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# Well-being and Perceived Stigma in Individuals With Rheumatoid Arthritis and Fibromyalgia

## A Daily Diary Study

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**Introduction:** The presence or absence of clearly defined symptoms and underlying pathophysiology may be a crucial variable related to variability in well-being and stigmatization in individuals with chronic pain (ICPs). In the context of pain, absence of clearly defined symptoms and pathophysiology deviates from the widely endorsed biomedical model and as such, may lead to stigmatization, which in turn could be related to ICPs' well-being.

**Objectives:** The present study compared physical, psychological, social well-being, and perceived stigmatization in individuals with clearly defined symptoms and underlying pathophysiology (rheumatoid arthritis, RA) and individuals with less well understood symptoms and pathophysiology (fibromyalgia, FM) using daily diaries. Furthermore, the association between daily perceived stigmatization and daily well-being was examined.

**Materials and Methods:** Seventy-nine participants with FM, 86 participants with RA, and 33 participants with both diagnoses completed a diary for 14 consecutive days.

**Results:** Compared to individuals with RA, individuals with FM and individuals with both diagnoses reported worse daily well-being. After controlling for age, pain duration, and daily pain, differences between FM and RA remained significant for social well-being and completion of plans. Differences between RA and the dual diagnosis group remained significant for completion of plans, negative affect, and isolation. Furthermore, results suggested more stigmatization in individuals with FM than in individuals with RA. Individuals with both diagnoses reported equal stigmatization as individuals with FM, but more stigmatization than individuals with RA. Finally, increased levels of perceived stigma were associated with lower well-being.

**Discussion:** Findings highlight that the absence of clearly defined symptoms and pathophysiology could be contributing to greater feelings of stigmatization, which may be detrimental for ICPs' well-being.

**Key Words:** chronic pain, fibromyalgia, rheumatoid arthritis, well-being, stigma

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Chronic pain often results in decreased well-being. Yet, not all individuals with chronic pain (ICPs) experience a similar impact on their well-being. The presence or absence of clearly defined symptoms and underlying pathophysiology has been put forward to be pivotal.<sup>1</sup> Particularly, it has been suggested that individuals experiencing pain with less clearly understood symptoms and pathophysiology may experience a lack of understanding of the illness and may worry about possible explanations, which may be detrimental for well-being.<sup>2</sup> In this context, research has shown that individuals with rheumatoid arthritis (RA) report better mental well-being in comparison with individuals with a condition with less clearly defined symptoms and pathophysiology (eg, fibromyalgia [FM]).<sup>3–6</sup> RA and FM are both musculoskeletal disorders that are amongst the most common causes of long-term pain and disability, often resulting in lower quality of life.<sup>3</sup> RA is an autoimmune and inflammatory condition that often affects multiple joints. The tissue damage associated with RA can cause severe chronic pain, deformity, and loss of function.<sup>7</sup> FM is a condition associated with widespread pain along with a complex set of symptoms including poor sleep, fatigue, depression, and cognitive difficulties.<sup>8–10</sup> Diagnosis of RA relies on a combination of patient's medical history, physical examination, laboratory tests, and imaging,<sup>7</sup> while FM is a diagnosis of exclusion and relies on the widespread pain index (counting number of painful body regions) and the symptom severity score.<sup>8,9</sup> No clear pathophysiology has been identified for FM.<sup>10</sup> Several studies have demonstrated that individuals with FM had worse physical and social well-being compared with individuals with RA,<sup>11,12</sup> yet, other studies found no difference between both.<sup>3,13,14</sup> Findings are inconclusive and available research is largely limited to cross-sectional research designs using questionnaires in which people reflect over a longer period of time, allowing retrospective bias and prohibiting to take the dynamic nature of pain and well-being into account.

One potential factor related to variability in well-being between ICPs may be the social environment and the prevailing medical norm. Particularly, an absence of tissue damage (cf. FM) deviates from the widely endorsed

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biomedical model and as such, may lead to suspicion about the genuineness of the ICPs' pain complaints<sup>15-18</sup> and stigmatization.<sup>17-21</sup> Stigma has been defined as devaluing and discrediting responses of observers toward individuals who possess a characteristic that deviates from societal norms.<sup>19,22</sup> Studies have shown that individuals in the general population,<sup>17,21,23,24</sup> medical students,<sup>25,26</sup> and health care practitioners<sup>18,27-29</sup> ascribe lower pain to ICPs and suspect deception when the symptoms and pathophysiology are less well understood.<sup>17,18</sup> In addition, ICPs in general report feelings of disbelief from romantic partners,<sup>30</sup> relatives,<sup>31</sup> friends,<sup>32</sup> colleagues,<sup>30,31,33</sup> and health care practitioners.<sup>34</sup> Uncertainty about the pathophysiology of chronic pain and lack of visible signs for the pain may elicit stigmatizing responses in others because people expect a visible injury explaining the pathophysiology of the pain.<sup>35</sup> In addition, the sick role may only be possessed for a limited period in time, which is violated in the context of chronic pain.<sup>36</sup>

Further, individuals with FM reported more perceived invalidation as compared with individuals with RA.<sup>37</sup> Invalidation has been defined as perceptions of non-acceptance by others, including perceptions of disbelief, suspicion of exaggerated or falsified symptoms, misunderstanding, stigmatization, and outright rejection.<sup>38</sup> According to this definition, overlap exists between stigma and invalidation, but they are not the same. Invalidation is highly similar to enacted stigma (which is the focus of the current study) as defined by Chaudoir et al:<sup>39</sup> both focus on perceptions of strained interactions in the past between stigmatized individuals and other people. Preliminary research showed that invalidation was associated with lower psychological and physical well-being in individuals with RA or FM.<sup>38,40</sup>

Based upon the Stigma Mechanisms in Health Disparities Model,<sup>39</sup> public stigma (ie, community's stigmatizing responses) ultimately leads to worse mental and physical health in stigmatized individuals. Perceived stigma, that is, the perception of being stigmatized, is proposed as one of the influential processes by which public stigma might impact upon ICP's well-being. One study found that internalized stigma (ie, self-stigma) was associated with lower self-esteem and pain self-efficacy, more catastrophizing thoughts and reduced sense of personal control in ICPs.<sup>41</sup> Another study showed that chronic pain stigma was related to more depression and disability.<sup>42</sup> Yet, systematic inquiry is largely lacking as to what extent perceived stigmatization is related to different aspects of well-being in conditions that are better understood in terms of symptoms and underlying pathophysiology versus conditions that are less well understood in terms of symptoms and pathophysiology.

The present study aimed at examining the difference in daily well-being and daily perceived stigmatization between ICPs associated with clearly defined symptoms and pathophysiology (RA) and ICPs that is less well understood in terms of symptoms and pathophysiology (FM)<sup>43,44</sup> using daily diaries. Furthermore, the study aimed at investigating the impact of daily perceived stigmatization upon daily well-being. We hypothesized that individuals with FM would report lower physical (disability, physical activity), psychological (positive and negative affect, self-esteem, completion of plans), and social (isolation, searched social contact) well-being<sup>45</sup> than individuals with RA. Second, we hypothesized that individuals with FM would perceive more daily stigmatization in comparison with individuals with RA. Third,

we hypothesized that daily perceived stigmatization would be related to ICPs' well-being.

## MATERIALS AND METHODS

### Participants

Participants were recruited through the Flemish Pain League (FPL), an organization for patients with chronic pain, and through the League for Rheumatoid Arthritis (LRA), an organization for patients with RA. All members (N = 1983) of the FPL and the LRA (N = 319) were sent an invitation letter to participate in studies on chronic pain and well-being at the Ghent Health Psychology Lab. Four hundred and seven members (20.5%) of the FPL, and 118 (37%) members of the LRA agreed to participate and were contacted by phone to provide further information about the study and to check the following inclusion criteria: (1) having chronic pain (ie, persistent or recurrent pain for at least 3 months), (2) being diagnosed with FM and/or RA, (3) speaking Dutch fluently, and (4) being older than 18 years. Approximately 40% of the members who were called met these inclusion criteria, resulting in a sample of 211 participants with FM, RA, or both diagnoses. We decided to include this dual diagnosis group because it represented a significant proportion of the sample (15.6% of all participants), and this way we could elucidate the impact of having both diagnoses. In particular, we aimed to explore whether they are more similar to the FM group or to RA group regarding daily well-being and daily perceived stigmatization. One hundred and eighteen participants (= 78%) of the FPL completed both the questionnaires and diaries; 2 participants filled out only the questionnaires. Further, 5 participants filled out only the diaries. The data from the latter group were excluded from the analyses as we were unable to secure their informed consent, which was included in the questionnaire set. Thirty nine participants (79%) from the LRA filled out both the questionnaire and diaries; 2 participants filled out only the questionnaire.

After data collection, 9 participants reported to have neither RA nor FM; 2 did not reconfirm being diagnosed with FM; and 2 reported to have pain for less than 3 months. Data of these participants were excluded. In sum, data of 79 participants with FM, 86 with RA, and 33 with both diagnoses were used for further analyses. All participants reported that the (FM or/and RA) diagnosis was provided by a physician.

The study was approved by the Ethical Committee of the Faculty of Psychology and Educational Sciences of Ghent University.

### Procedure

Participants were sent 2 weblinks, one to fill out the online sociodemographic and pain questionnaire, and one for the online end-of-day diary for 14 consecutive days. All questionnaires and diaries were preferable administered online through LimeSurvey, a protected web-based survey tool to obtain research data. Yet, 63 participants asked for a paper booklet containing the (daily) measures (32%).

A diary methodology diminishes retrospective bias<sup>46</sup> and allows to study thoughts, feelings, and behaviors in their natural context with possible fluctuations in social interactions,<sup>47</sup> which is highly informative in the context of stigmatizing responses. Also, diaries allow the investigation of factors contributing to daily variations in well-being.<sup>46</sup> Participants received detailed information and explanation

about the diary items by telephone, and were given the opportunity to receive text reminders every evening. Participants could fill out the diary questions as of 4 PM until 10 AM the following day. The completion of the diary items took 10 minutes each day and the questionnaires took, on average, 30 minutes.

### Sociodemographic Information and Pain Characteristics

A questionnaire including sociodemographic information (ie, sex, age, nationality, marital status, work status, education, pain diagnosis, and pain duration) was administered. Furthermore, pain grades were calculated by means of the Graded Chronic Pain Scale (GCPS<sup>48</sup>). Three items of the GCPS assess current, worst, and average experienced pain intensity during the past 6 months, and were rated on an 11-point scale ranging from 0 (no pain) to 10 (worst imaginable pain). Pain disability was assessed by 4 items of the GCPS, that is, the reported days in which the person was prevented from carrying out his/her usual activities (work, school, or household duties) during the past 6 months and 3 items measuring whether the participant was prevented from carrying out daily activities, recreational/social/familial activities, and work during the past 6 months, answered on an 11-point scale from 0 (no difficulties at all) to 10 (impossible to execute activities). Mean pain intensity was calculated by averaging the items measuring worst and average pain experienced during the past 6 months. The disability score was a combined score related to the number of disability days (<7 d=0 points, ≥7 and <15=1 point, ≥15 and <31=2 points, ≥31=3 points) and points related to 3 items that measure pain interference (score <30=0 points, score ≥30 and <50=1 point, score ≥50 and <70=2 points, score >70=3 points). The Cronbach  $\alpha$  was 0.83 for mean pain intensity, and 0.90 for the disability score.

In line with Von Korff et al,<sup>48</sup> participants were classified into 5 grades based on the scores for mean pain intensity and disability: grade 0 “no pain,” grade 1 “low intensity and low disability” (disability points <3 and pain intensity <50), grade 2 “high intensity and low disability” (disability points <3 and pain intensity ≥50) and, grade 3 “moderate disability, regardless of pain intensity” (disability points =3 or 4), and grade 4 “high disability, regardless of pain intensity” (disability points =4 or 5).

### Daily Measures

The diary consisted of 31 items to measure pain intensity, physical well-being (disability, physical activity), psychological well-being (positive and negative affect, self-esteem, completion of plans), social well-being (isolation, searched social contact), and perceived stigma on a daily basis (ie, each evening). No total scores for physical, psychological, or social well-being were calculated. Pain intensity, disability, physical activity, completion of plans, positive affect, negative affect, self-esteem, isolation, and searched social contact were included as separate constructs in the tested models. Following Geldhof et al,<sup>49</sup> a multilevel confirmatory factor analysis framework was used to measure level-specific reliabilities (see also<sup>50</sup>). Within level and between level  $\alpha$ 's are reported.

### Pain Intensity

To measure daily pain intensity we adapted 2 items of the Graded Chronic Pain Scale<sup>48</sup> to a daily context. The items “On average, how much pain did you have today?” and “How intense was your worst pain today?” were rated

on a scale from 0 (no pain) to 10 (pain as bad as it could be). A daily pain intensity score was calculated for each participant by averaging the scores on both items. The score was reliable (within-person  $\alpha$ =0.89; between-person  $\alpha$ =0.96).

### Physical Well-being

Daily disability was measured by an adapted item of the Graded Chronic Pain Scale.<sup>48</sup> The item “My pain hindered my activities today” was answered on an 11-point scale ranging from 0 (completely disagree) to 10 (completely agree).

Daily physical activity was assessed by means of the item “Today, I was physically active”. Participants answered this statement on an 11-point scale going from 0 (not at all true) to 10 (totally true). This item was developed by the research team informed by experts in the field.

### Psychological Well-being

Daily affect was measured through 17 adjectives describing 5 positive affective states (eg, proud, happy, relaxed) and 12 negative affective states (eg, sad, nervous, scared), derived from a validation study investigating the representation of emotion terms in a general population<sup>51,52</sup> and previously used in diary research within a pain context.<sup>53</sup> In the current study items were rated on a 7-point scale from 0 (totally disagree) to 6 (totally agree). A sum score was calculated for positive and negative affect. In the present study both scales were reliable (within-person  $\alpha$ =0.90 and 0.91; between-person  $\alpha$ =0.97 and 0.98 for positive respectively negative affect).

Daily self-esteem was measured by 4 adapted items of the Rosenberg Self-Esteem Scale:<sup>54,55</sup> “Today, all in all, I was inclined to feel that I am a failure,” “Today, I took a positive attitude toward myself,” “Today, on the whole, I am satisfied with myself,” and “Today, I thought at times that I am no good at all.” The 4 items were answered on a 4-point scale going from 1 (strongly disagree) to 4 (strongly agree). The first and last item were reverse scored after which the four items were summed. The score was reliable (within-person  $\alpha$ =0.69; between-person  $\alpha$ =0.93).

Completion of daily plans was assessed through a single item, that is, “Today, I did all activities/tasks that I intended to do today” on an 11-point scale ranging from 0 (not at all true) to 10 (totally true). This item was developed by the research team to assess the degree to which people succeed in completing meaningful activities that they planned to do.

### Social Well-being

Daily isolation and searched social contact were measured by the following items, respectively “Today, I have isolated myself from the outside world” and “Today, I sought contact with other people.” Both items were answered on an 11-point scale ranging from 0 (not at all true) to 10 (totally true). These items were developed by the research team informed by experts in the field.

### Perceived Stigma

Daily perceived stigma was measured by means of 3 diary items, using a scale from 0 (not at all true) to 10 (totally true). We adapted 2 items of the Illness Invalidation Inventory (I\*3) of Kool et al,<sup>38</sup> which measures perceptions of invalidating reactions from others on 2 subscales. The first item was adapted from the “discounting” subscale of the I\*3 questionnaire, that is, “Today, others made me feel

like I'm an exaggerator." The second item was adapted from the subscale "lack of understanding" of the I\*3: "Today, others did not take my complaints seriously." A third item, "Today, others avoided me," was included to assess perceived stigmatizing behavior of others. A daily perceived stigma score was obtained by averaging the participants' scores on the 3 items. The latter item was developed by the research based upon consultation of several questionnaires (including the Stigma Scale of Chronic Illness<sup>56</sup>) and experts in the field. The score was reliable (within-person  $\alpha=0.71$ ; between-person  $\alpha=0.96$ ).

### Data Handling and Analysis Plan

#### Descriptive Analyses

Descriptive analyses and internal consistency of the pain intensity and disability score extracted from the GCPS were conducted in SPSS (v.26; IBM Statistics). First, we investigated sociodemographic data (ie, sex, age, nationality, marital status, work status, and education) for each group and we examined whether the 3 groups (FM, RA, and the dual diagnosis group) differed on each of these variables.

Furthermore, we examined whether the 3 groups of participants differed regarding the level of reported pain duration.

#### Diary Analyses

A total of 2504 complete end-of-day observations were obtained, that is, 90.3% of the total potential of 2772 (198 individuals $\times$ 14 d) observations. Following Nezelek,<sup>57</sup> we deleted records that were completed after 10 AM the next morning and before 4 PM the same day. Diary data of 2493 completed observations remained in the final analyses (ie, 99.6% of observed complete end-of-day observations and 89.9% of total potential observations).

Using the lme4 package in R linear mixed models with within and between effects of daily pain and perceived stigma were fitted.<sup>58</sup> The diary data consisted of 2 levels, that is, the within-person (ie, daily) variables on level 1, and the between-person variables on level 2. Scores of daily pain and daily perceived stigma were group-mean centered to determine the within-subjects effects (ie, the mean of the individual's daily scores on pain and perceived stigma was subtracted from each individual's daily score for pain and perceived stigma). The means of the individual's daily scores on pain and perceived stigma were used as the between-

TABLE 1. Sociodemographic Characteristics

	FM, M (SD) or N (%)	RA, M (SD) or N (%)	FM and RA, M (SD) or N (%)	$\chi^2$ or F
Sex				3.52
Female	72 (91.1%)	69 (80.2%)	29 (87.9%)	
Male	7 (8.9%)	17 (19.8%)	4 (12.1%)	
Age	51.94 (8.61)	56.60 (13.02)	58.19 (9.15)	75.94***
Nationality				1.77
Belgium	78 (98.7%)	83 (96.5%)	32 (97%)	
Other	1 (1.3%)	3 (3.5%)	1 (3%)	
Marital status				5.32
Married or cohabiting	46 (58.2%)	61 (70.9%)	21 (63.6%)	
In a relationship	4 (5.1%)	4 (4.7%)	0	
Single	29 (36.7%)	20 (23.3%)	11 (12.8%)	
Missing	0	1 (1.2%)	2 (2.3%)	
Work status				34.20**
Student	1 (1.3%)	0	0	
Working	10 (12.7%)	21 (24.4%)	6 (18.2%)	
Housewife/man	3 (3.8%)	6 (7%)	0	
Unemployed	5 (6.3%)	4 (4.7%)	2 (6.1%)	
Full or partial allowance	52 (65.8%)	26 (30.2%)	17 (51.5%)	
Retired	7 (8.9%)	26 (30.2%)	7 (21.2%)	
Missing	1 (1.3%)	3 (3.5%)	1 (3%)	
Education				6.85
Primary school	2 (2.5%)	3 (3.5%)	1 (3%)	
Lower secondary	16 (20.3%)	13 (15.1%)	2 (6.1%)	
Higher secondary	27 (34.2%)	21 (24.4%)	13 (39.4%)	
Higher education	34 (43%)	48 (55.8%)	15 (45.5%)	
Missing	0	1 (1.1%)	2 (6.1%)	
Pain duration (mo)	200.17 (123.58)	158.52 (138.55)	228.20 (140.50)	48.74***
Pain grades				44.97***
Pain grade 0	0	0	0	
Pain grade I	2 (2.5%)	19 (22.1%)	0	
Pain grade II	3 (3.8%)	17 (21.5%)	6 (18.2%)	
Pain grade III	15 (19%)	23 (26.7%)	8 (9.3%)	
Pain grade IV	58 (73.4%)	25 (29.1%)	19 (57.6%)	
Missing	1 (1.3%)	2 (2.3%)	0	

Pain duration expressed in months.

FM indicates fibromyalgia; grade 0, no pain; grade I, low intensity and low disability; grade II, high intensity and low disability; grade III, moderate disability, regardless of pain intensity; grade IV, high disability, regardless of pain intensity; M, mean; RA, rheumatoid arthritis.

\* $P < 0.05$ .

\*\* $P \leq 0.01$ .

\*\*\* $P \leq 0.001$ .

**TABLE 2.** Means and SD of Daily Measures

	FM, M (SD)	RA, M (SD)	FM and RA, M (SD)
Pain intensity (0-10)	6.42 (1.34)	4.44 (2.02)	5.89 (1.46)
Disability (0-10)	5.10 (2.43)	3.89 (2.82)	5.63 (2.44)
Physical activity (0-10)	4.79 (2.76)	5.61 (2.91)	4.61 (2.37)
Plans (0-10)	4.34 (3.16)	5.94 (3.04)	4.31 (2.8)
Positive affect (0-30)	12.20 (7.47)	16.22 (7.92)	12.08 (6.77)
Negative affect (0-72)	18.04 (17.03)	10.09 (13.14)	18.95 (15.8)
Self-esteem (1-16)	8.05 (2.75)	9.12 (2.41)	8.06 (2.37)
Isolation (0-10)	2.94 (3.35)	1.51 (2.60)	3.26 (3.16)
Contact (0-10)	5.11 (3.44)	6.51 (3.21)	5.31 (2.96)
Perceived stigma (0-10)	0.89 (1.70)	0.56 (1.41)	1.17 (1.92)

FM indicates fibromyalgia; RA, rheumatoid arthritis.

subjects effects of daily pain and perceived stigma respectively.

First, linear mixed model analyses were fitted to examine the difference between participants with FM, participants with RA, and participants with both diagnoses regarding their daily pain intensity, physical well-being, psychological well-being, social well-being, and perceived stigma. Because analysis of variance (ANOVA) and *t* tests showed that the 3 groups differed regarding age, pain duration, and daily pain (see the Descriptive characteristics section), we further examined whether the group differences remained significant when these possible confounding variables were included in the models. Finally, we investigated whether daily perceived stigma was related to lower physical, psychological, and social well-being. Linear mixed models were fitted with age, pain duration, and within (level 1) and between (level 2) subjects effects of daily pain intensity included as control variables (Table 3). Statistical significance level was set at 5% and 95% confidence intervals (CIs) are reported.

**TABLE 3.** Group Differences in Daily Measures

	FM vs. RA		FM vs. FM and RA		RA vs. FM and RA	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
Pain intensity	1.99***	0.26	0.53	0.35	-1.46	0.35
Disability	2.05***†	0.30	0.34	0.39	-1.72***†	0.39
Physical activity	-0.78***†	0.27	0.21	0.36	0.99***†	0.35
Plans	-1.68***	0.31	-0.04	0.42	1.64***	0.42
Positive affect	-4.03***†	0.93	0.08	1.27	4.11***†	1.26
Negative affect	7.92***†	1.91	-0.66	2.60	-8.58**	2.59
Self-esteem	-1.08***†	0.31	-0.05	0.42	1.03*†	0.42
Isolation	1.47***	0.28	-0.24	0.28	-1.70***	0.28
Contact	-1.44***	0.31	-0.24	0.42	1.20***†	0.41
Perceived stigma	0.35	0.19	-0.25	0.25	-0.59*	0.24

†Effect was nonsignificant after controlling for age, pain duration, and daily pain.

*B* indicates estimate; FM, fibromyalgia; RA, rheumatoid arthritis.

\**P* < 0.05.

\*\**P* ≤ 0.01.

\*\*\**P* ≤ 0.001.

## RESULTS

### Descriptive Characteristics

As indicated in Table 1, 85.9% of the participants in the final sample (*N* = 198) were female, 97.5% had a Belgian nationality (4 participants had a Dutch nationality and 1 participant had a German nationality) and 30.3% was single. The mean age of the participants was 54.9 years (*SD* = 11.13; range: 19 to 86). Further, half of the participants had had an education beyond the age of 18, and 18.7% was working (full-time or part-time). Participants with FM did not differ significantly from participants with RA or participants with both diagnoses with regard to sex ( $\chi^2_{(2)} = 3.52, P = 0.172$ ), nationality ( $\chi^2_{(4)} = 1.77, P = 0.777$ ), marital status ( $\chi^2_{(6)} = 5.32, P = 0.504$ ), or education ( $\chi^2_{(6)} = 6.85, P = 0.335$ ). In contrast, the 3 groups differed significantly from each other on work status ( $\chi^2_{(16)} = 34.20, P = 0.005$ ), indicating a greater number of participants with RA who are working and a smaller number of participants with RA who receive an invalidity allowance as compared with participants with FM and participants with both diagnoses. Furthermore, a one-way ANOVA with age as dependent variable showed a significant difference between the 3 groups ( $F_{(2)} = 75.94, P < 0.001$ ), indicating that participants with FM (*M* = 51.94, *SD* = 8.61) were younger than participants with RA (*M* = 56.60, *SD* = 13.02), and participants with both diagnoses (*M* = 58.19, *SD* = 9.15). Next, a one-way ANOVA with pain duration as the dependent variable showed a significant difference between the groups ( $F_{(2)} = 48.74, P < 0.001$ ), indicating that individuals with RA (*M* = 158.52, *SD* = 138.55) reported a shorter period of pain symptoms (in months) as compared with individuals with FM (*M* = 200.17, *SD* = 123.58), and individuals with both diagnoses (*M* = 228.10, *SD* = 140.50). Finally, results also showed a significant difference regarding the distribution of pain grades between the 3 groups ( $\chi^2_{(6)} = 44.97, P < 0.001$ ) (see Table 1 for an overview).

### Group Differences in Pain Intensity and Physical, Psychological, and Social Well-being

All results regarding the comparison of well-being between the 3 groups can be found in Tables 2 and 3. In general, scores in the dual diagnosis group were highly similar to the scores in the FM group with regard to all daily measures. Differences between the RA and FM group are discussed below.

#### Pain Intensity

Participants with FM experienced, on a daily basis, a higher pain intensity than participants with RA (*B* = 1.99, *SE* = 0.26, *t*<sub>(195)</sub> = 7.50, *CI*: 1.46-2.51, *P* < 0.001) (Tables 2, 3).

#### Physical Well-being

Participants with FM reported, on a daily basis, more disability than participants with RA (*B* = 2.05, *SE* = 0.30, *t*<sub>(194)</sub> = 6.95, *CI*: 1.47-2.64, *P* < 0.001) (Tables 2, 3).

Participants with FM reported, on a daily basis, less physical activity than participants with RA (*B* = -0.78, *SE* = 0.27, *t*<sub>(192)</sub> = -2.92, *CI*: -1.30 to -0.25, *P* < 0.01) (Tables 2, 3).

After controlling for age, pain duration, and daily pain intensity differences between participants with RA and FM did not remain significant (Tables 2, 3).

**TABLE 4.** Effects of Perceived Stigma on Daily Outcome Measures Controlled for Age, Pain Duration, and Daily Pain

	Perceived Stigma			
	Within-subjects		Between-subjects	
	<i>B (SE)</i>	<i>t (df)</i>	<i>B (SE)</i>	<i>t (df)</i>
Disability	0.07* (0.03)	2.50 (2042)	0.15* (0.06)	2.42 (172)
Positive affect	-0.22* (0.09)	-2.38 (1972)	-1.24*** (0.37)	-3.35 (166)
Negative affect	1.06*** (0.19)	5.66 (1973)	5.39*** (0.64)	8.44 (168)
Physical activity	-0.06 (0.04)	-1.26 (2019)	0.005 (0.11)	0.04 (167)
Isolation	0.05 (0.05)	0.98 (2024)	0.48*** (0.11)	4.46 (167)
Contact	-0.03 (0.05)	-0.62 (2022)	-0.34** (0.13)	-2.65 (169)
Plans	-0.07 (0.05)	-1.51 (2022)	-0.22 (0.12)	-1.84 (171)
Self-esteem	-0.17*** (0.03)	-5.71 (2026)	-0.69*** (0.05)	4.87 (168)

*B* indicates estimate; *df*, degrees of freedom.

\**P* < 0.05.

\*\**P* ≤ 0.01.

\*\*\**P* ≤ 0.001.

### Psychological Well-being

Participants with FM reported, on a daily basis, less positive affect than participants with RA (*B* = -4.03, *SE* = 0.93, *t*<sub>(189)</sub> = -4.32, *CI*: -5.87 to -2.19, *P* < 0.001). Participants with FM reported, on a daily basis, more negative affect in comparison with participants with RA (*B* = 7.92, *SE* = 1.91, *t*<sub>(199)</sub> = 4.14, *CI*: 4.15 to 11.69, *P* < 0.001) (Tables 2, 3).

Furthermore, individuals with FM reported lower daily self-esteem as compared with individuals with RA (*B* = -1.08, *SE* = 0.31, *t*<sub>(194)</sub> = -3.42, *CI*: -1.70 to -0.45, *P* < 0.001) (Tables 2, 3).

In line with the previous results, participants with FM reported, on a daily basis, also less completed plans than participants with RA (*B* = -1.68, *SE* = 0.31, *t*<sub>(194)</sub> = -5.36, *CI*: -2.30 to -1.06, *P* < 0.001) (Tables 2, 3).

After controlling for age, pain duration, and daily pain intensity differences remained significant for completed plans (Tables 2, 3).

### Social Well-being

Participants with FM reported, on a daily basis, more isolation than participants with RA (*B* = 1.47, *SE* = 0.28, *t*<sub>(192)</sub> = 5.15, *CI*: 0.90-2.03, *P* < 0.001) (Tables 2, 3).

Finally, participants with FM also reported, on a daily basis, less searched contact with other people than participants with RA (*B* = -1.44, *SE* = 0.31, *t*<sub>(194)</sub> = -4.61, *CI*: -2.05 to -0.82, *P* < 0.001) (Tables 2, 3).

After controlling for age, pain duration, and daily pain intensity, differences for daily well-being between individuals with FM and individuals with RA remained significant for isolation and searched social contact (Tables 2, 3).

### Group Differences in Daily Perceived Stigma

Intraclass correlation revealed a substantial variance in perceived stigma within individuals (52%), and also between individuals (48%). The between subject variability did not significantly differ between the 3 groups. In contrast, the within subject variability in perceived daily stigma was significantly greater in the dual diagnosis group compared with the other 2 groups.

With regard to our second research question (Tables 2, 3), the findings suggest that participants with FM reported more daily stigmatizing reactions in comparison with participants with RA (*B* = 0.35, *SE* = 0.19, *CI*: -0.02 to 0.71,

*t*<sub>(195)</sub> = 1.87, *P* = 0.06); though, the difference just failed to reach significance. Results showed no significant difference between individuals with FM and individuals with both diagnoses (*B* = -0.25, *SE* = 0.25, *CI*: -0.73 to 0.24, *t*<sub>(195)</sub> = -1.00, *P* = 0.32). The dual diagnosis group reported significantly higher levels of daily perceived stigma than the RA group (*B* = -0.59, *SE* = 0.24, *CI*: -1.07 to -0.11, *t*<sub>(196)</sub> = -2.43, *P* = 0.02).

### Is Perceived Stigma Associated With Lower Physical, Psychological, and Social Well-being on a Daily Basis?

Within-subject and between-subject effects of daily perceived stigma were added in the linear mixed models (reported in the Group differences in Pain Intensity and Physical, Psychological, and Social Well-being section) to examine whether perceived stigma was related to daily physical, psychological, and social well-being after controlling for age, pain duration, and within-subjects and between-subjects effects of daily pain (Table 4).

Results indicated that increased levels of perceived stigma were related to decreased levels of positive affect (within: *B* = -0.22, *SE* = 0.09, *t*<sub>(1972)</sub> = -2.38, *P* < 0.05; between: *B* = -1.22, *SE* = 0.37, *t*<sub>(165)</sub> = -3.32, *P* < 0.01) and self-esteem (within: *B* = -0.18, *SE* = 0.03, *t*<sub>(2026)</sub> = -5.71, *P* < 0.001; between: *B* = -0.69, *SE* = 0.11, *t*<sub>(168)</sub> = -6.28, *P* < 0.001), and increased levels of negative affect (within: *B* = 1.06, *SE* = 0.19, *t*<sub>(1973)</sub> = 5.66, *P* < 0.001; between: *B* = 5.38, *SE* = 0.64, *t*<sub>(167)</sub> = 8.40, *P* < 0.001) and disability (within: *B* = 0.07, *SE* = 0.03, *t*<sub>(2042)</sub> = 2.48, *P* < 0.05; between: *B* = 0.15, *SE* = 0.06, *t*<sub>(171)</sub> = 2.42, *P* < 0.05), at the within-subjects level and the between-subjects level. This suggests on the one hand that daily variation in perceived stigma is related to variation in levels of positive affect, negative affect, disability, and self-esteem within an individual, and on the other hand that variation between individuals in the overall level (across days) of perceived stigma is related to differences between individuals in the overall level of positive affect, negative affect, disability, and self-esteem.

Furthermore, results indicated that increased levels of perceived stigma were related to increased levels of isolation (*B* = 0.48, *SE* = 0.11, *t*<sub>(167)</sub> = 4.43, *P* < 0.001), and decreased levels of searched social contact (*B* = -0.34, *SE* = 0.13, *t*<sub>(168)</sub> = -2.64, *P* < 0.01) at the between-subjects level. This means that variation between individuals in the overall level

of perceived stigma was related to differences between individuals in the overall level of isolation and searched contact. Results showed no effect of perceived stigma on physical activity and completion of plans (within-subjects and between-subjects level), and on isolation and searched contact (within-subjects level).

## DISCUSSION

The present study aimed to elucidate potential differences in daily well-being between ICPs associated with clearly defined symptoms and pathophysiology (RA) and ICPs that is less well understood in terms of symptoms and pathophysiology (FM) using a daily diary methodology. Next, the study aimed to examine differences in daily perceived stigmatization between the 2 groups. Finally, we investigated the association between daily perceived stigmatization and daily well-being. Results can be readily summarized. Compared with individuals with RA, individuals with FM reported worse daily well-being. Furthermore, results suggested more daily stigmatization in individuals with FM than in individuals with RA. Finally, increased levels of perceived stigma were in general associated with decreased levels of well-being.

The finding that individuals with FM reported lower levels of well-being than individuals with RA is consistent with findings of previous studies.<sup>3-6,12,40</sup> One potential explanation might be that a diagnosis of FM comes along with uncertainty as the condition lacks a clear etiology.<sup>59</sup> Uncertainty is aversive for most people,<sup>60</sup> subsequently this condition may be related to worse well-being as compared with conditions with a clear pathology. However, after controlling for age, pain duration, and daily pain only differences regarding social well-being and completion of plans remained significant. Subsequently, the question arises whether individuals with RA and FM differ primarily on features of social well-being, which could be examined in further research. Absence of well understood pathophysiology could lead to suspicion about the genuineness of the pain complaints.<sup>15-18</sup> Consequently, individuals with FM may hide their condition from others and avoid contact in order to protect themselves from experiences of disbelief,<sup>61</sup> which may negatively impact their social well-being.

As previous studies and our results show worse well-being in individuals with FM as compared with individuals with RA, it appears important to examine factors related to these differences. For this reason, the present study also shed light on differences in daily perceived stigma between individuals with RA and FM. Absence of clearly defined symptoms and pathophysiology for chronic pain may elicit stigmatizing and invalidating responses, which in turn could be related to worse well-being.<sup>17,18,21</sup> The current results suggested more perceived daily stigmatizing reactions in FM, but the effect just failed to reach significance. This suggestion is in line with a previous study, in which individuals with FM reported significantly more invalidating reactions from family, medical professionals, colleagues, and social services as compared with individuals with RA.<sup>38</sup> As symptoms and pathophysiology are less well understood in FM, people could perceive individuals with FM as personally responsible for their condition, and therefore invalidate their symptoms because of lack of understanding,<sup>38</sup> which ICPs may experience as highly stigmatizing. It has been argued before that ICPs reporting higher levels of pain severity or a severe impact of pain on their well-being,

relative to physical pathology, appear particularly vulnerable to stigmatization.<sup>28</sup> In the current study participants with FM reported elevated daily pain intensity and worse daily well-being as compared with individuals with RA, which is in correspondence with the latter statement. However, another study did not find a difference between FM and RA with regard to perceived stigma,<sup>62</sup> so further examination of stigma in individuals with well understood symptoms and pathophysiology and individuals with less well understood symptoms and pathophysiology is required. A possible explanation for the insignificant association between diagnosis and perceived stigma could be that the current stigma items were not sufficiently sensitive to capture differences in stigma between the 2 groups, and as such to differentiate between stigmatization related to chronic pain in general and stigma related to pain that is less well understood in terms of symptoms and pathophysiology. This is the first study that attempts to capture stigma experiences in ICPs on a daily basis. Up till now, it is therefore not known whether and how stigma can be measured in daily diary research. Subsequently, these items should be further tested in future research. For example, qualitative research may provide more insight into the way patients complete these diary items in order to refine the items and increase their sensitivity. Another possible explanation for the insignificant association between diagnosis and stigma is that the latter might not be a transient daily experience, but something that builds up over time and reflects a more robust perception of other's behavior and thoughts. Researchers indicated that salient stigmatizing events or experiences are probably better remembered by stigmatized individuals.<sup>63</sup> Also, when questioning people about stigmatizing experiences these salient events may form the centerpiece of the recalled experiences as the effects of the salient experience may linger over time. As such, daily diary methodologies may need other types of questions to capture salient stigmatizing events, for instance open-ended questions so that the reporting of stigmatizing events is not limited to predefined events. Another possibility is the use of Ecological Momentary Assessment with event-based reporting of stigmatizing events at periodic intervals during the day.

Findings show no significant differences between the dual diagnosis and FM group regarding daily well-being. If replicated, this could mean that having a pain condition that is less well understood in terms of symptoms and pathophysiology is detrimental for ICPs' well-being, regardless of the presence of other clearly defined symptoms. Further, our findings indicated better daily well-being in individuals with RA as compared with individuals with both diagnoses. A previous study found substantially more comorbid FM in RA patients who had more severe symptoms in comparison with RA patients with less severe symptoms.<sup>64</sup> This could explain why the dual diagnosis group reported worse well-being than the RA group, as the dual diagnosis group possibly experienced more severe pain complaints, which may be related to worse well-being. Furthermore, findings showed a higher level of perceived stigma in the dual diagnosis group as compared with the RA group. Again, the dual diagnosis group did not differ from the FM group as concerns daily perceived stigma.

Finally, the current study partially indicated that daily perceived stigmatization is related to worse daily well-being. This is in line with the Stigma Mechanisms in Health Disparities Model,<sup>39</sup> which ascribes poorer physical and mental

health to individuals who experience stigmatization. The current study is the first to approach the link between stigma and well-being in ICPs using daily diaries. Increased daily levels of perceived stigma were associated with decreased daily levels of positive affect and self-esteem, and increased daily levels of negative affect and disability. In addition, increased overall levels of perceived stigma were related to increased overall levels of disability, negative affect, isolation, and decreased overall levels of positive affect, self-esteem, and searched social contact. This accords with previous research which showed that perceived invalidation was associated with lower psychosocial and physical well-being among individuals with FM or RA.<sup>38,40</sup> In addition, previous research also found a relationship between internalized stigma and self-esteem, self-efficacy, catastrophizing, and sense of personal control,<sup>41</sup> and an association between stigma on the one hand and depression and disability on the other hand.<sup>42</sup> Moreover, abundant research showed a negative relation between stigmatization and well-being in other stigmatized groups (eg, HIV<sup>65</sup>, depression<sup>66</sup>). In the current study only daily physical activity and completion of plans were not associated with perceived stigmatization. This may be because of the fact that these two variables show a strong association with daily pain intensity, wherefore no residual variability in physical activity and completion of plans is related to variability in perceived stigmatization after controlling for pain intensity.

The Stigma Mechanisms in Health Disparities model illustrates that psychological stress may play an important role in explaining the relation between stigma and well-being.<sup>39</sup> Experiences of stigma can be very stressful, therefore stress is assumed to be one of the primary mediating processes by which stigma influences stigmatized individuals' well-being.<sup>39,67</sup> Moreover, ICPs are more susceptible to experience stress and are more vulnerable for the negative consequences of stress.<sup>68</sup> Further research could focus upon factors explaining the relationship between stigma and well-being, such as perceived stress.

The findings of the present study may have some clinical implications. Stigmatization may occur to the extent that observers think that ICPs are malingering, which may encourage observers to avoid contact and communication with these ICPs, which in turn could negatively impact ICPs' well-being.<sup>19</sup> Also, people adhering to a biomedical illness model might experience difficulties in communicating with ICPs, because their beliefs do not fit with the biopsychosocial nature of pain. Clearly, it appears highly important to focus on interventions targeted at diminishing stigma toward ICPs. For instance, interventions could first educate the public on pain and its symptoms, raise awareness about possible stigmatization against ICPs, and encourage the public to resist against negative evaluations of ICPs. Also, personal contact with the stigmatized group and perspective taking have been shown to be effective techniques to reduce stigma.<sup>69-71</sup> Intervention studies targeted at diminishing stigma in the general population have been shown to be effective in the context of mental and several other conditions illness (eg, mental illness<sup>72</sup>, HIV,<sup>73</sup> dementia).<sup>74</sup> However, not all individuals are equally affected by stigmatization, some ICPs show resilience against these responses.<sup>22</sup> So, clinical practice could aim at raising resilience and diminishing self-stigma in ICPs, which often mediates the detrimental influence of perceived stigma on ICPs' well-being.<sup>75</sup> Self-stigma can be defined as a stigmatized person's awareness and agreement with stereotypes describing the stigmatized group and the acknowledgment of discrimination.<sup>76</sup> Therapies such as Acceptance and

Commitment Therapy could focus upon decreasing the impact of perceived and self-stigma related thoughts and feelings on their daily functioning (eg, by helping ICPs to develop so-called defusion skills) and on encouraging ICPs to engage in meaningful activities despite the presence of stigmatization.<sup>77</sup>

A major strength of the current diary design is that both within-subject effects and between-subject effects were included in the analyses, which provide insight in daily variations and in variations in overall levels of stigma and well-being. Some indications for future research may be provided, some of which are related to limitations of the current study. First, the current study is based upon self-reports of ICPs, which are often subjected to social desirability. For instance, it is possible that participants reported less stigmatizing responses because they felt uncomfortable and did not want to put their personal environment in an unfavorable light. These dynamics could be examined in future research. Also, the sample was predominantly female and caution is needed when generalizing the current findings to men with chronic pain. However, a meta-analysis showed that the prevalence of chronic pain in women is double the prevalence in men,<sup>78</sup> implying that our sample may be representative for people experiencing chronic pain. No research exists regarding differences in perception of stigma between men and women with chronic pain. This could be addressed in future research. Second, future research could investigate whether some categories of significant people (family, friends, colleagues, health care practitioners, etc.) in ICPs' social networks stigmatize more than others or have differential impact upon ICPs' well-being. Third, it might be that participants, who did not report stigmatizing responses, have not seen anyone or did not talk about their condition with others, which implies that stigmatizing responses were less likely to occur. Therefore, future studies could explore the dynamic relationship between stigma and social isolation. Fourth, the contribution of social support as a buffer against the negative outcomes associated with stigmatizing responses, must be further investigated. Fifth, a limitation of the current study is the exploratory nature of this study. As it was difficult to predict effect sizes a priori, we did not perform a sample size calculation before the start of the study. We relied on a convenience sample that resulted in 2 relatively large groups (FM and RA) and one small group (the combination). Given the longitudinal nature of the study (with 14 assessments), the study was sufficiently powered to detect clinically meaningful differences between FM and RA, but not with the dual diagnosis group. With 75 participants per group and 14 assessments per participants (assuming an intracluster correlation of 0.30), the study had about 80% power to detect a Cohen  $d=0.25$  at the 5% significance level. Furthermore, we did not perform any corrections for multiple testing, in line with recommendations of Perneger<sup>79</sup> and Nakawaga.<sup>80</sup> The robustness of the findings in the different outcome measures is, however, reassuring. The findings of this study await replication in future research. Sixth, the choice of the diary items was made based upon expert opinion. Despite this careful approach, we do, however, acknowledge that items were not systematically piloted in a patient sample, which could be done in future research. Though, the diary items for daily pain intensity, disability, positive, and negative affect had been used before in other chronic pain studies of our research group.<sup>50,53</sup> The diary item regarding completion of plans did, however, not take into account whether these plans were meaningful for participants. Although this could be considered implicitly, future research should make this explicit as it is of crucial importance for people's well-being.<sup>81,82</sup> Also, the searched social contact item

could be optimized in future research as it is not a typical item measuring social well-being. However, it is instructive because experiences of stigmatization may be related to not seeking contact with others in order to avoid possible stigmatization. Finally, further studies could focus upon factors that contribute to resilience against stigmatizing responses. These factors could be informing for future interventions and management strategies to empower ICPs, which are also indirectly lowering the social and economic burden chronic pain has on families and communities at large.

## CONCLUSION

In conclusion, our findings provide insights into differences in daily well-being and perceived stigma between individuals with a pain condition associated with less well understood symptoms and pathophysiology versus a pain condition with more clearly defined symptoms and pathophysiology, and into the contribution of stigmatization toward ICPs' daily well-being. This was the first study to examine these dynamics on a daily basis. We provided further support to argue that well-being is worse in individuals with FM as compared with individuals with RA. Furthermore, we extended previous research by showing that perceived stigma is unfavorably related to ICPs' well-being on a daily basis. Upon replication, our findings may be informative for interventions focusing on diminishing stigma toward ICPs and on empowering ICPs to deal with stigmatizing responses.

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