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Original article

Exploring discordance between Health Literacy Questionnaire scores of people with RMDs and assessment by treating health professionals

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Abstract

Objectives. We studied discordance between health literacy of people with rheumatic and musculoskeletal diseases (RMDs) and assessment of health literacy by their treating health professionals, and explored whether discordance is associated with the patients' socioeconomic background.

Methods. Patients with RA, spondyloarthritis (SpA) or gout from three Dutch outpatient rheumatology clinics completed the nine-domain Health Literacy Questionnaire (HLQ). Treating health professionals assessed their patients on each HLQ domain. Discordance per domain was defined as a $\geq$2-point difference on a 0–10 scale (except if both scores were below three or above seven), leading to three categories: 'negative discordance' (i.e. professional scored lower), 'probably the same' or 'positive discordance' (i.e. professional scored higher). We used multivariable multilevel multinomial regression models with patients clustered by health professionals to test associations with socioeconomic factors (age, gender, education level, migration background, employment, disability for work, living alone).

Results. We observed considerable discordance (21–40% of patients) across HLQ domains. Most discordance occurred for 'Critically appraising information' (40.5%, domain 5). Comparatively, positive discordance occurred more frequently. Negative discordance was more frequently and strongly associated with socioeconomic factors, specifically lower education level and non-Western migration background (for five HLQ domains). Associations between socioeconomic factors and positive discordance were less consistent.

Conclusion. Frequent discordance between patients' scores and professionals' estimations indicates there may be hidden challenges in communication and care, which differ between socioeconomic groups. Successfully addressing patients' health literacy needs cannot solely depend on health professionals' estimations but will require measurement and dialogue.

CLINICAL SCIENCE

Video Abstract

A video abstract of this article can be found at https://www.youtube.com/watch?v=ggnB1rATdQ4.

Key words: health literacy, professionals' estimations, discordance, socioeconomic status, health inequalities

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Rheumatology key messages

- Discordance between patients' health literacy scores and professionals' assessment occurs frequently across HLQ domains.
- Low education and migration background are associated with negative discordance; patterns for positive discordance vary.
- Discordance and associated factors vary across HLQ domains, highlighting the multidimensional nature of health literacy.

Introduction

Health literacy, a multidimensional concept defined as *'the combination of personal competencies and situational resources needed for individuals to access, understand, appraise and use information and services to make decisions about health'* which *'includes the capacity to communicate, assert and act upon these decisions'* [1], is increasingly recognised as a critical determinant of health [2] that should be considered in delivering appropriate health care to patients [3–5]. 'Limited' health literacy, indicating people's difficulty with one or more dimensions of health literacy, is prevalent across the globe and concerns about one in every three adults in the Netherlands [6]. A clear social gradient exists, with people in vulnerable circumstances being disproportionally affected [7].

People with 'limited' health literacy are at risk of poor health outcomes, for example through reduced access to and utilisation of healthcare services, inadequate provider–patient interactions, and suboptimal self-management [4]. This is highly relevant considering the complexity of rheumatology care [8], which concerns chronic conditions and often long-term patient–professional relationships, requiring decision-making about medication, changes in lifestyle, and adequate support [9, 10], all highlighting how important it is for health professionals to understand patients' health literacy needs. Several studies in rheumatology indeed discuss the role of health literacy in patient activation and self-management [11], medication adherence [12, 13], functional status [14] and disease severity [15], but also in access to biological DMARDs [16]. To minimise these potential adverse effects of 'limited' health literacy, we advocate for tailoring rheumatology care to patients' health literacy needs [17]. Accommodating an individual patient's health literacy needs at the point of care would require either *measurement* of the health literacy of each patient with a robust tool (which might be not feasible in many contexts) or an ad hoc *estimation* of the patient's literacy needs by the treating healthcare professional. The feasibility and accuracy of such estimations are the subject of this paper.

Research in various settings shows that health professionals tend to over- and/or underestimate patients' [18] and their caregivers' [19] health literacy. A study conducted among general practitioners (GPs) in Belgium showed that inaccurate estimation was more likely to occur in patients with lower education levels and patients who had been under the GP's care for a shorter period of time [20]. In addition, a gender gap was observed, as male GPs were more likely to underestimate patients' health literacy [20]. Hawkins *et al.* [21] explored differing perspectives on health literacy between patients and health professionals on an item level, in a qualitative study using the Health Literacy Questionnaire (HLQ). In contrast to the studies referenced above, the authors did not conceptualise differences in assessment as over- or underestimation, but as discordance [21]. When discordance occurs, this may be due to differences in understanding specific wordings, perspectives on changing circumstances over time, expectations and criteria for assigning scores, or perspectives on the patients' reliance on healthcare providers [21]. No matter whether discordance is due to estimation errors or differing perspectives, it is important to signal these differences and the direction of any discordance in order to prevent potential communication gaps [22] and/or address them in the delivery of care.

To learn more about the prevalence and potential drivers of discordance in health literacy assessment in rheumatology, the two-fold aim of this study was (i) to investigate the discordance between health literacy of people with rheumatic and musculoskeletal diseases (RMDs) and assessment of health literacy by their treating health professionals, and (ii) to explore whether discordance was associated with the patients' socioeconomic background.

Methods

Study design

We conducted an observational cross-sectional study, as part of a health literacy project in rheumatology following the Optimising Health Literacy and Access (Ophelia) process [23]. A more extensive account of the methods of patient recruitment and data collection is described elsewhere [17]. One patient research partner (M.dW.) was involved throughout the research process.

Population and setting

This study was conducted in three outpatient rheumatology clinics in the Netherlands (in the South, West and East). We recruited adult patients diagnosed by a

rheumatologist with RA, spondyloarthritis (SpA) or gout, and their treating healthcare professional (rheumatologist, rheumatology fellow, nurse practitioner/physician assistant or rheumatology nurse). Data collection took place between May 2018 and May 2019.

Procedures and measurements

Consenting patients filled out a survey on paper, digitally, or orally in an interview format with a researcher, in their preferred language (Dutch, English, German or Arabic). The survey primarily included the Health Literacy Questionnaire (HLQ) [24, 25], which comprises 44 items addressing nine distinct domains of health literacy (Box 1). The HLQ provides a score for each domain (the higher the better) [24], as it was developed to identify strengths and weaknesses across domains that would not be revealed by a single summary score. Other survey questions included the Pearlin Mastery Scale (which assesses the extent to which a person feels like they have control over life's opportunities, score range 7–28 [26]) and questions on sociodemographic background and health status. Sociodemographic information included age (in years), gender, education level [low (no more than primary or lower secondary education)/medium/high (graduated tertiary education) using Dutch standardised categories [27]), migration background (Native Dutch, Western migrant or non-Western migrant [28]), employed (yes/no), (partially) work disabled (yes/no) and living alone (yes/no).

Following the clinical visit, the health professional who performed the consultation provided their assessment of the patient's level (or answered 'I do not know') on each of the nine domains of the HLQ using a 0–10 numeric rating scale (NRS). In addition, professionals indicated how well they knew the patient (not at all/barely, somewhat, fairly well, very well) and provided a professional's global assessment of the impact of the rheumatic disease on the functioning and health of the patient (NRS 0–10, 10 being maximum impact). Additionally, we documented the healthcare professionals' gender and profession. Before the start of the study, all participating health professionals attended a 1-h session to discuss health literacy, the study setup and how to fill out the survey. An explanation of the meaning of high and low scores on the nine domains [24] was provided to health professionals whenever they were assessing patients.

Ethics

This study was reviewed by the Medical Ethics Review Committee at Maastricht University Medical Center + (2018–0327) as well as by the designated committees at each participating hospital for local permission (Maastricht University Medical Center +, Maastricht: 18–4-037, Maasstad Hospital, Rotterdam: L2018057, Medisch Spectrum Twente, Enschede: KH18-23). All patients and professionals provided written informed consent.

Statistical analysis

In case of missing data, we contacted patients and healthcare professionals to complete missing items. Remaining missing HLQ data were treated according to the expectation maximisation algorithm used in Ophelia [29], before computing domain scores. We analysed discordance data using three categories: (i) 'The professional's assessment was lower than the patient's HLQ score' (negative discordance); (ii) 'The professional's assessment and patient's HLQ score were probably the same'; and (iii) 'The professional's assessment was higher than the patient's HLQ score' (positive discordance). Before categorisation, patients' HLQ domain scores were converted to a 0–10 scale to enable comparisons with the health professionals' assessments. Discordance was defined as a $\geq$2-point difference (in either direction). Given a $\geq$2-point difference at the extremes of the 0–10 scale implies the patient and health professional agree the score is either 'very high' or 'very low', such discordance is unlikely to be relevant. Therefore, we classified observations where both the professional and the patient scored $\leq$3 or $\geq$7 as 'probably the same' (i.e. no relevant discordance).

We used multilevel multinomial regression (mixed) models to test the role of socioeconomic factors in

Box 1 Health Literacy Questionnaire (HLQ) domains

Domain number and description	
1. Feeling understood and supported by healthcare providers (4 items)	Part I (score range 1–4)
2. Having sufficient information to manage my health (4 items)	
3. Actively managing my health (5 items)	
4. Having social support for health (5 items)	
5. Critical appraisal of health information (5 items)	
6. Ability to actively engage with healthcare providers (5 items)	Part II (score range 1–5)
7. Navigating the healthcare system (6 items)	
8. Ability to find good health information (5 items)	
9. Understanding health information well enough to know what to do (5 items)	

Part I measures level of agreement with items on a 4-point Likert scale: strongly disagree (1), disagree (2), agree (3) and strongly agree (4). Part II measures difficulty experienced with items on a 5-point Likert scale: always difficult/cannot do (1), usually difficult (2), sometimes difficult (3), usually easy (4) and always easy (5).

negative (i.e. professional scored lower than the patient) and positive (i.e. professional scored higher than the patient) relevant discordance in each of the nine HLQ domains (reference = 'probably the same'). To account for clustering within individual health professionals, we added a random intercept to the models. Intraclass correlation coefficients (ICCs) were computed. The base model included all socioeconomic factors of interest [age, gender, education level, migration background, being employed or (partially) work disabled, living alone]. Other potential predictors or confounding variables (type of rheumatic disease, patient-reported mastery, professionals' global assessment of disease impact, type of healthcare professional, gender of healthcare professional, and how well the healthcare professional knew the patient) were each tested separately in the base model. The final model was selected by retaining all base model variables and performing a backwards selection procedure for other variables that proved significant predictors or confounders when added to the base model. Analyses were performed in IBM SPSS Statistics 27 and Stata 15. Statistical significance was assumed at $\alpha = 5\%$.

Results

Treating health professionals filled out questionnaires for 778 out of 895 participating patients [17]. There were no important differences between the 778 patients included in analysis and those for whom a professional's questionnaire was not completed (Supplementary Table S1, available at *Rheumatology* online). Included patients had a mean age of 61.2 (SD 13.9); 52.1% were male; 51.7% reported to have a low education level; 17.5% had a Western or non-Western migration background; 32.5% were employed; 14.3% were (partially) work disabled; and 23.9% lived alone (Table 1). Thirty-nine healthcare professionals assessed between 1 and 85 patients; 23.1% of professionals were male; and 60% were rheumatologists (Table 1).

Discordance

Total relevant (negative and positive) discordance between patients' HLQ scores and professionals' assessments occurred in 161 (20.7%) to 315 (40.5%) patients per domain (Fig. 1). Professionals answered: 'I do not know' most often for 'Having social support for health' (19.4%, domain 4). Relevant positive discordance was observed more frequently than negative discordance. Most positive discordance was observed for 'Critically appraising information' (domain 5, 31.9% positive discordance), while most negative discordance was observed for 'Actively engaging with providers' (domain 6, 19.0% negative discordance).

Exploring the role of socioeconomic factors

Results of univariable associations between socioeconomic factors and discordance are provided as

Table 1 Participant characteristics

Patient characteristics (n = 778)	Mean (s.d.) [min–max][a]/ % (n)[b]
Age	61.2 (13.9) [18–89]
Gender: male	52.1 (405)
Education level	
Low	51.7 (402)
Medium	24.4 (190)
High	23.9 (186)
Migration background	
Non-Western migrant	8.9 (69)
Western migrant	8.6 (67)
Native Dutch	82.5 (642)
Occupation status[c]	
Employed	32.5 (253)
(Partially) work disabled	14.3 (111)
Household type[c]	
Living alone	23.9 (186)
Rheumatic disease	
RA	41.0 (319)
SpA	34.2 (266)
Gout	24.8 (193)
Treating hospital	
South	31.7 (247)
West	28.8 (224)
East	39.5 (307)
Treated by type of healthcare professional	
Rheumatologist	55.3 (430)
Rheumatology fellow	7.5 (58)
Nurse practitioner/physician assistant	21.0 (163)
Rheumatology nurse	16.3 (127)
Mastery	20.06 (3.44) [9-28][d]
Healthcare professional-reported outcomes	
Professionals' global assessment of disease impact	4.28 (2.39) [0-10]
How well professional knew the patient	
Not at all/barely	10.9 (85)
Somewhat	30.1 (234)
Fairly well	46.5 (362)
Very well	12.5 (97)
Health professional characteristics (n = 39)	
Gender: male	23.1 (9)
Type of professional	
Rheumatologist	60.0 (23)
Rheumatology fellow	20.5 (8)
Nurse practitioner/physician assistant	10.3 (4)
Rheumatology nurse	10.3 (4)
Employing hospital	
South	30.8 (12)
West	30.8 (12)
East	38.5 (15)
Number of patients assessed	19.9 (16.8) [1-85]

[a]for continuous variables. [b]for categorical variables. [c]Described as yes/no variable. For occupation status, patients may belong to both or neither of these groups. [d]$n = 777$ (1 questionnaire administered in Arabic without Mastery scale because no validated translation is available). SpA: spondyloarthritis.

Fig. 1 Classification of relevant discordance per Health Literacy Questionnaire domain

Classification by occurrence and direction [i.e. negative (professional scored lower) or positive (professional scored higher) discordance] of relevant discordance between patients' Health Literacy Questionnaire scores and their healthcare professionals' estimation per domain ($n = 778$).

Supplementary Table S2, available at *Rheumatology* online. Tables 2 and 3 and Fig. 2A and B show the multivariable multilevel multinomial models. Socioeconomic factors played a role in discordance in all domains except 'Healthcare provider support' (domain 1). Patients' gender was not associated with relevant discordance in health literacy scores. Observed ICCs exposed clustering of discordance by professional.

Negative discordance (i.e. professional scored lower than the patient)

Fig. 2A and Table 2 present odds ratios of negative discordance (compared with 'probably the same') per domain. Education level and migration background were most frequently and strongly associated with negative discordance. Having *low education level* or *medium education level* (compared with *high education level*) was associated with negative discordance in five and three domains, respectively, with highest odds observed for 'Actively engaging with providers' [domain 6, OR low education 3.97 (2.06–7.64), OR medium education 3.03 (1.47–6.24)]. *Non-Western migration background* (compared with *Native Dutch*) was associated with negative discordance in five domains, with the highest odds observed for 'Understanding health information' [domain 9, OR 8.52 (4.12–17.61)], the only domain in which *Western migration background* was additionally associated with professionals underscoring patients [OR 2.41 (1.12–5.21)].

Other observed associations were less consistent across domains. Living alone and not being employed were each associated with negative discordance in single HLQ domains. People *living alone* were more likely to be underscored by professionals for 'Having social support' [domain 4, OR 3.51 (1.52–8.10)]. People *not employed* were more likely to be underscored by professionals for 'Navigating the health system' [domain 7, OR 2.28 (1.09–4.78)]. People who were (*partially) work disabled* had higher odds of being underscored only for 'Actively managing health' [domain 3, OR 2.09 (1.02–4.30)]. Age was not associated with negative discordance in any domain.

Positive discordance (i.e. professional scored higher than the patient)

Fig. 2B and Table 3 present odds ratios of positive discordance (compared with 'probably the same') per domain. While positive discordance occurred more frequently than negative discordance (mean 17.1 and 10.5% per domain, respectively, Fig. 1), it was less often and less strongly associated with socioeconomic determinants. Having *low education level* (compared with *high education level*) was negatively associated with positive discordance for 'Having sufficient information' [domain 2, OR 0.45 (0.28–0.73)], 'Actively managing health' [domain 3, OR 0.65 (0.42–0.99)], and 'Critically appraising information' [domain 5, OR 0.53 (0.35–0.79)], and positively associated with positive discordance for 'Finding health information' and 'Understanding health information' [domains 8 and 9, OR 2.89 (1.41–5.93) and 2.34 (1.12–4.90)]. Having *medium education level* (compared with *high education level*) was negatively associated with positive discordance in two domains: 'Having sufficient information' [domain 2, OR 0.57 (0.34–0.96)] and 'Navigating the health system' [domain 7, OR 0.43 (0.22–0.85)]. Of note, migration background was not associated with positive discordance in any of the domains.

While not a factor in negative discordance, being of *higher age* was associated with positive discordance in

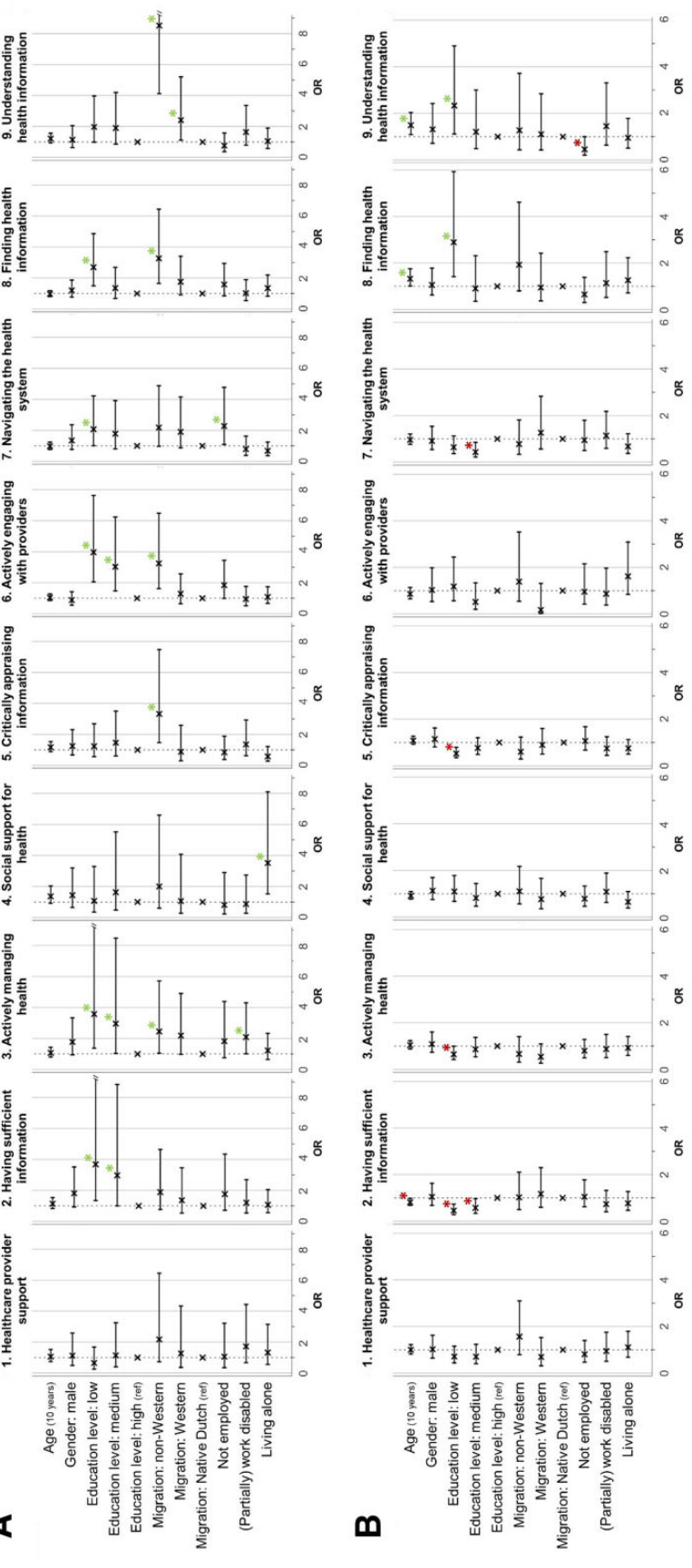

FIG. 2 Associations of socioeconomic factors with negative (**A**) and positive (**B**) discordance

Odds ratios (ORs) and 95% CI of socioeconomic factors associated with discordance. Fig. 2A shows associations with negative discordance (professionals scored lower *vs* 'probably the same'). Fig. 2B shows associations with positive discordance (professionals scored higher *vs* 'probably the same'). * indicates higher odds with $P < 0.05$, * indicates lower odds with $P < 0.05$, // indicates upper limit exceeds 0–9 scale.

Table 2 Odds ratios for negative discordance (professional scored lower) per domain, results from adjusted multilevel multinomial models ($n = 778$)[a]

HLQ domains	1. Healthcare provider support ($n = 768$)	2. Having sufficient information ($n = 770$)	3. Actively managing health ($n = 763$)	4. Having social support for health ($n = 626$)	5. Critically appraising information ($n = 776$)	6. Actively engaging with providers ($n = 774$)	7. Navigating the health system ($n = 765$)	8. Finding health information ($n = 752$)	9. Understanding health information ($n = 765$)
Variables of interest:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.06 [0.74, 1.52]	1.14 [0.84, 1.54]	1.07 [0.80, 1.43]	1.36 [0.91, 2.03]	1.17 [0.89, 1.54]	1.04 [0.85, 1.28]	0.98 [0.77, 1.25]	0.97 [0.80, 1.19]	1.22 [0.94, 1.57]
Gender: male	1.13 [0.49, 2.58]	1.81 [0.94, 3.52]	1.78 [0.95, 3.33]	1.44 [0.65, 3.19]	1.25 [0.68, 2.31]	0.89 [0.55, 1.42]	1.35 [0.77, 2.37]	1.20 [0.78, 1.87]	1.15 [0.64, 2.05]
Gender: female (ref)	—	—	—	—	—	—	—	—	—
Education level: low	0.65 [0.25, 1.68]	**3.69 [1.35, 10.11]**	**3.58 [1.37, 9.33]**	1.07 [0.35, 3.29]	1.24 [0.57, 2.69]	**3.97 [2.06–7.64]**	**2.07 [1.02, 4.22]**	**2.69 [1.49, 4.86]**	1.97 [0.98, 3.97]
Education level: medium	1.14 [0.40, 3.25]	**2.97 [1.00, 8.84]**	**2.96 [1.03, 8.47]**	1.63 [0.48, 5.52]	1.47 [0.61, 3.51]	**3.03 [1.47, 6.24]**	1.79 [0.81, 3.92]	1.35 [0.68, 2.69]	1.90 [0.86, 4.20]
Education level: high (ref)	—	—	—	—	—	—	—	—	—
Migration background: non-Western	2.18 [0.73, 6.45]	1.89 [0.77, 4.65]	**2.45 [1.05, 5.72]**	2.00 [0.61, 6.60]	**3.33 [1.48, 7.48]**	**3.25 [1.62, 6.49]**	2.18 [0.97, 4.88]	**3.27 [1.66, 6.44]**	**8.52 [4.12–17.61]**
Migration background: Western	1.27 [0.37, 4.33]	1.36 [0.54, 3.46]	2.19 [0.98, 4.91]	1.06 [0.28, 4.08]	0.88 [0.30, 2.59]	1.29 [0.65, 2.57]	1.91 [0.88, 4.16]	1.76 [0.91, 3.40]	**2.41 [1.12, 5.21]**
Migration background: Native Dutch (ref)	—	—	—	—	—	—	—	—	—
Not employed	1.06 [0.35, 3.22]	1.76 [0.72, 4.35]	1.83 [0.76, 4.39]	0.81 [0.23, 2.90]	0.85 [0.38, 1.88]	1.85 [0.99, 3.44]	**2.28 [1.09, 4.78]**	1.58 [0.85, 2.94]	0.77 [0.37, 1.58]
Employed (ref)	—	—	—	—	—	—	—	—	—
(Partially) work disabled: yes	1.72 [0.67, 4.43]	1.21 [0.54, 2.69]	**2.09 [1.02, 4.30]**	0.87 [0.28, 2.74]	1.36 [0.63, 2.93]	0.95 [0.52, 1.76]	0.79 [0.39, 1.63]	1.02 [0.55, 1.89]	1.64 [0.80, 3.36]
(Partially) work disabled: no (ref)	—	—	—	—	—	—	—	—	—
Living alone: yes	1.32 [0.56, 3.15]	1.07 [0.56, 2.05]	1.23 [0.65, 2.33]	**3.51 [1.52, 8.10]**	0.58 [0.28, 1.22]	1.08 [0.67, 1.74]	0.68 [0.37, 1.25]	1.35 [0.83, 2.20]	1.06 [0.59, 1.90]
Living alone: no (ref)	—	—	—	—	—	—	—	—	—
Fixed intercept	0.00 [0.00, 0.05]	0.00 [0.00, 0.03]	0.02 [0.00, 0.32]	0.00 [0.00, 0.08]	0.01 [0.00, 0.08]	0.00 [0.00, 0.01]	0.00 [0.00, 0.02]	0.02 [0.00, 0.14]	0.01 [0.00, 0.15]
Other predictors/ confounders:									
Disease: gout	0.85 [0.24, 3.03]	1.84 [0.79, 4.31]	1.33 [0.54, 3.27]	N/A	N/A	**2.43 [1.26, 4.67]**	0.86 [0.38, 1.92]	N/A	1.53 [0.71, 3.32]
Disease: SpA	1.00 [0.41, 2.44]	0.90 [0.42, 1.93]	2.05 [1.00, 4.20]	N/A	N/A	0.86 [0.50, 1.46]	0.78 [0.42, 1.46]	N/A	0.74 [0.38, 1.44]
Disease: RA (ref)	—	—	—	N/A	N/A	—	—	N/A	—
Mastery	N/A	1.02 [0.94, 1.12]	0.94 [0.86, 1.02]	0.97 [0.87, 1.09]	N/A	**1.09 [1.02, 1.16]**	**1.12 [1.04, 1.21]**	1.07 [1.00–1.14]	1.01 [0.94, 1.09]
Professionals' global disease impact	**1.36 [1.11, 1.67]**	**1.27 [1.10, 1.46]**	**1.23 [1.07, 1.43]**	**1.24 [1.01, 1.51]**	**1.27 [1.10, 1.47]**	**1.18 [1.06, 1.30]**	**1.24 [1.09, 1.41]**	N/A	N/A
Professional type: nurse	2.41 [0.38, 15.20]	N/A	N/A	1.33 [0.27, 6.66]	0.68 [0.14, 3.27]	N/A	N/A	N/A	N/A
Professional type: NP/PA	0.65 [0.09, 4.75]	N/A	N/A	1.65 [0.45, 6.08]	1.00 [0.27, 3.70]	N/A	N/A	N/A	N/A
Professional type: fellow	**4.55 [1.04, 19.91]**	N/A	N/A	**6.92 [2.02, 23.71]**	**4.22 [1.32, 13.44]**	N/A	N/A	N/A	N/A
Professional type: rheumatologist (ref)	—	N/A	N/A	—	—	N/A	N/A	N/A	N/A
Professional gender: male	N/A	N/A	N/A	**3.21 [1.14, 9.05]**	N/A	N/A	N/A	N/A	N/A
Professional gender: female (ref)	N/A	N/A	N/A	—	N/A	N/A	N/A	N/A	N/A

(continued)

Table 2 Continued

HLQ domains	1. Healthcare provider support (*n* = 768)	2. Having sufficient information (*n* = 770)	3. Actively managing health (*n* = 763)	4. Having social support for health (*n* = 626)	5. Critically appraising information (*n* = 776)	6. Actively engaging with providers (*n* = 774)	7. Navigating the health system (*n* = 765)	8. Finding health information (*n* = 752)	9. Understanding health information (*n* = 765)
How well the professional knew the patient: very well	N/A	N/A	**0.25 [0.07, 0.96]**	N/A	0.61 [0.16, 2.33]	1.02 [0.34, 3.08]	0.96 [0.28, 3.26]	N/A	0.60 [0.17, 2.09]
How well the professional knew the patient: fairly well	N/A	N/A	0.51 [0.20, 1.27]	N/A	1.03 [0.38, 2.81]	2.37 [1.04–5.39]	1.29 [0.51, 3.30]	N/A	1.05 [0.43, 2.59]
How well the professional knew the patient: somewhat	N/A	N/A	0.74 [0.31, 1.79]	N/A	1.11 [0.41, 3.03]	2.63 [1.19, 5.80]	1.73 [0.70, 4.27]	N/A	1.12 [0.46, 2.70]
How well the professional knew the patient: not/ barely (ref)	N/A	N/A	—	N/A	—	—	—	N/A	—
ICC	0.32 [0.16, 0.54]	0.26 [0.14, 0.44]	0.17 [0.07, 0.36]	0.14 [0.03, 0.47]	0.21 [0.09, 0.42]	0.16 [0.08, 0.31]	0.21 [0.10, 0.40]	0.15 [0.06, 0.31]	0.22 [0.10, 0.40]

Results from adjusted multilevel multinomial models, 'probably the same' as reference category. [a]*n* differs between domains due to exclusion of 'I do not know' and one patient with missing data for 'Mastery'. (ref) and —: reference category (no OR), N/A: not applicable (variable not included in model), HLQ: Health Literacy Questionnaire, ICC: intraclass correlation coefficient, NP/PA: nurse practitioner/physician assistant, OR: odds ratio, SpA: spondyloarthritis. Bold values indicate $P < 0.05$.

three domains, although the direction of the effect was inconsistent. Professionals were more likely to overscore *older patients* for 'Finding health information' and 'Understanding health information' [domains 8 and 9, 10-year difference OR 1.32 (1.01–1.75) and 1.49 (1.09–2.03) respectively], and *younger patients* for 'Having sufficient information' [domain 2, 10-year difference OR 0.81 (0.68–0.98)]. People *not employed* had lower odds of being overscored by professionals only for 'Understanding health information' [domain 9, OR 0.45 (0.21–1.00)].

Exploring the role of other factors

Besides associations with socioeconomic determinants, we observed several relevant associations between discordance and other patient and health professionals' characteristics. These associations differed between negative and positive discordance.

Negative discordance (i.e. professional scored lower than the patient)

The most common factor associated with negative discordance (Table 2) was *professionals' global assessment of disease impact*, with higher impact increasing the odds of negative discordance in the first seven HLQ domains. Compared with rheumatologists, *fellows* were more likely to underscore their patient on 'Healthcare provider support' (domain 1), 'Having social support for health' (domain 4), and 'Critically appraising information' (domain 5). In cases where health professionals stated they *knew the patient very well* (compared with *not at all/barely*), negative discordance was less likely for 'Actively managing health' (domain 3). Patients with *gout* (compared with patients with RA) were more likely to be underscored for 'Actively engaging with providers' (domain 6). The gender of the health professional was only of relevance in one domain: male professionals were more likely to underscore patients on 'Having social support for health' (domain 4).

Positive discordance (i.e. professional scored higher than the patient)

The most relevant factor associated with positive discordance was *patients' mastery*. *Lower mastery* was associated with positive discordance in six domains (Table 3). In cases where health professionals stated they *knew the patient very well*, positive discordance was more likely for 'Actively managing health' (domain 3) and 'Navigating the health system' (domain 7). Patients with *gout* (compared with patients with *RA*) were more likely to be overscored by professionals for 'Healthcare provider support' (domain 1) and 'Navigating the health system' (domain 7).

Discussion

We found discordance between Health Literacy Questionnaire scores of people with RMDs and assessment of health literacy by their treating health professionals in more than a quarter of all cases. This indicates

Table 3 Odds ratios for positive discordance (professional scored higher) per domain, results from adjusted multilevel multinomial models ($n = 778$)[a]

HLQ domains	1. Healthcare provider support ($n = 768$)	2. Having sufficient information ($n = 770$)	3. Actively managing health ($n = 763$)	4. Having social support for health ($n = 626$)	5. Critically appraising information ($n = 776$)	6. Actively engaging with providers ($n = 774$)	7. Navigating the health system ($n = 765$)	8. Finding health information ($n = 752$)	9. Understanding health information ($n = 765$)
Variables of interest:	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Age (10 years)	1.00 [0.82, 1.22]	**0.81 [0.68, 0.98]**	1.04 [0.88, 1.23]	0.91 [0.77, 1.09]	1.08 [0.92, 1.27]	0.86 [0.65, 1.14]	0.96 [0.76, 1.21]	**1.32 [1.01, 1.75]**	**1.49 [1.09, 2.03]**
Gender: male	1.02 [0.65, 1.62]	1.05 [0.67, 1.63]	1.09 [0.73, 1.61]	1.13 [0.75, 1.70]	1.15 [0.81, 1.63]	1.03 [0.54, 1.98]	0.91 [0.54, 1.54]	1.06 [0.63, 1.78]	1.31 [0.71, 2.42]
Gender: female (ref)	—	—	—	—	—	—	—	—	—
Education level: low	0.71 [0.44, 1.16]	**0.45 [0.28, 0.73]**	**0.65 [0.42, 0.99]**	1.10 [0.68, 1.78]	**0.53 [0.35, 0.79]**	1.18 [0.57, 2.45]	0.64 [0.37, 1.12]	**2.89 [1.41, 5.93]**	**2.34 [1.12, 4.90]**
Education level: medium	0.71 [0.40, 1.24]	**0.57 [0.34, 0.96]**	0.86 [0.54, 1.37]	0.82 [0.47, 1.44]	0.77 [0.49, 1.20]	0.52 [0.20, 1.34]	**0.43 [0.22, 0.85]**	0.91 [0.36, 2.31]	1.21 [0.49, 3.00]
Education level: high (ref)	—	—	—	—	—	—	—	—	—
Migration background: non-Western	1.57 [0.79, 3.10]	1.02 [0.50, 2.10]	0.66 [0.31, 1.41]	1.11 [0.57, 2.17]	0.60 [0.29, 1.23]	1.39 [0.55, 3.52]	0.78 [0.34, 1.82]	1.93 [0.80, 4.62]	1.27 [0.44, 3.72]
Migration background: Western	0.69 [0.32, 1.53]	1.17 [0.60, 2.30]	0.54 [0.27, 1.09]	0.77 [0.36, 1.66]	0.90 [0.50, 1.60]	0.17 [0.02, 1.31]	1.27 [0.57, 2.83]	0.95 [0.37, 2.42]	1.10 [0.43, 2.84]
Migration background: Native Dutch (ref)	—	—	—	—	—	—	—	—	—
Not employed	0.81 [0.47, 1.40]	1.05 [0.62, 1.77]	0.80 [0.50, 1.29]	0.79 [0.46, 1.33]	1.07 [0.68, 1.68]	0.96 [0.42, 2.16]	0.95 [0.50, 1.80]	0.65 [0.31, 1.38]	**0.45 [0.21, 1.00]**
Employed (ref)	—	—	—	—	—	—	—	—	—
(Partially) work disabled: yes	0.95 [0.51, 1.76]	0.73 [0.41, 1.32]	0.87 [0.51, 1.50]	1.09 [0.63, 1.89]	0.75 [0.45, 1.25]	0.87 [0.38, 1.97]	1.14 [0.60, 2.18]	1.14 [0.52, 2.49]	1.45 [0.64, 3.31]
(Partially) work disabled: no (ref)	—	—	—	—	—	—	—	—	—
Living alone: yes	1.11 [0.69, 1.79]	0.77 [0.46, 1.27]	0.92 [0.60, 1.41]	0.65 [0.39, 1.09]	0.75 [0.50, 1.13]	1.62 [0.85, 3.09]	0.68 [0.38, 1.22]	1.26 [0.71, 2.23]	0.95 [0.51, 1.78]
Living alone: no (ref)	—	—	—	—	—	—	—	—	—
Fixed intercept	0.33 [0.09, 1.19]	23.31 [3.31, 164.22]	1.01 [0.16, 6.38]	17.40 [2.48, 122.24]	0.78 [0.25, 2.40]	12.35 [0.60, 252.57]	5.55 [0.49, 63.49]	0.09 [0.01, 1.01]	0.09 [0.01, 1.39]
Other predictors/confounders:									
Disease: gout	**1.82 [1.01, 3.29]**	1.18 [0.63, 2.18]	0.88 [0.50, 1.57]	N/A	N/A	1.40 [0.56, 3.52]	**2.73 [1.31, 5.71]**	N/A	1.53 [0.67, 3.50]
Disease: SpA	1.18 [0.70, 1.98]	1.36 [0.83, 2.22]	1.08 [0.70, 1.67]	N/A	N/A	1.26 [0.60, 2.63]	1.37 [0.75, 2.50]	N/A	1.16 [0.57, 2.38]
Disease: RA (ref)	—	—	—	N/A	N/A	—	—	N/A	—
Mastery	N/A	**0.87 [0.82, 0.93]**	0.97 [0.92, 1.03]	**0.86 [0.81, 0.92]**	N/A	**0.82 [0.74, 0.90]**	**0.84 [0.78, 0.91]**	**0.91 [0.84, 0.98]**	**0.87 [0.80, 0.94]**
Professionals' global disease impact	0.95 [0.86, 1.04]	0.94 [0.85, 1.03]	**0.90 [0.83, 0.98]**	0.97 [0.88, 1.07]	0.94 [0.87, 1.02]	0.97 [0.85, 1.11]	0.98 [0.88, 1.09]	N/A	N/A
Professional type: nurse	0.74 [0.38, 1.46]	N/A	N/A	0.77 [0.33, 1.84]	1.10 [0.54, 2.21]	N/A	N/A	N/A	N/A
Professional type: NP/PA	0.73 [0.39, 1.37]	N/A	N/A	0.92 [0.41, 2.09]	0.73 [0.37, 1.44]	N/A	N/A	N/A	N/A
Professional type: fellow	0.67 [0.27, 1.64]	N/A	N/A	0.72 [0.28, 1.85]	1.36 [0.62, 2.98]	N/A	N/A	N/A	N/A
Professional type: rheumatologist (ref)	—	N/A	N/A	—	—	N/A	N/A	N/A	N/A
Professional gender: male	N/A	N/A	N/A	1.13 [0.55, 2.32]	N/A	N/A	N/A	N/A	N/A
Professional gender: female (ref)	N/A	N/A	N/A	—	N/A	N/A	N/A	N/A	N/A

(continued)

Table 3 Continued

HLQ domains	1. Healthcare provider support ($n = 768$)	2. Having sufficient information ($n = 770$)	3. Actively managing health ($n = 763$)	4. Having social support for health ($n = 626$)	5. Critically appraising information ($n = 776$)	6. Actively engaging with providers ($n = 774$)	7. Navigating the health system ($n = 765$)	8. Finding health information ($n = 752$)	9. Understanding health information ($n = 765$)
How well the professional knew the patient: very well	N/A	N/A	**2.60 [1.19, 5.70]**	N/A	1.54 [0.76, 3.15]	0.74 [0.22, 2.57]	**3.83 [1.45, 10.09]**	N/A	1.40 [0.43, 4.56]
How well the professional knew the patient: fairly well	N/A	N/A	1.49 [0.78, 2.87]	N/A	0.91 [0.51, 1.60]	1.04 [0.39, 2.78]	1.38 [0.60, 3.18]	N/A	1.08 [0.42, 2.78]
How well the professional knew the patient: somewhat	N/A	N/A	1.11 [0.57, 2.13]	N/A	**0.56 [0.31, 1.00]**	0.56 [0.20, 1.62]	0.95 [0.41, 2.21]	N/A	0.87 [0.35, 2.16]
How well the professional knew the patient: not/barely (ref)	N/A	N/A	—	N/A	—	—	—	N/A	—
ICC	0.02 [0.00, 0.47]	0.04 [0.01, 0.18]	0.06 [0.02, 0.16]	0.09 [0.03, 0.22]	0.06 [0.02, 0.18]	0.01 [0.00, 1.00]	0.05 [0.01, 0.23]	0.11 [0.04, 0.28]	0.12 [0.04, 0.30]

Results from adjusted multilevel multinomial models, 'probably the same' as reference category. [a]*n* differs between domains due to exclusion of 'I do not know' and one patient with missing data for 'Mastery'. (ref) and —: reference category (no OR); N/A: not applicable (variable not included in model); HLQ: Health Literacy Questionnaire; ICC: intraclass correlation coefficient; NP/PA: nurse practitioner/physician assistant; OR: odds ratio; SpA: spondyloarthritis. Bold values indicate $P < 0.05$.

hidden challenges in communication and care. Most positive discordance (i.e. professional scored higher than the patient) occurred for 'Critically appraising information' (domain 5, 31.9%), while most negative discordance (i.e. professional scored lower than the patient) was observed for 'Actively engaging with providers' (domain 6, 19.0%). Professionals were most often unsure about their patient 'Having social support for health' (domain 4, 19.4% 'I do not know'). In addition, we found that risks of discordance were not equal across socioeconomic groups. Discordance was frequently associated with patients' socioeconomic background, particularly education level and migration background. Risk of negative discordance was higher in patients with low education level and/or non-Western migration background. Risk of positive discordance was higher in patients with low education level for finding and understanding health information (domains 8 and 9) and higher in patients with high education level in four other domains.

Our findings support and expand upon findings from previous studies. Voigt-Barbarowicz and Brütt [18] systematically reviewed health literacy assessment studies (using other measurement tools than the HLQ [18, 20, 22, 30–34]) in hospital-based and primary care populations with somatic conditions. In these studies, misclassification by professionals was also common, and while the biggest concern was overestimation (ranging from 9% to 58% of all patients per study), six out of seven studies also reported underestimation in 5% to 29% of all patients [20, 22, 30–33]. Storms *et al.* [20] additionally investigated the impact of patients' and GPs' characteristics on discordance in single-score health literacy assessment and noted the GPs were more likely to have discordant judgement (over- or underestimation) for patients with low education. Our work expanded on these findings, showing positive discordance occurred more frequently, but negative discordance was more strongly associated with socioeconomic factors. Furthermore, the multidimensional nature of the HLQ allowed us to conduct more nuanced analyses, suggesting that (associations with) discordance may be domain-dependent. For example, contrasting conclusions that particularly underestimation was more likely in patients who had been under the GP's care for a shorter period of time and in patients treated by a male GP [20], we only observed these effects in single domains ['Actively managing health' (domain 3) and 'Having social support for health' (domain 4), respectively].

This paper describes the first study to quantify discordance between patients' health literacy scores and professionals' assessment using the multidimensional HLQ. In a qualitative study, Hawkins *et al.* [21] showed that differing perspectives can be a reason for discordance in HLQ scores between patients and professionals. For example, some patients saw goalsetting and making plans to be healthy as 'Actively managing health' (domain 3), while clinicians expected patients to convert these goals and plans into action. Lacking a gold

standard for objective health literacy measurement, we do not know if the discordance in this study means professionals over- or underestimate patients, patients over- or underestimate themselves, or that the truth is somewhere in the middle. Notwithstanding, the present data uncover a considerable disconnect between patients' and professionals' views on patients' health literacy needs. Moreover, professionals strikingly often answered 'I do not know' in estimating 'Having social support for health' (domain 4), indicating this may not receive sufficient attention in clinical consultations. The findings highlight that we cannot expect all health professionals to accurately understand and address all patients' health literacy needs adequately at the point of care based on subjective estimations alone. Instead, we require strategies to address health literacy needs that rely on health literacy measurement and dialogue with patients and professionals, either at the point of care, or in the development of organisational interventions based on patients' needs [23]. The Conversational Health Literacy Assessment Tool (CHAT) could assist health professionals in this process [35].

Knowing that health literacy needs are not static but can change over time or between contexts [36, 37], and that risk of discordance differs between socioeconomic groups, we also need to reflect on the assumptions we make in research and practice to fill the discordance gap. Dijkstra and Horstman [38] discussed that we should challenge the construction and characterisation of socioeconomic background to understand health inequalities, to prevent perpetuating (possibly inaccurate) negative notions of 'low socioeconomic status' and break away from the narrative of groups 'known to be unhealthy'. The differing risks of discordance based on education level and migration background suggest that pre-existing notions of what health literacy entails in people belonging to specific socioeconomic groups indeed play a role in assessment by health professionals. In order for patients and health professionals to better understand each other, we may need to challenge these pre-existing notions of health literacy and socioeconomic background in our daily work. Of note, discordance between patients' and professionals' perspectives is not unique to health literacy, but has also been documented in concepts such as patient activation [39] and goal-setting [40], which highlights general challenges in clinical communication.

There are additional implications of this study for health literacy and discordance research and practice. First, the ICCs indicated substantial clustering by professional, supporting our assumption that professionals' assessments are highly dependent on the assessor. While many past discordance studies in rheumatology (focusing on other outcomes) did not adjust for possible correlation of scores within health professionals [41–45], our results suggest the clustered nature of the data should be considered in the statistical analyses of future discordance research. Second, we saw clear diversity in discordance and associations with discordance across domains. This further highlights that assessing or estimating single summary scores may fail to capture the complexity of the role of health literacy in health care delivery. Health literacy needs are not grounded in scores on a single domain, but rather follow from a pattern of strengths and weaknesses across health literacy domains [17, 29]. We therefore second Voigt-Barbarowicz and Brütt [18], recommending the use of multidimensional health literacy assessment tools in research and practice.

Our paper reports on a large, inclusive, multicentre study in rheumatology using a multidimensional health literacy tool, giving valuable new insights into health literacy assessment and the role of socioeconomic factors. Nevertheless, it should be seen in the light of a few limitations. First, in contrast to Hawkins *et al.* [21], health professionals did not fill out the full HLQ, but estimated domain scores (for feasibility reasons). This may have exacerbated discordance, also because HLQ scores had to be converted to a 0–10 scale. Second, the choice of categorisation and threshold of 'discordance' as a 2-point difference in observations could be debated. We made this decision based on commonly used cut-offs in rheumatology research [43–46], but no true consensus exists [47], and future studies should determine what difference in health literacy scoring could impact patient–professional relationships and communication. Third, we explored many associations, risking that some of our observations may be due to chance. Therefore, the strong, consistent findings are more likely to reflect true patterns, while less consistent patterns need to be validated in further research. Fourth, some of the associations observed in this cross-sectional study were not consistent between domains, such as the increased risk of both negative and positive discordance in people with low education level for finding and understanding health information (domains 8 and 9), and not consistent with previous research [18, 20]. While these inconsistencies hint at the complexity of health literacy assessment, we cannot be sure if the role of socioeconomic factors in discordance is indeed inconsistent or if there may be other factors (not explored in this study) that can explain discordance patterns and confound the observed associations. Last, we were unable to explore the impact of discordance on outcomes such as quality of care, health status or the occurrence of adverse events. We hypothesise these associations exist, but future research on this topic is warranted.

In conclusion, our study shows that accurate estimation of patients' health literacy by professionals in rheumatology is not a given. Discordance between patients' health literacy scores and professionals' estimations indicates that there may be hidden challenges in communication and care in about a quarter of all patients. Risks are not equal across socioeconomic groups (particularly higher for people with low education level and/or non-Western migration background) and

domains of health literacy, which highlights the multidimensional nature of health literacy and indicates that challenges in addressing health literacy needs may be unequal between socioeconomic groups as well. While increasing awareness among health professionals could potentially reduce discordance and improve understanding between patients and professionals, we suggest health literacy measurement and dialogue with patients and health professionals are vital to addressing health literacy needs, which cannot rely on health professionals' estimations alone.

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Data availability statement

The data underlying this article cannot be shared publicly due to privacy of individuals that participated in the study. They did not consent to have their data shared.

Supplementary data

Supplementary data are available at *Rheumatology* online.

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