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ABSTRACT. The transition from pediatric to adult care is the focus of growing research. It is important to identify how to direct future research efforts for maximum effect. Our goals were to perform a scoping review of the transition literature, highlight gaps in transition research, and offer stakeholder guidance on the importance and feasibility of research questions designed to fill identified gaps. The transition literature on rheumatic diseases and other common pediatric-onset chronic diseases was grouped and summarized. Based on the findings, a survey was developed and disseminated to pediatric rheumatologists and young adults with rheumatic diseases as well as their caregivers. The transitional care needs of patients, healthcare teams, and caregivers is well described in the literature. While various transition readiness scales exist, no longitudinal posttransfer study confirms their predictive validity. Multiple outcome measures are used alone or in combination to define a successful transition or intervention. Multimodal interventions are most effective at improving transition-related outcomes. How broader health policy affects transition is poorly studied. Research questions that ranked highest for importance and feasibility included those related to identifying and tracking persons with psychosocial vulnerabilities or other risk factors for poor outcomes. Interventions surrounding improving self-efficacy and health literacy were also ranked highly. In contrast to healthcare teams (n = 107), young adults/caregivers (n = 23) prioritized research surrounding improved work, school, or social function. The relevant transition literature is summarized and future research questions prioritized, including the creation of processes to identify and support young adults vulnerable to poor outcomes.

Key Indexing Terms: pediatric transition to adult care, transfer from pediatric to adult care, transfer to adult care, transferring to adult care, transition to adult care

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The transition from pediatric to adult medical care is a vulnerable period for adolescents (ages 10-17 yrs) and young adults (ages 18-25 yrs).¹ Following transfer to adult care, young adults with chronic childhood-onset medical conditions are reported to have worse health outcomes, including increased rates of emergency room visits and hospitalizations²⁻⁴; nonadherence to care, loss to follow-up, and gaps in care⁴⁻⁹; poorer disease control and health-related complications including organ failure and death^{4,8,10,11}; school/work dysfunction¹²; and increases in healthcare costs. These complications are well described among young adults with rheumatic diseases (RDs), especially among those with systemic lupus erythematosus (SLE).^{4,7,8,10,11} Research related to the transition of adolescents and young adults (AYAs) with pediatric RDs to adult health care has increased in recent years, but significant gaps in knowledge remain.

Goals for this project, adapted from the Agency for Healthcare Research and Quality Prioritization Criteria Methods¹³ (Supplement A, available with the online version of this article), were the following: (1) Perform a scoping review of existing pediatric to adult healthcare transition research as it relates to specific childhood-onset chronic illnesses (RDs, inflammatory bowel disease, type 1 diabetes, sickle cell disease, cystic fibrosis, as well as transplant recipients). These conditions were selected based on the overlap between the transition-related challenges encountered by persons with RDs and those with other complex chronic conditions. (2) Identify transition research gaps based on the scoping review and articulate questions for research in discussion with stakeholders—clinicians, young adults, and parents involved in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Transition Workgroup. (3) Survey stakeholders to prioritize transition research questions by importance and feasibility.

In order to organize existing literature surrounding transition, we identified the following 6 key domains: (1) transition outcome measures, (2) transitional care needs (of patients, the healthcare team, and caregivers), (3) transition readiness, (4) transition education and self-efficacy, (5) transition interventions or programs, and (6) transition-related health policy.

METHODS

Search strategy. We used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) scoping reviews methodology.¹⁴ Database searches were conducted in PubMed and EMBASE to identify articles from January 2000 through November 2020 (Supplement B, available with the online version of this article). Searches for each domain were conducted separately, and articles could be included in more than 1 domain.

Abstract inclusion criteria. For each domain, 2 research team members independently reviewed abstracts from the literature search for inclusion in the full manuscript review. A third reviewer broke ties in case of disagreement. Articles included for full review were English-language abstracts reflecting full manuscripts published in peer-reviewed journals as original research that addressed a domain topic. Reviews, opinion pieces, consensus statements, and conference articles or abstracts were excluded.

Data extraction, synthesis, and analysis. Full manuscripts were reviewed by 2 research team members and summarized in a domain-specific charting table. Elements extracted for the charting table included study design, study population, sample size, outcome measure(s), intervention, key findings, and limitations. The key findings for each domain were synthesized and

summarized by subthemes. Finally, research gaps in the transition literature were underscored.

Survey development and dissemination. Two sessions were held among members of the CARRA Transition Workgroup, which discussed potential research questions based on the identified knowledge gaps. We then developed a 22-item survey to determine the importance and feasibility of transition-related research questions, which was reviewed by 2 young adults with RDs for clarity. We obtained institutional review board exemption from Boston Children's Hospital (protocol number IRB-P00039656) for survey distribution.

The survey was disseminated to all CARRA members by email invitation, with up to 2 email requests welcoming participation. Young adult and parent stakeholders were recruited by social media through the Arthritis Foundation and the Lupus Foundation of America. Survey participants responded anonymously and were asked to self-identify as healthcare providers, young adults with RDs, caregivers, or other. Participants were asked to rank research questions based on the importance of each item on a 5-point Likert scale (1 = least important; 5 = most important). Mean and SD were calculated; scores based on self-identified group (healthcare team member vs young adult/caregiver) were also computed.

A separate 10-member task force from the CARRA Transition Workgroup ranked the feasibility of conducting a study to answer each research question (1 = least feasible; 5 = most feasible).

RESULTS

The electronic database search yielded 1491 abstracts across the 6 domains, of which 271 were included in the final scoping review (Supplement C, available with the online version of this article). For space considerations, references in this manuscript were significantly limited. Please reference Supplement D for this same manuscript with full references included.

Domain 1: Transition outcome measures. There are no standardized pediatric to adult healthcare transition outcome measures to determine the success or failure of a specific transition process or intervention. Multiple transition outcome measures across several categories have been used alone or in combination in the transition literature (Table 1; Supplement E). These include process outcomes, healthcare utilization, healthcare coordination, cost of care, insurance-related outcomes, and disease and clinical outcome measures.^{2-11,15-40} For juvenile idiopathic arthritis or SLE, clinical outcome measures included standardized and self-reported disease activity measures, self-reported end-organ manifestations during the previous 12 months, cumulative disease manifestations, progression to endstage renal disease in SLE, and death.^{8,10,11,18,37-39} Additional outcome measures included patient or family satisfaction and perceived quality of care, psychosocial and quality of life outcomes, parental outcomes, and self-management outcomes, including medication and appointment-related adherence.^{4-10,12,17,24,26-29,32,35,37,38,40-49} Four Delphi method studies on outcome measures suggested composite outcomes from the above categories.^{40,43}

Domain 2: Transitional care needs. Patient, clinician, and caregiver transitional care needs are well described (Table 2; Supplement F, available with the online version of this article). From the patient perspective, during the transition to adult care, it is essential to address preparation for life-long disease self-management and the psychosocial and nonmedical logistical needs of AYAs.^{12,18,36,50-63} A structured transition plan with a clear point

Table 1. Transition outcome measures.

Process outcomes ¹⁵⁻¹⁷	Acceptability, feasibility (often defined in terms of recruitment, retention, or program fidelity), utilization of program components
Healthcare utilization ^{2,5,7-11,17-29}	Unscheduled hospitalizations, disease-related hospitalizations, length of stay, readmissions, severity of hospitalizations, ED visits, ED reliance (ED visits/[outpatient visits + ED visits]), clinic attendance, retention in care, no-show at first posttransfer visit, no-show rate, disease-related surgical procedures, radiological studies, laboratory use, and pharmacotherapy use
Healthcare coordination ^{4,18,24}	Time between pediatric and adult visits, gaps in care, loss to follow-up rates, proportion of patients explicitly tracked during transfer, communication and coordination between pediatric and adult clinicians
Cost of care ^{19,24,30}	Cost per patient per year, cost of hospitalizations, surgery or medications; cost as function of length of stay for hospitalizations; cost-effectiveness
Insurance-related outcomes ^{10,31}	Loss of insurance rates, insurance rates at discharge from hospitalization
Disease and clinical outcomes ^{6,8,10,11,18,19,21,22,24-30,32-40}	Control of disease, acute and chronic disease complications, screening rates for complications, disease activity measures, disease remission, stable disease trajectory, disease exacerbations, cumulative disease manifestations, end-organ manifestations, need for surgical interventions, mortality, hospitalized deaths, need for escalating medications, continued use of medications posttransfer
Perceived quality and care satisfaction ^{28,32,37,40-44}	Perceived patient-centered communication, patient-centeredness, trust in adult and pediatric care clinicians, starting transition planning at an early age, patient satisfaction with pediatric or adult programs or with transition process, family experience of care
QOL and psychosocial outcomes ^{4,8,10,12,24,26,27,29,38,40,45,46}	Health-related QOL, global QOL, physical and psychological well-being, emotional and social functioning, global life satisfaction, quality of relationships with parents and clinicians, employment or vocational status, educational status, participation in adult life, perceived life stress, anxiety surrounding transition
Parental outcomes ^{45,46}	Promotion of independence, parental level of behavioral control, balance of parental support and autonomy
Adherence to medications, appointments, and other self-management outcomes ^{5-7,9,17,24,26-28,35,37,40-49}	Medication levels, filled prescriptions, proportion of medication days covered, self-reported or documented medication nonadherence, visit attendance rates, show rate at first and second adult visits, reported self-efficacy, self-management and independence, developmentally based skills, interdependent communication, decision making, disease-related knowledge

ED: emergency department; QOL: quality of life.

of contact is important, with early discussions about transition, recognition of adult care expectations, and positive yet realistic perceptions of adult care.^{51,52,57,59,60,64} Direction from the pediatric team in finding an adult clinician is valuable, ideally with a shared clinic appointment with all key stakeholders in a developmentally appropriate setting.^{18,51-53,55} A supportive family, with decreased parental involvement over time is also influential for long-term success.^{50,51,53,55}

Risk factors for poor transition outcomes include distance to an adult specialty center, transfer to adult care in a different city, public or no insurance, SLE diagnosis, Black race, social complexity, a high degree of stressful life circumstances, and uncontrolled disease prior to transfer.^{18,36}

Clinicians favor transition programs that are formalized and accompanied by established protocols, a trained multidisciplinary team, institutional support, funding for transition services, and collaboration between pediatric and adult teams.^{52-54,59,60,62,65-69}

Caregivers desire early discussions on how best to support a child's development over time, as well as education about confidentiality, the transition and transfer processes, and the differences in pediatric and adult care cultures.^{59,60,64,70}

Domain 3: Transition readiness. Transition readiness refers to indicators that AYAs can begin and successfully complete the transition process. There were several subthemes under the domain of transition readiness (Table 3; Supplement G, available with the online version of this article). With the exception of 1 longitudinal study,⁷¹ all studies describing transition

readiness were cross-sectional. Predictors of transition readiness (often, though not exclusively, as determined by scores in validated transition readiness assessment tools such as the Transition Readiness Assessment Questionnaire [TRAQ] or TRxANSITION Scale) included self-efficacy, demographic variables, greater responsibility/lower parental involvement, family cohesion, provider communication, and higher adherence.⁷¹⁻⁸² However, these variables were less important after accounting for the individual psychosocial resilience and self-efficacy of AYAs.⁷²⁻⁷⁴ Developmental maturity and executive functioning are also important considerations for all AYAs when considering transition preparedness.⁸³ Several transition readiness assessment tools were described, both disease-specific tools and general assessments.^{84,85} The only longitudinal study on transition readiness revealed that baseline TRAQ scores did not predict transfer or time to transfer over a 3-year period.⁷¹

Domain 4: Education and self-efficacy. Meaningful outcomes associated with higher educational attainment and self-efficacy included an improved transition experience and disease control.⁸⁶ Thus, optimizing patient educational goals and building self-efficacy were important themes in the transition literature (Table 4; Supplement H, available with the online version of this article).

Multiple educational interventions were described including group educational sessions,⁸⁷ educational handouts,⁸⁸ workshops,⁸⁹ nurse-led efforts,⁹⁰ and tool kits.⁹¹ These generally resulted in improved transition readiness⁹¹ and competency,⁸⁹ medical knowledge,⁹² life-related skills,⁸⁸ patient satisfaction,⁹⁰

Table 2. Transitional care needs.

Patient needs	Preparation for disease self-management, self-advocacy, self-efficacy, graduated independence ⁵⁰⁻⁵⁷ Addressing psychosocial, mental health, life skills, and vocational needs ^{12,36,50,55,59-63} Addressing insurance, logistical, and transportation needs ^{18,54,57} Considering the emotional impact of leaving pediatrics and restarting in adult care Education regarding disease, medications, high-risk behaviors ^{58,59} Structured, clear, individualized transition process ^{52,59} Transition discussions starting early during the transition process ^{51,57,64} Transition coordinator or clear point of contact during transfer process Developmentally appropriate interactions with clinicians, adolescent space ^{51,52,55} Caregiver modeling of involvement with health care and how to engage with healthcare team ⁵⁰ Optimally involved and supportive family ^{50,51,53} High-quality maternal relationship without overprotection ⁵⁵ Awareness of adult systems' expectations and differences in care ⁶⁰ Positive, realistic perception of adult care, trust/confidence in adult clinician Direction/help from pediatric team in finding an adult physician, care coordination ^{18,53} Meeting adult physician prior to transfer, introduction by pediatrics ⁵³ Patient characteristics: resourceful, resilient, interdependent, optimal coping skills ⁵⁰ Peer and social support, mentors ^{50,60} Presence of medical home
Clinician needs	Program resources, time; multidisciplinary, coordinated team trained in transition; transition coordinator ^{52,54,59,60,62,65-68} Established transition protocols and structured procedures ⁵⁹ Leadership from systems, institutional/administrative support ^{52,66} National approach to transition, ⁶⁰ funding and reimbursement for transition services ^{66,68} Pediatric clinician: learning how to bring therapeutic relationship to an end Adult clinician: receipt of medical summary, psychosocial summary ⁶⁸ Pediatric and adult clinicians understanding and respecting each other's perspective, subcultures, and care constraints ^{52,53} Collaboration and communication between adult and pediatric clinicians, adult clinicians willing to accept patients ^{52,53,65,68,69} Teaching material that is developmentally appropriate ⁵⁴ Transition training and practice in communicating with families and other clinicians for practicing physicians, junior doctors, and trainees ^{54,68,69}
Caregiver needs	Early discussion of transition and expectation of parents, expected role change, and concrete guidance on how to support child's development of self-management skills and graduated independence ^{55,59,64} Education about medical confidentiality in adulthood, ⁶⁴ information about transition Pediatric team to take a more directive role on patient autonomy Positive and realistic perception of adult care, awareness of differences in care cultures ⁶⁰ Appropriate level of inclusion in adult care with balanced family support ^{50,51,53} Recognition of child's appropriate developmental needs, discussion of transition as a family Support systems for parents of adolescents and young adults, peer/group sessions for parents ⁷⁰

improved medication adherence and led to variable improvements in disease control.⁹⁰ Technology-based educational interventions were also described including computer-based or online modules,^{17,93,94} telehealth sessions,¹⁵ and interactive tablet quiz games.⁹⁵ Results ranged from no change in appointment adherence or self-management confidence ratings^{17,94} to increased transition readiness and self-management skills acquisition,¹⁵ and improved adherence, self-efficacy, and empowerment for those who actively contributed to a social media intervention.⁹³

Interventions designed to improve self-efficacy or self-management included a tool kit promoting organization and goal setting, a transition coordinator focused on improving self-management,⁹⁶ a randomized trial of a problem-solving skills training on medication adherence delivered by telephone,⁹⁷ and an educational and case management-based group intervention. These interventions had variable outcomes, ranging from improvement in trust without change in self-management related outcomes, to modest improvements in adherence,⁹⁷ to significant increases in self-management skills acquisition and disease remission.^{96,98-101}

Domain 5: Transition interventions. We reviewed transition interventions beyond the education/self-efficacy interventions described above (Table 5; Supplement I, available with the online version of this article). Specialized or combined transition clinics were described, some with a multidisciplinary team^{19,30,34,42,62} and most including both a pediatric and adult clinician.^{25,42,102} These resulted in high patient/parent satisfaction,^{42,62,102,103} high rates of retention in adult care,^{62,102} posttransfer disease remission or disease control,²⁵ high adherence, improved rates of hospitalizations,¹⁹ decreased death or allograft failure posttransfer,³⁰ and greater cost-effectiveness.^{19,30} While most revealed favorable outcomes, some transition clinic interventions did not demonstrate an improvement in adherence, change in clinical outcomes,^{34,103} or consistent improvements in healthcare utilization outcomes.

Interventions focused on scheduling appointments in adult care had variable results, either not changing rates of disengagement posttransfer¹⁰⁴ or improving dropout rates in adult care.¹⁰⁵ Similarly, interventions centered on the role of a transition

Table 3. Transition readiness.

Predictors of transition readiness (cross-sectional studies) ⁷¹⁻⁸³	Self-efficacy, resilience, patient activation, self-care beliefs, self-management competency, hopeful future expectation, self-advocacy Demographic variables: older age, female gender, White race, private insurance Greater adolescent responsibility, decreased parental involvement in completing medical tasks, better academic performance, higher executive functioning, more developmental maturity Family cohesion, parent and friend knowledge/helpfulness, family support Higher patient-provider transition communication, favoring healthcare provider as source of medical information Greater adherence, especially medication adherence, fewer emergency department visits
Factors not associated with transition readiness (cross-sectional studies) ⁷²⁻⁷⁴	After consideration of self-efficacy and resilience, no demographic, disease, or socioeconomic parameter informed transition readiness scores Length of time with diagnosis, disease groups, Physician Global Assessment, patient/parent disease management confidence rating Parent/guardian characteristics
Components of transition readiness ^{76,86}	Health literacy-related readiness for transition Independent self-management Self-efficacy and psychological maturity Skills in money management, living arrangements, vocational skills
Gaps in transition readiness skills ⁵⁸	Some Health Care Transition Skills Not Mastered Until \geq age 18, including self-management skills Communication with medical team did not improve with age (for those aged 10-21 yrs) Low scores in knowledge of health insurance Knowledge gaps in medication dosages, potential side effects, scheduling appointments, appointment keeping
Discrepancies in transition assessments ⁸⁴	No studies show the predictive validity of transition readiness assessment tools Baseline transition readiness scores do not predict time to transfer There are discrepancies between physician, patient, and caregiver ratings in self-care skills management and readiness to assume responsibility

coordinator were inconsistent. Some demonstrated improved patient satisfaction,^{41,106} transfer rates,⁴¹ disease control,^{96,106} medication adherence, and hospitalizations.¹⁰⁶ One transition coordinator-based intervention demonstrated improvement in patient satisfaction and clinic attendance during the study period, but not 1 year following the intervention.^{28,107} Other interventions resulted in no change in retention rates in adult care, disease control,²⁹ or medication adherence. Only 1 study reported on transition-related interventions focused on a learning network for healthcare systems, which led to improvements in care. Educational interventions (Table 4) demonstrated positive results.^{15,17,48,88,89,90,98}

The most effective interventions described several components implemented simultaneously. Multimodal interventions resulted in improved clinical and disease outcomes,^{26,27} post-transfer retention in care,^{21,44} shorter duration of transfer,¹⁰⁸ improved medication adherence,¹⁰⁸ reductions in stress and improvements in well-being,^{16,27,45,46,109} self-efficacy and self-advocacy,⁴⁴ improved healthcare utilization variables,^{21,26} satisfaction with care,^{16,44,109} and improved process outcomes.¹¹⁰ All multimodal interventions resulted in improvement in some aspect of care, although 1 only resulted in improvements to documentation rather than transitional milestones¹¹⁰ and some resulted in no change to hospitalizations or other utilization variables, disease control,²¹ medication adherence,^{45,46} or disease knowledge. Some interventions experienced significant feasibility and sustainability challenges.^{16,109}

Domain 6: Health policy. Very few studies addressed broader health policies and their effect on AYAs' transition to adult care.^{31,111,112} One analysis of hospitalized patients did identify

improvements in uninsured hospitalized young adults in the US following the implementation of the Affordable Care Act.³¹

Gaps in Transition Research. In summarizing the pediatric to adult healthcare transition literature, it became evident that gaps in research remain within each domain. While multiple outcome measures have been used, no study evaluated clinician satisfaction and few addressed how disease-related functioning and disability impact young adults longitudinally.^{10,12,40} The literature describes patients', clinicians', and caregivers' needs during the transition process well, but the needs of healthcare organization leaders, administrators, and payors surrounding transition efforts were very rarely addressed.¹¹² A rapid way to identify and track AYAs at risk for poor outcomes during the transition to adult care has not been established. For instance, a scoring system that accounts for social determinants of health has not been validated. Despite the myriad of studies on transition readiness, no transition assessment tool has been studied longitudinally posttransfer or has been shown to predict post-transfer outcomes.

There were no educational interventions described for parents, and very few studies focused on the importance of health literacy for transition.⁷⁶ The role of community organizations in fostering education during the transition process is also poorly studied. While a few studies described self-efficacy as an outcome measure,^{96,98} it was unclear whether higher levels of self-efficacy are predictive of longitudinal successful posttransfer outcomes.^{49,99}

Multimodal interventions were found to be most effective, but it was difficult to separate which components of an intervention were most important and relevant. Many of the

Table 4. Education and self-efficacy.

Education and transition-related outcomes ^{32,76,99-101}	Higher disease-related knowledge was associated with older age, greater healthcare satisfaction, higher self-efficacy, and more frequent patient–provider communication Adolescents with more education had more knowledge of testing and medications Medication knowledge was associated with better adherence only for certain medications Anticipatory healthcare education resulted in increased satisfaction with care and health Health literacy-related readiness for transition was very low and overestimated by clinicians
Educational interventions and outcomes ⁸⁰	Preferred learning methods of young adults included clear transition information communicated through mobile ⁸⁷⁻⁹² technology, one-on-one instruction, handouts, and websites Quarterly educational sessions improved medical knowledge scores and medication adherence Skills-based educational handouts improved skills deficits in certain areas Educational interventions taking psychosocial factors into account improved health outcomes Educational tool kits improved disease and preparedness knowledge Transition workshops improved transition competence and self-efficacy Nurse-led consultations in pediatric and adult care had high satisfaction but low improvements in disease control
Educational interventions using technology ^{15,17,32,93-95,99}	Computer-based education modules did not improve adherence posttransfer An in-person group session followed by individual telehealth sessions increased skill acquisition, disease knowledge, and transfer readiness An 8-session online educational intervention improved adherence and self-efficacy, but only if participants provided responses to the sessions in a social media forum Completion of more web-based modules correlated with improved disease knowledge but not self-management confidence ratings
Self-efficacy ^{49,57,72,75,86,99,101}	Self-efficacy influenced the transition experience and higher autonomous motivation was associated with perceived knowledge and positive attitude toward HCT preparation Better disease control was associated with self-efficacy, resilience, and higher quality of life Problem-solving and self-advocacy skills were associated with better disease control Those with stable vs unstable HCT had higher resilience and interdependence Self-efficacy was associated with intentional self-regulation and hopeful future expectation Self-efficacy was associated with higher psychosocial quality of life scores and also with independent living skills, education/vocation planning, and transition readiness scores Some self-management skills improved with age; self-advocacy and communication did not improve with age Medication adherence and clinical remission were more important than self-efficacy scores in predicting posttransfer outcomes
Caregivers and self-efficacy ¹⁰⁰	Higher adherence was associated with better maternal relationship quality Parental modeling was important but parent involvement in completing medical tasks decreased readiness to transition Self-efficacy and self-management ratings were often consistent among patients, caregivers, and clinicians
Interventions to improve self-efficacy or self-management ⁹⁶⁻⁹⁸	Transition coordinator for self-management increased skills acquisition and disease remission Transition clinic improved satisfaction and trust in physician but not self-management Problem-solving training on medication adherence by phone-delivered sessions modestly improved adherence among those with imperfect baseline adherence Some online tools to promote self-management had modest utility but intensive web- and text-delivered interventions on disease management and skills building improved self-efficacy and disease-management tasks

HCT: healthcare transition.

interventions used proximal outcomes to determine success, and few interventions measured cost-effectiveness.^{19,30} While 1 study focused an intervention on AYAs with more complex disease, most did not specifically address the effect of interventions on people with complex medical and psychosocial needs. Only 1 study reported on a telehealth intervention.¹⁵ No study was designed to ensure equity in delivery of services or addressed implementation of complex interventions in settings with few resources.

Several opportunities for pediatric to adult healthcare transition research were recognized in the realm of health policy, including the need to investigate the effects of the Affordable Care Act on insurance and retention rates in adult care. It also remains to be seen whether the introduction of Current

Procedural Terminology transition-related billing codes affects the provision of transitional care.¹¹³ There is no literature to date investigating the effect of insurance policies (eg, financial incentives for joint pediatric/adult transition clinics) or government mandates on transition-related care.

Survey of transition research priorities. A survey of transition research questions was formulated based on our identified gaps in transition research (Supplement J, available with the online version of this article). Between October and November 2021, all 509 CARRA members were invited to complete the survey, ranking the importance of each research question. There were 107 respondents recruited through the CARRA network: 103 healthcare team members, 1 researcher who did not self-identify as a healthcare provider, and 3 healthcare team members who

Table 5. Transition interventions.

Transition clinics or joint clinics ^{19,25,30,34,42,62,102,103}	<p>Patient/family satisfaction was high or improved in all studies that reported patient satisfaction</p> <p>Some studies demonstrated improved disease control or remission</p> <p>One study reported on improvement in mortality and 2 on cost-effectiveness</p> <p>Studies reporting on hospitalizations noted trend toward or lower hospitalizations</p> <p>Improvements were noted in clinic attendance rates/retention in adult care if the patient met the adult clinician prior to transfer and if guided by pediatrician</p> <p>Mixed results in studies that reported medication adherence</p>
Appointment aid ^{104,105}	<p>Systems navigator or appointment manager/rebooking of missed appointment had variable success in retention of care</p>
Transition coordinator ^{28,29,41,96,106,107}	<p>In 2 studies, a transition coordinator did not improve medication adherence or retention in care when only present in pediatric care</p> <p>In 1 study, a transition coordinator that spanned pediatric and adult care improved clinic attendance and patient satisfaction during the program, but not 12 months postintervention</p> <p>In 4 studies, interventions with a transition coordinator who provided several services (including education, an individualized transition plan, appointment-making, after-hours phone support service) resulted in improvements in transfer rates, disease control, and decreased hospitalizations (depending on study)</p>
System-wide interventions	<p>A learning network of healthcare systems with local qualitative improvement project teams and senior leadership support led to improvements in transition care</p>
Educational interventions ^{15,17,48,88,89,90,98}	<p>8 of 11 educational interventions led to improved outcomes (improved self-efficacy, transition competence, quality of life, disease management, self-management skills, reduced non-adherence)</p> <p>2 of 11 interventions showed no effect on medication non-adherence or self-management skills</p> <p>1 of 11 interventions demonstrated high satisfaction but no change in disease control</p>
Multimodal interventions ^{16,21,26,27,44-46,108-110}	<p>22 of 23 studies that included multi-component interventions (including among other interventions: patient/family education, joint visits with adult/pediatric clinicians, standardized transition protocols, individualized transition plans, case management, transition navigator, workshops, group and individual sessions with a psychologist, a multidisciplinary team to address patients' psychosocial needs, consultation partly alone with the adolescent, a young adult clinic, parental guidance, staff training) were successful (resulting in improved disease control, less disease complications, improved medication adherence, higher post-transfer clinic attendance rates, decreased hospitalizations and readmissions, increased patient retention in adult care, improved well-being and health-related quality of life, higher self-efficacy scores, improved patient satisfaction, or optimized parenting climate)</p> <p>8 of 23 interventions were noted to have several meaningful clinical outcomes but also reported feasibility challenges, low uptake of full program, continued poor disease knowledge, no improvement in disease control, no changes in hospitalizations, or no changes in medication adherence (ie, not all outcomes met)</p> <p>1 of 23 interventions resulted in improved documentation of transition-related issues but no meaningful improvement in clinical outcomes</p>

also reported a history of childhood-onset RDs (whose responses were grouped with healthcare team members). There were 23 participants recruited through social media, of whom 21 were adults with RDs and 2 were caregivers.

Simultaneously, a 10-member volunteer task force that included clinicians and researchers as well as a young adult and a parent met to rank the feasibility of each research question. Feasibility was ranked by this expert task force only.

Survey results (Figure) comprise 4 ranked sets: more important and more feasible, more important but less feasible, less important but more feasible, and less important and less feasible. Accounting for all responses, the more important and relatively more feasible transition research questions address identifying, tracking, and improving outcomes for young people with psychosocial vulnerabilities and other risk factors for poor outcomes. In addition, interventions focused on improving self-efficacy and health literacy were rated highly in importance and feasibility.

We found differences in importance rankings based on self-reported group (healthcare team member vs young adults/

caregivers; Figure). Given the very small number of caregivers who responded, young adults and caregiver responses were grouped together. For young adults/caregivers, the top research priorities were related to evaluating or improving work, school, and social functioning. In comparison, healthcare team members prioritized identification of young people at high risk for poor outcomes, understanding the contribution of psychosocial determinants of health to transition outcomes, and tracking at-risk patients.

DISCUSSION

In this scoping review of transition-related research relevant to AYAs with RDs, we summarized the transition literature across 6 key domains. We identified gaps in transition research and performed a survey of clinical team members as well as individuals with RDs and their caregivers. The research questions that were ranked highest in importance and feasibility were those related to identifying and tracking patients with psychosocial vulnerabilities and at high risk for poor outcomes. Young adults and their caregivers, in particular, ranked research questions

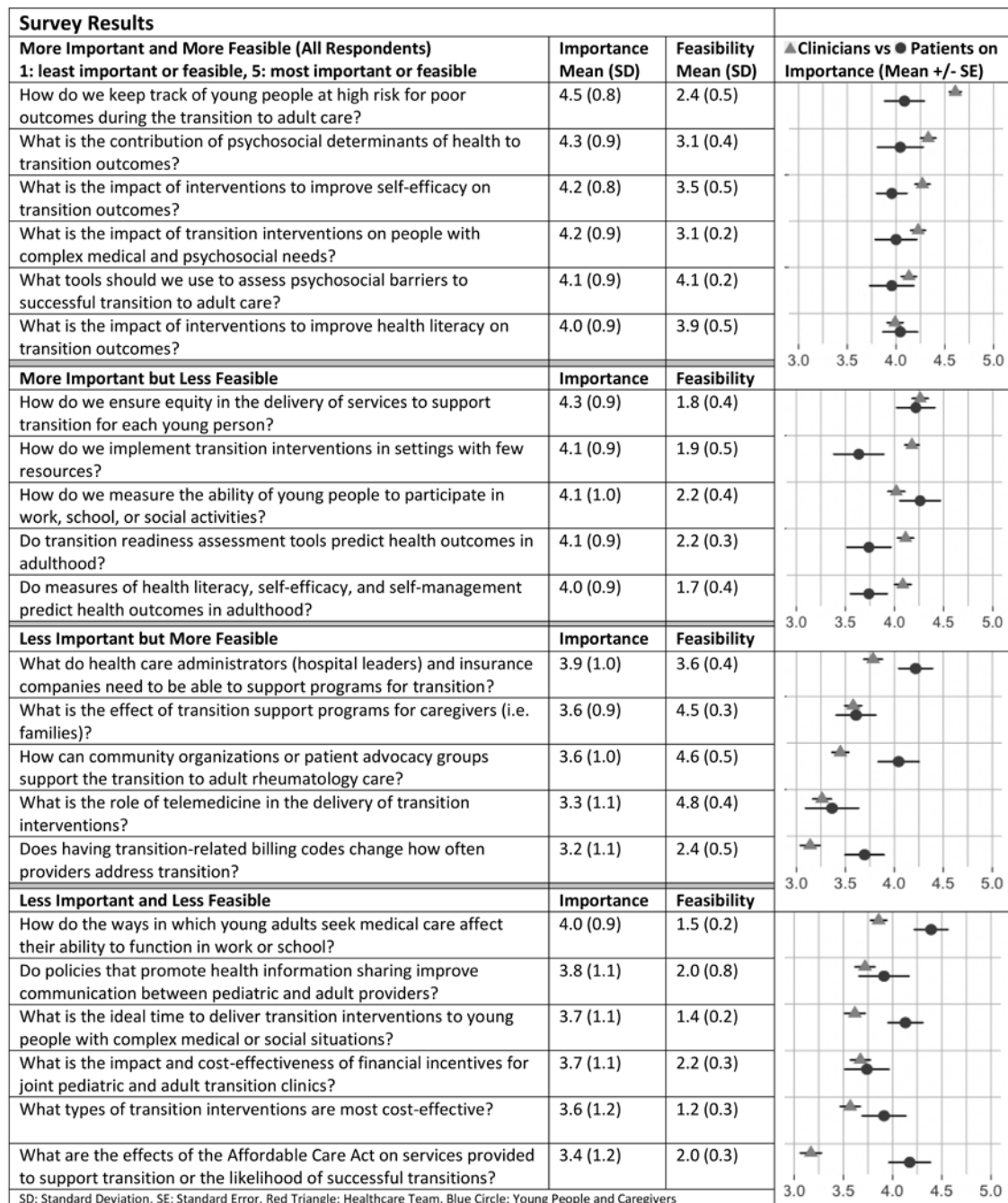


Figure. Survey results.

assessing the determinants of work, school, or social functioning highest in importance; however, studies aimed at answering these questions may require more creative study designs to conduct based on lower feasibility scores. In the following paragraphs, we discuss several opportunity areas with high priority, including social functioning, predictors of adult outcomes beyond transition readiness, delivery of educational or self-efficacy interventions, effects of health policies, and tools to track high-risk individuals.

We found that multiple transition-related outcome measures have been used alone or in combination to define a successful

transition or intervention. There are no standardized measures in this field of research, as has been noted by other reviews.¹¹⁴ A systematic review of transition research identified that only 3 studies used outcome measures across all domains of the triple aim of healthcare framework (patient experience of care, population health, and cost of care).¹¹⁵ Most commonly, population health measures are used to define outcomes.¹¹⁵ Inclusion of quality of life outcomes in this category is an important goal.¹¹⁶ Given differences in diseases, populations, and program resources, use of standardized measures across all transition-related studies may not be realistic in real-world situations. However, using a

combination of outcome measures such as those defined by the quadruple aim of health care (which adds to the triple aim of health care by including the experience of providing care¹¹⁷) may be the ideal approach for future research studies in AYAs with RDs. Based on our survey results, future studies should also aim to include outcomes that address functioning of young adults in work, school, and social settings.

A review of factors associated with transition readiness¹¹⁸ identified several modifiable factors, including self-management and transition education, and nonmodifiable factors, including demographic, ecological, and disease factors. Our review further demonstrates the lack of longitudinal studies of outcomes after transfer to adult care confirming the predictive validity of published transition readiness scales. Future studies will need to explore whether tools that measure health literacy, self-efficacy, patient activation, self-management, or other psychosocial determinants of health are better predictors of transition-related outcomes in adulthood.

Transition education and self-efficacy are important themes in the literature that are potentially modifiable. Self-management skills, trust in adult care, sense of self-efficacy, social support, sociodemographic status, and interdisciplinary cooperation were identified as important factors influencing transition within an integrative framework in 1 review.¹¹⁹ Others have also concluded that knowledge and education are key facilitators to a successful transition for AYAs with childhood cancers,¹²⁰ in agreement with our findings. Fortunately, effective interventions to improve education and self-efficacy have been described and can be implemented by individual institutions or on a broader scale to benefit AYAs with RDs. How community organizations can partner with health systems to effectively promote education of young adults during the transition period will require further study.

While education and other needs of patients, healthcare teams, and caregivers are well described in the literature, health policy as it relates to transition is a vastly underresearched topic, particularly in the US.¹¹³ There are rich opportunities for research in this area, especially utilizing large or administrative datasets.

Systematic reviews of transition interventions with statistically significant positive outcomes reveal that structured transition interventions improve outcomes.¹²¹ Successful studies describe transfer assistance and often include transition planning support and integration into adult care.¹²² Similarly, we found that multimodal interventions are the most effective in improving transition-related outcomes, although the current literature does not identify the critical component(s) of multimodal interventions. Further, the field is lacking evidence as to how healthcare teams can target interventions to those AYAs at highest-risk for poor outcomes. Therefore, next steps include developing mechanisms for identifying and tracking AYAs with RDs at risk for poor transition outcomes before, during, and after transition interventions. Tools to do so may consider incorporating known determinants of care gaps and poor outcomes¹²³ to identify at-risk AYAs. As pediatric to adult care transition interventions are often complex, unique ways of evaluating them may be necessary.

There is overlap between the results of our survey and surveys of stakeholders involved in the care of Children and Youth with Special Health Care Needs (CYSHCN) program, who also prioritize research topics centered on social determinants of health and transition of care.¹²⁴ A national research agenda on transition for CYSHCN recommended investigation of service models in partnership with youth and families, defining process and outcome measures, and evaluating fiscal policies to incentivize improved transitional care.¹²⁵ While healthcare team members and young adults or their caregivers responding to our survey largely agreed regarding transition research priorities, there were also meaningful distinctions between the 2 groups. Research questions addressing psychosocial vulnerabilities, implementing interventions in settings with few resources, and measuring the effect of self-efficacy ranked as more important to healthcare team members compared to young adults and their caregivers. Meanwhile, young adults and their caregivers tended to rank research assessing the importance of healthcare policies and community organizations higher than healthcare team members. Top-ranked priorities for young adults and their caregivers pertained to work, school, and social function. Collectively, these rankings chart a course for future patient-oriented research in transition.

The results of our survey are limited in several ways. First, there were fewer young adults, and particularly caregivers, who responded compared to healthcare team members, which could affect generalizability. Given that most respondents outside of the CARRA network were recruited through social media, their RDs were self-reported rather than clinician-verified and no further demographic information was obtained from these individuals. Finally, the research prioritization efforts were offered primarily by pediatric rheumatology providers, with limited input from adult rheumatologists or other adult allied health members. Nevertheless, this is the first published survey, to our knowledge, that captures both clinician and patient/caregiver opinion regarding research prioritization. An additional strength is the dual categorization of research questions regarding both importance and feasibility.

We herein summarized the current state of the literature relevant to healthcare transition for AYAs with childhood-onset chronic illnesses. In addition to identifying remaining research questions in this field, we provide a useful construct for understanding the prioritization of these questions for rheumatology healthcare teams as well as for young adults living with pediatric RDs and their caregivers. This prioritized research agenda can inform and guide the design of future research aimed at improving transition from pediatric to adult rheumatology care.

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ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

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