

# Transitioning to Employment with a Rheumatic Disease: The Role of Independence, Overprotection, and Social Support

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**ABSTRACT. Objective.** To examine perceived independence, overprotection, and support, and their association with the employment participation of young adults with rheumatic disease.

**Methods.** One hundred and forty-three young adults, ages 18 to 30 years, with systemic lupus erythematosus (54.5%) and juvenile arthritis (45.5%) completed a 30-min online questionnaire of their work and education experiences. Information collected was demographic, health (e.g., pain, fatigue, disease activity), work context (e.g., career satisfaction, helpfulness of job accommodation/benefits, and workplace activity limitations), and psychosocial (e.g., independence, social support, and overprotection). Log-Poisson regression analysis examined factors associated with employment status.

**Results.** Over half of respondents were employed (59%) and 26% were enrolled in school. Respondents reported moderate to high perceptions of independence and social support. However, 27% reported that “quite a bit” to “a great deal” of overprotection characterized their relationships with those closest to them. At the bivariate level, employed participants and those indicating greater perceived independence reported greater social support and less overprotection. Multivariable analysis revealed that being employed was associated with older age, more job accommodations/benefits perceived as being helpful, and greater perceived independence.

**Conclusion.** This is one of the first studies examining the employment of young adults with rheumatic diseases. Findings highlight the importance of psychosocial perceptions such as independence and overprotection, in addition to support related to working. Additional research is needed to better understand the role of those close to young adults with rheumatic diseases in supporting independence and encouraging employment. (J Rheumatol First Release Oct 1 2014; doi:10.3899/jrheum.140419)

## Key Indexing Terms:

YOUNG ADULTHOOD      INDEPENDENCE      SOCIAL SUPPORT      EMPLOYMENT  
SYSTEMIC LUPUS ERYTHEMATOSUS      JUVENILE ARTHRITIS

Young adulthood is a transitional life phase spanning the ages of 18 to 30 years. During this time, individuals typically shift from the dependency of childhood to greater independence in a range of social roles<sup>1</sup>. Obtaining a fulltime job is a particularly important milestone of a

successful transition to adulthood and provides opportunities for the generation of income, building one's self-identity, acquiring new skills, and gaining access to other health and social benefits of work<sup>2,3,4,5,6</sup>. Difficulty with early job experiences may have potential adverse,

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longer-term consequences, such as the risk of unemployment or underemployment, reduced earnings, or deterioration of skills<sup>2,5,6,7</sup>. Among the few studies of young people with rheumatic disease, findings show that employment rates vary from 11% to 73% depending on the characteristics of the sample being studied<sup>8,9,10,11,12,13,14,15,16</sup>, and that young adults with rheumatic diseases are less likely than healthy controls to be employed<sup>6,8,9,11,12,13,16</sup>. In these studies, health factors such as disease severity and activity limitations have been primarily examined as barriers to employment while psychosocial factors have not been well examined<sup>6,10,11,12,17</sup>.

Guiding research on young adults are theories such as that of Arnett<sup>1</sup>, which provides a historical context for research on employment and suggest that young people in industrialized countries are delaying the transition to adulthood by prolonging education or participating in multiple prevocational work experiences to gain the skills needed for employment. As a result of this extended transitional phase, fewer differences exist between those aged 18 and 30 years in terms of involvement in independent adult social roles than in previous generations<sup>1</sup>. Arnett also characterizes transitions as being perceived as positive or negative. Positively perceived life transitions can include vocational milestones (e.g., completing university and starting work) and social role changes (e.g., new relationships) that highlight independence<sup>1</sup>. However, transitions can also be stressful as young people learn to navigate new adult roles and responsibilities. This stress may be exacerbated if others are not supportive of changes. To date, research using theories such as Arnett's have focused on healthy individuals. Little is known about the transition to adult work roles of young people with rheumatic diseases such as systemic lupus erythematosus (SLE) and juvenile arthritis (JA), and even less is known about factors such as their perceptions of independence and support from others.

Perceptions of independence have been theorized to be particularly important to the transition to adulthood for young people and may be relevant to employment<sup>1,5,7,18</sup>. Independence is defined as an appraisal that one is free from unwanted control, influence, or aid from others, and where a person is able to act and make decisions without constraints<sup>19,20,21,22,23</sup>. Research shows that among the most distressing aspects of living with a disabling health condition is the loss of independence and the potential need to rely on others for support<sup>21,22,23,24,25</sup>. Young adults with disabilities may also feel overprotected by others<sup>26,27,28</sup>. That is, they may report perceptions of excessive assistance, restriction of activities, vigilance, and repetitious reminders related to managing their health and self-care<sup>26,27</sup>. Both independence and overprotection have primarily been examined with respect to transitions from pediatric to adult healthcare to study changing health service needs<sup>18,29</sup>, and have not, to the best of our knowledge, been investigated in

studies on employment of young adults with rheumatic diseases<sup>27,28</sup>.

Our study examines perceptions of independence, social support, and overprotection, the associations among these concepts, and their relationship with employment in a sample of young adults living with rheumatic diseases. We expect that perceived independence and support will be separate concepts that are modestly, positively associated with one another and that will be negatively associated with perceptions of overprotection. Young adults with SLE and JA are expected to report similar levels of support and independence. However, given that JA is often diagnosed at earlier ages than SLE, young adults with JA may report greater levels of perceived overprotection. We expect that respondents who report more supportive relationships and perceive that they have greater independence will be more likely to be employed, even when controlling for demographic (e.g., age, education), health (e.g., diagnosis, disease activity, activity limitations), and work context variables (e.g., workplace activity limitations, career satisfaction), which have been found to be important in previous research on adults with arthritis<sup>17,30,31,32</sup>. Greater perceptions of overprotection are expected to be associated with living with one's parents and a lower likelihood of employment when controlling for other factors.

## MATERIALS AND METHODS

**Participants.** One hundred and forty-three young adults living with SLE and JA were recruited using convenience sampling from 4 Canadian provinces, including Ontario (n = 65 SLE), Saskatchewan (n = 38 JA), Calgary (n = 25 JA, n = 1 SLE), and British Columbia (n = 12 SLE, n = 2 JA). Potential respondents were directly invited to participate through pediatric rheumatology clinics where nurses or physicians provided eligible participants with study information, mail-based invitations using patient registries consisting of young adults with SLE or JA, and posters displayed in clinic common areas. Because of clinic confidentiality agreements, information on the number and characteristics of participants who did not respond to the study invitation was not made available and a total response rate could not be calculated. Participants were eligible if they were aged 18 to 30 years at the time of the survey; received a physician diagnosis of SLE, juvenile rheumatoid arthritis, juvenile idiopathic arthritis, or juvenile chronic arthritis; and were fluent in English. Individuals were excluded if they reported being diagnosed with other disabling conditions or had a cognitive or developmental impairment that limited their activities. All potential participants were provided with an invitation that included detailed information about the research and survey instructions. Those participating in the study provided informed consent online prior to completing the survey. Data security procedures included giving each participant a unique login, storing data in an encrypted folder, and removing all personal identifiers from the questionnaire. The study protocol was approved by the Research and Ethics Board of the University Health Network, Toronto (REB# 11-0371-AE). Participants received a \$10 CDN downloadable gift certificate for their involvement.

**Procedure.** Participants completed a cross-sectional, online questionnaire taking about 30 min to complete<sup>33</sup>.

**Measures.** Demographic details collected were age, sex, educational attainment, marital status, living arrangements, and personal income.

Respondents selected the option that best described their current employment status: employed fulltime, employed parttime, short-term

leave, longterm leave, not employed and looking for work, not employed and not looking for work, student, homemaker, or not working for other reasons.

**Social support:** The 8-item Short Form Lubben Social Network Scale measured social contacts and perceptions of support (e.g., "How many relatives do you see or hear from at least once a month?")<sup>34</sup>. Items were rated on a 5-point scale (0 = none; 5 = 9 or more) and a total score was produced<sup>34</sup>. Cronbach's alpha coefficient, a measure of the internal consistency of the items, was 0.85. Scores less than 12 indicate social isolation and less cohesiveness within a social network<sup>34</sup>.

Seven items measuring perceived independence were created for the study (e.g., "I am limited in my choices because of the attitudes of others" or "I behave in ways that are based on my own preferences and values"). Items were rated on a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree) and a mean score produced ( $\alpha = 0.79$ ; items listed in Appendix 1).

**Overprotection:** participants were asked, "In general, to what extent, if at all, do you feel your family is overprotective of you when it comes to your health?" (1 = not at all; 5 = a great deal). An initial examination of the validity of the global item found that it did not exhibit any floor or ceiling effects and was easily understood by respondents.

**Symptom severity:** self-reported diagnosis and disease subtype was collected. Disease type (not subtype) was confirmed by the clinic. Clinic confidentiality agreements did not permit confirmation of details of disease subtype. To allow comparisons between SLE and JA, general rather than disease-specific health measures were administered. Pain, fatigue, and disease activity were assessed with visual analog scales (0 = no pain/fatigue/disease activity; 10 = worst possible pain/fatigue/most activity). Participants were asked about disease flares experienced in the past 3 months (0 = no flares; 3 = severe flares)<sup>35</sup>.

**Activity limitations:** the 20-item Health Assessment Questionnaire Patient-Reported Outcome Measurement Information System was administered to assess self-reported functional status and disability with everyday activities (e.g., walking, climbing stairs, lifting)<sup>36</sup>. Items were totaled to create a score out of 100 ( $\alpha = 0.96$ ).

**Disease duration:** respondents were asked the time since diagnosis, in years.

Difficulties with workplace acts and tasks were assessed using the 12-item Workplace Activities Limitations Scale, gauging problems with lower mobility (e.g., getting around the workplace), upper mobility (e.g., reaching), and concentration at work and the pace and schedule of work (0 = no difficulty/not applicable to job; 3 = unable to do). Items were totaled to produce a score ranging from 0 to 36<sup>37,38</sup> ( $\alpha = 0.91$ ).

The 5-item Career Satisfaction Scale measured subjective perceptions of success in general career domains, including progress toward goals, income, and development of skills (1 = not at all satisfied; 5 = extremely satisfied)<sup>39</sup>. A mean score ranging from 1 to 5 was produced ( $\alpha = 0.91$ ).

Respondents were asked about the perceived helpfulness of health-related job accommodations and benefits. Respondents were given a list of 12 benefits and job practices (e.g., flexible hours, drug benefits) and modifications (e.g., breaks and rest periods), and were asked to indicate whether they believed the accommodation/benefit would help them maintain employment (if employed) or enable employment (if not employed; 1 = yes; 0 = no)<sup>37</sup>.

**Statistical analysis.** Univariate analyses were conducted for descriptive purposes including frequencies, means, and SD. Distributions of the data were also examined for normality. Bivariate analyses were performed including Pearson correlations to examine interrelationships between interval-level data. Analyses of variance and chi-square tests determined whether study variables differed based on health condition, living situation, or employment status. Log-Poisson regression analysis was conducted to examine the relationship between psychosocial perceptions (e.g., independence, social support, and overprotection) and employment participation, controlling for demographic, health, and work context factors. A 2-level dichotomous categorical outcome variable ("employed" and "not

working") was developed. Participants who classified their current employment status as being on longterm leave, not employed, homemaking, or as being a student were combined to produce the "not working" group that was set as the reference category. Independent variables were included in the model if they were related to employment status ( $p < 0.20$ ) at the bivariate level and did not exhibit multicollinearity or floor or ceiling effects. Analyses were carried out using SAS 9.0 (SAS Institute Inc.).

## RESULTS

Sample characteristics are provided in Table 1. The mean age of participants was 23.3 years (SD = 3.6), most were women (79%), and 77% were enrolled in or had completed postsecondary school (vocational training, college, university, or graduate school). Half of the sample lived with parents (52%) and 20% were married. Most respondents reported that their condition was well controlled with low mean levels of pain and fatigue, and few activity limitations. Participants also reported relatively low mean disease activity and moderate flare severity. Participants with SLE were more likely to be women ( $p < 0.01$ ) and to live with parents ( $p < 0.05$ ), and were less likely to be married ( $p < 0.001$ ). Participants with SLE also reported significantly greater fatigue ( $p < 0.05$ ), shorter disease duration ( $p < 0.05$ ), and less severe flares ( $p < 0.001$ ) than those with JA. When asked about their JA subtype, 54% reported not knowing their specific diagnosis. Among those who indicated a specific subtype, bivariate analysis did not reveal significant differences in employment or psychosocial perceptions.

In general, perceptions of independence, support, and overprotection appeared to be separate constructs that were only moderately related with one another (Table 2). Pearson correlation coefficients showed that greater independence was positively correlated with perceived support ( $r 0.35$ ,  $p < 0.001$ ) and negatively associated with perceptions of overprotection ( $r -0.21$ ,  $p < 0.01$ ). Participants reported moderate to high perceptions of independence (mean = 3.9, SD = 0.65) with no significant differences between respondents with SLE and JA. Most participants also reported being well-supported from those closest to them with only 6% having a social support score that indicated potential social isolation (score < 12). Respondents with JA reported significantly greater support and less overprotection than did participants with SLE ( $p < 0.01$  and  $< 0.001$ , respectively). Additional bivariate analyses found that participants living with their parents reported greater overprotection ( $p < 0.05$ ) and less independence ( $p < 0.05$ ) than those not living with their parents (Figure 1).

Nearly 60% (59.5%) of study respondents were employed. Among those working, 54.3% were employed fulltime and 42.4% were employed parttime. Over a quarter were students (25.9%) and 9.1% of participants were not employed, but were looking for work. Of interest, among those participants who were employed, more than 1 in 4 were also pursuing an education (26.6%). Although their

Table 1. Sample characteristics for all participants and for those with SLE and JA (n = 143). P values are the level of significance for bivariate ANOVA for continuous variables or chi-square tests for categorical variables.

Characteristics	Total, n = 143 n (%) / median ± SD	SLE, n = 78 n (%) / median ± SD	JA, n = 65 n (%) / median ± SD	p <sup>a</sup>
<b>Demographics</b>				
Age, yrs	23.3 ± 3.6	23.3 ± 3.5	23.2 ± 3.7	
Female	113 (79.0)	69 (88.5)	44 (67.7)	**
Lives with parents	75 (52.4)	48 (61.5)	27 (41.5)	*
Married or living as if married	28 (19.6)	8 (10.3)	20 (30.8)	***
Postsecondary education	110 (76.9)	63 (80.8)	47 (72.3)	
<b>Health</b>				
Pain, 1–10	3.2 ± 2.8	3.1 ± 3.0	3.3 ± 2.6	
Fatigue, 1–10	4.2 ± 2.8	4.8 ± 2.9	3.6 ± 2.7	*
Activity limitations, 0–100	3.1 ± 2.8	3.0 ± 2.8	3.1 ± 2.8	
Disease activity, 1–10	21.1 ± 13.4	19.4 ± 12.1	22.7 ± 14.6	
Flare severity, 0–3	1.7 ± 1.0	1.3 ± 1.0	2.0 ± 0.9	***
Disease duration, yrs	10.8 ± 6.2	7.6 ± 4.7	14.0 ± 7.7	*
<b>Psychosocial perceptions</b>				
Perceived independence, 1–5	3.9 ± .65	3.8 ± .70	3.9 ± .60	
Social support, 0–40	22.5 ± 7.0	20.8 ± 7.5	24.2 ± 6.5	**
Perceived overprotection, 1–5	2.8 ± 1.4	3.2 ± 1.4	2.3 ± 1.3	***
<b>Employment and work context</b>				
<b>Employment status</b>				
Employed fulltime	47 (32.9)	24 (30.8)	23 (35.4)	
Employed parttime	38 (26.6)	17 (21.8)	21 (32.3)	
Short-term leave	3 (2.1)	3 (3.8)	0 (0)	
Student	37 (25.9)	24 (30.8)	13 (20.0)	
Not employed and looking for work	13 (9.1)	7 (9.0)	6 (9.2)	
Not employed and not looking for work	2 (1.4)	2 (2.6)	0 (0)	
Not employed for other reasons <sup>‡</sup>	3 (2.1)	1 (1.3)	2 (3.1)	
Employed and in school <sup>†</sup>	38 (26.6)	19 (43.2)	19 (46.3)	
Hrs worked per week	31.2 ± 13.0	31.5 ± 13.2	30.9 ± 12.8	
Yrs employed	2.4 ± 2.4	2.5 ± 2.5	2.2 ± 2.2	
<b>Job sector</b>				
Business and administration	15 (10.5)	9 (20.5)	6 (13.6)	
Health, science, and teaching	27 (18.9)	16 (36.4)	11 (25.0)	
Sales and service	32 (22.4)	15 (34.1)	17 (38.6)	
Trades and transport	14 (9.8)	4 (5.1)	10 (22.7)	
<b>Income, CDN</b>				
< \$29,999	43 (30.1)	20 (45.5)	23 (52.3)	
\$30,000–\$59,999	23 (16.1)	12 (27.3)	11 (25.0)	
\$60,000–\$89,999	6 (4.2)	3 (6.8)	3 (4.6)	
≥ \$90,000	3 (2.1)	0 (0)	3 (4.6)	
Workplace activity limitations, 0–36	6.2 ± 5.4	5.7 ± 5.6	6.7 ± 5.1	
Career satisfaction, 1–5	3.5 ± .95	3.3 ± 1.0	3.6 ± .90	
Perceived helpfulness of job accommodations/benefits, 0–12	6.1 ± 4.2	6.8 ± 4.3	5.4 ± 4.1	

\*p < 0.05. \*\*p < 0.01. \*\*\*p < 0.001. <sup>a</sup>Only statistically significant p values included in the table. <sup>‡</sup>Participants not working for other reasons includes homemakers and those volunteering at the time of the survey. <sup>†</sup>Participants who reported that employment was their primary occupational role, but were also enrolled in an educational program. SLE: systemic lupus erythematosus; JA: juvenile arthritis.

Table 2. Correlations among independence, overprotection, and social support.

Characteristics	Independence, r	Overprotection, r	Social Support, r
Independence	•	–0.21*	0.35**
Overprotection		•	–0.11
Social support			•

\*p < 0.01. \*\*p < 0.001.

health was relatively good, participants reported moderate workplace activity limitations and an average of 6 of 12 said that job accommodations/benefits would be helpful to them in finding or maintaining work. Generally, participants reported high satisfaction with their career progress. Participants with SLE and JA did not significantly differ in terms of their employment status or any work context variables. As a result, we combined the SLE and JA groups in subsequent analyses and included diagnosis as a potential predictor.



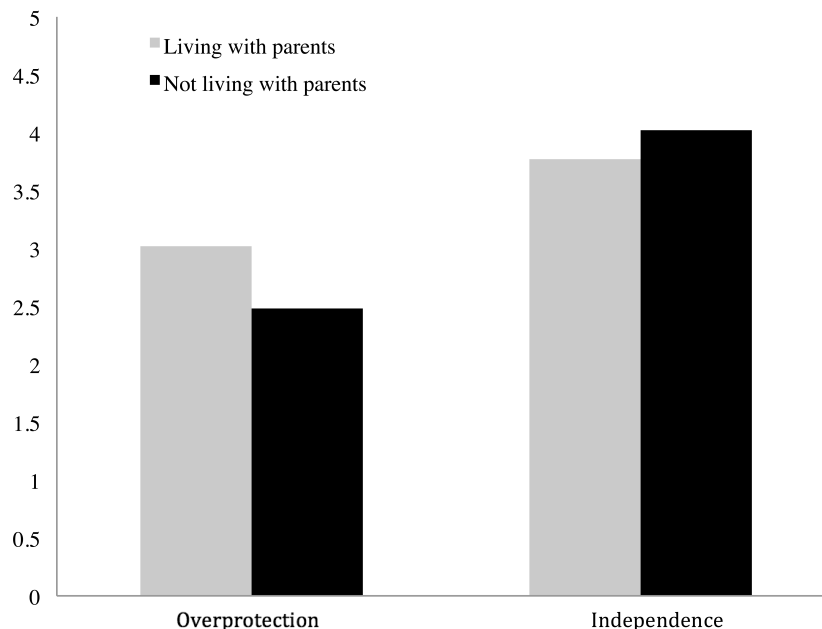


Figure 1. Perceived independence and overprotection compared by whether a participant lived with their parents. Participants living with their parents reported significantly more overprotection [F (1, 127) 4.8,  $p < 0.05$ ] and less independence [F (1, 129) 5.01,  $p < 0.05$ ] compared to those not living with their parents.

Table 3 examines bivariate associations of demographic, health, psychosocial, and work context variables with employment status (employed/not employed). Variables significant at  $p < 0.20$  were subsequently included in multivariable analyses. This included age, education, diagnosis, independence, support, overprotection, career satisfaction, and perceived helpfulness of job accommodation/benefits.

Table 4 presents results of the multivariable log-Poisson regression model examining demographic, health, psychosocial, and work context factors associated with employment. Older age (PR 1.1, 95% CI 1.0–1.2) was associated with an increased likelihood of being employed. Perceiving that a greater number of job accommodations/benefits would be helpful to employment was associated with being less likely to work (PR 0.91, 95% CI 0.88–0.95). Social support and perceptions of overprotection were not significantly related to employment status at the multivariable level. However, greater perceived independence was associated with employment (PR 1.3, 95% CI 1.0–1.6). Health factors were not significantly related to employment status when controlling for other factors.

## DISCUSSION

Guided by theoretical frameworks that have highlighted the importance of independence and support in the transition to adult roles, our study expands upon research in the area of rheumatic disease and employment by focusing on work

participation of young adults living with SLE and JA. It also examined perceptions of overprotection that previous studies have found to characterize the support relationships of young people with chronic diseases. While there were some demographic and health differences between the samples of young adults with SLE and JA, there were notable similarities in their work experiences. Moreover, perceptions of independence in those with SLE and JA were related to employment and may warrant greater attention in future studies along with health and work context factors in young adults with rheumatic disease.

Our results point to the role of close others as being complex. Analyses revealed significant but modest correlations between perceptions of independence, support, and overprotection, suggesting that all 3 concepts provided somewhat unique information about young adults' experiences that could be important to understanding their health and employment. Specifically, many participants indicated having a supportive social network. Yet, more than 1 in 4 respondents also reported "quite a bit" to "a great deal" of overprotection by those closest to them. Overprotection was especially high among those living with their parents. This finding is consistent with previous research with young people living with chronic conditions who often note that parents and close others have concerns for their health and well-being that can extend as far as restricting activities<sup>18,26,29</sup>. A better understanding of the potentially complex family dynamics that can occur while young adults

*Table 3.* Sample characteristics presented by employment status as well as bivariate analyses for explanatory variables by employment status (n = 143). P values are the level of significance for bivariate ANOVA for continuous variables or chi-square tests for categorical variables.

Characteristics	Employed, n = 85 n (%) / median ± SD	Not Working, n = 65 n (%) / median ± SD	p <sup>a</sup>
<b>Demographic</b>			
Age, yrs	24.0 ± 3.6	22.8 ± 3.4	**
Female	67 (78.8)	46 (70.8)	
Lives with parents	44 (51.8)	31 (47.7)	
Married or living as if married	21 (24.7)	7 (10.8)	
Postsecondary education	68 (80.0)	42 (64.6)	◇
<b>Health factors</b>			
Diagnosis			
SLE	41 (48.2)	37 (56.9)	◇
JA	44 (51.8)	21 (32.3)	
Pain, 1–10	3.5 ± 3.1	3.2 ± 2.7	◇
Fatigue, 1–10	4.3 ± 3.1	4.5 ± 2.7	
Activity limitation, 0–100	25.6 ± 16.7	25.9 ± 16.6	
Disease activity, 1–10	3.1 ± 3.0	3.0 ± 2.7	
Disease flares, 0–3	1.6 ± .9	1.7 ± 1.0	
Disease duration, yrs	11.3 ± 7.7	9.1 ± 6.2	
<b>Psychosocial perceptions</b>			
Perceived independence, 1–5	4.0 ± .60	3.4 ± .80	**
Social support, 0–40	21.8 ± 7.0	23.8 ± 7.8	*
Perceived overprotection, 1–5	2.6 ± 1.4	3.1 ± 1.2	◇
<b>Work context</b>			
Workplace activity limitations, 0–36	5.9 ± 4.9	7.5 ± 6.7	
Career satisfaction, 1–5	3.4 ± 1.0	3.3 ± .90	◇
Perceived helpfulness of job accommodations/benefits, 0–12	5.0 ± 3.5	8.1 ± 4.8	**

<sup>a</sup>Only statistically significant p values included in the table. ◇p < 0.20. \*p < 0.05. \*\*p < 0.01. SLE: systemic lupus erythematosus; JA: juvenile arthritis.

*Table 4.* Summary of Log-Poisson model, examining the factors related to the likelihood of being employed among respondents living with rheumatic disease (n = 143). Outcome variable is employment status (1 = yes; 0 = no). Not employed group included those who were unemployed, students, homemakers, or volunteers at the time of the survey.

Characteristics	Employment, PR	95 % CI
<b>Demographic factors</b>		
Age, yrs	1.1	1.0–1.2*
Postsecondary education <sup>†</sup>	0.91	0.65–1.3
<b>Health factors</b>		
Diagnosis <sup>††</sup>	1.2	0.86–1.5
Pain, 1–10	1.0	0.98–1.1
<b>Psychosocial perceptions</b>		
Independence, 1–5 Δ	1.3	1.0–1.6*
Social support, 0–40	0.98	0.97–1.0
Overprotection, 1–5	0.96	0.87–1.1
<b>Perceptions regarding working</b>		
Career satisfaction, 1–5	1.00	0.88–1.1
Job accommodations/benefits, 0–12	0.91	0.88–0.95*

\*p < 0.05. \*\*p < 0.01. <sup>†</sup>Not having a postsecondary education is the reference education category. <sup>††</sup>Juvenile arthritis is the condition reference category.

transition from pediatric to adult care is important as many clinicians work with both patients and their family members.

Interestingly, participants with JA reported significantly greater support and less overprotection than respondents with SLE. Although there were no differences in employ-

ment status between the conditions, individuals with JA had their disease for a longer period of time and were less likely to be living with parents and more likely to be married. The longer disease duration reported by respondents with JA may mean that those closest to them have had more time to become accustomed to living with someone who has a chronic condition and, as a result, had fewer concerns about their role participation. These findings need to be replicated in additional samples with larger numbers of young adults. Issues of overprotection and support also warrant greater attention in longitudinal research and in comparative studies with age-matched healthy controls. Fewer participants in our study reported being employed and more lived with their parents when compared to Canadian population-level data of their healthy peers (76% employed, 42% lived with parents<sup>40</sup>). These differences are in keeping with other studies on rheumatic diseases and suggest that young adults with JA and SLE may face added challenges that delay their transition to adult roles. However, consistent with their life phase, over a quarter of respondents in our study were in school<sup>1</sup>. It may be that family support and/or worries about a family member's health may actually encourage young adults with chronic diseases to focus efforts on continuing education so that jobs with greater flexibility and control and fewer physical demands are attainable. This could result in the longterm employment experiences of young adults with SLE and JA being better than previous generations.

As noted earlier, although there were some demographic and health differences between those with SLE and JA, their employment experiences were similar. There were no significant differences in their hours of work, employment sector, workplace activity limitations, career satisfaction, or in the kinds of job accommodations/benefits that they thought might be helpful in working. These results add to a growing body of literature finding that despite differences in clinical features of many rheumatic diseases, there are often similarities across conditions in terms of their effect on work<sup>38,41,42</sup>. The results also suggest that it may be possible to design similar employment-related interventions for youth with diverse rheumatic diseases. However, additional research is needed.

Participants with SLE and JA reported similarly high perceived independence scores. Greater perceptions of independence were associated with a greater likelihood of employment after controlling for demographic, health, and work context factors. Because the research was cross-sectional, the direction of the relationship cannot be ascertained. It may be that perceiving oneself to be independent changes behaviors in ways that can facilitate employment. For example, it might promote seeking information about job opportunities, ways to better manage health at work, or job modifications<sup>25,37</sup>. Alternatively, being employed may influence perceptions of independence. The sense of accomplishment and the building of an

autonomous identity that comes through employment, as well as the generation of resources for current and future needs, may serve to promote personal and financial independence<sup>43</sup>. Finally, the relationships between independence and employment could be reciprocal and reinforce one another. Greater independence may increase the likelihood of being employed, which further heightens perceptions of independence. Additional research is needed to better understand the potential interrelationships between independence and employment. Strategies aimed at fostering the independence of young adults with rheumatic diseases and that are directed at participation in social roles may deserve greater attention among healthcare providers.

Also of note was that health factors were not significantly related to employment status, which differs from some previous research<sup>6,10</sup>. This may be because respondents in our study were recruited from specialized clinics and their health may have been well monitored and managed, which resulted in them being better able to work or attend school. It also may be that previous studies with young adults have included fewer work context factors and psychosocial variables than this research. As reflected in our study and in research of adults with arthritis<sup>31,42,44</sup>, work context factors are significantly related to employment. For example, participants who reported that a greater number of job accommodations/benefits would be helpful in their being able to work were less likely to be employed. While job accommodations/benefits could directly help people find work and remain employed, they may also be a proxy for current or anticipated future health needs. Additional research on the relationship between work context and health factors in the young adult life phase is necessary.

Several limitations to our research need to be acknowledged, including the cross-sectional study design, potential sample homogeneity, additional validation of psychosocial items and measures, and access to employment outcome measures. A longitudinal design would allow researchers to better understand how health, psychosocial, and work context factors change over time and their relationship to employment among young adults transitioning to adulthood. This convenience sample primarily consisted of well-managed young adults mostly recruited from patient registries and specialty clinics. More diverse sampling strategies and greater numbers of young adults with different types of rheumatic conditions and subtypes from a representative range of provinces would help researchers minimize potential biases and understand similarities and unique needs that may deserve attention in intervention efforts to increase employment. Although the measures designed for overprotection and independence showed promise, further research is required to establish their validity in studies of young people with arthritis, as well as their relationship to well-being, including stress and depression. Finally, concepts such as independence, support, and overprotection

need to be examined in research looking at other employment outcomes, including at-work productivity (e.g., presenteeism) and absenteeism.

Our study provides insights into the employment experiences of young adults with JA and SLE, and their perceptions of independence, support, and overprotection. To the best of our knowledge, these perceptions have not been examined previously. However, they may be particularly relevant for young adults who are trying to manage their health and transition to new social roles. Findings suggest that many young adults with SLE and JA perceive themselves to be independent and well supported, although additional research is needed related to overprotection and its association with employment, especially among young adults with SLE. The findings may help to inform or enhance interventions for young people and their families that are aimed at increasing participation in a wide array of social roles.

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**APPENDIX 1.** Items measuring perceived independence.

Items	Response Options				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
a. I am dependent on others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I feel independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I don't let others tell me what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I am free to make decisions for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I can pursue goals in my own way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I behave in ways that are based on my own preferences and values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am limited in my choices because of the attitudes of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Note: A mean score was created across the 7 items.