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A survey of Canadian adult rheumatologists' knowledge, comfort level, and barriers in assessing psychosocial needs of young adults with rheumatic diseases

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Abstract

To assess adult rheumatologists' comfort level, current practices, and barriers to provision of optimal care in supporting young adults with pediatric-onset rheumatic conditions in Canada. Survey questions were informed by literature review, a needs assessment, and using milestones listed by the Royal College of Physicians and Surgeons of Canada for the entrustable professional activities (EPAs) applicable to care for rheumatology patients transitioning to adult practice. The electronic survey was distributed to adult rheumatology members of the Canadian Rheumatology Association over 4 months. Four hundred and fifty-one rheumatologists received the survey, with a response rate of 15.2%. Most respondents were from Ontario and had been in practice ≥ 10 years. Three quarters reported a lack of training in transition care although the same proportion were interested in learning more about the same. Approximately 40% felt comfortable discussing psychosocial concerns such as gender identity, sexuality, contraception, drug and alcohol use, vaping, and mental health. Despite this, 45–50% reported not discussing vaping or gender identity at all. The most frequently reported barriers to providing transition care were lack of primary care providers, allied health support, and training in caring for this age group. Most adult rheumatologists lack formal training in transition care and view it as a barrier to providing care for this unique patient population. Future educational initiatives for adult rheumatology trainees should include issues pertaining to adolescents and young adults. More research is needed to assess the effectiveness of resources such as transition navigators in ensuring a successful transition process.

Keywords Transition to adult care · Education · Medical · Rheumatology · Psychosocial functioning · Surveys and questionnaires · Observational research

Introduction

Chronic rheumatic diseases diagnosed in childhood often require long-term medical management, and the transition period from pediatric to adult rheumatology care is an important and often vulnerable time in patients' lives [1]. Adult care is more patient focused than family focused and requires more independence. Inadequate preparation for adult care combined with the vulnerable state patients can lead to gaps in care and loss to follow-up [2, 3]. Existing resources for transition include the American College of Rheumatology (ACR) pediatric transition toolkit and the European Alliance of Associations for Rheumatology (EULAR) Standards and Recommendations for the Transitional Care of Young People with Juvenile-Onset Rheumatic Diseases [4, 5]. However, in a recent publication, only 31% of both adult and pediatric health care providers reported using these resources to help with the transition process [6].

For youth, gaps in care and loss to follow-up may occur for a multitude of reasons, many of which may be personal including psychosocial concerns, and important life milestones as well as disease relapses, medication side effects and difficulties accessing care [7, 8]. Disruptions in medical care may also be related to their initial experiences with their adult practitioner [9]. There have been limited studies reporting the perspectives of adult rheumatologists

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in transition [6, 10]. A recent survey of adult rheumatologists, based out of the United States, self-identified as having inadequate training in transition issues of young adults, specifically psychosocial concerns [11]. This contrasts with pediatric healthcare providers who have familiarity working with adolescent psychosocial concerns and behaviors [12]. Adult rheumatologists reported a lack of comfort in managing patients with pediatric-onset disease and endorsed less familiarity with transition guidelines compared to pediatric healthcare providers [11].

The objectives for this Canadian survey of adult rheumatologists and adult rheumatology trainees were to determine the comfort level and barriers to caring for young adult patients with pediatric-onset rheumatic disease after transfer to adult care. In addition, the management of psychosocial needs in the adolescent and young adult population including comfort level and frequency of discussions around these topics were assessed.

Methods

A combination of literature review, building on prior work from the United States-based study by Zisman et al. and information provided by a needs assessment conducted by the Canadian Rheumatology Association (CRA), formed the basis of our survey [11, 13]. The survey incorporated entrustable professional activities (EPAs) designed by the Royal College of Canada for Rheumatology trainees which are specific tasks that trainees can be trusted to perform independently in different contexts [14]. Specifically, Core EPA #12 P: Supporting adolescents/young adults with rheumatologic disease in the transition from the pediatric to adult care setting and its individual milestones were used for each question. This EPA focuses on developmental readiness and the risks that can occur as patients develop autonomy regarding their health [14]. The initial survey was drafted by two pediatric rheumatologists, a pediatric resident and a clinical researcher. It was then reviewed by two adult rheumatologists whose revisions were incorporated prior to sharing it with four adult rheumatologist members of the CRA Transition Working Group for final edits, comments, and feedback. The Consensus-based Checklist for reporting of Survey Studies (CROSS) and EQUATOR guidelines were followed during survey preparation and reporting [15]. The survey collected information on demographics, current practice, comfort in managing psychosocial aspects of transition care and perceived barriers to providing care to this population. Responses to questions were graded on a five-point Likert scale. The project was approved by the Hamilton Integrated Research Ethics Board (Project #13568) on September 16th, 2021. The survey was distributed by email via the CRA using the Alchemer platform (www.alchemer.com) on November 3rd, 2021 to adult rheumatologists and trainees who were CRA members. Pediatric rheumatologists and trainees were not included. Data collection occurred until March 18th, 2022 with monthly reminders sent by the CRA.

Statistical analysis

Descriptive statistics (frequencies and proportions) summarizing survey responses were determined using SPSS v.28 (IBM SPSS Statistics, USA). Responses from the five-point Likert scale were then translated to a dichotomous outcome to better analyze data due to the relatively small sample size in the study. For example, those who answered questions regarding comfort level with agree or strongly agree were designated as comfortable and those who answered strongly disagree, disagree, and neutral were designated not comfortable.

Results

Demographics

The survey was sent to 490 rheumatologists (451 in English and 39 in French) and 15.2% ($n = 69$) completed the survey. More than half were female with ≥ 10 years of experience in practice and had trained in Canada. Most respondents were practicing in Ontario and had either a university-based practice or a combined university- and community-based practice (Table 1). Approximately half reported involvement in providing transition care. Fifty-one rheumatologists (74%) reported that they had no formal training in transition care (Table 1). Of those who had received training, it was primarily in fellowship and by continuing medical education at their own institution.

Current transition practices

Providers most commonly saw patients being transferred to them between 16 and 18 years of age and were referred by pediatric rheumatologists. The ideal age for transfer was felt to be between 16 and 20 years old. About 45% had a multidisciplinary team to help support transitioned patients which included nursing, physiotherapy, social work, and occupational therapy. On average, 40% had resources in their office for patients such as an orientation to the adult rheumatologists' practice, self-management skills assessments and tools (pamphlets, phone apps, etc.). More than half of the participants reported no formal transition policy at their institution with one-third reporting an informal policy was being followed. Approximately 40% of individuals felt comfortable discussing psychosocial concerns such as gender identity, sexuality, contraception, drug and alcohol use,

Table 1 Demographic characteristics and current practices of the rheumatologists surveyed

Demographics	Number of respondents (%)
Level of practice	
Adult rheumatologist	63 (91%)
Adult rheumatology fellow	6 (9%)
Age	
< 35	10 (15%)
36–45	23 (33%)
46–55	10 (26%)
56–65	7 (10%)
> 65	11 (16%)
Gender identity	
Female	44 (64%)
Male	21 (30%)
Other	1 (1%)
Prefer not to say	3 (4%)
Years in practice	
5–10	11 (16%)
11–15	12 (17%)
16–20	8 (12%)
> 20	21 (30%)
Undefined	17 (25%)
Type of practice	
University/academic based	44 (68%)
Community based	31(48%)
Outreach clinic	3 (4.6%)
Other	1 (1.5%)
Formal training in transition care	
Yes specific to rheumatology	17 (25%)
Yes not specific to rheumatology	1 (1.4%)
No	51 (74%)
Proportion of patients < 25 years old	
0	3 (5.4%)
1–5	27 (48%)
5–10	18 (32%)
> 10	8 (14%)
Involvement in transition care	
Yes	30 (54%)
No	21 (38%)
Have been in the past	5 (9%)
Access to multidisciplinary support	
Yes	25 (45%)
No	27 (48%)
Unsure	4 (7%)

vaping, depression, and anxiety (Table 2); however, about half reported discussing vaping and gender identity not at all or rarely.

Barriers to transition

More than two-thirds of respondents reported insufficient skills to address transition-related concerns while only 13% reported having sufficient resources and personnel to adequately address these concerns. Greater than 75% reported lack of time and renumeration for providing transition care. The most frequently reported barriers to providing optimal care to patients transitioning to adult care were: (1) lack of primary care providers, (2) lack of allied health support, (3) inadequate training in caring for this age group, and (4) not being able to be reimbursed or having time listed to provide transition care. Despite this, the majority (75%) expressed an interest in learning more about providing transition care to adolescents. Three quarters of respondents believed that the family physician should be the provider to discuss psychosocial concerns such as mental health, body image, drug use, gender identity and sexuality, and educational goals (Table 2). About 40% felt that tele-rheumatology can be a helpful resource in transition care.

Discussion

The key findings from this survey highlight that most adult rheumatologists lack training in caring for the adolescent population and express a lack of supportive medical care, both family physicians and allied health, to help them care for this population. Further, while they may feel comfortable—specifically discussing psychosocial concerns—the majority believe that it is the family physician's responsibility to do so.

Compared to previous studies, there were similarities regarding the overall transition process and the barriers to a successful transition. For example, approximately one-third of respondents in our survey had no formal transition policy at their institution but an informal procedure that is followed, which is comparable to the findings in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) survey completed in 2010 and the survey in 2014 by Zisman et al. [6, 10, 11]. In addition, the most frequently encountered barriers such as lack of training in caring for this age group, allied health providers, primary care providers, not being able to be renumerated appropriately and time constraints were common themes that have been found in previous studies [13, 16].

Almost half of adult rheumatologists reported feeling comfortable discussing psychosocial concerns with patients which is higher than previous studies (Table 2) [11]. However, this was self-reported and patient perspectives were not sought. Topics such as alcohol and tobacco use, contraception, and fertility were reported to be discussed either most or all the time by the majority of rheumatologists. However,

Table 2 Psychosocial concerns are listed in the first column and the comfort level of adult rheumatologists addressing these issues is listed in the second column

	Number of respondents (%) who were "Comfortable" or "Very Comfortable" discussing psychosocial concerns	Number of respondents (%) who believed that the family physician should address psychosocial concerns
Alcohol, tobacco, drugs	33 (61%)	40 (75%)
Vaping and side effects	23 (42%)	42 (79%)
Gender identity and sexuality	17 (31%)	45 (86%)
Contraception and fertility	26 (48%)	39 (74%)
Depression and anxiety	23 (43%)	46 (88%)
Nutrition and healthy body image	22 (41%)	43 (82%)

This is compared to their belief that the family physician should address the same issues in the third column

45% reported discussing vaping either "not at all" or "rarely" despite the same number feeling comfortable discussing the topic. Given the increase in incidence and the detrimental effects on lung function in youth with chronic conditions, this topic should be addressed consistently in this population [17].

Despite half of the participants reporting comfort in discussing psychosocial topics, more than 75% believed that the family physician should be the provider to discuss these issues (Table 2). Many of these concerns are related to the patient's rheumatic disease and/or medications and side effects leading to difficulties with body image, self-esteem and, ultimately, to mental health concerns [7]. This can place patients in a difficult position as both health care providers feel as though it is the other's responsibility to address these concerns. Unfortunately, many patients do not have a family doctor due to an overall shortage of primary care physicians in Canada or may have difficulty accessing their primary care provider [18]. In addition, many adolescents with chronic rheumatic disease are otherwise generally healthy and medically stable, and their rheumatologist may be the only physician they see regularly. Ideally, conversations about psychosocial issues would happen jointly among health care providers and the primary care provider should be included in the transition process.

The majority of transition research is targeted toward the pediatric healthcare provider's care and perspective. Following a patient from childhood into adulthood establishes strong relationships between patients, their families, and the pediatric care team [2]; however, adult healthcare providers will ultimately spend a far longer time with patients over their life course. It is, therefore, essential to gain an understanding of their current practices and perceptions of gaps in care to ensure that patients receive optimal care. This survey adds to the body of research and provides a Canadian perspective on this topic. This survey design is unique in that it incorporated the competency by design framework. As more programs shift toward a competency by design curriculum, these milestones are now mandatory for trainees to complete their training [19]. The questions are not only applicable to rheumatology but can be used to assess transition in other pediatric sub-specialities with chronic conditions. It also looked at multiple aspects of psychosocial care, which have not been previously evaluated, such as vaping and gender identity.

Despite reminder emails, our study was limited by the relatively low response rate (15.2%) and small numbers of individuals in certain demographic groups (e.g., physicians 46–55 years old, practicing 6–15 years) making subgroup comparisons infeasible. In addition, many rheumatologists do not provide transition care and may not have completed the survey as a result. It is also probable that the survey was completed by adult rheumatologists who were already interested in transition care, leading to response bias and a limited perspective, thereby affecting the generalizability of results to the general adult rheumatology community. Although the survey was released in 2021, the impact of the COVID-19 pandemic upon transitional care and psychosocial concerns of patients was not included in the survey.

These results demonstrate that adult rheumatologists would benefit from more training, multidisciplinary support, resources, and appropriate renumeration to optimize the provision of transition care to young adult patients. Knowledge and treatment of psychosocial factors related to the young adult population should be emphasized during training. Educational initiatives such as workshops and peer teaching sessions with patient engagement should be co-created to improve the transition knowledge and skills for adult health care providers. Tele-rheumatology is a resource that can be valuable for this population as it can be used when patients are away for university/college for follow-up appointments and make it easier to have joint appointments with health care providers. A transition navigator or coach may be a valuable resource to bridge the divide between pediatric and adult care, provide psychosocial support to young adult patients, and provide continuity to patients during this challenging time [20, 21]. Transition navigators have been found to improve adherence to medication, attendance at clinic, and reduce acute complications of disease in other chronic disease populations [22]. Future research should be aimed toward assessing the impact of educational initiatives in subspecialty training of rheumatologists in their comfort supporting the young adult patient population with pediatric-onset disease. Furthermore, the effectiveness of implementing the above resources such as transition navigators upon the transition process from the patient, primary care provider and subspecialist perspective should also be obtained.

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Data availability The data underlying this article will be shared on reasonable request to the corresponding author.

Declarations

Conflict of interest None of the authors have any conflict of interest to declare.

Ethical approval The questionnaire and methodology for this study were approved by the Hamilton Integrated Research Ethics Board (Project #13568) on September 16, 2021.

Consent to participate Informed consent was obtained from all individual participants who answered the questionnaire.

Consent to publish Participants consented to having data published. No identifying information is included in the article.

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