portal. Having access to their medical records increased their feelings of being in control; e-consult may lead to easier and better communication ^b	Medium
Ammerlaan et al, 2017 [42]	Randomised controlled trial	72 (JIA) Aged 16-25 y 88% women Netherlands	36 post intervention (1 month) Comparator: 36 controls	Learning experience (0-10 Likert) ^a Self-efficacy (Dutch-ASES) ↔ Health education impact (Dutch heiQ) ↔ Functional capacity (HAQ-DI) ↔ Perceived pain (0-10 Likert) ↔ Perceived well-being (0-10 Likert) ↔ Perceived fatigue (0-10 Likert) ↔ Perceived disease activity (0-10 Likert) ↔ Medication (DMARD and NSAID) ↔	Medium
Ammerlaan et al, 2017 [43]	Qualitative	HPRs	N/A	Young people demanded integrating young people priorities and respecting their decisions ^b	High
Walter et al, 2017 [44]	Qualitative	32 (JIA: 72%) Aged 14-20 y 69% women 33 (parents) Netherlands	N/A	Missed topics during consultations ^b Experiences of preparation for transfer ^b Self-management skills ^b	Medium
Walter et al, 2018 [45]	Cross-sectional	154 (JIA: 68%) Aged 12-14 y 64% women Netherlands	76 transferred to JIA clinic Comparator: 78 not transferred to JIA clinic	Continuity to adult care (%) ↑ Individual transitional plan (%) ^e ↑ ^d Satisfaction (OYOF-TES) ^e ↔ Self-efficacy (OYOF-SES) ^e ↔ Disease activity (ESR) ^e ↔ Vocational restrictions by the disease ^e ↔	Medium
McColl et al, 2021 [46]	Cross-sectional	70 (JIA: 87%, SLE: 13%) Aged 14-20 y 65 women Canada	N/A	Self-management skills (TRANSITION-Q) ^a	Medium
Overbury et al, 2021 [8]	Cohort	57 (JIA: 63%) Aged 14-27 y 75% women USA	N/A	Continuity to adult care (%) ^a	Medium
Teh et al, 2022 [47]	Cross-sectional	152 (JIA: 47%, SLE: 40%) Aged 15-22 y 65% women Singapore	111 aged <20 y Comparator: 41 aged ≥20 y	Medical healthcare knowledge (MKHU) ↓ ^d Transitional readiness (TRAQ) ↓ ^d Transition importance (0-10 Likert) ↔	Medium
Chang et al, 2023 [49]	Cross-sectional and qualitative	9 clinics USA	N/A	Organisational Readiness for Implementing Change (ORIC) Challenges, facilitators, and overall experience with the transition implementation process	Medium
Boeker et al, 2022 [51]	Cross-sectional	85 (JIA: 71%) Ages 18-44 y 71% women Germany	Average German population Participants without continued care	Continuity to adult care (%) ^a Physical activity ↑ Health-related quality of life (EQ-5D-5L) ↓ Satisfaction (VAS) ↑ Disease activity (PGA) ↓ Physical activity ↑ Health-related quality of life (EQ-5D-5L) ↑	Low

(continued)

Table 3 (Continued)

Studies	Design	Population	Comparator	Main outcomes (instruments) and results	Risk of bias
Carandang et al, 2022 [48]	Qualitative	39 (JIA: 85%) Aged 16-28 y 82% women USA	N/A	Recommendations on implementation: Frame healthcare transition as an opportunity for empowerment, implement a structured education plan and consider the role of parents ^b	Low
Cox et al, 2023 [7]	Cross-sectional and qualitative	6 clinics USA	N/A	Transition implementation (0-5 Likert) ↑ ^d Results, suggestions and barriers ^b The programme improved organisation, efficiency, follow-up care, structured communication, and availability of helpful resources Main barriers included documenting the transition process, non-specific documents and insufficient time	High

ASES, Arthritis Self-efficacy Scale; DMARD, disease-modifying antirheumatic drug; EQ-5D-5L, EuroQoL 5-Dimension 5-Level; ESR, erythrocyte sedimentation rate; HAQ, Health Assessment Questionnaire; HEADS, Home, Education, Activities, Drugs, Suicide; heiQ, Health Education Impact Questionnaire; HPR, Health Professional in Rheumatology; JAQQ, Juvenile Arthritis Quality of Life Questionnaire; JIA, juvenile idiopathic arthritis; jRMD, juvenile-onset rheumatic and musculoskeletal disease; MDT, multidisciplinary team; MFI, Modified Fatigue Index; MKHU, Medical Knowledge and Healthcare Usage; ; N/A, not applicable; NSAID, nonsteroidal anti-inflammatory drug; OYOF-SES, On-your-own-feet self-efficacy scale; OYOF-TES, On-your-own-feet transition experiences scales; PedsQL, Pediatric Quality of Life; PGA, Physician Global Assessment; PRS-YSR, Parental Regulation Scale–Youth Self-Report; PVF, Promotion of Volitional Functioning (Autonomy Support Scale); SF-36, 36-Item Short Form Survey; SLE, systemic lupus erythematosus; TAM, Technology Acceptance Model; TRAQ, Transition Readiness Assessment Questionnaire; VAS, visual analogue scale.

Change in scores: ↑ increments, ↓ decrements, ↔ no differences.

- ^a No comparative analyses are available.
- ^b Qualitative analyses.
- ^c Results from partial sample.
- ^d 75% with inactive disease.
- ^e Clinical trial protocol, no results available
- ^f Significant change, $P < .05$.
- ^g Significant change, $ES > 0.30$.

the qualitative experiences and perceptions of those involved, and the quantitative outcomes associated with these programmes. First, we observed a lack of consensus on practices for transitional care programmes in rheumatology, as existing programmes are markedly varied. Second, satisfaction with these programmes appears relatively good among young people with jRMDs and their families, although it remains unknown for healthcare professionals. Third, evidence supporting favourable outcomes remains limited, as few well-designed RCTs have evaluated the effectiveness of these programmes.

Structure and implementation of transitional care programmes in rheumatology: current practices and future directions

The considerable structural differences emerging from the identified programmes underscores the need for clearer and standardised guidance promoting evidence-based transitional care programmes in rheumatology. Indeed, a number of studies offered limited details on essential components (eg, programme duration, follow-up procedure, and delivery mode), suggesting that reporting quality in this field may benefit from improvement. Additionally, information on how well these programmes align with the unique needs, preferences and resources of young people and their families was also missing [54], offering limited insights into whether they are suitably tailored to serve young people with jRMDs. Despite these limitations, certain foundational principles from the 2017 EULAR/PreS (general) standards and recommendations [1] were reflected across the included studies. First, a dedicated coordinator to organise care, schedule follow-ups, serve as the primary contact for patients and families, and link

paediatric and adult healthcare providers. Second, a multidisciplinary team including paediatric and adult rheumatologists and HPRs (eg, nurses, occupational therapists, physiotherapists, social workers, psychologists, and sports scientists) to ensure holistic care that addresses the unique medical, psychological, and social needs of each young person with jRMDs. Third, efficient communication between healthcare providers, young people with jRMDs and their families is essential to align treatment goals and foster informed engagement. Fourth, comprehensive care plans that combine, when indicated, pharmacologic and nonpharmacologic approaches, tailored to the evolving needs, preferences and resources of each young person. Fifth, to engage young people in informed shared decision-making to foster ownership and tailor care delivery to their needs, preferences, and resources, empowering them to self-manage their jRMDs.

Considering the high rates of physical inactivity [55,56] and challenges in self-management of pain commonly observed among young people with jRMDs [57–59], our task force identified the clinically relevant and timely need of developing specific guidelines for patient education in physical activity and self-management of pain during transitional care in rheumatology. This review, together with individual semistructured interviews and additional literature, informed the task force discussions that established the EULAR PtC on patient education in physical activity and self-management of pain for young people with jRMDs during transitional care [17]. By launching these EULAR PtC, we aim to optimise the design of transitional care programmes in rheumatology through clear, standardised guidance on patient education. This approach may support a smoother transition to adult care and fosters sustainable, long-term health outcomes.

Qualitative and quantitative evidence on transitional care programmes in rheumatology

Young people with jRMDs and their families generally express high satisfaction with existing transitional care programmes, appreciating initiatives that foster independence through early psychosocial support for young individuals and education for parents. The literature highlights the importance of peer support, education on self-management, and personalised transitional care tailored to individual needs, priorities, preferences, capabilities, resources, and contexts. In addition to these positive aspects, young people with jRMDs and their families also identified barriers to access transitional care such as insufficient resources and the need for coordinated, multidisciplinary, and specialised healthcare teams. While qualitative evidence is generally positive, the quantitative findings remain uncertain. The literature suggests that transitional care programmes may have the potential to enhance readiness to transfer, continuity of care, health literacy, and daily participation. However, most of these findings come from limited, individual studies with varying designs, highlighting the need for well-designed RCTs to establish robust quantitative evidence on key outcomes of transitional care.

Limitations

It is likely that not all existing transitional care programmes in rheumatology are included in this review, which may be considered the main limitation of this work. This may be explained by the exclusion of potentially relevant databases from our search (eg, CINAHL, PsycInfo, and PEDro) and the exclusion of transitional care programmes whose essential structural components were not described in detail in the screened manuscripts. Additionally, as most included studies focused on juvenile idiopathic arthritis and juvenile-onset systemic lupus erythematosus, the generalisability of our findings to other jRMDs is limited. Similarly, our results may not be relevant to people from minorities, populations at risk of social exclusion, and those underrepresented in research or with limited access to care. Moreover, as our literature review did not have temporal restrictions, the evolution of practices and resources must be considered when interpreting the findings (eg, some previously identified barriers may now be easier to overcome).

CONCLUSION

In conclusion, this systematic literature review synthesises the state-of-the-art in current transitional care practices in rheumatology. These insights, together with additional information, informed the discussions of the members of the task force establishing the EULAR PtC for patient education in physical activity and self-management of pain during transitional care. Further research is warranted to establish quantitative evidence on programme effectiveness and to explore additional areas critical for young people with jRMDs, such as healthy lifestyle, self-management of fatigue, sleep hygiene, mental health and social support, ensuring that transitional care evolves to meet their diverse needs. Importantly, to enhance the inclusivity and reach of transitional care, it is essential to address accessibility barriers, particularly for people from underrepresented groups with limited healthcare access.

Competing interests

DC: Speaker bureau—Pfizer, Novartis and Roche, KM: Honoraria from Amgen, Pfizer, Novartis and Medac. JCI, RPM, EBV, PAV, SA, JA, IB, MC, WC, DDC, AD, LL, AM, AFM, AN, SO, GP, ZS, TV, NW, AZ, YP, LC, and FEL have no conflicts of interest to declare.

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Contributors

All authors are members of the EULAR's task force HPR051. JCI and RPM were the fellows. FEL was the convenor of the task force and JCI was the guarantor of this review. LC and FEL were the co-methodologists. All authors have contributed to the work and read and finally approved the manuscript for submission.

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Patient and public involvement

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Patient consent for publication

Not applicable.

Ethics approval

Not applicable.

Provenance and peer review

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Data availability statement

Data sharing is not applicable as no datasets were generated and/or analysed for this study. All data relevant to the study are included in the article or uploaded as supplementary information.

Supplementary materials

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