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Title: The role of support from significant others in the association between disease-related factors and sickness absence in early rheumatoid arthritis – a longitudinal study

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Keywords: rheumatoid arthritis, work life, support, quantitative research

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Abstract

<u>Objectives:</u> The aim of this study was to analyse how support from significant others affects the associations between disease-related variables and sickness absence during the first two years after rheumatoid arthritis (RA) diagnosis.

Methods: Data from 274 persons with RA (73% women) of working age (18-63 years) were retrieved from the Swedish early RA cohort TIRA-2. These data concerned disease-related variables (disease activity, activity limitations, pain intensity, and grip force), sickness absence, and perceived support from significant others. Associations of disease-related variables with sickness absence and how these associations were moderated by support from significant others were analysed using zero-inflated negative binomial regression.

<u>Results:</u> During the two years after diagnosis, higher disease activity was significantly associated with increased odds of sickness absence, a connection strengthened by perceived support from family during the first year. More perceived support was also directly and significantly associated with increased odds of sickness absence during the first year.

<u>Conclusions:</u> Support from significant others is related to sickness absence in RA, specifically during the first year after diagnosis. Although patients report high levels of support from significant others, this does not necessarily lead to more positive work outcomes. Therefore, it is important to consider other aspects of support that might influence work outcomes, like type and quality of support. Future research should investigate these forms of support and when significant others should be encouraged to support in the rehabilitation process to increase the possibility for persons with RA to have a well-functioning and sustainable work life.

Keywords: rheumatoid arthritis, work life, support, quantitative research

Introduction

In Europe, musculoskeletal diseases affect over 100 million people, resulting in 50% of all absences from work and 60% of permanent work incapacity (1). In 2017, musculoskeletal diseases cost Swedish society approximately SEK 88 billion (≈EUR 8.1 billion), with costs due to sickness absence accounting for almost SEK 53 billion (≈EUR 4.9 billion) (2). Today's strategies of early medication in rheumatoid arthritis (RA) and the development of biological treatments have lowered the disease activity (3). However, disability, pain, and activity

limitations still persist several years after diagnosis, even with the use of biological treatments (4).

Furthermore, patients' ability to work is negatively affected during the early years of RA (5,6). A Danish study concludes that people with RA, compared to the general population, are at higher risk of sickness absence and dropping out of the work force (7). Moreover, the diagnosis is associated with early retirement (8). Previous research reports that disease activity (8,9) and activity limitation (10,11) are connected to a patient's ability to continue working. However, Blomjous et al. (12) recently reported that sickness absence and worker productivity of people diagnosed with early RA are mainly predicted by non-disease-specific variables. That is, sickness absence due to RA is multifactorial.

Work is a high priority among persons with RA, as it is perceived to be important to wellbeing and identity (13,14) and provides social stimulation (15). In order for persons with RA to continue working, support from their partner, employers, and colleagues is necessary (13). Support is often referred to as types of instrumental, emotional, or informational resources provided by the social environment (16). These various types of support are associated with different aspects of mental wellbeing (17) as well as self-management (18), coping (19), and health behaviours (20,21). Significant others who provide encouragement and motivation improve the likelihood persons with chronic diseases will continue working (22).

Support from significant others is desired regarding the management of symptoms such as pain and fatigue (23). Furthermore, support can positively influence health, but is also suggested to play a moderating role (24). As direct association between disease-related variables and sickness absence has been established, we wanted to investigate the possible moderating effect that support might have on these associations. Therefore, the aim of this study was to analyse how support from significant others affects the associations between disease-related variables (disease activity, activity limitations, pain intensity, and grip force) at the time of RA diagnosis and sickness absence during the two years after diagnosis. We hypothesised that during the two years after RA diagnosis there is a positive association between disease-related variables and sickness absence and that this association is moderated by higher perceived support (i.e., the association is weaker the higher the perceived support). Thereby, we anticipated that support is a positive influence associated with lower sickness absence despite substantial impact of disease-related variables.

Materials and methods

The Swedish Social Insurance System

All Swedish residents aged 16-64 who have an income are granted economic security by the Swedish Social Insurance Agency (Försäkringskassan) in the event of sickness, disability, or injury (25). Economic compensation can be in the form of sickness benefit, activity compensation, or disability pension. In addition, it is possible to be compensated with more than one type of compensation at the same time. The first day of sickness absence is unpaid and during the first 14 days compensation is obtained from the employer as sick pay. Sickness absence longer than 14 days is registered with the Swedish Social Insurance Agency and obtained as a sickness benefit. The retirement age in Sweden is 65 years. In this study, sickness absence refers to any type of absence from work due to sickness or disability that is compensated for through sickness benefit, activity compensation, or disability pension.

The TIRA project

This study is part of the Early Interventions in Rheumatoid Arthritis project (TIRA-2) (26). The main purpose of the TIRA project was to establish clinical routines for early diagnosis and early instituted multi-professional interventions. Patients were included at the time of diagnosis (baseline). To be included in the project, patients must satisfy at least four of the criteria according to the American College of Rheumatology (ACR-87) (27), or at least morning stiffness, symmetrical arthritis, and arthritis of the small joints. Patients were offered multi-professional interventions based on their needs and regular follow-ups were performed for eight years from diagnosis. The TIRA project also aims to create a database for prospective follow-up of medication and a wide range of aspects representing disease activity and disability. This study is based on disease-related variables, work situation, sickness absence, and perceived support measured by Visual Analogue Scale (VAS) from baseline, one year and two years after diagnosis. Between 2006 and 2009, a total of 522 patients were included in the TIRA-2 cohort. The present study includes the 274 patients who were 63 years old or younger at baseline.

Outcome

Data relating to disease, perceived support, and sickness absence were registered at baseline, at the one-year follow up, and the two-year follow up. Disease activity was assessed using the Disease Activity Score in 28 joints (DAS28) (28), and activity limitation was assessed using the Health Assessment Questionnaire (HAQ) (29). Pain intensity was reported in millimetres (mm) marked on a VAS, and grip force was tested in newtons (N) using a GrippitTM (AB Detektor, Gothenburg, Sweden) (30). In a postal survey, the patients were asked if they were provided with support from family and friends. This information was marked on two scales, one for family and one for friends: Do you receive practical and/or emotional support from friends?. Zero mm indicated no perceived support, and 100 mm indicated full perceived support. The scales, designed specifically for this study, were based on aspects related to the chapter 'Support and relationships' as part of the contextual factors of the International Classification of Function, Disability and Health (ICF) (31). Data relating to sickness absence were retrieved from the Swedish Social Insurance Agency as the number of days with absence from work during year one and year two after diagnosis.

Statistical analyses

Sickness absence during year one and two after diagnosis was analysed both as 'yes' (days of sickness absence reported) vs 'no' (no days of sickness absence reported), and if 'yes' as number of days. The analysis was performed using zero-inflated negative binomial regression, with disease variables (disease activity, activity limitation, pain intensity, and grip force) as independent variables. To examine whether support from significant others during year one and year two after diagnosis (i.e., from family and from friends separately) moderated the associations between disease variables and sickness absence, support was included as a moderator of these associations. The conceptual model is presented in Figure 1a and the corresponding statistical model is presented in Figure 1b, where i1 and i2 represent the moderations (in the association of the interaction between disease variable and support and sickness absence). The same types of analyses were performed at both year one and year two. First, direct associations between each of the disease variables at baseline and sickness absence during year one were tested. Thereafter, moderations of those associations were tested. In the event that these were non-significant, they were tested separately (i.e., i1 and i2 from Figure 1b were tested separately). The same procedure was performed for disease variables at the one-year follow-up, and sickness absence during year two. Statistical analyses

were performed using IBM SPSS Statistics v. 24 and Mplus v. 7.4, and p < .05 was considered statistically significant.

[Insert Figure 1 near here]

Ethics

This study was conducted in accordance with the ethical standards of the Declaration of Helsinki, and approved by the Regional Ethics Committee in Linköping, Sweden. M168-05.

Results

Participant characteristics

At the time of inclusion, the participants' mean age was 50 years (*SD*=11), and most of the participants (73%) were women. The disease activity (DAS28) score was rather high (mean=4.72, *SD*=1.34), activity limitation was moderate (HAQ score m=0.90, *SD*=0.61), pain intensity was high (VAS mm m=49, *SD*=23), and grip force was low (Newton m=135, *SD*=105). The majority (90%) were prescribed DMARDs. Differences between sickness absence 'yes' and 'no' are illustrated in Table 1.

[Insert Table 1 near here]

Year one after inclusion

Disease-related variables and sickness absence

During the first year after inclusion, higher disease activity (DAS28) at baseline was significantly associated with increased odds of sickness absence (p=.003) and days of sickness absence (p=.031).

Higher activity limitation (HAQ) at baseline was significantly associated with increased odds of sickness absence (p<.001) as well as the number of days (p=.001) during year one after diagnosis. In addition, a higher HAQ score was associated with increased odds of prolonged sickness absence.

Higher pain intensity at baseline was significantly associated with increased odds of sickness absence (p=.005), but not with the odds of prolonged sickness absence during the first year after diagnosis.

Grip force, measured using a Grippit at baseline, was not significantly related to the odds of sickness absence during year one. However, given sickness absence, grip force was significantly related to number of days (p=.035) – i.e., lower grip force was associated with an increased odds of prolonged sickness absence.

Support and sickness absence

For family support at baseline as a moderator in the models (Figure 1), the association between disease activity (DAS28) and sickness absence was strengthened (p=.029), but support (from family or friends) was not a significant moderator of the association between activity limitation (HAQ), pain intensity, or grip force at baseline and sickness absence. Support did not significantly moderate any association with number of days of sickness absence.

However, for the direct association between support and sickness absence, higher perceived support from family and friends at baseline was significantly associated with increased odds of sickness absence (family p=.007; friends p=.025) during the first year after diagnosis.

[Insert Table 2 near here]

Year two after inclusion

Two years after inclusion, higher disease activity (DAS28) at the one-year follow-up was still significantly associated with increased odds of sickness absence (p<.001) during year two after diagnosis. However, there was no longer any significant relationship with number of days.

Higher activity limitation (HAQ) one year after diagnosis was still significantly associated with increased odds of sickness absence (p<001) as well as days of sickness absence (p<.001) during the second year after diagnosis.

Higher pain intensity at the one-year follow-up was still significantly associated with increased odds of sickness absence (p<.001) but had no significant relationship with the number of days during year two after diagnosis.

Grip force at one year after diagnosis was significantly associated with both increased odds of sickness absence and the number of days of sickness absence during year two after diagnosis. A lower grip force was associated with increased odds of sickness absence (p=.001) and the number of days (p=.017).

Support and sickness absence

Support from family and friends did not significantly moderate the relationships between disease-related variables at one year after diagnosis and sickness absence during the second year after diagnosis. In addition, there were no significant associations between support from family or friends and sickness absence.

[Insert Table 3 near here]

Discussion

Our main findings show that perceived support from family at baseline moderated the association between disease activity and sickness absence during the first year after diagnosis. This finding demonstrates that support from family had an impact during the first year after diagnosis, with higher perceived support increasing the odds of sickness absence, although this impact could not be shown during the second year.

To our knowledge, this is the first study to investigate the impact of support on the previously known associations between disease-related variables and sickness absence. Our results could suggest that the patients' significant others encourage them to claim sickness absence and that the patients feel supported in their decision. However, family members could also act protectively; for example, significant others of persons living with low back pain can negatively influence their return to work by expressing mistrust in the treatment and reinforcing illness perceptions (32). Still, recent findings show that significant others providing encouragement and practical support are appreciated by patients and can have a positive effect on staying at or returning to work (22). Correspondingly, low social support

has been reported to be a predictor of sickness absence in persons with musculoskeletal problems (33). Our findings, however, show that support does not inevitably enhance the chances of staying at work. Therefore, we need to acknowledge sickness absence as a two-sided issue and not necessarily as solely negative for the individual. In addition, instead of looking at the amount of support, we ought to look further into the types and timing of the support.

Several benefits have been reported in relation to support, both in persons with RA and other conditions, such as different types of support affecting aspects of mental well-being of people with physical disabilities (17). Furthermore, support facilitates self-management behaviour (18) and health behaviours such as physical activity (20,21), and emotional support in particular is a well-used coping strategy in RA (19). Because the question our patients were asked consisted of emotional and practical support jointly, no conclusions can be drawn from our results regarding emotional support exclusively. However, emotional support has been identified as more beneficial if the stressor is uncontrollable (16). Because RA is often unpredictable, one can presume that emotional support is valuable to our patients. Prang et al. (24) suggest that support might vary in relation to the different stages of a condition, a finding that can be connected to our results showing the largest impact during the first year after diagnosis. However, the amount of support is not necessarily the most important aspect of support; that is, the effectiveness of support depends more on the quality, type, and timing of the support provided.

Our results confirm previous research regarding high disease activity (9,34) and HAQ scores (9) being related to lost work days. In addition, reduced pain intensity has been reported to significantly correlate with improved work productivity (35), and improved grip force has been connected to improved work ability (36). Previous research also shows that a strong predictor for sickness absence is earlier sickness absence (12,37). Furthermore, the earlier biologic treatment starts, the greater the possibility of returning to work (38). This finding emphasises the importance of effective interventions soon after the diagnosis. Our results suggest a greater impact of support during the first year after diagnosis. Although this impact is neither solely positive nor negative, it is important to further investigate possible interventions related to support at an early stage.

Patients with inflammatory arthritis desire wish for more support than was is received (23), a situation that reveals a discrepancy between desired and received support, further raising the question of how and when to address support. Our findings that perceived support negatively

moderates the relationship between disease-related variables and sickness absence might be related to the amount and content of support as well as this discrepancy between desired and perceived support. In this study, the content of support has been limited to 'practical and/or emotional' support, leaving it up to the person to interpret the content to some extent. Because this definition is very broad, people might apply different definitions. This might also be a reason for the discrepancy. In future studies, the specific types of support should be considered to a larger degree to determine how these can be combined and implemented for the best effect.

Support should also be related to the person's specific needs. As our results show that support from significant others is related to increased sickness absence, it is important to look further into both the amount and content of the support as well as when it is provided. Work may be a fundamental part of life, but fulltime employment might not be the ultimate goal for everyone with RA. Therefore, it is vital to focus on person-centred rehabilitation since people's needs are unique. That it, it is important to investigate support on a specific level to ensure that the right type of support can be provided in the right way at the right time.

Methodological considerations

Few rheumatology studies have considered the support of significant others. One of this study's strengths is its longitudinal design, which enabled the investigation of the topic several years after diagnosis. The study's sample size was reasonable and reflects the gender division among persons with RA (39). Temporary sickness absence and disability pension have been analysed jointly, which should be considered a strength since temporary sickness absence can progress into disability pension (37).

In this study, we only had access to data for sickness absence longer than 14 days due to the way the Swedish Social Insurance Agency is organised. Therefore, more days of sickness absence probably exist, but longer periods (> 14 days) have not gone unnoticed. Furthermore, we have no control over the cause of sickness absence, so days with sickness absence might be due to reasons other than RA. Another point not accounted for in our analyses is type of work, which is known to affect sickness absence (40). In addition, we have not focused on gender differences, although such differences exist in HAQ, pain intensity, and Grippit; however, these differences were outside the scope of this study. Since there were also

differences in ages between patients with and without sickness absence, a follow-up analysis where moderation was tested while controlling for age only affected the results marginally.

A limitation in this study is that the VAS for perceived support consisted of a broad term for support, namely 'practical and/or emotional' support. This leaves room for individual interpretations. We found that our particular aim did not fit into existing scales or questionnaires, so scales were designed specifically for this study. These scales are based on ICF (31), and VAS in general is well used and tested. Scales without intervals can be a challenge to complete as well as interpret; however, support is self-assessed, which is important in this study. By including only this wide definition of the concept, we have presented a broad overview and a starting point. Future studies should investigate validated scales or instruments when scrutinising the concept further. Future research should also focus specifically on the different types of support.

There is a general discussion about potential problems when comparing results related to sickness absence as there are variations in definitions, measures, outcomes, and systems worldwide. Large differences between European countries in terms of rules and regulations of social security systems have been found without any particular patterns to explain these differences (41). Therefore, the patients in our study may not have had the same choices as patients in other studies focusing on sickness absence. Nevertheless, the cross-sectional method used in this study to observe work status and risk factors has been considered sufficient in studies focusing on returning to work after temporary sickness absence (42). In addition, return to work is one outcome and work ability is another. In this study, we studied sickness absence. In other words, the conditions surrounding work absence due to disability can be studied in different ways, reflecting the complexity of the issue.

Conclusions

Our main finding is that the associations between disease activity and sickness absence change with the amount of perceived support from significant others. In addition, more support is directly associated with increased odds of sickness absence during the first year after RA diagnosis. Since this is not inevitably a positive outcome, the amount of perceived support might not be the most important or adequate predictor of positive work outcomes – i.e., other specific aspects of support may be more important. Hence, further research is needed to identify which kind of support from significant others might be of greatest value. In

addition, future studies should investigate how significant others should be involved in the rehabilitation process to enable them to provide support that increases the possibility for persons with RA to have a well-functioning and sustainable work life.

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Conflict of interest

None.

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Table 1. Characteristics of patients.

N=274	At time of diagnosis N=274			Year 1	after diagno	Year 2 after diagnosis N=252		
	Sickness absence next year (year 1)		P	Sickness absence next year (year 2)		p		
Variables	No	Yes		No	Yes			
	N=149	N=125		N=160	N=114			
Categorical	n (%)	n (%)		n (%)	n (%)		n (%)	
Female	99 (79)	103 (69)	.059	116 (73)	86 (75)	.123	•••	
DMARDs	109 (88)	136 (92)	.273	131 (88)	84 (80)	.057	240 (81)	
Continuous	M (SD)	M (SD)		M (SD)	M (SD)		M (SD)	
Age (years)	46 (13)	54 (8)	<.001	48 (12)	53 (9)	<.001		
DAS28	4.4 (1.3)	4.9 (1.4)	.004	2.3 (1.1)	3.2 (1.4)	<.001	2.6 (1.3)	
HAQ	0.7(0.5)	1.1(0.7)	<.001	0.3(0.4)	0.6(0.5)	<.001	0.4(0.5)	
Pain intensity (mm)	45 (22)	53 (24)	.003	24 (21)	37 (24)	<.001	27 (24)	
Grippit (Newton)	147 (107)	124 (102)	.023	214 (116)	163 (113)	<.001	192 (109)	
Support from family	81 (21)	88 (14)	.011	83 (20)	85 (16)	.518	84(17)	
Support from friends	77 (23)	83 (17)	.069	79 (20)	81 (17)	.593	79(22)	

DMARDs: Disease Modifying Anti-rheumatic Drugs; DAS28: Disease Activity Score 28 Joint Count; HAQ: Health Assessment Questionnaire

Table 2. First year's associations between disease-related variables and sickness absence both as 'yes' vs 'no' and in case of sickness absence as number of days.

Support	Disease related variables	Sickness absence (yes vs no)				Sickness absence (number of days)				
		Direct association		Moderation by support		Direct association		Moderation by support		
		beta	р	beta	р	beta	р	beta	р	
Without support										
-	DAS28	-3.020	.003*	-	-	2.158	.031*	-	-	
-	HAQ	-5.240	<.001*	-	-	3.219	.001*	-	-	
-	Pain intensity	-2.819	.005*	-	-	1.755	.079	-	-	
-	Grippit	1.708	.088			-2.112	.035*	-	-	
With support										
Family	DAS28	-2.740	.006*	-2.189	.029*	2.481	.013*	-	-	
	Support variables	Direct association				Dir assoc				
	only	beta	р			beta	р			
-	Family	-2.708	.007*			-0.488	.626			
-	Friends	-2.238	.025*			-0.914	.361			

First associations without support are reported. Thereafter, models where either family support or friends support moderate any of these associations are reported. DAS28: Disease Activity Score 28 Joint Count; HAQ: Health Assessment Questionnaire. *Statically significant relation

Table 3. Second year's associations between disease-related variables and sickness absence both as 'yes' vs 'no' and in case of sickness absence as number of days.

	Disease related variables	Sickness absence (yes vs no)				Sickness absence (number of days)				
		Direct association		Moderation by support		Direct association		Moderation by support		
Support		beta	р	beta	р	beta	р	beta	p	
Without support										
-	DAS28	-4.715	<.001*	-	-	0.188	.851	-	-	
-	HAQ	-4.961	<.001*	-	-	3.664	<.001*	-	-	
-	Pain intensity	-4.193	<.001*	-	-	1.109	.267	-	-	
-	Grippit	3.278	.001*			-2.378	.017*	-	-	
	Support	Direct association				Di	rect			
	variables					assoc	iation			
	only	beta	P			beta	р			
	Family	-0.632	.527			1.169	.242			
	Friends	-1.048	.294			0.545	.586			

Family or friends support did not moderate any of those associations and are not reported. DAS28: Disease Activity Score 28 Joint Count; HAQ: Health Assessment Questionnaire. *Statically significant relation