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Consensus evidence-based recommendations for transition of care for adolescents with juvenile idiopathic arthritis: meeting patients', parents', and rheumatologists' perspectives

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Abstract

Background Transition of care means the process of educating and empowering adolescents and young adults to take an active role in their own healthcare, develop decision-making skills, and eventually transition from paediatric to adult healthcare providers. Most people do not switch doctors until they are young adults, but it can be beneficial to start preparing children earlier. We aimed to develop a specific toolkit tailored to paediatric and adult rheumatologists to assist them in transitioning of care of young people with juvenile onset rheumatic musculoskeletal diseases from the paediatric to adult rheumatology care.

Results The expert panel was confined to an online survey ($n=18$), all the experts completed the two rounds. At the conclusion of round 2, a total of 10 points were gathered. The range of respondents (ranks 7–9) who agreed with the recommendations was 88.9 to 100%. All 10 clinical standards identified by the scientific committee were written in the same way. Based on the answers to the structured key questions and the literature review, a structured template was developed presenting transition of care integrated pathway.

Conclusion The developed rheumatology-specific guideline offers adolescents and young adults a focussed, multidisciplinary transition of care approach with equity of access, quality of care and flexibility and set up standards for transitional care for young adults with juvenile rheumatological diseases.

Keywords Transition of care, Juvenile rheumatological diseases, Egyptian College of Pediatric Rheumatology

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Background

Effective transition of care for young adults and adolescents with juvenile rheumatological diseases is fundamental to rheumatology care provision. The Society for Adolescent Medicine has defined the transition of care as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult-oriented healthcare systems” [1]. The transition is often looked at as a one-time incident of transfer, in which young adult/adolescents’ care is handed over from children-centred to adult-centred services. In fact, it is an active, holistic, multidisciplinary as well as multidimensional process, which tackles the young adults’ medical, psychosocial and educational/vocational needs [2]. This approach of a holistic ‘life course’ to care, has been emphasized by the available evidence of ‘best practice’ for transitional care [3–5]. This is a critical aspect of this stage in life, where responsibility shifts from parents/caregivers to a shared responsibility which eventually is handed over to the young adults themselves if they have capacity.

Despite the increasing calls that the young adult patients with special health care needs, do require individualized targeted care and attention, changes have been sluggish to take place [6–8]. On the other hand, the need for such a coordinated systematic transition of care from paediatric to adult providers has increased as advances in health care have facilitated decline in morbidity and mortality of children with juvenile rheumatological diseases. Earlier published data revealed that more than 90% of children with special health care needs are projected to survive to adulthood and require transitional services [9]. Unfortunately, there have been several barriers to efficacious and successful transition, both nationally as well as internationally. One barrier is the sense of ownership and lack of coordination between professionals in both the paediatric and adult care teams [10]. Another challenge is the unmet education and training needs for healthcare professionals involved in this process with gaps in knowledge and the paucity of resources or guidelines [11]. A third barrier is the lack of transition support for such a change that young adults experience in the transition of care process. Another aspect to consider is that adolescence is a very important period in the young adult’s life. Attention to this age has been called by the mental health professionals, as this period of life is the time when individual identity develops [12]. This is vital as 50% of the children with juvenile idiopathic arthritis associated with depression suffer their first episode between 15 and 25 years [13].

Based on these data, the Egyptian College of Pediatric Rheumatology has taken the initiative to develop rheumatology-specific guidelines and set up standards

for transitional care for young adults with juvenile rheumatological diseases. The objective of this work was to develop a specific toolkit tailored to paediatric and adult rheumatologists to assist them in transitioning of care of young people living with juvenile onset rheumatic musculoskeletal diseases from the paediatric to adult rheumatology care. These guidelines are meant to be implemented across paediatric, adolescents and adult rheumatology healthcare settings.

Methods

Design

The study design was formulated based on the “Clinical, Evidence-based, Guidelines” (CEG) development protocol which involves a consensus, based on the existing scientific evidence and clinical experience. The aim was to determine the extent to which experts agree about a particular issue, with the ultimate goal of providing a unified expert opinion. This manuscript conformed to the preferred reporting items for systematic reviews and meta-analyses guidelines for reporting systematic reviews [14].

Study teams

Core team

To supervise, coordinate and assist with developing the scope of the project and initial clinical questions, nominating the expert panel and drafting the manuscript, they were adult and paediatric rheumatologists.

Key questions used to develop the guideline

This guideline was centred on a series of structured key questions that define the target population, the intervention, and outcomes. The evidence to answer the clinical questions was collected according to the following steps: formulation of key clinical questions, structuring of the questions, search for evidence, critical evaluation and selection of evidence, presentation of results, and recommendations. The questions (Table 1) formed the basis of the systematic literature search and consequently the clinical care standards.

Literature review team whose main task was to complete the literature search, data abstraction as well as the quality of evidence rating. The team was led by an experienced literature review consultant and based on the specific research questions identified to focus on “transition of care”. The literature review was conducted with the assistance of an expert in methodology.

Data sources

To acquire proper evidence-based background knowledge for considerations, the systematic literature search was carried using PubMed/MEDLINE, EMBASE, and Cochrane databases. Following the data abstraction,

Table 1 Key clinical questions

Domain	Key clinical questions
1. Targets	-Who are the Targeted audience? -Who are the targeted patients? - Who are the targeted authorities?
2. Change of the service	What are the differences between paediatric and adult rheumatology care?
3. Scope	Why transition of care should be an integral part of a patient's journey throughout a health care system?
4. Objectives	What are the objectives of the transition of care program?
5. Transition model	What are the core elements of transition of care?
6. Time Frame	What are the advised chronological stages of transition of care?
7. Tools	What are the tools to be used for assessment of the core elements?
8. Service structure	What is the set-up of the transition of care clinic?
9. Role of Adult rheumatology care	What is the role of the adult rheumatologist?
10. Outcomes	How to evaluate the process, the transition completion, and the outcomes?

reviewing the published recommendations, the quality of evidence rating [12, 15]; revision was carried out by the experts responsible for the literature review, who provided a comprehensive list of propositions for the “transition of care” based on the available research evidence and their own clinical expertise. The level of evidence was determined for each section using the Oxford Centre for Evidence-based Medicine (CEBM) system [12].

Study selection

Relevant studies were selected by applying inclusion and exclusion criteria to the literature retrieved with the search strategies.

Inclusion criteria

Articles included were systematic reviews, randomized controlled trials (RCTs), uncontrolled trials, observational studies including cohort, case control, and cross-sectional studies, or those where economic evaluation was made. The included studies should have the formal process for establishing recommendations (Delphi exercise, panel conference) outlined.

Exclusion criteria

Editorials, commentaries, conference abstracts and non-evidence-based narrative/personal reviews, manuscripts lacking of English version, were excluded.

Expert panel

Those were be appointed by the core team. The participants should have the professional knowledge, training, and experience in the field of pediatric rheumatology, with active participation in scientific research in this field.

Target audience

The guideline has been developed to provide assistance to healthcare professionals who treat and manage patients with juvenile rheumatological diseases. The guideline should also provide a helpful resource for patients and those responsible for commissioning care for patients with juvenile arthritis in the National Health Service.

Delphi

The Delphi technique is a well-established approach developed to answer research question(s) through the identification of a consensus view across the subject experts. Its methodology is based on a series of questionnaires or “rounds” addressed to experts [16].

Consensus process

Two Delphi rounds were carried out to establish consensus regarding the “transition of care” of young adults/adolescents living with juvenile rheumatological diseases. The structured Delphi approach ensures that the opinions of participants are equally considered. The Delphi process was conducted through online questionnaires. The first round of the electronic questionnaire included 10 domains involved in the “transition of care” process.

Voting process

Live online delivered voting was carried out in two rounds that were strictly time limited. All members of the task force were invited to participate and were pre-informed of the time of opening and closure of each round of votes. Unique access links were sent out, and anonymous votes were gathered and processed. Comments on re-phrasing, potential ambiguity, unidentified overlaps were gathered regarding each statement at the

same time in the voting process. Only the members of the task force had the right to vote on the statements.

Chronogram of Delphi rounds

The first round took place between 27th November and 2nd December 2022 (5 days). The aspects about which respondents did not reach consensus in this first round were revised in view of the comments and included in the second round. The second round took place on 9th of December 2022 (1 week after the first round) and lasted for 5 days (9th–13th December 2022).

Rating

Each statement was rated between 1 and 9 with 1 indicative of ‘complete disagreement’ and 9 indicating ‘complete agreement’. Generally, 1–3, 4–6, and 7–9 represent disagreement, uncertainty and agreement, respectively. Voting on all statements was not mandatory, and the members were encouraged to refrain if they feel that a statement falls outside their area of expertise. An ‘uncertainty’ vote represents ‘inconvenience about the accuracy of the recommendation’. All statements were allowed for the entry of comments which were reviewed by the scientific committee after each round of voting. In all the votes’ rounds, particularly wherever they vote a disagreement, the members were urged to leave comments. This enabled the panel to identify an instance of misinterpretation of statement and invalidate the vote on that statement.

Definition of consensus

Definition of consensus was established before data analyses. It was determined that consensus, consequently, to become a recommendation in this guideline, would be achieved if at least 80% of participants reached agreement (score 7–9) or disagreement (score 1–3) [16–18]. A statement was retired if it had a mean vote below 3 or a ‘low’ level of agreement. Statements whose rate came in the uncertainty score, (4–6), were revised in view of the comments. The levels of agreement on each statement of recommendation were defined as ‘high’ if after the second round of votes, all votes on a statement fell into the agreement bracket (7–9) [19, 20].

Translation of the Transition Readiness Assessment Questionnaire

The translation of Transition Readiness Assessment Questionnaire (TRAQ) [21] into Arabic was done following the proposed guidelines by Guillemin et al. [22]. Three translators were involved, who included two professional translators with a medical background and one of the authors. Two different professional translators and another author carried out the back translation.

The translators were instructed that it was important for them to translate the exact activity listed in the original questionnaire precisely and accurately, but using literal, simple Arabic words that would be understood by all Arabic cultures. Illustrations were added for simplification and based on previous experience in developing the illustrated patient reported outcome measures questionnaire [23] (Additional file 1). A pilot study was performed before starting the present study to test the applicability and comprehensibility of the questionnaire as well as the alterations performed.

Developing the transition of care pathway and outcome evaluation form

Based on the answers to the structured key questions and the literature review, a structured template was developed presenting transition of care integrated pathway (Additional file 2). A proposed tracking record to monitor the transitioned patients has also been developed and included in the outcome evaluation.

Ethical aspects

This study was performed in accordance with the Helsinki Declaration. The “Clinical, Evidence-based, Guidelines” (CEG) initiative protocol was approved the local ethical committee: ethical approval code: 34,842/8/21, ethical board **** University. Written ethics approval from the experts sharing in this work was deemed unnecessary according to national regulations. As per the Egyptian national Ethical Committee regulations, verbal informed consent was required from all the participants included in the study. All the participants were kept anonymous, in compliance with data protection regulations.

Results

Literature research and evidence selection

In the study selection process, we found that 156 potentially relevant studies by search strategy. Eighty three percent were excluded for duplicate or after screening of title and abstracts (studies did not examine population or intervention of interest, did not match study design of interest, or did not report outcome measures of interest). Therefore, relevant 73 studies were included for full-article review. About 42 studies were excluded as citations did not provide level of evidence or quality indicators. Therefore, we included 31 studies in this work.

Expert panel characteristics

The Delphi form was sent to expert panel ($n=18$), who participated in the three rounds. The experts panel included both pediatric and adult rheumatologists who had experience in the field of pediatric rheumatology.

Respondents were drawn from different governorates and health centres across **: ** University (22.2%), ** University (16.7%), ** University (11.1%), ** University (5.5%), ** University (16.7%), ** University (5.5%), ** University (11.1%), ** University (5.5%), and ** (5.5%).

Delphi round 1

Round 1's response rate was 100% (18/18). On all of the 10 key questions, consensus was reached on 100% of the items, indicating that 75% of respondents strongly agreed or agreed. Comments raised regarding the wording of some of the recommendations were considered and the wording of 6 questions were amended. There was no diversity of opinion in round 1.

Delphi round 2

The response rate for round 2 was 100% (18/18). The percentage of those who received a high-rank recommendation (rank 7–9) ranged from 88.9 to 100%. On all of the standards, there was agreement (i.e., 75% of respondents strongly agreed or agreed). The wording of the remarks was unanimously agreed upon (> 80% agreement).

Overarching principles

- Youth living with juvenile onset rheumatological diseases should have access to coordinated, high-quality transition of care, set up on an individual basis and delivered through partnership with healthcare professionals, the youth and their parents/caregiver.
- The transition of care process should be initiated as early as possible; directly after the diagnosis in adolescent-onset disease or in early adolescence.
- In pediatric rheumatology clinic, staff should help patients to become more independent with their own health care
- There must be 'direct' contacts between paediatric and adult rheumatologist teams. During the process of transition, such 'direct' communication between the key contributors (as a minimum, to include a member each of the pediatric and adult rheumatologist teams, the youth as well as their parent/caregivers) should be secured before and after the actual transfer of care.
- Individualized transition plan and progress should be planned with the youth and their families and also, carefully documented in the patient's medical records.
- There must be a written and approved, as well as regularly updated transition policy to be implemented

by every rheumatology service and clinical network providing transition of care.

- There should be clear documentation and description of the role of the multidisciplinary team involved in the transition of care process. There must be a designated transition coordinator identified.
- The transition of care services should be developmentally appropriate, patient-centered, and address the complexity of the youth development
- A transfer document should be available for every patient.
- Healthcare professionals involved in the transition of care process must receive professional training in generic adolescent care and childhood-onset musculoskeletal disorders

Statements

Target audience

Mean \pm SD: 8.61 ± 1.19 , percentage of agreement: 94.4%, Level of agreement: high

- Who are the targeted audience?
- All healthcare professionals and support persons involved in the care of the young subjects living with juvenile onset rheumatic musculoskeletal diseases who require medical care to continue into adulthood.
- All healthcare professionals and support persons involved in the care of the young subjects living with juvenile onset rheumatic musculoskeletal diseases who require medical care to continue into adulthood.
- Who are the targeted patients?
Young subjects with chronic illnesses (including juvenile-onset rheumatic and musculoskeletal diseases who require continuity of medical care should be aware of the transition of care policy and informed broadly of the approach. These include the following:

Early adolescence (defined as 10–13 years),
Mid adolescence (14–16 years),
Late adolescence (17–19 years)
Young adulthood (20–24 years).

- Who are the targeted authorities?
Stakeholders and policy making organizations

What are the differences between paediatric and adult rheumatology care?

Mean \pm SD: 8.44 ± 1.25 , percentage of agreement: 94.4%, level of agreement: high

There are many differences between paediatric and adult rheumatology care, and they are summarized in Table 2.

Scope: why transition of care should be an integral part of a patient's journey throughout a health care system?

Mean \pm SD: 8.56 ± 1.04 , percentage of agreement: 94.4%, level of agreement: high

- There are significant gaps in current delivery of transition of care services
- There is no standard format of the service and how to run it in Egypt
- There are unmet training requirements for rheumatologists in adolescent health, transition of medical care causing poor appreciation and understanding of the young patients' expectations and requirements
- There is lack of transition readiness of the youth and/or of their parents/carers.
- Lack of robust quality indicators or cost-effective strategies.

What are the objectives of the transition of care program?

Mean \pm SD: 8.5 ± 1.15 ; percentage of agreement: 88.9%, level of agreement: high

- Optimise the delivery of transition of care for arthritic adolescents and young adults
- Maintain medical care and disease management.
- Improve the youth's physical, psychological, social, vocational, and illness-related outcomes.
- To facilitate continuity of care within adult rheumatology,
- To promote evidence-based practice in transitional care,
- To facilitate clinical networks of healthcare professionals (paediatric and adult), who are engaged, interested, and trained in the care of young patients.
- Improve the patients' experience within the rheumatology service

Transition model: what are the core elements of transition of care?

I. Transition policy:

Mean \pm SD: 8.89 ± 0.47 , percentage of agreement: 100%, level of agreement: high

1. To develop formal guidelines and policies outlining the transition process
2. Staff education

II. Identification and tracking:

Mean \pm SD: 8.67 ± 0.49 , percentage of agreement: 100%, level of agreement: high

1. Set the identification criteria and process for recognizing the adolescents who are candidates for transitioning have their data recorded in the registry.
2. Integrate the six core elements into the day-to-day clinical practice
3. Tracking and monitoring of the transition process through having a registry or a flow sheet to track the individual youth's transition progress for each item included in the Six Core Elements

III. Readiness for transition:

Mean \pm SD: 8.56 ± 0.78 , percentage of agreement: 94.4%, level of agreement: high

1. Regular assessments for readiness for transition, starting at the age of 14 years, to identify the youth's needs and goals in self-care and approach to get under the adult healthcare care.
2. Based on the identified goals, actions should be prioritized actions
3. Document regularly and update the plan of care.
4. Discuss the outcomes of the readiness assessment, the goals and the actions taken with both the youth as well as the parent/caregiver.

Table 2 The differences between paediatric and adult rheumatology care

Item	Paediatric care	Adult care
Patient care	Family-centered	Individual patient-based
Model of care	Developmentally oriented	Disease focused
Strategy	Nurturing, high level psychosocial support	Cognitive style
Approach	Interdisciplinary	Multidisciplinary
Pattern	Flexible, involve family members require parent direction and consent	direct, requires patient to be confident and functionally independent

IV. Planning of the transition process:

Mean \pm SD: 8.72 \pm 0.57, percentage of agreement: 100%, level of agreement: high

1. Individualized transition plan to be set up
2. Keep a record of the following:
 - Regular update and documentation of the readiness assessment outcomes, agreed goals, the actions that have been prioritized.
 - The youth's medical summary and emergency care plan
 - Any legal document or a condition fact sheet.
3. Preparation: Introduction to adult health care system and proper transfer through:
 - Youth and parent/caregiver education on transition and empowerment around self-management
 - Endorsing independent communication and engagement with healthcare providers
 - Set up shared clinic and identify designated coordinator for the transition of care.
 - Inform the youth and parent/caregiver of the legal changes in decision-making and privacy as well as consent, self-advocacy, and access to information
 - For the youth with intellectual challenges identify the need for decision-making supports with reference to legal resources
4. Timing: the optimum timing of the transfer of care should be agreed with the young adult and parent/caregiver. This should also be discussed and agreed with both the paediatrics and adult rheumatology care teams involved
5. Consent agreed: consent from both the youth/guardian should be obtained for the release of medical information
6. Assistance: Help the youth to identify an appropriate adult rheumatology care provider and communicate with the chosen provider about the transfer arrangement.
7. Referrals: arrange referrals for self-care management, information, school, and culturally appropriate supports

V. Transfer of care:

Mean \pm SD: 8.83 \pm 0.38, percentage of agreement: 100%, level of agreement: high

- Clinical: disease activity should be stable before the transfer of care
- Paediatric care provider: confirm with adult provider the paediatric rheumatology clinic/practice's responsibility for care until young adult is seen in adult setting
- Adult care provider: a cover letter is included with the transfer package, to be sent to the adult provider, and confirm the adult rheumatology care provider's receipt of the transfer package
- Date of transfer: confirm a date for the first appointment with the adult rheumatology care provider
- Documentation: ensure that the transfer package, including medical summary final transition readiness assessment, plan of care with goals of the transition as well as the pending actions, and emergency care plan have been forwarded to the adult care provider. Documentation should also include the legal documents, condition fact sheet, and additional provider records.

VI. Completion of the transfer:

Mean \pm SD: 8.67 \pm 0.77, percentage of agreement: 94.4%, Level of agreement: high

- Contact young adult and parent/caregiver 3–6 months after last paediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process
- Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed
- Build ongoing and collaborative partnerships with adult practices

What are the advised chronological stages of transition of care?

Mean \pm SD: 8.33 \pm 1.9, percentage of agreement: 94.4%, level of agreement: high

- Early-stage of transition:
 - Phase 1: 9–12 years old: primary phase of assessment of readiness
- Middle-stage of transition: 12–13 years old:
 - Activities not completed, or requiring further input are identified and tackled, tracking and monitoring
 - Second phase of assessment of Readiness for transition

- Late-stage of transition: 13–14/14–18 years old (subject to local regulations and cultural factors):
 - Should be carried out in a dedicated transition clinic for adolescents
 - Assessment of abilities and skills, preparing health care record plan, goals, and medical summary
 - Complete transition skills checklist.
- 18–21 years old: transfer of care
 - Transfer/welcome letters to adult rheumatology provider and integration into the adult practice
 - Confirm transfer completion and produce the young adult feedback

Tools: what are the tools to be used for assessment of the core elements?

Mean \pm SD: 8.89 ± 0.32 , percentage of agreement: 100%, level of agreement: high

The tools to be used for assessment of the core elements differ between adults and children, they are summarized in Table 3.

Service structure: what is the setup of the transition of care clinic?

Mean \pm SD: 8.44 ± 1.54 , percentage of agreement: 88.9%, level of agreement: high

Setting up the service

- The service must ensure the inclusion of a coordinator, medical, psychological, as well as educational and vocational aspects
- Members of the adult rheumatology in the transition program will take part in clinics with the paediatric rheumatology team and conversely the paediatric rheumatology team members attend clinics in the adult hospital.
- Development of simplified animated information leaflets for juvenile idiopathic arthritis.
- The use of a modified illustrated form of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) both parent and child version during follow up visits of JIA patients.

- Promotion of shared decision-making strategy and training in JIA patients starting from 7 to 12 years using Arabic toolkit for it.
- Updated Medical record
- Information leaflet and other tools should be available for patients' education.

What is the role of the adult rheumatologist?

Mean \pm SD: 8.83 ± 0.51 , percentage of agreement: 100%, level of agreement: high

- The adult rheumatologist should be a member of the transition of care process whilst the youth is under paediatric care.
- The adult rheumatologist should ensure smooth integration of patients into adult practices which is considered one of the more difficult aspects of the transition of care process.
- To establish and nurture the new youth-adult rheumatologist relationship, usually, more than one adult appointment is required.

Outcomes: how to evaluate the process, the transition completion, and the outcomes?

Mean \pm SD: 8.77 ± 0.55 , percentage of agreement: 100%, level of agreement: high

1. Assessment of outcomes: as by regular visits and follow-up (summarized in Table 4).
2. Tracking the transitioned patients: (Table 5)

Discussion

Since most childhood-onset rheumatic diseases persist into adulthood, transition of care is a vital phase in rheumatology. The main objective of this initiative was to develop recommendations and standards to be used in clinical practice and act as a guide to transition of care service development, benchmark the quality of transition services and be used by patient organisations to enhance patient expectations of care. The goals of the transition

Table 3 The tools to be used for assessment of the core elements

Tools for the paediatric rheumatology	Tools for the adult rheumatology
<ul style="list-style-type: none"> - Transition policy - Arabic Transition Readiness Assessment for Youth - PROMs: illustrated Arabic PROMs - A medical summary including Disease activity score, and pGALs (paediatric Gait, Arms, Legs and Spine) - Transfer letter 	<ul style="list-style-type: none"> - Condition fact sheet: directed to adult rheumatologists and include pearls about caring for adolescents and young adults living with juvenile musculoskeletal conditions - Welcome letter - Medical summary - Arabic Adult self-assessment tool

pGALs paediatric Gait, Arms, Legs and Spine, PROMs patient-reported outcome measures

Table 4 Health service and individual outcomes

Health service outcomes	Individual outcomes
<ul style="list-style-type: none"> - Regular access to adult health care service - Good follow-up rates of patients transferred, with few DNA (did not attend) visits - Hospitalisation 	<ul style="list-style-type: none"> - Stability or improvement of the disease activity - Adherence to therapy - PROMs and school/university/college attendance record - Patients' feedback

Table 5 Tracking the transitioned patients

Patient	Disease	Age of diagnosis	Age at first transition assessment	Age of transition	Disease activity score at transition	Functional ability	Quality of life	Comorbidity	Motivation score	Patient global assessment	Patient experience	Adherence to therapy	No. of missed appointments	Disease activity score

process are (1) to facilitate improving the young adults/adolescents' ability to effectively use health services and be able to manage their own health; (2) to set up an organized clinical process in both paediatric and adult practices to smooth transition preparation, transfer of care, and integration into adult healthcare service; (3) promote evidence-based practice in transition of care to facilitate the continuity of care within adult rheumatology and endorse clinical networks of healthcare professionals involved in the process; (4) endorse the implementation of new concepts such as self-management and shared decision making into the patient's management care plan.

There is growing evidence that a structured transition program improves outcomes [24]. The developed guideline adopted the six core elements of health care transition, which define the basic components of a structured transition process and include customizable tools for each core element [25]. This is in alignment with the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians who formed the ACR (American College of Rheumatology) Transition Work Group [26]. In the UK, McDonagh et al. proposed a transition program based on needs assessments using focus groups, a national survey of health professionals, Delphi analysis and retrospective case audits [27]. On another front, Tucker and Cabral proposed a transition model involving joint clinic between pediatric and adult rheumatologists, with assistance of a multidisciplinary team [28]. Regionally, Oman used translated Arabic version of UNC TRxANSITION Scale for the transition of care of adolescents to adult care [29].

Planning and implementation of transitional care is relative to young adult development, rather than relative to a health system-defined age of transfer to adult

care. Adolescent health development can be stratified into phases: early adolescence (defined as 10–13 years), mid adolescence (14–16 years), late adolescence (17–19 years) to young adulthood (20–24 years) [30, 31]. Timing has been shown to be a key component of transition planning. Therefore, to ensure effective implementation of the transition of care process, both the child and adult healthcare services should cover the full range of adolescence to adulthood. However, this work stratified the transition of care process into relatively expedited chronologic phases. Such accelerated transition of care has been attributed to religious and cultural restrictions. Perhaps this can be handled by setting-up a dedicated transition clinic for adolescents. Evidence to support starting transitional care in late childhood/early adolescence has been embedded in national guidance across a number of countries, including the UK, USA, and Canada [32–36]. As the second phase of the transition process, focuses on the transfer process, it leans toward having fixed age criteria, influenced more by the healthcare system and to a less extent by the individual's developmental status [31]. In contrast, there is less evidence available to support when the third and final phase of the transition process shall occur [32]. However, within these recommendations, the optimal time of transfer is advised to be tailored to the individual needs of each adolescent/young adult and all primary and subspecialty care providers should be involved.

Transitional care can be split into three-stage process, an initial lengthy phase of preparation and getting ready for transfer which begins in late childhood and early adolescence; a second phase around the event of transfer, usually in late adolescence; and then a third phase of variable length following the event of transfer when the young adult gradually engages with the new

adult services [31]. In agreement with this, the developed guideline provided toolkit for each of the pediatric as well as adult rheumatologists. The third phase which aims to evaluate the process, the transition completion, and the outcomes, has been stratified into health service outcomes and individual outcomes. In comparison to the first and second phases which have been thoroughly evaluated in systematic reviews [32, 33, 38], unfortunately, the third phase tends to be disproportionately under-researched and neglected. This study presented key quality indicators to evaluate the outcomes of the service delivered and to inform the research agenda. As there is no single key outcome of a “successful” transition, relevant and potential parameters have been proposed as key quality indicators. These include clinical parameters (disease activity and status), patient (and family) experience (of care), health-related quality of life, psychosocial, knowledge/educational and vocational status, participation in adult life, attendance and engagement in adult healthcare, adherence to treatment and achievement of young adult developmental tasks [39, 40].

In this work, we used illustrated patient questionnaires to assess for readiness as well as for patient reported outcomes. Earlier data revealed that the illustrated questionnaires are valid and reliable. They provide informative, quantitative measure for the disease activity score set data, and in the meantime, facilitates the assessment of the children's adherence to therapy, functional abilities, comorbidities, and motivation on an individual basis [23]. This is important to monitor and record during transition to adult care, as there is a tendency toward increased disease activity. Furthermore, it is vital to use the same tool for evaluation during the preparation, transfer, integration as well as to assess for the outcomes [9]. Making use of new technologies including different applications, information videos and mobile messages may facilitate all stages of transition including preparatory stage, assessment of readiness, appointments, and assessment of completion of the transition process. Telehealth can also play an important role in the transition of care delivery particularly in the late-stage. Remote clinics, digital led—tailored care service as well as digital visual feedback can facilitate the delivery of the service and make the data meaningful [41].

In conclusion, adolescents/young adults living with chronic rheumatological diseases are at high risk of negative impact on their personal abilities with limitation in participation later in life, early morbidity, as well as disability. This cohort of patients are in need to regular and continuous care during the adolescence and beyond to ensure optimal outcomes in adulthood. There are significant gaps in current delivery of transition services. This is supported by earlier data which reported that nearly 50%

of the young adults do not achieve a successful transfer to adult rheumatology and consequently are at risk of adverse outcomes. The developed guideline offers adolescents and young adults a focussed, multidisciplinary transition of care approach with equity of access, quality of care, and flexibility. However, the model of care during transition should be tailored to the availability as well as location of both pediatric and adult rheumatology services. Pediatric health care provider should help young patients in choosing the adult care provider and give options if feasible. In developing countries especially in Middle Eastern countries, earlier preparation of children for transition is recommended due to the different age at which the actual transfer should occur. Involvement of authorities responsible for insurance is an important element for successful transition of care. This is vital to ensure continuity of treatment provision.

Abbreviations

CEBM	Centre for Evidence-based Medicine
CEG	Clinical, Evidence-based, Guidelines
JAMAR	Juvenile Arthritis Multidimensional Assessment Report
pGALS	Pediatric Gait, Arms, Legs and Spine
PICO	Patient/Population, Intervention, Comparison, and Outcomes.
PROMs	Patient-reported outcome measures
RCTs	Randomized controlled trials
TRAQ	Transition Readiness Assessment Questionnaire

Supplementary Information

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Additional file 1. Transition readiness youth.

Additional file 2. Transition to Adult Health Services Integrated Care Pathway.

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Authors' contributions

Conceptualization and design: YEM, MHA. Acquisition of data: YEM, MHA, ME, SAT, WH. Formal analysis: MEG. Investigation: HL and YEM. Methodology: all authors. Writing—original draft: YEM and MHA. Final approval of the version to be submitted: all authors.

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Availability of data and materials

The data will be available upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was performed in accordance with the Helsinki Declaration. The “Clinical, Evidence-based, Guidelines” (CEG) initiative protocol was approved the local ethical committee: ethical approval code: 34842/8/21, ethical board Tanta University. Written ethics approval from the experts sharing in this work was deemed unnecessary according to national regulations. As per the

Egyptian national Ethical Committee regulations, verbal informed consent was required from all the participants included in the study. All the participants were kept anonymous, in compliance with data protection regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare that Mohammed H Abu-Zaid is associate editor in the Egyptian Rheumatology and Rehabilitation, Waleed Hassan, Mohammed Mor-tada, and Yasser El Miedany are from editorial board of the journal. All other authors declare that they have no competing interests.

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