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# Rheumatic Disease Disclosure at the Early Career Phase and Its Impact on the Relationship Between Workplace Supports and Presenteeism

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Objective. Young adults with rheumatic disease face challenges communicating health needs, accessing workplace support, and sustaining productivity. Our objective was to examine whether disclosure modifies the relationship between workplace support and presenteeism.

Methods. An online survey was administered to Canadian young adults with rheumatic disease and asked about presenteeism (0 = health had no effect on work; 10 = health completely prevented working), workplace support need, availability, and use and whether health details were disclosed to an immediate supervisor. A multivariable robust linear regression model was conducted and stratified by those who did and did not disclose the details of their health to their supervisor.

**Results.** A total of 306 participants completed the survey with a mean ± SD presenteeism score of 4.89 ± 2.65. More than 70% disclosed health details to their supervisor; those who disclosed reported greater presenteeism (mean ± SD 5.2 ± 2.5) when compared to those who did not disclose (mean ± SD 4.2 ± 2.61). Greater disease severity was associated with disclosure. Half of the participants reported unmet workplace support needs (53%), 32% reported that their workplace support needs were met, and 15% reported exceeded workplace support needs. The relationship between presenteeism and workplace support needs was modified by disclosure. For participants who disclosed, workplace support needs that were unmet ( $\beta = 1.59$  [95% confidence interval (95% CI) 0.75, 2.43]) and that were met (β = 1.25 [95% CI 0.39, 2.11]) were associated with greater presenteeism when compared to those with exceeded workplace support needs.

Conclusion. To address presenteeism, strategies should be developed for young adults with rheumatic disease to foster access to available workplace supports and to navigate disclosure decisions.

# INTRODUCTION

Young adulthood, a period spanning 18-35 years, represents a critical transitional life phase where a person establishes themselves within the labor market, often making occupational changes toward achieving full-time work. Presenteeism (i.e., working while unwell) during young adulthood can impact early career success and contribute to difficulties with sustaining and advancing within the workforce (1). Increasingly, studies show that a rheumatic disease in young adulthood can be

associated with barriers to employment that are attributed to the severity of symptoms and to work environments that lack appropriate supports (2). Moreover, the invisible and episodic nature of many rheumatic diseases may add to the complexity related to the disclosure of health needs and requesting workplace supports that are necessary to addressing employment barriers. We examined how disclosure of health details can modify the relationship between workplace support and presenteeism, using data from a Canadian survey of young adults with rheumatic disease.

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## **SIGNIFICANCE & INNOVATIONS**

- Our study is one of the first to unpack the relationship between the disclosure of health details, workplace support needs, and presenteeism for young adults with rheumatic disease.
- More than half of young adults with rheumatic disease in our study reported that their workplace support needs were unmet.
- More than two-thirds of young adults with rheumatic disease described disclosing health details to their supervisor; those with a more severe disease were more likely to disclose.
- The relationship between unmet workplace support needs and presenteeism was significant for participants who disclosed health details.

Within industrialized countries, rheumatic disease is one of the most prevalent chronic health conditions affecting the working population and is a frequently reported cause of lost productivity (3-5). For young adults, a rheumatic disease may be associated with unique challenges in the school-to-work transition, including difficulties finding and sustaining stable employment, sustaining productivity, and achieving career advancement while balancing work, health, and personal responsibilities (2,6-9). Challenges in the school-to-work transition can be exacerbated by ongoing needs for health care that can change as a young person moves from pediatric to adult health care settings (10,11). A Canadian survey of young adults living with juvenile arthritis (JA) and systemic lupus erythematosus (SLE) indicated that >40% reported lost productivity, including health-related missed work days and job disruption. Productivity loss was more likely to be reported by young adults with more severe rheumatic disease symptoms (e.g., greater pain, fatigue, and activity limitations) and by those who reported more challenging work contexts (e.g., less job control or supervisor support) (12).

A supportive work environment can play an important role in addressing presenteeism and strengthening person–job fit for people with chronic disease (13–15). Studies with older age groups living with rheumatic disease show that diverse workplace support needs remaining unmet (e.g., job accommodation, work modification, and health benefits) are often associated with presenteeism and greater workplace activity limitations, while having workplace support needs met or even exceeded are related to less presenteeism (13,16,17). Importantly, existing research on workplace supports may not always be relevant to young adults with rheumatic disease, who have less established employment histories and who are more likely to work in nonstandard employment where formal accommodations are less likely to be available (18).

The disclosure of rheumatic disease by employees within the workplace may play an important role in determining access to workplace supports, especially for those requiring an

accommodation (e.g., accessible workstation) or access to a work modification (e.g., scheduling flexibility) (19). When compared to older age groups, young adults with rheumatic disease report greater hesitancy in communicating details about their health to their supervisor (15,20). Qualitative research has found that intermittent and unpredictable disease symptoms coupled with less job tenure, inexperience with workplace self-advocacy, and poorly established relationships with a supervisor are commonly described barriers to communicating needs and requesting workplace supports (15,20). Life course research suggests that the timing of events can also impact work-related perceptions and behaviors. Specifically, a rheumatic disease is often seen by others as a condition of older adults. A rheumatic disease may be considered by others as occurring at a nonnormative time when experienced by a young adult (21-23). Consequently, there may be apprehension in requesting assistance out of concern of a negative reaction from supervisors (7,15,20). At the same time, privacy legislation within many industrialized countries means that workers with rheumatic disease are not legally obligated to reveal their health condition to an employer unless there is a safety concern (24). Other research indicates that the disclosure of a health condition to an immediate supervisor may modify the relationship between workplace supports and presenteeism; those who disclose may be more likely to have their workplace supports met, thereby attenuating the impact of health on work (19,24).

Little research has examined the association between rheumatic disease disclosure at the early career phases and how it modifies the relationship between workplace support needs and presenteeism. Our study aimed to address this knowledge gap in a cohort of Canadian young adults with rheumatic disease. We addressed 4 study objectives: 1) to describe the proportion of participants who reported that their workplace support needs were unmet, met, or exceeded, and who reported disclosing the details of their health to their immediate supervisor; 2) to examine the relationship between disclosure of health details to an immediate supervisor and whether workplace support needs were unmet, met, or exceeded; 3) to compare whether presenteeism differed according to whether workplace support needs were unmet, met, or exceeded and whether or not a participant disclosed the details of their health to an immediate supervisor; and 4) to examine whether the relationship between workplace support needs and presenteeism was modified by disclosure of health details when adjusting for sociodemographic, disease/ health, and work context factors.

# **MATERIALS AND METHODS**

We analyzed cross-sectional data from an ongoing longitudinal online survey of young adults with rheumatic disease. To be eligible, participants had to be between ages 18 and 35 years, report a doctor-diagnosed rheumatic condition (e.g., JA, SLE, rheumatoid arthritis) and have paid employment in the past

**Table 1.** Description of total sample of young adults with rheumatic disease and by whether a participant disclosed health details to their immediate supervisor or manager\*

	Total sample (n = 306)	Disclosed (n = 216)	Not disclosed (n = 90)	Р
Sociodemographic factors				
Age, years	$28.5 \pm 4.5$	$28.7 \pm 4.5$	$28.0 \pm 4.4$	0.25
Sex, no. (%)				
Women	187 (63.1)	136 (63)	57 (63.3)	0.95
Men	113 (36.9)	80 (37.0)	33 (36.7)	-
Educational attainment, no. (%)				
<postsecondary education<="" td=""><td>51 (16.7)</td><td>35 (16.2)</td><td>16 (17.8)</td><td>0.95</td></postsecondary>	51 (16.7)	35 (16.2)	16 (17.8)	0.95
≥Postsecondary education†	255 (83.3)	181 (83.8)	74 (82.2)	-
Married/living as if married	138 (45.1)	105 (48.6)	33 (36.7)	0.06
Primary childcare responsibilities	69 (22.6)	55 (25.5)	14 (15.6)	0.06
Disease/health factors				
Pediatric disease onset (age <18 years), no. (%)	157 (51.3)	108 (50.0)	49 (54.4)	0.48
Pain (0–10)	$5.5 \pm 2.5$	$5.8 \pm 2.4$	$5.1 \pm 2.7$	0.03
Fatigue (0–10)	6.1 ± 2.3	$6.3 \pm 2.2$	$5.6 \pm 2.6$	0.03
Disease activity (0–10)	$4.9 \pm 2.6$	$5.1 \pm 2.5$	$4.4 \pm 3.0$	0.04
Self-rated health, no. (%)				
Poor	30 (9.8)	21 (9.7)	9 (10.0)	0.01
Fair	128 (41.8)	101 (46.8)	27 (30.0)	-
Good	101 (33.0)	65 (30.1)	36 (40.0)	-
Very good	38 (12.4)	24 (11.1)	14 (15.6)	-
Excellent	9 (2.9)	5 (2.3)	4 (4.4)	-
Depression (PHQ-2), no. (%)	109 (35.6)	80 (37.0)	29 (32.2)	0.42
Workplace activity limitations	11.6 ± 6.4	$12.6 \pm 6.2$	$9.2 \pm 6.2$	0.001
(WALS: 0–36)				
Work context factors				
Employed status, no. (%)	200 (60 0)	1 17 (60 1)	61 (69 0)	0.96
Full-time (≥30 hours/week) Part-time (<30 hours/week)	208 (68.0)	147 (68.1) 69 (31.9)	61 (68.0) 29 (32.2)	0.96
Employment contract, no. (%)	98 (32.0)	09 (31.9)	29 (32.2)	_
Permanent	232 (75.8)	167 (77.3)	65 (72.2)	0.34
Temporary	74 (24.2)	49 (22.7)	25 (27.8)	0.54
Job tenure, years	$2.9 \pm 2.7$	$3.06 \pm 2.8$	$2.53 \pm 2.5$	0.13
lob sector	2.3 ± 2.7	3.00 ± 2.0	2.33 ± 2.3	0.15
Trades, no. (%)	61 (19.9)	44 (20.4)	17 (18.9)	0.92
Sales and services	39 (12.8)	28 (13.0)	11 (12.2)	-
Professional services	67 (21.9)	45 (20.8)	22 (24.4)	_
Health care/social services	119 (38.9)	86 (39.8)	33 (36.7)	_
Technology	20 (6.5)	13 (6.0)	7 (7.8)	_
Job control (1–5)	2.8 ± 1.1	$2.8 \pm 1.0$	2.8 ± 1.1	0.72
Workplace physical activity requirements (1–5)	$3.0 \pm 1.2$	$3.0 \pm 1.2$	$3.0 \pm 1.3$	0.99
Mental job demands (1–5)	3.5 ± 1.1	$3.5 \pm 1.1$	3.5 ± 1.1	0.86
Job stress (1–5)	3.1 ± 0.9	$3.2 \pm 0.9$	3.0 ± 1.0	0.11
Organizational support (1–5)	$3.1 \pm 0.3$ $3.2 \pm 1.2$	$3.2 \pm 1.11$	3.1 ± 1.3	0.27
Workplace support needs, no. (%)				
Workplace support needs exceeded	48 (15.7)	32 (14.8)	16 (17.8)	0.80
Workplace support needs met	97 (31.7)	68 (31.5)	29 (32.2)	_
Workplace support needs unmet	161 (52.6)	116 (53.7)	45 (50.0)	_
Presenteeism (0–10)	4.89 ± 2.65	$5.18 \pm 2.47$	4.19 ± 2.61	0.006

\* Values are the mean  $\pm$  SD unless indicated otherwise. PHQ-2 = 2-item Patient Health Questionnaire; WALS = Workplace Activity Limitations Scale.

year. Self-reported doctor diagnosis of rheumatic disease is considered a valid case-finding approach for public health research (25). Also, our decision to include different rheumatic diseases when constructing our cohort was informed by previous research showing that at-work experiences and workplace support needs are comparable even though clinical features may differ (26).

We used 3 recruitment approaches to maximize engagement. Participants were recruited directly from clinics in 3 Canadian provinces (British Columbia, Ontario, and Quebec). Eligible participants recruited through clinics were provided with a study invitation card by a clinic representative with a link to the online questionnaire. Second, young adult participants with rheumatic disease were recruited using an existing panel maintained by a

<sup>†</sup> Postsecondary educational attainment includes training from a college or university.

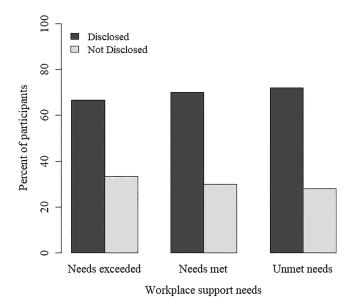
Table 2.	Workplace supports that young adults with rheumatic disease reported as being needed, available, and
used*	

	Needed	Available	Used
Work schedule flexibility	277 (90.5)	239 (78.1)	260 (85.0)
Prescription drug coverage	264 (86.3)	224 (73.2)	236 (77.1)
Extended health benefits	261 (85.3)	208 (68.0)	216 (70.6)
Paid sick leave	246 (80.4)	196 (64.1)	197 (64.6)
Modified job duties	235 (76.8)	194 (63.4)	190 (62.1)
Informal work modification	216 (70.6)	201 (65.7)	192 (62.8)
Facilities or opportunities to manage health at work	209 (68.3)	195 (63.7)	168 (54.9)
Workstation adaptations	199 (65.0)	196 (64.1)	169 (55.2)
Work-from-home arrangements	192 (62.6)	140 (45.8)	153 (50.0)
Employee assistance program	184 (60.1)	179 (58.5)	141 (46.1)
Accessible workplace	184 (60.1)	214 (69.9)	166 (54.3)
Assistive devices or technology	166 (54.3)	163 (53.3)	146 (47.5)
Other workplace supports	112 (36.6)	45 (14.7)	65 (21.2)

<sup>\*</sup> Values are the number (%).

research firm consisting of >1 million Canadians that is nationally representative according to region and income. Third, community-based recruitment was conducted through 3 non-profit organizations that support the health and employment needs of young people with rheumatic conditions. Each community organization shared study advertisements through their list-servs or social media accounts. All potential participants were provided with study information, and informed consent was obtained before they completed the questionnaire (27). Study procedures were approved by the University of Toronto Research Ethics Board (REB# 36588).

**Survey.** The online questionnaire was in English or French and took ~30 minutes to complete. Survey items were



**Figure 1.** Frequency of disclosure of health details to an immediate supervisor or manager based on whether young adult participants with rheumatic disease reported that their workplace support needs were unmet, met, or exceeded.

selected based on their psychometric properties and use in previous studies.

Outcome measure: presenteeism. A global item from the Work Productivity and Activity Impairment Questionnaire asked participants to rate the extent to which their health affected presenteeism in the past week: "During the past seven days, how much did your health affect your productivity while you were working?" Response options were provided on an 11-point scale (0 = health had no effect on my work; 10 = health completely prevented me from working) (28).

Independent variable: workplace support needs unmet, met, or exceeded. A list of 13 job accommodations (e.g., workstation adaptation), modifications (e.g., work schedule flexibility), or benefits (e.g., prescription drug coverage) were presented to participants, based on previous studies of accommodation practices for people with rheumatic disease (15). Participants were asked whether a particular job accommodation, modification, or benefit was available (yes/no/don't know), needed (yes/no), and used (yes/no). Using responses, a 3-level variable was constructed: 1) unmet workplace support need (participant's need for workplace supports was greater than their use of available workplace support), 2) workplace support needs met (participant's need for workplace support was equal to their use of available workplace support), and 3) workplace support needs exceeded (participant's need for workplace support was less than the available workplace supports) (13).

Modifier variable: disclosure to supervisor. A single item asked whether a participant had disclosed their health details to their immediate supervisor: "Have you talked to your immediate supervisor/manager about any limitations you have that might affect your work and that are related to your rheumatic disease?" Respondents provided a dichotomous response (0 = no; 1 = yes) (19).

Covariates. Sociodemographic, disease/health, and work context factors were collected for descriptive purposes and were adjusted for in multivariable models. Sociodemographic factors included age (years), sex/gender, education (postsecondary

**Table 3.** Univariable linear regression models examining factors associated with presenteeism, including workplace support needs that were exceeded, met, or unmet, disclosure of health details to an immediate supervisor or manager, and study covariates\*

	Values
Sociodemographic factors	
Age, years	0.02 (-0.0, 0.09)
Sex	
Men	0.35 (-0.27, 0.98)
Women	-
Educational attainment	
<postsecondary education<="" td=""><td>-</td></postsecondary>	-
≥Postsecondary education†	0.22 (-0.58, 1.02)
Married/living as if married	-0.07 (-0.67, 0.52)
Primary childcare responsibilities	0.52 (-0.19, 1.23)
Disease/health factors	
Pediatric disease onset (<18 years)	-0.78 (-1.37, -0.19)‡
Pain (0–10)	0.60 (-0.04, 0.09)
Fatigue (0–10)	0.54 (0.42, 0.65)‡
Disease activity (0–10)	0.56 (0.47, 0.66)
Self-rated health	
Poor/fair	-
Good/very good/excellent	-1.18 (-1.77, -0.60)‡
Depression (PHQ-2)	1.97 (1.39, 2.55)‡
Workplace activity limitations	0.19 (0.15, 0.24)‡
(WALS: 0–36)	
Work context factors	
Employment status	0.20 / 0.04 0.24)
Full-time (≥30 hours/week) Part-time (<30 hours/week)	-0.30 (-0.94, 0.34)
Employment contract	-
Temporary	
Permanent	-0.09 (-0.79, 0.60)
Job sector	0.03 ( 0.73, 0.00)
Sales and services	_
Professional services	0.44 (-0.60, 1.49)
Health care/social services	0.18 (-0.78, 1.13)
Technology	0.76 (-0.66, 2.19)
Job control (1–5)	0.03 (-0.25, 0.31)
Workplace physical activity	0.16 (-0.08, 0.40)
requirements (1-5)	, , ,
Mental job demands (1–5)	-0.02 (-0.29, 0.25)
Job stress (1–5)	0.81 (0.50, 1.12)
Organizational support (1–5)	-0.24 (-0.49, 0.01)
Disclosed to supervisor or manager	0.99 (0.35, 1.64)‡
Workplace support needs	
Workplace support needs	-
exceeded	
Workplace support needs met	1.51 (0.61, 2.41)‡
Workplace support needs unmet	1.61 (0.77, 2.45)‡

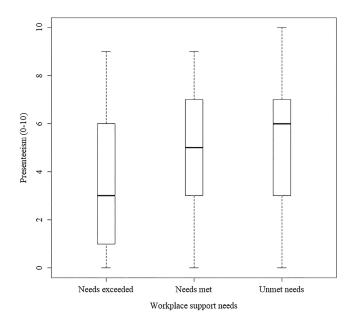
<sup>\*</sup>Values are the  $\beta$  estimate from univariable linear regression model (95% confidence interval). Presenteeism was measured on an 11-point scale (0 = health had no effect on my work; 10 = health completely prevented me from working). PHQ-2 = 2-item Patient Health Questionnaire; WALS = Workplace Activity Limitations Scale. † Postsecondary educational attainment includes training from a

educational attainment including training from college or university), and marital status (married/living as if married). Disease/health factors, including information on pediatric onset of a rheumatic disease (age <18 years) and self-rated health (1 = poor; 5 = excellent), were obtained. Self-reported pain, fatigue, and disease activity were

measured using 11-point scales (0 = no pain/fatigue/disease activity; 10 = worst possible pain/fatigue/disease activity) (29). Participants were asked about the frequency of depressed mood in the last 2 weeks using the 2-item Patient Health Questionnaire (0 = not at all; 3 = nearly every day). A total sum score of >3 suggested the likelihood of depression (30). Participants also completed the Workplace Activity Limitation Scale (WALS) to measure difficulties with workplace activities and tasks. WALS is a 12-item scale that asks about problems with lower mobility, upper mobility, concentration, and the pace and schedule of work (0 = no difficulty/not applicable to job; 3 = unable to do). Items were summed to produce a score ranging from 0 to 36 (31).

Work context factors were obtained by asking participants about the details of their current or recent employment, including whether they worked part-time (<30 hours/week) or full-time hours ( $\ge$ 30 hours/week) and whether they had a permanent or temporary contract. Participants were also asked about their job tenure (years), job sector in which they were employed (trades/transportation, sales/services, professional services, health care/social services, technology), and the extent to which their employment had physical activity requirements (1 = not at all; 5 = a great deal) and mental job demands (1 = not at all; 5 = a great deal). Additionally, participants were asked about their perceptions of job control, job stress, and organizational support (1 = not at all; 5 = a great deal).

**Statistical analysis.** Descriptive statistics were used to examine variable distributions. Chi-square tests and *t*-tests were conducted to examine how study variables differed for those



**Figure 2.** Box plot comparing presenteeism based on participants' workplace support needs being exceeded, met, or unmet. Solid line shows median presenteeism score; lower and upper whiskers represent lower and upper adjacent values.

college or university. ‡ Statistically significant.

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**Table 4.** Stratified multivariable robust regression model examining the relationship between presenteeism and whether work-place support needs were exceeded, met, or unmet\*

	Disclosed (n = 216)	Not disclosed (n = 90)
Sociodemographic factors		
Age, years	0.00 (-0.07, 0.07)	0.02 (-0.07, 0.11)
Sex		
Women	_	_
Men	0.52 (-0.12, 1.17)	0.09 (-0.93, 1.11)
Education		
<postsecondary education<="" td=""><td>_</td><td>_</td></postsecondary>	_	_
≥Postsecondary education†	0.81 (0.10, 1.54)‡	-0.32 (-1.46, 0.82)
Married/living as if married	-0.25 (-0.83, 0.33)	0.12 (-0.71, 0.95)
Primary childcare responsibilities	-0.43 (0.34, -1.10)	-0.46 (-1.61, 0.70)
Disease/health factors		
Pediatric disease onset (<18 years)	0.08 (-0.52, 0.69)	0.30 (-0.55, 1.15)
Pain (0–10)	0.40 (0.09, 0.22)‡	0.14 (-0.09, 0.38)
Fatigue (0–10)	0.17 (0.01, 0.33)‡	0.23 (-0.01, 0.47)‡
Disease activity (0–10)	0.06 (-0.11, 0.24)	0.47 (0.24, 0.71)‡
Self-rated health		
Poor/fair	-	-
Good/very good/excellent	0.04 (-0.56, 0.64)	0.27 (-0.69, 1.23)
Depression (PHQ-2)	0.62 (0.01, 1.23)‡	0.16 (-0.74, 1.06)
Workplace activity limitations (WALS: 0–36)	0.11 (0.06, 0.16)‡	0.10 (0.02, 0.17)‡
Work context factors		
Employment status		
Full-time (≥30 hours/week)	-	-
Part-time (<30 hours/week)	-0.20 (-0.84, 0.45)	0.17 (-0.70, 1.05)
Employment contract		
Temporary	-	-
Permanent	-0.98 (-1.64, -0.31)‡	-0.06 (-0.96, 0.83)
Job sector		
Sales and services	_	<del>-</del>
Trades and transportation	0.01 (-1.01, 1.03)	1.75 (0.32, 3.17)‡
Professional services	-0.20 (-1.25, 0.85)	0.90 (-0.36, 2.16)
Health care/social services	-0.39 (-1.33, 0.56)	0.87 (-0.44, 2.17)
Technology	0.65 (-0.72, 2.01)	1.27 (-0.36, 2.90)
Job control (1–5)	0.18 (-0.10, 0.46)	0.05 (-0.28, 0.37)
Workplace physical activity requirement (1–5)	-0.34 (-0.58, -0.10)‡	0.27 (-0.03, 0.57)
Mental job demands (1–5)	-0.02 (-0.28, 0.23)	-0.12 (-0.51, 0.28)
Workplace support needs		
Workplace support needs exceeded	<del>-</del>	-
Workplace support needs meet	1.25 (0.39, 2.11)‡	-0.58 (-1.66, 0.50)
Workplace support needs unmet	1.59 (0.75, 2.43)‡	-0.79 (-1.86, 0.27)

<sup>\*</sup> Values are the  $\beta$  estimate from robust multivariable linear regression model (95% confidence interval). The model was stratified according to whether a young adult with rheumatic disease disclosed the details of their health to their immediate supervisor. Presenteeism was measured on an 11-point scale (0 = health had no effect on my work; 10 = health completely prevented me from working). PHQ-2 = 2-item Patient Health Questionnaire; WALS = Workplace Activity Limitations Scale. † Postsecondary educational attainment includes training from a college or university.

who had disclosed the details of their health to the supervisor and those who had not. Univariable linear regression analyses were conducted to examine the association between the study variables and presenteeism. Covariates of theoretical importance as well those significantly related to presenteeism at the univariable level were carried forward to the final multivariable model. To test study hypotheses, a multivariable linear regression model was developed that was stratified for those who did and did not disclose the details of their health to their supervisor. A robust regression was chosen because it is less sensitive to data with variables that may not exhibit normality or may possess atypical values when compared to linear regression models with ordinary

least-squares estimators (32). Analyses were conducted using SAS software, version 9.3 (33).

#### **RESULTS**

A total of 306 young adults with a rheumatic disease completed the survey (mean age  $28.5\pm4.5$  years), of whom less than two-thirds were recruited through the research firm (64%), 26% were recruited through community-based organizations, and 11% were recruited from rheumatology clinics (27).

The sample is described in Table 1. Approximately twothirds of participants were women (63%), 45% were married/living

<sup>‡</sup> Statistically significant.

as married, 23% reported childcare responsibilities, and most reported obtaining a postsecondary education (83%). Half of the participants reported a pediatric onset of their rheumatic disease, over half of the sample indicated poor/fair self-rated health (52%), and 36% indicated depression. More than two-thirds of participants reported full-time employment (68%), and three-fourths held a permanent contract (76%). Mean  $\pm$  SD job tenure was  $2.9 \pm 2.7$  years. Notably, of a possible 10 points, participants reported a mean  $\pm$  SD presenteeism score of  $4.89 \pm 2.65$ .

Close to 70% of participants reported disclosing the details of their health to their immediate supervisor or manager at work. When compared to those who did not disclose health details, participants who disclosed reported significantly greater mean pain (5.1 versus 5.8), fatigue (5.6 versus 6.3), disease activity (4.4 versus 5.1), and WALS scores (9.2 versus 12.6). Also, when compared to those who did not disclose, a significantly greater frequency of participants who reported disclosing the health details indicated fair/poor health (40% versus 57%). A greater frequency of participants who disclosed health details indicated depression when compared to those who did not disclose (37% versus 32%), but this relationship was not statistically significant.

An examination of the specific workplace supports needed, available, and used are reported in Table 2. The most needed workplace supports included work schedule flexibility (91%), prescription drug coverage (86%), extended health benefits (85%), paid sick leave (80%), and modified job duties (77%). With the exception of an accessible workplace, participants reported that their need for the different workplace supports exceeded the reported availability and use. More than half of participants reported that their workplace support needs were unmet (53%). In comparison, 32% reported that their workplace support needs were met, and 16% reported that their workplace support needs were exceeded. There were no significant differences in the frequency of participants disclosing the details of their health to their supervisor based on workplace support needs being reported as unmet, met, or exceeded (Table 1 and Figure 1).

Univariable analyses examined the relationships between workplace support needs, disclosure of health details, and presenteeism. Participants who reported disclosing health details to their supervisor reported greater presenteeism compared to those who did not disclose ( $\beta=0.99$  [95% confidence interval (95% CI) 0.35, 1.64]) (Table 3). Additionally, at the univariable level, those who reported that their workplace support needs were met ( $\beta=1.51$  [95% CI 0.61, 2.41]) or unmet ( $\beta=1.61$  [95% CI 0.77, 2.45]) reported greater presenteeism when compared to those who reported that their workplace support needs were exceeded (Figure 2).

The final multivariable model examined the relationship between workplace support needs and presenteeism and was stratified by disclosure (Table 4). The model was adjusted for sociodemographic, disease/health, and work context factors.

The relationship between presenteeism and workplace support needs was statistically significant for participants who reported disclosure of health details. Workplace support needs reported as being unmet were associated with a 1.59-point increase in presenteeism when compared to those reporting workplace support needs as being exceeded ( $\beta$  = 1.59 [95% CI 0.75, 2.43]). Workplace support needs reported as being met were associated with a 1.25-point increase in presenteeism when compared to those who reported that their needs were exceeded ( $\beta$  = 1.25 [95% CI 0.39, 2.11]). Of note, for those who disclosed, greater pain ( $\beta$  = 0.40 [95% CI 0.09, 0.22]) and having depression ( $\beta$  = 0.62 [95% CI 0.01, 1.23]) were associated with greater presenteeism. For participants not disclosing their health details, the relationship between workplace support needs and presenteeism was not statistically significant.

#### DISCUSSION

Employment at an early career phase can shape longer-term experiences in the labor market. Our survey is one of the first to unpack the complex relationship between the disclosure of health details, supportiveness of the work environment, and productivity for Canadian young adults with rheumatic disease. Our survey highlighted the fact that workplace support needs at the early career phase can go unmet. What is more, we found that unmet workplace needs were associated with greater presenteeism for those who reported disclosing at least some health details to their supervisor. Encouraging productive employment at the early career phase can play an important role in enhancing work and health outcomes across the life course (1,34). Findings have implications for young adults with rheumatic disease and their clinical care teams to encourage the identification and acquisition of employment in supportive work environments and to help navigate disclosure decisions. Results also have implications for supervisors and other workplace stakeholders (e.g., human resource representatives and disability management professionals) to facilitate availability and access to diverse job accommodations, modifications, and benefits for young adults entering the workplace and to create work environments where employees are comfortable discussing their needs.

Our survey is one of the largest of its kind to ask young adults with rheumatic disease with employment experience about their workplace support needs. Aligning with previous research of older age groups with rheumatic disease, the most needed workplace supports among our young adult sample included employer-provided prescription drug coverage and extended health benefits, work schedule flexibility, and modified job duties (13,14). These accommodations play an important role in addressing the impact of rheumatic disease symptoms and activity limitations on employment participation (15). Of concern, more than half of the participants in our study reported that their workplace support needs were unmet. Our findings provide evidence that

young workers with rheumatic disease may start their career in work environments where supports are less accessible (18,35). Results can be explained by Canadian labor market analyses, which show that, when compared to older age groups, young adults are more likely to be employed precariously and in jobs where formal accommodations and extended health benefits are less likely to be provided (20,36). Additional research is required to expand on the barriers and facilitators within the work environment that may be unique to young adults with rheumatic disease and to determine access to workplace supports.

The relationship between unmet workplace support needs and presenteeism is complex and may depend on the extent to which a young person communicates the details of their health at work. More than two-thirds of young adults in our study indicated disclosing health details to their supervisor. Those who did disclose the details of their condition indicated greater disease severity, more workplace activity limitations, and greater presenteeism when compared to those who did not disclose the details of their condition. Moreover, the relationship between unmet workplace support needs and presenteeism was only significant for those who had disclosed the health details to their supervisor. Importantly, existing Canadian privacy legislation means that young workers with rheumatic disease are not obligated to disclose the details of their health condition (24). Those with a well-managed disease and less severe symptoms that interfere with work may not be required to disclose health details to obtain assistance.

Findings could also be explained by emerging research on disclosure decisions conducted in samples living with a broader range of invisible and episodic chronic health conditions. These studies find that individuals may choose to communicate health details when there is a crisis situation (e.g., severe flares of pain or depressive episode) and when a workplace support is necessary to address lost productivity (24). Additionally, having a rheumatic disease at a young age, which may be invisible to others, could be associated with unique challenges in communicating health needs. Past studies have found that young adults with rheumatic disease may choose to not disclose so as to protect themselves from the potential of a negative reaction from a supervisor or to ensure that they are not excluded from career advancement opportunities (e.g., job upskilling, business travel) (7,36). Our results draw greater attention toward the development of resources that are directed to the unique needs of young people with rheumatic disease to understand the pros and cons of communicating health needs at work (20).

Of interest, when compared to those with unmet or met workplace support needs, participants who indicated that their needs were exceeded by their employer were significantly less likely to report presenteeism. Importantly, these study findings are cross-sectional, and causation cannot be determined. Nonetheless, our study adds to growing evidence on the importance of the work context to fostering the productivity of people with

rheumatic disease (37-39). In particular, our study shows that employers who offer diverse workplace supports can attenuate the relationship between rheumatic disease and presenteeism at the early career phase. Alternatively, for young adults with rheumatic disease, the absence of workplace supports may contribute to a lack of fit between health needs and characteristics of the work environment. Importantly, employers often report being unaware of the number of employees who are living with chronic disease and the types of accommodations and modifications that are most needed (40). Our study suggests that targeted knowledge translation efforts to employers may be needed to increase awareness of the benefits of a supportive work environment for young workers with rheumatic disease and to provide recommendations on ways the employers can support employment success. Findings may also inform vocational rehabilitation recommendations for young adult patients in transitional rheumatology settings, to encourage a consideration of the importance of supportive work environments and the specific accommodations, modifications, and benefits that can address health needs and boost productivity.

A strength of our study was our diverse sample of employed young adults with rheumatic disease from across Canada. In particular, our purposive recruitment approach enabled us to construct a cohort of young people with rheumatic disease from clinical and community settings who may differ in terms of access to health care and who ranged according to personal, disease/ health, and work context factors. At the same time, a majority of participants in our study indicated having a postsecondary education. Also, while our multivariable model controlled for work context factors, we did not have the statistical power to examine differences in the availability and need of workplace support according to specific job sectors. Additional research of participants who may range in educational attainment and are working across a broader range of job sectors could be beneficial in further understanding the experiences of young adults with rheumatic disease within different work environments and occupations, and such research may enhance the generalizability of our findings. While our survey captured self-reported information on disclosure of health details, details on the content and amount of information shared with a supervisor are unclear. Future research on the disclosure processes (e.g., details communicated to an employer, timing of disclosure) could advance recommendations provided to young adults with rheumatic disease on the communication of their health information. Finally, our study was cross-sectional. Longitudinal research across the school-to-work transition is needed to expand on our results and determine causal pathways in the relationship between disclosure, workplace supports, and presenteeism.

Supporting productivity at the early career phase can have important implications for young people with rheumatic disease as they enter the labor market and across their working life. Our study highlights the complex interrelationship between disease

disclosure, unmet workplace support needs, and presenteeism. Indeed, employers who offer diverse job accommodations, modifications, and health benefits provide a more supportive work environment and play an important role in ensuring that young workers with rheumatic disease are able to sustain productivity. However, the benefits of workplace support may only be accessed by those who communicate their needs. Findings underscore the importance of equipping young people with resources that can be used to navigate disease disclosure and requests for support as they establish their careers with a rheumatic disease.

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#### **AUTHOR CONTRIBUTIONS**

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Jetha had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design.** Jetha, Tucker, Backman, Kristman, Bowring, Proulx, Gignac.

Acquisition of data. Tucker, Bowring, Hazel, Perlin, Gignac. Analysis and interpretation of data. Jetha, Chen.

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