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Disease disclosure in the workplace in people living with rheumatic diseases: an exploratory study

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SUMMARY

Objective. Rheumatic musculoskeletal diseases (RMDs) are the causes of frequent absence from work and loss of productivity. As (in)visible diseases, it is up to the individuals to decide if disclosing their diagnosis, with important repercussions also within the workplace. Still little is known about disease disclosure in the workplace (DD-W) in patients with RMDs. This study aimed to investigate socio-demographic, clinical, and psychological predictors of DD-W among working patients with RMDs.

Methods. A cross-sectional Italian national study captured DD-W in people with RMDs. An online survey was developed using *ad-hoc* questions and scientific questionnaires to explore demographics and work-related, clinical, and psychological factors. Stepwise logistic regressions were run to identify significant predictors of DD-W.

Results. A total of 250 working rheumatic patients completed the survey; 81.2% of the participants enacted DD-W. DD-W behaviors were predicted by perceived visibility of the RMD ($p=0.008$), work type ($p=0.022$), general DD behaviors ($p<0.001$), and perceived family support ($p=0.023$). Among RMD patients, psoriatic arthritis participants had higher probabilities of DD-W ($p=0.02$), whereas lower probabilities were detected in fibromyalgia patients ($p=0.003$). Lower disease duration corresponded in the sample to higher probabilities of DD-W ($p=0.036$).

Conclusions. The majority of RMD patients in this study enacted DD-W. DD-W was associated with medical, occupational, and psychological factors, supporting the multidimensionality of the process. Further research on the subject might help foster better DD-W decision-making processes for RMD patients while promoting intervention strategies in education, policy, and culture.

***Key words**: Rheumatic disease, invisible disability, chronic disease, disease disclosure, health disclosure.*

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INTRODUCTION

Rheumatic musculoskeletal diseases (RMDs) are a diverse group of medical conditions (over 200) affecting people of any age and causing significant morbidity, comorbidity, and mortality (1, 2). RMDs affect joints, muscles, bones, and inner organs, are characterized by pain and inflammation, and are associated with functional impairments leading to disability in severe cases (2). RMDs are among the most frequent causes of absence from work and loss of work productivity, workability, and work participation in the working population (3-5). Moreover, some RMDs are commonly associated with fatigue (6), anxiety, and depression symptoms (7-9), which further worsen the impact of such chronic conditions on the quality of life and workability

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of patients. In the last decades, nevertheless, research advances, improved treatment options, as well as targeted and early clinical and pharmacological management of RMDs have significantly decreased rheumatic patients' psychological distress and physical disability, with positive effects on quality of life and work productivity (10-12). In most cases, RMDs are nowadays concealable or (in)visible conditions; thus, it is up to the individual to determine whether, how, when, and to whom to disclose their diagnosis and whether to engage in an actual coming-out process about their health (13, 14).

The terms "health disclosure" or "disease disclosure" (DD) designate the act of a subject deliberately, verbally divulging personal information – unlikely to be discovered in other ways (15) – concerning his/her own diagnosis or health condition (16). The enacting (or avoidance) of DD behaviors is determined by specific decision-making processes (16), implying the accurate assessment of possible personal risks and benefits deriving by the decision of (un)disclosing his/her health status. Having benefited from psychological support and perceiving higher levels of social support turned out to be predictors of more frequent DD behaviors in various life contexts among a sample of Italian RMD patients (17).

The workplace, as a complex crossroads of social identities, self-images, roles, desires, opportunities, and expectations, represents a particularly significant context to be observed when studying DD in people living with RMDs, especially in the light of the role that RMDs play in industrialized countries, as a major reported cause of loss of productivity (18): it is therefore of crucial importance to further investigate DD in the workplace (DD-W) in the rheumatic working population.

This study makes a novel contribution to the literature by assessing DD-W among a sample of Italian individuals with chronic RMDs. The goals of this project were i) to explore attitudes and beliefs towards DD-W and ii) to determine socio-demographic, clinical, and psychological factors most predictive of DD-W.

MATERIALS AND METHODS

Participants were recruited from the nonprofit Rheumatic Patients Association (ALOMAR ODV) – Lombard Association for Rheumatic Diseases. A call for survey completion, outlining the nature and objectives of the study, was sent using the ALOMAR mailing list and the related website and social network (http://www.alomar.it/). Circulating through social media, the survey also intercepted rheumatic patients who were not members of any patients' association. The survey was conducted between June 18th and July 9th, 2020. The study population included: actively working rheumatic patients aged 18 or older, residents of Italy, fluent in the use of the Italian language, who responded to the online survey by accepting the information and expressing consent to participate. The survey was anonymous, and the confidentiality of information was assured. The study was approved by the Board of Directors of ALOMAR ODV.

The survey was divided into the following sections:

1) socio-demographic information (*i.e.*, gender, age, work type);
2) clinical information (*i.e.*, RMD diagnosis, disease duration, pharmacological therapy, comorbidity);
3) disease-disclosure information (*i.e.*, perceived barriers, beliefs, attitudes).

Furthermore, the Italian versions of the following validated psychological questionnaires were administered:

1) Patient Health Questionnaire-4 (PHQ-4) (19), an ultra-brief tool for detecting anxiety and depressive symptoms. The PHQ-4 consists of the first two items of the Generalized Anxiety Disorder Scale (GAD-7) (20) and the first two items of the longer Patient Health Questionnaire (21). Responses are provided on a Likert scale ranging from 0 ("not at all") to 3 ("nearly every day"). Cronbach's α in this study was 0.902.
2) Chronic Illness Anticipated Stigma Scale (CIASS) (22, 23), a tool consisting of 12 items referring to possible experiences of stigma, contextualized in

three social scenarios: friends and family (*i.e.*, "a friend or family member will think badly of you"), work colleagues (*i.e.*, "someone at work will discriminate against you"), health workers (*i.e.*, "a health worker will feel frustrated because of you"). Participants are asked to rate the likelihood of encountering such situations on a Likert scale from 1 ("very unlikely") to 5 ("very likely"). Cronbach's α in this study was 0.883.

3) Patient Health Engagement Scale (PHE-S) (24), a 5-item questionnaire, validated in the Italian population, which evaluates the degree of emotional elaboration reached by the patient concerning his/her own health. The PHE-S is made up of ordinal elements placed along an experiential continuum. The response options include responses corresponding to the 4 PHE positions (blackout, arousal, adhesion, eudaimonic project) as well as intermediate positions (*i.e.*, when thinking about my illness; "I feel lost", "I feel alarmed", "I am conscious", "I feel serene"). Cronbach's α in this study was 0.905.
4) Multidimensional Scale of Perceived Support (MSPSS) (25, 26), a tool consisting of 12 items relating to perceived social support from family, (*i.e.*, "my family really tries to help me"), friends (*i.e.*, "I can count on my friends when things go wrong"), significant other (*i.e.*, "I have a particular person who is an authentic source of comfort for me"). Participants are asked to express their level of agreement or disagreement with the statements on a Likert scale from 1 ("very much disagree") to 6 ("very much agree"). Cronbach's α in this study was 0.931.
5) Work-Health Balance Questionnaire (WHBQ) (27), a tool consisting of 17 items aimed at detecting: the intrinsic dimension of the incompatibility between health and work (INC) (*i.e.*, "your work is an obstacle to health"), the extrinsic dimension of flexibility and support perceived in the workplace (FLS) (*i.e.*, "your manager listens to you when you talk to him/her about your health"), and the extrinsic dimension of the corporate health climate. We have chosen to include only the INC and FLS subscales in the questionnaire. Participants are asked to express how often in their experience what is stated in the items occurs on a Likert scale from 1 ("never") to 5 ("always"). Cronbach's α in this study was 0.877.
6) Perceived general health status was measured using a single item from the 36-item Short-Form Health Survey (SF-36) (28, 29). Response is provided on a Likert scale ranging from 1 ("excellent") to 5 ("poor").

Analyses were run *via* SPSS 27 (IBM Corp., Armonk, NY, USA) and jamovi 1.6 (the jamovi project, 2021), with a two-tailed α set at .05. Multiple comparisons were Bonferroni-corrected whenever necessary.

Two separate sets of stepwise, logistic regression models were run to identify which variables predicted DD-W (0 = no; 1 = yes) among socio-demographic, clinical and psychometric (age, gender, education, perceived disease visibility, General DD, relationship status, work type, psychological support, perceived health, and PHQ-4, PHE, MSPSS-significant other, MSPSS-family, MSPSS-friends, CIASS-total scale, CIASS-work colleagues subscale, WHB-INC and WHB-FLS scores; Model 1) and disease-related measures (presence/absence of a given condition, disease duration and comorbidity; model 2), respectively. Only main terms were entered in these models. Fit was assessed through Akaike's information criterion (AIC). Finally, χ^2 tests were run to identify response patterns in DD-related outcomes.

RESULTS

In this cross-sectional survey, we retrieved a total of 250 questionnaires completed by actively working rheumatic patients. The majority of them reported suffering from rheumatoid arthritis (36.4%), fibromyalgia (28.4%), both in primary or secondary form, and psoriatic arthritis (12%). Diagnoses of juvenile idiopathic arthritis, Sjögren syndrome, ankylosing spondylitis, systemic sclerosis, systemic lupus erythematosus, osteoporosis, osteoarthritis, mixed disease, Behçet's syndrome, Paget's disease and vasculitis were also represented in the sample.

The vast majority of the sample was composed of women (n=228); 68.8% of the participants were in a relationship, 46.8% had a high school education, and 82.8% were employees. The participants had a mean age of 45.47 years (±10.82) and a mean disease duration of 13.93 years (±10.86). Socio-demographic and clinical measures are summarized in Table I.

The majority of respondents (81.2%) disclosed their RMD in the workplace. 24.8% of those who enacted DD-W felt "quite comfortable"; on the other hand, 26.8.% reported feeling "quite uncomfortable" when disclosing their disease in the workplace.

The topic respondents mostly talk about when disclosing their disease in the workplace relates to RMD's symptoms (49.6%). The prevalence of the RMD-related topics disclosed by patients when enacting DD-W is shown in Figure 1.

The majority of the respondents (51.2%) perceives that after disclosing their RMD in the workplace their personal relationship with the DD-W's receivers has not changed. The fear of being labeled as "sick" is the perceived barrier to DD-W that conveys the highest agreement among the respondents (33.2%), while the presence of a trustful relationship with the DD-W's receiver is the perceived facilitator to DD-W conveying the highest agreement among the respondents (35.2%). Participants' socio-demographic, clinical, and psychological measures are summarized in a comparison between groups (DD-W and no DD-W) in Table II.

Model 1 (AIC=198.68) yielded significant predictors of DD-W: perceived disease visibility [$\chi^2(2)=9.75$; p=0.008], work type [$\chi^2(1)=5.21$; p=0.022], general DD [$\chi^2(1)=29.62$; p<0.001] and MSPSS-family scores [$\chi^2(1)=5.16$; p=0.023]. At Bonferroni-adjusted *post-hoc* comparisons, patients stating that their condition was "sometimes" visible reported significantly (p=0.012) higher probabilities of DD-W (M=0.92; SE=0.03) when compared to

Table I - Participants' demographic and clinical measures.

	% (n)
Sex	
Female	91.2 (228)
Male	8.8 (22)
	M (SD)
Age (years)	45.47±10.82 (20-77)
Education, % (n)	
Primary/middle school	14.0 (35)
High school	46.8 (117)
University	31.6 (79)
Master or PhD	7.6 (19)
Relationship status, % (n)	
Single	31.2 (78)
In a relationship	68.8 (172)
Member of a patients' association, % (n)	
Yes	63.2 (158)
No	36.8 (92)
DD-W, % (n)	
Yes	81.2 (203)
No	18.8 (47)
Work Type, % (n)	
Employee	82.8 (207)
Self-employee	17.2 (43)
Rheumatic diagnosis (both primary or secondary)	
Rheumatoid arthritis	36.4 (91)
Fibromyalgia	28.4 (71)
Psoriatic arthritis	12.0 (30)
Ankylosing spondylitis	10.4 (26)
Rheumatic comorbidity	
Yes	31.2 (78)
No	68.8 (172)
Perceived disease visibility	
Yes	9.6 (24)
No	49.6 8124)
Sometimes	40.8 (102)
Psychological support	
Yes	34.4 (86)
No	65.6 (164)
	M (SD)
Disease duration (years)	11.93±10.86 (0-45)

SD, standard deviation; DD-W, disease disclosure in the workplace.

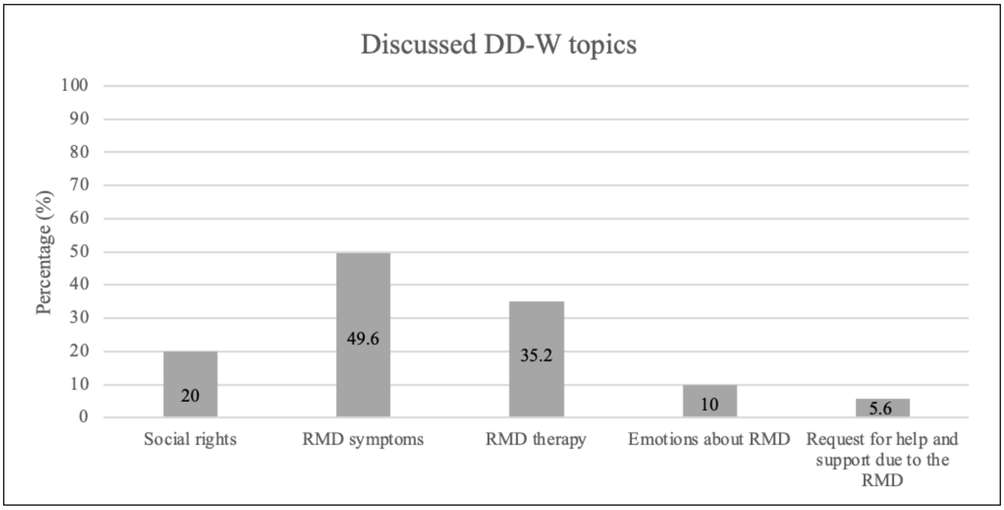

Figure 1 - Prevalence of discussed disease disclosure in the workplace's topics in the study population. DD-W, disease disclosure in the workplace; RMD, rheumatic musculoskeletal diseases.

Table II - Participants' demographic, clinical and psychological measures: a comparison between groups [disease disclosure in the workplace (DD-W) and no DD-W].

	No DD-W % (n)	DD-W % (n)	p
Sex			**0.222**
Female	95.7 (45)	90.1 (183)	
Male	4.3 (2)	9.9 (20)	
Age (years)	46.21±13.13 (20-77)	45.30±10.24 (23-66)	0.114
Education			**0.985**
Primary/middle school	14.9 (7)	13.8 (28)	
High school	44.7 (21)	47.3 (96)	
University	31.9 (15)	31.5 (64)	
Master or PhD	8.5 (4)	7.4 (15)	
Relationship status			**0.062**
Single	42.6 (20)	28.6 (58)	
In a relationship	57.4 (27)	71.4 (145)	
Member of a patients' association			**0.149**
Yes	72.3 (34)	61.1 (124)	
No	27.7 (13)	38.9 (79)	
General DD			**<0.001**
Always	2.1 (1)	1.9 (4)	
Very often	2.1 (1)	20.1 (41)	
Sometimes	59.5 (28)	74.3 (151)	
Never	36.1 (17)	3.4 (7)	
Work type			**0.035**
Employee	72.3 (34)	85.2 (173)	
Self-employee	27.7 (13)	14.8 (30)	

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	No DD-W % (n)	DD-W % (n)	p
Rheumatic comorbidity			**0.561**
Yes	72.3 (34)	68.0 (138)	
No	27.7 (13)	32.0 (65)	
Perceived disease visibility			**0.001**
Yes	12.8 (6)	8.9 (18)	
No	70.2 (33)	44.8 (91)	
Sometimes	17.0 (8)	46.3 (94)	
Psychological support			**0.460**
Yes	29.8 (14)	35.5 (72)	
No	70.2 (33)	64.5 (131)	
Perceived general health status			**0.818**
Very good	4.3 (2)	5.4 (11)	
Good	42.6 (20)	32.5 (66)	
Fair	31.9 (15)	37.4 (76)	
Poor	21.3 (10)	24.6 (50)	
	M (SD)	M (SD)	
Disease duration (years)	16.55±12.07 (2-47)	13.33±10.49 (2-46)	0.236
CIASS			
Total scale	2.34±0.93 (1-4.75)	2.16±0.90 (1-4.83)	0.813
Friends and family subscale	2.06±1.23 (1-5)	1.90±1.07 (1-5)	0.223
Work colleagues subscale	2.93±1.40 (1-5)	2.61±1.34 (1-5)	0.968
Healthcare professionals subscale	2.04±1.09 (1-5)	1.96±1.00 (1-5)	0.636
MSPSS			
Total scale	4.28±1.37 (1-6.5)	5.09±1.32 (1-7)	0.003
Significant other subscale	4.60±1.77 (1-7)	5.42±1.57 (1-7)	0.030
Family subscale	4.52±1.83 (1-7)	5.20±1.59 (1-7)	0.121
Friends subscale	3.71±1.65 (1-7)	4.65±1.59 (1-7)	0.009
PHE (%)			**0.571**
Blackout	12.8 (6)	13.3 (27)	
Arousal	36.2 (17)	30.0 (61)	
Adhesion	46.8 (22)	46.3 (94)	
Eudaimonic project	4.3 (2)	10.3 (21)	
PHQ-4			**0.491**
Total scale	4.51±3.15 (0-12)	4.18±2.83 (0-12)	
WHB			
INC subscale	3.08±0.54 (2-4)	3.11±0.54 (1-4.33)	0.787
FLS subscale	2.46±1.10 (1-5)	2.53 ±0.99 (1-5)	0.431

CIASS, Chronic Illness Anticipated Stigma Scale; MSPSS, Multidimensional Scale of Perceived Social Support; PHEs, Patient Health Engagement Scale; PHQ-4, Patient Health Questionnaire 4; WHBQ, Work Health Balance Questionnaire; DD-W, disease disclosure in the workplace; SD, standard deviation.

those stating it was not visible (M=0.76; SE=0.05), with no other significant comparisons being found. As to work type, employees showed higher probabilities of DD-W (M=0.89; SE=0.03) when compared to self-employed workers (M=0.74; SE=0.08). When decomposing the main effects of continuous predictors *via* simple slope analyses at their mean, high (M+1 SD) and low (M-1 SD) levels, patients with overall higher DD levels had higher probabilities of DD-W (M=0.94; SE=0.02) when descriptively compared to those with mean (M=0.83; SE=0.04) or low levels (M=0.61; SE=0.07) of general DD. Similarly, higher scores of MSPSS-family were predictive of a higher probability of DD-W (M=0.88; SE=0.04) when descriptively compared to both mean (M=0.83; SE=0.04) and low levels (M=0.77; SE=0.06) of the predictor.

As to Model 2 (AIC=232.89), only psoriatic arthritis [$\chi^2(1)=5.43$; p=0.02], fibromyalgia [$\chi^2(1)=8.64$; p=0.003] and disease duration [$\chi^2(1)=4.52$; p=0.036] yielded significant effects. An opposite pattern was detected for the above two conditions, with patients affected with psoriatic arthritis having higher probabilities of disclosing their disease in the workplace (M=0.93; SE=0.07) when compared to those with other conditions (M=0.76; SE=0.03), and patients with fibromyalgia having lower probabilities (M=0.76; SE=0.05) than those with other rheumatic disorders (M=0.92; SE=0.04). Moreover, lower disease duration corresponded to higher probabilities of DD-W (M=0.9; SE=0.04) when descriptively compared to patients with middle (M=0.84; SE=0.04) and advanced disease duration (M=0.79; SE=0.05).

DISCUSSION AND CONCLUSIONS

The PARE Youth Research Project has shed the first light on DD behaviors among European young RMD patients (aged 18-35), also targeting DD-W (30, 31): the research revealed that 43% of the participants prefer not to talk about their RMD during a job interview, while 38% hide their condition at work. People living with an RMD may be reluctant to disclose their disease in the workplace because they feel it might change what work associates think of them; sometimes, there might be even fear of dismissal or demotion due to the RMD (18). Meanwhile, DD-W is necessary for the effective management of illness regimens at work and for access to various forms of support (*e.g.*, ergonomic equipment, flexible working hours, sick leave) (32, 33).

The tension between these two opposite options – to disclose or not to disclose to supervisors and colleagues – configures the act of DD-W as a possible dialectical dilemma (34), requiring targeted studies to observe its implications and the role played by possible DD-W predictors, such as self-advocacy skills, quality of the relationship with supervisors and colleagues (33), anticipated stigma at work, flexibility and support at work (27), duration, severity, and visibility of the disease. A recent study among young adults with RMDs found that those who enacted DD-W reported greater presenteeism when compared to those who did not; furthermore, in this study, greater disease severity was associated with DD-W (18).

To the best of our knowledge, only a few studies have examined the topic of DD-W in chronic patients, and, within it, most studies were conducted for individuals suffering from HIV (32, 35), multiple sclerosis (36), cystic fibrosis (37), inflammatory bowel diseases (38), diabetes (39), cancer (40), mental illnesses (41), and autism (42). Expectations and previous experiences of discrimination, fear of health-related stigma (43), satisfaction with previous DD-W, supporting work environment and social support (44), disease duration, severity and perceived visibility of the disease, and type of job profiles (33) are the main factors associated with the enactment or the avoidance of DD-W in chronic patients. Scientific literature exploring DD-W in individuals with RMDs is growing (7, 18, 45-47) but further research is nevertheless needed to explore in depth this construct and its correlates in this specific population.

To our knowledge, this is the first study exploring DD-W among Italian RMD patients.

The first aim of this study was to explore the attitudes and beliefs of RMD-working patients towards DD-W. We showed that the majority of the participants (81.2%) disclosed their RMD in the workplace; this result seems to be in line with the findings of previous studies dedicated to DD-W of people with RMDs, which reported over 70% of the participants performing DD-W (18). The PARE Youth Research Project noted, on the other hand, a higher prevalence of RMD young patients (38%) not informing their supervisor about their RMD (30, 31). Since in our study no statistically significant difference in DD-W was observed based on age, a possible explanation for this discrepancy could lie for example in the cultural differences among different European countries observed in the PARE Youth Research Project. Moreover, the study dates back to 2014, and this could suggest – as a hypothesis to be verified through targeted studies – an evolution in social sensitivity relating to DD-W in recent years.

Our results are in line with the findings of the study of Olesen *et al*. (2017) on diabetes, where 23% of the sample had not disclosed their type 2 diabetes to their current employer (39). Our study observes, on the other hand, a higher percentage of DD-W in comparison to what was observed in the studies of Munir *et al*. (2005) and Gignac *et al*. (2021) on different chronic conditions where about half of the sample had disclosed their disability to their current employer (33, 44).

The topics respondents mostly revealed that DD-W relates to RMD's symptoms (49.6%) and pharmacological therapy (35.2%), consistent with the fact that both these factors might need to be disclosed in order to motivate absences or to request accommodations (17, 18, 36). Nevertheless, only 5.6% of those who enact DD-W ask for help and support in the workplace, suggesting that revelation of the disease and the request of support represent two complex social communication acts, which are not necessarily concomitant.

The majority of the sample (51.2%) reports that the relationship with the receivers has not changed after DD-W, undermining the assumption that disclosure systematically fosters the creation of intimate relationships (48). Of the sample, 13,6% reported that after DD-W the relationship with the receivers got worse, while 14,8% reported an improvement. In the sample, the most perceived barrier to DD-W was the fear of undergoing a labeling process (33.2%), supporting the need to further investigate the role of health-related stigma for RMD patients in the unveiling of concealable stigmatized identities in the workplace. This also reinforces the assumption that perceptions of stigma decrease the intention to disclose (16).

The second aim of this study was to explore socio-demographic, clinical, and psychological factors associated with DD-W in this specific population. No statistically significant difference in DD-W was observed in the sample based on gender, age, perceived general health status, relationship status, or affiliation with patient associations.

We found an association between DD-W and work type, with employees showing higher probabilities of DD-W when compared to self-employees, in line with what was observed by Munir *et al*. (2005) (33). This behavior can be motivated by the greater flexibility characterizing self-employed work, which facilitates the RMD's management without the need for DD-W, whereas in the context of dependent work, coordinating one's activities with colleagues and superiors and notifying absences due to illness or illness management might require disclosure. We found that those who perceived their RMD as visible to others (always or sometimes) tended to carry out more frequently DD-W behaviors, confirming how greater perceived symptoms visibility, which tends to be associated with greater disease severity, increases intentions of disclosure (16, 17). This aspect supports the idea that some patients postpone the enactment of DD until the perceived visibility of their symptoms turns the act of DD itself into "an explanation more than a revelation" (36). Besides, this allows us to hypothesize that a specific influence on implementing DD-W is constituted by the intensification of one's health needs, driven by increasing disease severity underlying higher symptoms visibility (49). Meanwhile, in our sample we also observed no statistically significant difference in DD-W based on perceived general health status: this is a critical issue that needs to be further investigated and should suggest to think on the complex relational, contextual, and interactive nature of the DD-W construct. We also observed that a general attitude of more frequent DD across various life contexts (family, friends, partners, social media) is associated in the sample with higher DD-W, suggesting a tendency to implement DD transversely to different life contexts.

Furthermore, in this study, we confirmed the key role of perceived social support, observing that it is a predictor of a higher probability of DD-W. This data outlines a dynamic and dialectical association between feeling more socially supported and feeling more effective in enacting DD (17). Concerning clinical characteristics, we observed that lower disease duration corresponded to higher probabilities of DD-W. This interesting point should be further investigated and might be explained by the need to share information about the health status at work when facing a critical situation, such as RMD severe flares (18). Crisis situations can indeed frequently characterize the onset phases of the disease, due both to a lower level of disease activity control, and thus a higher need for support, and a lower level of consolidated self-management skills. We also observed that patients affected with psoriatic arthritis had significantly higher probabilities of disclosing their disease in the workplace when compared to those with other conditions, whereas patients with fibromyalgia had lower probabilities. This observation deserves to be investigated in the future, starting from some preliminary hypotheses drawn also upon the findings of this research on the crucial role of the perceived (in)visibility of the RMD in the enactment of DD, with visibility of symptoms tending to be associated with increased intentions of disclosure (16). Psoriatic arthritis might indeed present visible cutaneous manifestations that could elicit greater DD-W; fibromyalgia, on the contrary, presents itself as an invisible pathology.

This study presents some limitations. First of all, the population under study is not representative of the working population living with RMDs in Italy: as an open web-based survey promoted by a patients' association, the research incurs a specific self-selection bias, the volunteer effect (50). Moreover, geographic differences were not considered, and this severely limits the possibility of capturing important aspects such as disparity in access to care or the patients' journeys. Secondly, we used a cross-sectional approach, structurally unable to longitudinally account for the unfolding over time of DD-W behaviors. Third, the study observed the presence/absence of DD-W, but not its depth, underlying motivations, or interaction patterns. Qualitative research, integrating also the DD-W's receivers' perspective, is necessary to deepen these issues. A further limitation of our study consists in not having observed a series of potentially relevant aspects for the purposes of an in-depth study of DD-W, including the targets (managers *versus* coworkers) and the timing of DD-W.

In conclusion, this preliminary study, part of the growing literature dedicated to DD-W, sketches a range of possible further research directions aiming at exploring DD-W as a complex dialectical, multifaceted socially relevant act through new combinations of methods, and at better identifying predictors and characteristics of DD-W in the working rheumatic population.

Further research on the subject is needed in order to provide better support to RMD working patients, helping them navigate the complex dialectic dilemmas underlying DD-W, with a particular focus on detecting and managing stigmatizing contexts, mitigating possible risks related to DD-W, evaluating logistics and timing of DD-W, and promoting self-advocacy skills. This could foster more and more integrated, flexible, conscious DD-W decision-making processes, that might generate positive consequences not only for the well-being of the individual but also for the work organization (51). The findings of this study might be relevant to clinicians, psychologists, nurses, social workers, and patients' associations in effectively supporting those suffering from RMDs throughout their – sometimes complex – DD-W journey. This could be accomplished also through the tuning of targeted training, campaigns, services, resources, and toolkits (52), aimed at improving DD-W processes in those living with RMDs, with the broader goal of stimulating increasingly inclusive policies based on socio-ecological, participative, supportive perspectives and of promoting a better quality of life for those living with (in)visible chronic conditions such as RMDs.

Contributions

All the authors made a substantial intellectual contribution, read and approved the final version of the manuscript, and agreed to be accountable for all aspects of the work.

Conflict of interest

VS, received compensation for consulting services and/or speaking activities from AveXis, Cytokinetics, Italfarmaco, Liquidweb S.r.l., and Novartis Pharma AG, receives or has received research supports from the Italian Ministry of Health, AriSLA, and E-Rare Joint Transnational Call. He is on the Editorial Board of Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, European Neurology, American Journal of Neurodegenerative Diseases, Frontiers in Neurology. BP received compensation for consulting services and/or speaking activities from Liquidweb S.r.l. The other authors declare no potential conflict of interest.

Ethics approval and consent to participate

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved on the 12th of June 2020 by the Board of Directors of ALOMAR ODV, the institution which promoted the work.

Informed consent

Informed consent was obtained from all subjects involved in the study.

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Availability of data and materials

Data and materials are available from the corresponding author upon request.

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