Transitioning Youth with Rheumatic Conditions: Perspectives of Pediatric Rheumatology Providers in the United States and Canada

Peter Chira, Tova Ronis, Stacy Ardoin, and Patience White

ABSTRACT. ***Objective.*** To assess North American pediatric rheumatology providers' perspectives on practices, barriers, and opportunities concerning the transition from pediatric-centered to adult-centered care.

Methods. Childhood Arthritis and Rheumatology Research Alliance (CARRA) members completed a 25-item survey assessing current transition practices, transition policy awareness, and transitional care barriers and needs. Results were compared to the American Academy of Pediatrics (AAP) 2008 survey on transitional care.

Results. Over half (158/288, 55%) of CARRA members completed the survey. Fewer than 10% are very familiar with AAP guidelines about transition care for youth with special healthcare needs. Eight percent have a formal written transition policy, but 42% use an informal approach. Patient request (75%) most frequently initiates transfer to adult care. Two major barriers to transition are fragmented adult medical care and lack of sufficient time to provide services. Compared with AAP survey participants, pediatric rheumatology providers are significantly more likely to help youth find an adult specialist (63% vs 45%) and discuss confidentiality and consent before age 18 (45% vs 33%), but are less likely to help with medical summary creation (16% vs 27%) or find a primary care provider (25% vs 47%). Outcomes ranked as "very important" in defining a successful transition are survival (76%), seeing an adult rheumatologist within 6 months of final pediatric rheumatology visit (66%), and maintaining insurance coverage (57%).

Conclusion. This comprehensive survey of North American pediatric rheumatology providers regarding transitional care practices demonstrates deficiencies in education, resources, and a formalized process. Respondents support development of standardized rheumatology-specific transition practices. (First Release March 1 2014; J Rheumatol 2014;41:768–79; doi:10.3899/jrheum.130615)

Key Indexing Terms:
PEDIATRIC RHEUMATOLOGY PRACTICE GUIDELINES SURVEYS
TRANSITIONAL CARE ADOLESCENTS

In the United States, about 300,000 children under 18 years of age have a rheumatic illness such as juvenile idiopathic arthritis (JIA) or systemic lupus erythematosus[1]. In Canada, the estimated prevalence of adolescents ages 12–19 years with arthritis or rheumatism is 7 per 1000 (which may be higher than previous estimates because the definition included chronic back pain and pain syndromes) using the 1996 National Population Health Survey[2]. With 10-year survival rates at 99.7%, the vast majority of youth with rheumatic conditions are surviving into adulthood, stressing the importance of adequately preparing these patients for the adult healthcare system[3].

About 12.8% to 19.3% of children and adolescents in the United States have special healthcare needs (SHCN), as defined by "those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"[4,5]. The majority of these individuals are surviving into adulthood, prompting attention to ensure continued high-quality medical care into adulthood for adolescents and young adults (known collectively as youth) with SHCN and highlighting the need for transitional care best practices[5,6]. Transition is defined by the Society of

From the Department of Pediatrics, Section of Pediatric Rheumatology, Indiana University School of Medicine, Indianapolis, Indiana; Department of Pediatrics, Pediatric Rheumatology Division, George Washington University School of Medicine, Washington, DC; Departments of Medicine and Pediatrics, Adult and Pediatric Rheumatology, Ohio State University, Columbus, Ohio; Joint Health and Autoimmune Diseases, George Washington University School of Medicine and Health Sciences and the Arthritis Foundation, Washington, DC, USA.

P. Chira, MD, MS, Assistant Professor of Clinical Pediatrics, Department of Pediatrics, Section of Pediatric Rheumatology, Indiana University School of Medicine; T. Ronis, MD, Assistant Professor of Pediatrics, Department of Pediatrics, Pediatric Rheumatology Division, George Washington University School of Medicine; S. Ardoin, MD, MSc, Assistant Professor of Medicine and Pediatrics, Departments of Medicine and Pediatrics, Adult and Pediatric Rheumatology, Ohio State University; P. White, MD, MA, Professor of Medicine and of Pediatrics, Joint Health and Autoimmune Diseases, George Washington University School of Medicine and Health Sciences and the Arthritis Foundation.

Address correspondence to Dr. P. Chira, Indiana University School of Medicine, Riley Hospital for Children, 699 Riley Hospital Drive, RR 307, Indianapolis, Indiana 46202, USA. E-mail: pchira@iu.edu

Accepted for publication November 12, 2013.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

Adolescent Health and Medicine (SAHM) as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems"[7]. Optimally, transition is a gradual process, which over time promotes youth's self-care skills and medical independence. Unfortunately, addressing transitional care for youth with SHCN is not standardized and often occurs abruptly at the time of transfer to the new adult care provider without adequate preparation of the youth, their families, and the pediatric and adult providers for the changes involved[8,9].

Despite acknowledgment of the importance of transitional care of youth with SHCN, pediatricians in the United States often feel ill-prepared to deal with the complexities of caring for adolescents and young adults with and without SHCN, as highlighted by a 2008 survey of American Academy of Pediatrics (AAP) members[10,11]. This AAP survey included a broad set of questions on adolescent healthcare and was sent to a random sample of 1605 US working members, which included general pediatricians and pediatrics subspecialists. Within this sample, 628 respondents provided health supervision to patients ages 12 years and above, and the survey achieved a 64% response rate[10,11]. The survey revealed that pediatricians often find it difficult to break the patient-provider bond with patients; do not have adequate time, defined practice processes, or resources to address transition concerns; and do not have the necessary training to deal with the complex care issues for youth as they transition into adulthood.

Research from the United Kingdom demonstrates that rheumatologists who care for adolescents with rheumatic diseases lack familiarity and knowledge regarding transition and outlines the systematic challenges of how to best implement transition services into clinical practice[12,13]. There has not been a comprehensive survey among pediatric rheumatology providers in the United States and Canada about transitional care. The purpose of our study was to assess North American pediatric rheumatology providers' current transition practices; knowledge about transition policies; barriers and opportunities to implement transitional care; and the prospects to improve transition through evaluation.

MATERIAL AND METHODS

A 25-question online survey was administered in April 2010 to members of the Childhood Arthritis and Rheumatology Research Alliance (CARRA), a research network comprising primarily pediatric rheumatologists in Canada and the United States. In April 2010, CARRA included 288 total members (208 board certified or board eligible pediatric rheumatologists, 71 trainees, and 9 affiliated researchers or allied healthcare professionals). Most practicing pediatric rheumatologists in the United States and Canada belong to CARRA. We administered the online questionnaire using Survey Monkey. The cross-sectional survey was submitted but exempted from human subjects review at Stanford University.

Several questions were based on the AAP 2008 survey on transitional care (Appendix 1), and assessed current practices and knowledge about transition policies. Our survey also inquired about outcome measures providers felt were important for tracking transition and its success (Appendix 2). Survey questions were not pilot-tested but were screened, edited, and chosen by the authors (except TR) and 2 other pediatric rheumatologists at Stanford University to assure clarity and ease of administration online. The questions did not have input from patients, families, or other staff members associated with the transition process. Descriptive statistics are presented. Results acquired from surveyed CARRA pediatric rheumatologists were compared to responses from the AAP 2008 survey on transitional care, when applicable, using comparisons of differences between proportions z test statistical analysis, assuming independence of the 2 cohorts (using a 99% CI and $\alpha = 0.01$, given the multiple comparisons being made)[14,15].

RESULTS

Respondent demographics and characteristics. The survey was e-mailed to the CARRA membership as of April 2010 (n = 288), and 158/288 responded (55% response rate). Two followup reminder e-mails prompted members to complete the online questionnaire over a 2-month period. Respondents' demographic and practice characteristics are summarized in Table 1, with 74 different sites responding, and respondents per site ranging between 1 and 6 providers. The majority of respondents (89%) work in a university-affiliated practice, and within this subgroup about one-third reported access to a structured, multidisciplinary transition

Table 1. Childhood Arthritis and Rheumatology Research Alliance (CARRA) Survey Respondent characteristics (n = 158).

Characteristic	Response	Number or Percentage
Country	United States	88.5%
	Canada	11.5
Position	Pediatric rheumatologist	79.6%
	Adult/pediatric rheumatologist	4.5
	Fellow	14.5
Years in practice	< 5	17.2%
	5–10	49.0
	10–15	23.6
	> 15	8.3
Number of rheumatologist(s) in practice	1	7.0%
	2	24.8
	3	19.1
	4	13.4
	≥ 5	35.7
Practice type	University affiliated	89.1%
	Private practice	4.5
	Other	6.4
Proportion of patients ages 12–18 years seen weekly	0%–24%	10.2%
	25%–49%	49.0
	50%–74%	34.4
	75%–100%	6.4
Proportion of patients age > 19 years seen weekly	0%	17.2%
	1%–5%	49.0
	6%–10%	23.6
	> 11%	10.2

Demographic and practice characteristics of CARRA respondents show that most are from the United States, are pediatric rheumatologists, and are at university-affiliated centers.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

service program. Over 80% of respondents see patients older than 19 years and had completed pediatric rheumatology training, and 66% of respondents stated that patients aged 19–25 years make up less than 5% of their practice. Fewer than 2 percent stated this age group makes up more than 16% of their practice. Familiarity is low with consensus statements created by the AAP, SAHM, American College of Physicians (ACP), and the American Academy of Family Physicians (AAFP) on healthcare transition care for youth and young adults with SHCN. Only 8% of CARRA respondents reported they were very familiar, 35% somewhat familiar, and 56% had never heard about the consensus statement. The majority of respondents (83%) would like rheumatology-specific guidelines for transition, and almost all (90%) feel it is their responsibility to refer to an adult rheumatologist.

Transition policy, tools, and timing. Only 8% of survey respondents have a formal written transition policy, but 42% reported using an informal approach to transition. Thirty-three percent use available tools for youth transition and/or healthcare maintenance, such as institutional-specific transition checklists, patient-reported self-efficacy assessments, or the American Medical Association Guidelines for Adolescent Preventive Services[16]. Thirty percent have a designated team member as a transition coordinator, who may be a nurse (33%), physician (30%), or social worker (26%). As a part of routine transition care services for youth ages 14 years and older, 66% of CARRA pediatric rheumatology providers discuss patients' educational and vocational plans, and 33% ask about youth behaviors including tobacco use, illicit drug use, and sexual activity. Fewer than half (48%) review a medical summary and about one-third (33%) use a routine assessment tool for transition.

Most providers initiate transition discussions around ages 15–17 years (43% of respondents), with the remainder discussing the process earlier between ages 12–14 years (25%) or later between ages 18–20 years (25%). Thirty-seven percent of the CARRA pediatric rheumatology respondents plan to transfer patients by 19–20 years of age and 47% report that actual transfer typically occurs > 21 years of age.

In descending order, factors classified as "very important" for influencing timing of transfer of care to adult providers include patient request (75%), patient getting married or starting a family (55%), parental request (53%), patient's age (51%), practice workload (38%), and patient's health insurance coverage (32%). The majority of respondents (72%) refer directly to an adult rheumatologist rather than to an adult primary care physician, but about 20% report making referrals to both. "Very important" factors in choosing the provider include perceived quality of care of the adult provider (68%) and patient's insurance (53%).

Barriers to transition. Over half (56%) of respondents agree that their current transition practices are unsatisfactory; citing inadequate training (51%), inadequate time (60%), insufficient resources and personnel (66%), or lack of reimbursement for time spent (75%) as obstacles. When asked to designate the major barriers to transition, CARRA respondents said the top 2 are fragmented adult medical care (35%) and lack of sufficient time to provide services (37%; Table 2). While youth preparation and self-management are definite problem areas, provider skills in transition and patient/parent/provider bond are also perceived major

Table 2. Barriers affecting the provision of transition support services in pediatric rheumatology practices with comparisons to American Academy of Pediatrics (AAP) responses (noted in parentheses).

Barriers	Major Barrier	Somewhat of a Barrier
Pediatric staff lack sufficient time to provide transition services	37% (36%)	41% (45%)
Fragmentation of primary and specialty care in adult care	35% (39%)	41% (46%)
Adolescents/parents/physicians have developed an effective bond that is hard to break	30% (32%)	54% (58%)
Adolescents' lack of knowledge about their own condition and/or skills to self-advocate at physician visits	28% (19%)	56% (65%)
Pediatric staff lack skills in transition planning	26% (33%)	47% (46%)
Lack of knowledge about or linkages to community resources that support older adolescents/young adults	24% (39%)*	54% (49%)
Lack of available adult specialists to care for older adolescents/young adults with special needs	24% (40%)*	44% (38%)
Lack of insurance reimbursement for transition services	23% (38%)*	35% (38%)
Lack of available family physicians and internal medicine physicians to care for older adolescents/young adults with special needs	22% (41%)*	41% (39%)

Many barriers exist for pediatric rheumatology providers, but insufficient time, fragmentation of adult care services, and difficulty to break bonds are cited as the top major barriers for CARRA respondents. Comparisons with AAP respondents showed statistically significant differences, *$p < 0.001$, in major barriers for lack of providers, knowledge, and reimbursement.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

barriers in pediatric rheumatology practices for about one-quarter of CARRA members.

Country comparisons within CARRA responses. When analyzing the CARRA data comparing Canadian and US responses, Canadian respondents were significantly more likely to have a multidisciplinary transition program (64% vs 26%, $p < 0.001$; CI 99%: 0.248007, 0.791993, and have a written transition policy statement 44% vs 5%, $p < 0.001$; CI 99%: 0.0874845, 0.698515), and trends showed that Canadian providers were more likely to have a designated transition coordinator and less likely to have patients between 19–25 years old, but these comparisons were not statistically significant.

Comparisons between CARRA and AAP responses. Highlights of the comparison between CARRA and AAP survey responses include significant differences in having a designated staff member who directs transition (30% vs 11%, $p < 0.001$; CI 99%: 0.091, 0.289) and older age (18–20 years old) at initiation of transition planning (25% vs 62%, $p < 0.001$; CI 99%: –0.472, –0.268). Many opinions from CARRA respondents regarding major barriers to transition are similar to AAP survey responses (Table 2), although the CARRA respondents were slightly more concerned about youth's lack of knowledge and self-care (28% vs 19%) as a major barrier, but the difference was not statistically significant. AAP respondents were significantly more concerned than CARRA members about the major barriers of the lack of primary care or subspecialty care providers for youth with SHCN (41% and 40% considered major barrier vs 22% and 24%, $p < 0.001$ for both; CI 99%: –0.289, –0.091 and CI 99%: –0.261, –0.059, respectively), as well as the lack of reimbursement for transition services (38% vs 23%, $p < 0.001$; CI 99%: 0.0491387, 0.250861) and the lack of knowledge about community resources (38% vs 23%, $p < 0.001$; CI 99%: 0.05037, 0.24963).

Compared with AAP survey participants, pediatric rheumatologists are significantly more likely in their transition practices to help with referrals to adult subspecialists (63% vs 45%, $p < 0.001$; CI 99%: 0.069, 0.291), discuss consent and confidentiality before 18 (45% vs 33%, $p = 0.005$; CI 99%: 0.007, 0.233), identify insurance options (30% vs 19%, $p < 0.001$; CI 99%: 0.046, 0.234), and provide educational packets (25% vs 11%, $p = 0.002$; CI 99%: 0.008, 0.212), but are less likely to help refer to a primary care provider (25% vs 47%, $p < 0.001$; CI 99%: –0.322, –0.118), or assist in creating a medical summary (16% vs 27%, $p = 0.004$; CI 99%: –0.198, –0.022). Both groups were unlikely to assist in creating an individualized transition care plan (6% vs 12%; Figure 1).

Outcome tracking. Outcomes ranked as very important in defining a successful transition included patient survival (76%), seeing an adult rheumatologist within 6 months of the final pediatric rheumatology visit (66%), and maintaining insurance coverage (57%). Patient quality of life (33%) and provider satisfaction (35%) with the process were deemed less important in the assessment of transition outcomes.

DISCUSSION

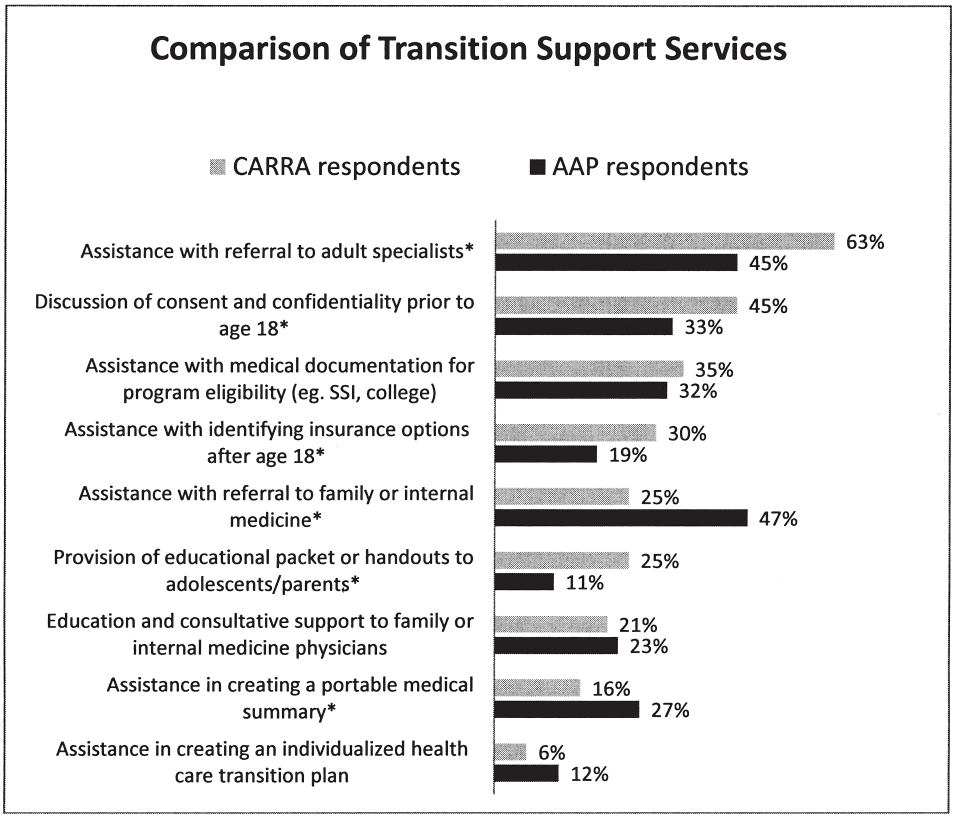
This is the first comprehensive survey of transition practices among North American pediatric rheumatology providers. Given the chronic nature of rheumatologic disorders, such as JIA and childhood-onset systemic lupus erythematosus, transitional care is needed for the majority of children and adolescents with rheumatic diseases. However, existing rheumatology transition approaches mainly focus on programs that are few in number, small in size, and location-specific and have not been systematically evaluated[17,18]. To date, the implementation of transition recommendations and guidelines has been limited and has not been disseminated into practical transitional care for the majority of youth with SHCN[19,20,21]. Further, standardized outcome measures for transition care are not well defined, making assessment of short- and longterm transition outcomes difficult to perform.

Canadian CARRA members seem to have further developed transition policies and programs compared to the US members, and this likely reflects the differences between the US and Canadian healthcare systems, such as use of family practice providers, insurance coverage, and age limitations and restriction in pediatric-based practices. Respondents to our survey were less likely than AAP survey respondents to assist youth with finding a primary care provider, who is often a core member for the designated "medical home", a critical concept of transitional care for youth with SHCN[22]. As pediatric rheumatologists largely serve the role as subspecialty consultant, they may expect that the pediatric or family practice primary care provider should coordinate transition to an adult primary care provider. As a corollary, the expectation would lie on the pediatric rheumatologist to find the appropriate subspecialty provider. However, because of the frequency of visits and longstanding relationships, many patients and families identify the pediatric rheumatologist as the primary provider and rely less on the primary care provider to discuss and initiate transition.

There is a clear deficiency in creating an annually updated medical summary by all pediatric providers, despite the medical summary being one of the top requests by adult providers when asked about needs in accepting youth in transition[23]. For many pediatric rheumatology providers, prolongation of care of youth beyond the anticipated age to transfer care is commonplace; providers express concern that their adolescent patients lack the necessary preparation and skills to manage their own condition and maneuver through the adult medical system. Results of this survey echo the sentiments of the AAP respondents that there continue to be unmet needs in improving youth

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org



* $p < 0.01$. CI 99%

Figure 1. Comparison of transition support services offered by Childhood Arthritis and Rheumatology Research Alliance (CARRA) pediatric rheumatology providers and American Academy of Pediatrics (AAP) survey pediatrician respondents. CARRA survey respondents significantly differ in providing guidance with referrals to adult subspecialists and discussing consent and confidentiality issues before age 18, whereas AAP respondents are significantly more likely to assist with referrals to primary care providers and assist with medical summary creation.

self-efficacy, preparing youth for transfer of care, and in assuring adequate provider time for education and reimbursement for transition planning.

A survey of attitudes of rheumatology providers at the Pediatric Rheumatology European Society (PRES) Congress in September 2010 toward transition and transfer endorsed themes similar to our survey results. Only one-third of PRES respondents reported having a formal transition program with most lacking a transition coordinator. PRES respondents said rheumatology caregivers' assessment of youth's readiness is a critical component for initiating a transfer[24]. Surveys of internists who eventually assume care of young adults with SHCN often find patients inadequately prepared for the transfer, and they also express concerns about parents or guardians not providing sufficient youth autonomy[23,25]. In contrast, a survey of adolescents with arthritis found that pediatric rheumatologists overly focus on self-care in transition preparation rather than the practical components such as finding adult providers, obtaining insurance coverage, and discussing how their healthcare needs will change as an adult[26]. Similar sentiments were found in interviews of adults with JIA who recommended that transition preparation include regulating parental involvement and arranging a youth-oriented environment to help ease the transfer[27].

Our survey results identify an unmet need for development of standardized transition guidelines for youth with rheumatic diseases, similar to those developed by gastroenterologists for patients with childhood-onset inflammatory bowel disease[28]. Recently, the AAP/AAFP/ACP has developed a clinical report providing a 6-step algorithm to explicitly help to guide providers through the process[29], and the Bureau of Maternal and Child Health's National Center of Transition (Gottransition.org) provides examples of transition tools and policies and indices to assist practices to measure their proficiency in offering transition care[30]. These can be further adapted for guidelines in the transition of youth with childhood-onset rheumatic diseases.

The lack of accepted transition outcome measures hampers transition research. Results of this survey support

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

the development of standardized transition outcome assessments, which incorporate survival, maintenance of insurance coverage, and timeliness of visit with adult provider after transfer of care. These items will be important to evaluate in combination with current approaches of patient-centered outcome research (e.g., Patient-Centered Outcomes Research Institute) and patient-reported outcome measurements (e.g., Patient Reported Outcomes Measurement Information System initiative from the US National Institutes of Health), which incorporate qualitative measures such as satisfaction, quality of life, and patient input into the medical decision making and healthcare delivery process[31,32]. Using disease registries, such as the current CARRA registry, will allow more longterm tracking to understand better how well these transition tools work[33]. Implementation of the best transition practice processes and outcome measures will also require adult rheumatologists' input. Surveys of internal medicine providers describe deficiencies in provider knowledge and tools to assist youth and young adults with SHCN through this transition period[23,25]. A formal survey of adult rheumatologists in the US and Canada concerning their transition practices and needs is warranted.

Study limitations include surveying only CARRA members; thus results may not be generalizable. However, given that there are about 300 pediatric rheumatologists currently in practice or training in the US and Canada and most are members of CARRA, this survey did capture a substantial number of respondents (n = 158). Within CARRA, members who are primarily researchers and do not provide clinical care may have abstained from completing the survey, and this may explain the lower response rate. Canadian providers may not be familiar with the AAP transition policies, but rather the Canadian Paediatric Society's statement on transition, and this could have influenced that result. We did not survey rheumatologists for adults or others involved (nurses, social workers, psychologists, and physical and occupational therapists), adult primary care providers, parents or families, nor the youth and young adults themselves, which will be important in the process of defining transition programs, guidelines, or recommendations. Comparing the AAP and the CARRA response data was limited by differences in sample sizes (628 vs 288), time between the 2 surveys, practice types and locations (academic centers vs private practice, urban/suburban vs rural), and inclusion of Canadians in the CARRA survey. However, many questions were nearly identical (Appendices 1 and 2), and the comparison of results provides useful information about potential differences in attitudes between the pediatric rheumatology provider community and the general AAP membership, which primarily represents primary care providers. There is a possibility that the same respondents answered both surveys. For statistical purposes, we assumed that the 2 groups were independent of each other, which is likely given the high number of younger CARRA respondents and the inclusion of Canadians.

Our survey suggests that transition planning and care by many North American pediatric rheumatologists do not necessarily follow recommended current transition consensus recommendations. Results from this survey highlight opportunities to enhance provider knowledge about transition policy and practice and identify a need to develop rheumatology-specific transition guidelines. Opportunities for future study include assessing adult rheumatology providers' knowledge about transition policies and practices; standardizing transition readiness assessments and annual medical summary preparation; and developing a rheumatology transition outcome measurement.

ACKNOWLEDGMENT

Vaishali Tenkale was instrumental in disseminating the survey to CARRA membership. Kim Miller helped with editing the manuscript.

REFERENCES

1. Sacks JJ, Helmick CG, Luo YH, Ilowite NT, Bowyer S. Prevalence of and annual ambulatory health care visits for pediatric arthritis and other rheumatologic conditions in the United States in 2001–2004. Arthritis Rheum 2007;57:1439-45.
2. Adam V, St-Pierre Y, Fautrel B, Clarke AE, Duffy CM, Penrod JR. What is the impact of adolescent arthritis and rheumatism? Evidence from a national sample of Canadians. J Rheumatol 2005;32:354-61.
3. Hashkes PJ, Wright BM, Lauer MS, Worley SE, Tang AS, Roettcher PA, et al. Mortality outcomes in pediatric rheumatology in the US. Arthritis Rheum 2010;62:599-608.
4. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, et al. A new definition of children with special health care needs. Pediatrics 1998;1 Part 1:137-40.
5. Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. Matern Child Health J 2008;12:1-14.
6. Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: results from the 2005–2006 National Survey of Children With Special Health Care Needs. Pediatrics 2009;123:e145-e52.
7. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993;14:570-6.
8. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 2002;6 Part 2:1304-6.
9. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions. Position paper of the Society for Adolescent Medicine. J Adolesc Health 2003;33:309-11.
10. Fox HB, McManus M, O'Connor KG, Klein JD, Diaz A, Wibbelsman CJ. Fact sheet no. 7: Pediatricians' interest in expanding services and making practice changes to improve the care of adolescents. Washington, D.C.: National Alliance to Advance Adolescent Health; 2009.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

11. McManus M, Fox H, O'Connor K, Chapman T, MacKinnon J. Fact sheet no. 6: Pediatric perspective and practices on transitioning adolescents with special needs to adult health care. Washington, DC: National Alliance to Advance Adolescent Health; 2008.
12. McDonagh JE, Foster HE, Hall MA, Chamberlain MA. Audit of rheumatology services for adolescents and young adults in the UK. British Paediatric Rheumatology Group. Rheumatology 2000;39:596-602.
13. McDonagh JE, Southwood TR, Shaw KL; British Paediatric Rheumatology Group. Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. Rheumatology 2004;43:737-43.
14. Newcombe RG. Interval estimation for the difference between independent proportions: comparison of eleven methods. Stat Med 1998;17:873-90.
15. Wilson EB. Probable inference, the law of succession, and statistical inference. J Am Statistic Assoc 1927;22:209-12.
16. Elster AB, Kuznets NJ. Guidelines for adolescent preventive services (GAPS): recommendations and rationale. Baltimore: Williams and Wilkins; 1994.
17. McDonagh JE, Shaw KL, Southwood TR. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. J Child Health Care 2006; 10:22-42.
18. Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. Pediatr Clin North Am 2005;52:641-52, viii.
19. Okumura MJ. Growing up and getting old(er) with childhood-onset chronic diseases: paving the way to better chronic illness care worldwide. J Adolesc Health 2009;45:541-2.
20. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. Pediatrics 2005;115:112-20.
21. Callahan ST, Winitzer RF, Keenan P. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. Curr Opin Pediatr 2001;13:310-6.
22. Burdo-Hartman WA, Patel DR. Medical home and transition planning for children and youth with special health care needs. Pediatr Clin North Am 2008;55:1287-97, vii.
23. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists' perspectives. Pediatrics 2009;123:417-23.
24. Hilderson D, Moons P, Westhovens R, Wouters C. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. Rheumatol Int 2012;32:3887-96.
25. Suris J-C, Akré C, Rutishauser C. How adult specialists deal with the principles of a successful transition. J Adolesc Health 2009;45:551-5.
26. Scal P, Horvath K, Garwick A. Preparing for adulthood: health care transition counseling for youth with arthritis. Arthritis Rheum 2009;61:52-7.
27. Hilderson D, Eyckmans L, Van der Elst K, Westhovens R, Wouters C, Moons P. Transfer from paediatric rheumatology to the adult rheumatology setting: experiences and expectations of young adults with juvenile idiopathic arthritis. Clin Rheumatol 2013;32:575-83.
28. Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. Inflamm Bowel Dis 2011;17:2169-73.
29. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2011;128:182-200.
30. got transition? Concord, New Hampshire: National Health Care Transition Center; 2013. [Internet. Accessed Jan 2, 2014.] Available from: www.gottransition.org/
31. PCORI. Washington, DC: Patient-Centered Outcomes Research Institute; c2012-2013. [Internet. Accessed Jan 2, 2014.] Available from: www.pcori.org/
32. Patient Reported Outcomes Measurement Information System (PROMIS). Silver Spring, Maryland: PROMIS Network Center; 2011-2013. [Internet. Accessed Jan 2, 2014.] Available from: www.nihpromis.org/
33. CARRA Registry. Raleigh, North Carolina: Duke Clinical Research Institute; 2010-2013 [Internet. Accessed Jan 2, 2014.] Available from: https://carranetwork.org/

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

APPENDIX 1. Transition-focused questions from American Academy of Pediatrics Periodic Survey 71. These questions formed the basis for part of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) membership survey. From Fox, et al. Washington, DC: National Alliance to Advance Adolescent Health; 2009. With permission.

American Academy of Pediatrics Periodic Survey of Fellows #71 — **Transitional Care Questions**

TRANSFER FROM PEDIATRIC TO ADULT CARE

19. At what age do you think transition planning from pediatric to adult health care should begin for adolescents with or without special health care needs? *Circle one response for each*

	<12y	12y-14y	15y-17y	18y-20y	Don't know
With special health care needs					
Without special health care needs					

20. Is there a dedicated staff member in your practice who has responsibility for coordinating transition planning for adolescents with or without special health care needs? *Circle one response for each*

	No	Yes	Don't Know
With special health care needs			
Without special health care needs			

The following set of questions pertain only to adolescents with special health care needs (SHCN):

21. Which of the following services does your practice have in place to support transition from pediatric to adult health care for adolescents with special health care needs? *Circle one response for each service*

	For nearly all or most SHCN adolescents	For some SHCN adolescents	Do not provide this service
Provide adolescents/parents with an educational packet or handouts			
Discuss consent and confidentiality issues prior to age 18			
Discuss assent to care issues prior to age 18			
Assist in creating a portable medical summary			
Create an individualized health care transition plan			
Assist with establishing referral to specific family or internal medicine physicians			
Assist with establishing referral to specific adult specialists			
Support family or internal medicine physicians with education and consultation			
Assist with medical documentation for program eligibility (e.g. SSI, vocational rehabilitation, college)			
Assist with identifying options to maintain health care insurance after age 18			

22. Has your practice expanded its health care transition services for adolescents with special health care needs in the last two years?

No Yes

23. To what extent do the following act as barriers to transitioning from pediatric to adult health care for adolescents with special health care needs? *Circle one response for each barrier*

Barriers:	Not a barrier	Somewhat a barrier	Major barrier
Lack of available family physicians, internal medicine physicians to care for older adolescents/young adults with special needs			
Lack of available adult specialists to care for older adolescents/young adults with special needs			
Adolescents/parents/pediatricians have developed an effective bond that is hard to break			
Adolescents' lack of knowledge about their own condition and/or skills to self-advocate at physician visits			
Pediatric staff lack sufficient time to provide transition services			
Pediatric staff lack skills in transition planning			
Fragmentation of primary and specialty care in adult care			
Lack of insurance reimbursement for transition services			
Lack of knowledge about or linkages to community resources that support older adolescents/young adults			

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

APPENDIX 2. Online survey questions to Childhood Arthritis and Rheumatology Research Alliance (CARRA) membership regarding transition practices. Questions covered demographics, current practices, barriers, and opportunities.

Introduction

Many problems can arise when adolescents and young adults transition from child-centered to adult-centered rheumatologic care. Currently, there is no consensus as to how pediatric rheumatologists should best help patients and families negotiate this transition. With this survey, we aim to better understand how pediatric rheumatologists currently approach this transition and to ascertain what resources are used and needed to define and facilitate successful transition.

This survey should take you less than 15 minutes to complete. Your participation is entirely voluntary. All responses are anonymous. There is no financial compensation for completing this survey. Although there is no direct benefit to you for participating, we hope that the information gathered from this survey will help to inform future transition practices and policies. We will share the results with you in a future abstract and publication.

Demographics

1. Please select the one response below which best describes your position
   - Pediatric rheumatologist
   - Adult rheumatologist
   - Adult and pediatric rheumatologist (completed fellowships in both)
   - Fellow in a pediatric rheumatology program or a combined adult and pediatric rheumatology program
   - Pediatrician
   - Internist or family practitioner
   - Nurse practitioner or physician assistant
   - Nurse
   - Social worker
2. Please select the one response below which best describes your practice
   - University affiliated practice
   - Government or military medical center
   - Private practice/HMO
   - Other, please specify
3. Approximately what percentage of rheumatology patients do you personally see per week who are between 12-18 years old?
   - 0-24%
   - 25-49%
   - 50-74%
   - 75-100%
4. Approximately what percentage of rheumatology patients do you personally see per week who are between 19-25 years old?
   - 0%
   - 1-5%
   - 6-10%
   - 11-15%
   - >16%
5. Where do you practice?
   - US
   - Canada
   - Other, please specify
6. How many attending rheumatologists are in your practice, including yourself?
   - 1
   - 2
   - 3
   - 4
   - ≥5
7. How long have you been caring for pediatric and adolescent rheumatology patients (including fellowship training)?
   - < 5 years
   - 5-10 years
   - 11-15 years
   - > 15 years

Transition Practices

8. Regarding transition from pediatric to adult care, select one of the below which best describes your practice:
   - My practice has a written transition policy which we follow most of the time
   - My practice has a written transition policy, but we do not follow it most of the time.
   - We do not have a written transition policy but follow a fairly standard, informal procedure in transitioning our patients
   - We are working on developing a transition policy but do not yet have one formalized
   - We do not have a transition policy but are interested in developing one
   - I do not think that a transition policy is necessary at this point
   - I have not given it much thought
9. Is there a designated staff member in your practice who has primary responsibility for coordinating transition process?
   - Yes
   - No

   (if answer to #8 is "yes", then answer #9. If answer is "no," then skip to #10)

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

APPENDIX 2. *Continued*

10. If you do have a designated staff member in your practice, what is his/her role?
    - Nurse
    - Nurse practitioner
    - Office manager/assistant
    - Social worker
    - Physician
    - Other, please specify
11. When you are transferring care of your adolescents and young adults, do you refer to
    - Adult primary care (internist or family medicine doctor)
    - Adult rheumatologist
    - Both
    - Neither (I expect the family or patient to find a referring doctor)
12. How important are the following factors in selecting an adult rheumatology provider? (range from not important to very important)
    - Your personal acquaintance with the provider
    - Provider's reputation in the community
    - Location of provider's practice
    - Patient's insurance accepted by provider's practice
    - Provider's appointment availability
    - Feedback from other patients who have transitioned to this provider
    - Quality of communication you have received from this provider with prior patients you have transitioned
    - Quality of care you believe other patients have received from this provider
    - Other, please specify
13. Do you use any of the following tools in your practice when transitioning adolescents and young adults to adult-centered care? Check all that apply
    - AAP forms or website, including AAP National Center for Medical Home
    - Bright Futures (National Center for Education in Maternal and Child Health and AAP)
    - GAPS (American Medical Association's Guidelines for Adolescent Preventive Services, i.e. HEADS assessment)
    - Healthy and Ready to Work forms
    - Self efficacy or transition readiness patient report measures
    - Transition checklist
    - I do not use any of these tools
    - I use tools which are not listed here, please specify…
14. In general, by what age on average do you **aim** to transfer care to adult providers?
    - 14 years
    - 15-17 years
    - 18 years
    - 19-20 years
    - ≥ 21 years
15. In general, by what age on average do you **actually** transfer care to adult providers?
    - 14 years
    - 15-17 years
    - 18 years
    - 19-20 years
    - ≥ 21 years

At what age do you think transition planning from pediatric to adult health care should begin for adolescents with rheumatic illness?

- <12 years
- 12-14 years
- 15-17 years
- 18-20 years
- Don't know

17. How much do each of the following factors influence your decision about when to transfer an adolescent or young adult to adult-centered rheumatologic care? (answers here range from not important to very important)
    - Age of patient
    - Patient's health insurance coverage
    - Patient is going to college/post-secondary education
    - Patient is entering workforce
    - Patient is getting married/starting a family
    - Patient is graduating from college
    - Patient requests to transition
    - Parent requests to transition
    - Patient needs provider to address adult issues such as sexuality, contraception, drug use.
    - Distance patient lives from pediatric rheumatology center
    - Busy workload in your practice and need for space for new patients
    - Disease activity of patient
    - Patient assessed to be ready by independently explaining condition, medications, and medical history

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

APPENDIX 2. *Continued*

18. Does your institution offer multidisciplinary transition services? (Respondents should encounter this question only if their response to #2 was "University affiliated practice" or "Government or military medical center"; otherwise, this question should be skipped)

- Yes
- No

19. Which of the following services does your practice have in place to support transition from pediatric to adult health care for adolescents with rheumatic diseases? *Mark one response for each service*

	For nearly all or most adolescent patients	For some adolescent patients	Do not provide this service
Provide adolescents/parents with an educational packet or handouts			
Discuss consent and confidentiality issues prior to age 18			
Discuss assent to care issues prior to age 18			
Assist in creating/co-developing a portable medical summary with patient			
Create a written individualized health care transition plan			
Assist with establishing referral to specific family or internal medicine physicians			
Assist with establishing referral to specific adult specialists			
Support family or internal medicine physicians with education and consultation			
Assist with medical documentation for program eligibility (e.g. SSI, vocational rehabilitation, college)			
Assist with identifying options to maintain health care insurance after age 18			

20. For your rheumatology patients who are 14 years and older, how much of the time do you…
(answers range from never to all of the time)

- Complete part of the encounter without parent/guardian in room
- Have patients 18 years and older sign consent for release of information to parent/family
- Develop a portable medical summary
- Review yearly the patient's portable medical summary
- Formally assess transition readiness by using standard tool or protocol
- Have patient discuss transition with social worker
- Have patient meet adult provider one or more times prior to final transfer of care
- Discuss use of tobacco, alcohol, drugs at most visits
- Discuss sexuality, fertility, contraception at most visits
- Assess patient's knowledge of his/her health insurance status
- Assess whether patient can independently describe his/her condition(s), medications, and previous treatments
- Discuss patient's educational and vocational plans

21. Please indicate how much you agree with the following statements

- I am satisfied with the current way I transition adolescents and young adults to adult-centered care
- I have sufficient resources and personnel to adequately address transition care
- I have sufficient time in clinic to address transition with my patients
- I am able to code in order to be reimbursed for the time I spend transitioning patients to adult care
- I am adequately trained to address the transition needs of my patients
- I am in need of additional tools to facilitate transition in my practice
- Pediatric rheumatologists should be primarily responsible for transitioning patients to adult rheumatologic care
- Primary care providers should be primarily responsible for transitioning patients to adult rheumatologic care
- Patients and families should be primarily responsible for transitioning patients to adult rheumatologic care
- A consensus statement outlining recommended guidelines for transitioning adolescent rheumatology patients to adult-centered care would be useful to me.

22. How familiar are you with the Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs of the AAP, AAFP, ACP/ASIM

- Very familiar ◊ Have never heard of it

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org

APPENDIX 2. *Continued*

23. To what extent do the following act as barriers to transitioning from pediatric to adult health care for adolescents with rheumatic diseases? *Mark one response for each barrier*

Barriers:	Not a barrier	Somewhat a barrier	Major barrier
Lack of available family physicians, internal medicine physicians to care for older adolescents/young adults with special needs			
Lack of available adult specialists to care for older adolescents/young adults with special needs			
Adolescents/parents/pediatricians have developed an effective bond that is hard to break			
Adolescents' lack of knowledge about their own condition and/or skills to self-advocate at physician visits			
Pediatric staff lack sufficient time to provide transition services			
Pediatric staff lack skills in transition planning			
Fragmentation of primary and specialty care in adult care			
Lack of insurance reimbursement for transition services			
Lack of knowledge about or linkages to community resources that support older adolescents/young adults			

24. Of the following resources, what do you think will help and be useful to facilitate adolescent engagement in the transition process? For each item thought to be helpful/useful, please mark a response regarding your use in practice.

Resource	Specific type	Helpful, Useful	already in use	would use, if tool available	would never use
Brochures, pamphlets	Written				
	Online				
Didactic program	Face-to-face individual or group session				
	Written, home-based				
	Online or electronic (CD, DVD-Rom)				
Improving communication	Open ended discussions during visits				
	Written questions by teens				
	Telephone				
	Email				
	Texting (SMS)				
	Social networking media (e.g. facebook)				
	Hospital/ health insurance portal				
Portable personal health record/ medical record	Written/ paper				
	Online				
	other electronic means (USB memory stick/ flash drive, smart phone application, or PDA)				

25. We are interested in developing an outcome measure that would help to define a successful transition to adult-centered rheumatologic care. This outcome measure would apply to all of your patients and would not be disease specific. Please rank the following as to whether you think they are important in defining a successful transition to adult rheumatologic care:

(answers range from not important to very important)

- See adult rheumatology provider within 6 months of final visit with pediatric rheumatology provider
- See adult rheumatology provider within 12 months of final visit with pediatric rheumatology provider
- Patient-reported measure of satisfaction with transition process
- Provider-reported measure of satisfaction with transition process
- Patient maintains health insurance coverage
- Patient remains in school or employed (if not medically disabled).
- Patient survival
- Patient generic health-related quality of life measure (eg, SF-36)
- Other, please describe

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on April 18, 2024 from www.jrheum.org