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# Illness perceptions in patients with fibromyalgia

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ABSTRACT

*Objective:* Former studies in chronic diseases showed the importance of patients' beliefs and perceptions. The Revised Illness Perception Questionnaire was developed to assess these illness perceptions. Our goal was to investigate psychometric properties of the IPQ-R for Fibromyalgia Dutch language version (IPQ-R FM-Dlv) and to describe illness perceptions of participants with FM.
*Methods:* 196 patients completed the IPQ-R FM-Dlv. Internal consistency, domain structure and inter domain correlations were calculated and compared to the IPQ-R English language version. Scores were compared with chronic fatigue syndrome (CFS), rheumatoid arthritis (RA), and coronary heart disease (CHD).
*Results:* Most psychometric properties were comparable to those of the original IPQ-R. Participants showed a lack of understanding of their illness, expected their FM to be chronic and to have a lot of negative consequences on functioning. In 17 out of 24 domains significant differences were found between FM and CFS, RA, and CHD patients.
*Conclusion:* The IPQ-R FM-Dlv showed acceptable psychometric properties, although some aspects need closer examination. Illness perceptions of FM patients on the Dutch questionnaire were non-comparable to CFS, RA, and CHD patients on the English questionnaire.
*Practice implications:* The IPQ-R FM-Dlv can be used to assess illness perceptions of Dutch FM patients.


## 1. Introduction

Fibromyalgia is characterized by widespread musculoskeletal pain of at least three months' duration, fatigue, poor sleep and tenderness on palpation in at least 11 of 18 specific tender point sites [1]. The etiology of fibromyalgia syndrome is still unknown [2–4]. Its' diagnosis is primarily based on exclusion, established only after other causes of joint or muscle pain are ruled out [4]. For the majority of patients the localized long-standing muscle pain gradually spreads to multiple sites and becomes continuous. The prevalence of fibromyalgia in the Western world most likely ranges from 2 to 3% with particularly high prevalence rates in women and in age groups of 55–64 years [3,5–7]. Fibromyalgia is related to a poor quality of life and sustained disability [8–12].

For fibromyalgia some risk factors are known; female gender, low level of income, living in a socially comprised housing area, depression, anxiety and panic disorder [3,13–16]. Beliefs or perceptions about pain may influence experienced pain intensity [17–19]. Several studies found that patients who have catastrophical illness perceptions experience more pain, feel more disabled by their pain, suffer more psychological distress and have poor outcomes of pain treatment [20–24]. Possible explanations for this relation range from an increased attention to pain and heightened emotional responses to pain to direct amplification of the central nervous system's processing of pain causing inactivity which might result in diminished function and increased pain [21,22,24].

Spinhoven et al. [23] found that a reduction of negative illness perceptions mediated the reduction of depression and reduced pain behavior in patients with chronic low back pain. Another study found better treatment outcome in patients with more positive illness perceptions like believing to have control over pain, believing that one is not necessarily disabled by fibromyalgia and

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that pain is not necessarily a sign of damage, compared to patients with negative illness perceptions [25].

To analyze illness perceptions, Leventhal et al. [26] developed a self-regulatory model describing how patients construct their own representations of illness perceptions. The five core components of this model are beliefs about the etiology of the illness, its symptoms and label, the personal consequences of the illness, how long it will last, and the extent to which the illness is amenable to control by the patient or to cure [27,28]. The Illness Perception Questionnaire (IPQ) was developed to provide a quantitative assessment of these representations of illness perceptions. A few years later a revised version of the questionnaire was constructed: the Revised Illness Perception Questionnaire (IPQ-R), in which some items were restructured and new items were added [28]. Several studies provide support for the structural relations between the five components of illness representation described by Leventhal, and for the expected links between illness perceptions and a range of psychological outcomes, and between illness perceptions and functional adaptation [29–31]. The IPQ-R has been described in patients with chronic diseases such as coronary heart disease (CHD), chronic fatigue syndrome (CFS), and rheumatoid arthritis (RA) [32,33].

In order for the IPQ-R to be useful in patients with fibromyalgia, information about the psychometric properties in this patient group is essential. Therefore, the purpose of this study was to describe the psychometric properties of the Revised Illness Perception Questionnaire for Fibromyalgia Dutch language version (IPQ-R FM-Dlv), compared to the English language version, and to describe illness perceptions in patients with fibromyalgia using the IPQ-R FM-Dlv. For a better understanding of the illness perceptions in patients with FM, the illness perceptions of our patient group will be compared to illness perceptions in patients with other chronic conditions.

## 2. Methods

### 2.1. Participants

Participants were recruited from a physical therapy treatment center. The center provided a list of all fibromyalgia patients that had visited the center at least once in the last 15 years. Participants were selected from this list according to the following criteria: diagnosed with fibromyalgia according to the ACR criteria, age $\geq$18 years and experiencing pain from FM at the time they completed the survey. A total of 322 fibromyalgia patients were eligible to the study. These patients were sent a letter containing information about the study, in which they were asked to participate, and asked for informed consent. Two hundred fifty patients gave informed consent, they received the questionnaire that could be returned by mail. Finally 196 patients (response rate 61%) returned the questionnaire and were included in the study.

### 2.2. Questionnaire

The questionnaire consists of two parts. The first part asks for general information like gender, age and marital status and information about the duration of fibromyalgia and medication use. Also a Visual Analogue Scale (VAS) is used to rate perceived pain, perceived stiffness and perceived fatigue at the moment. The second part consists of the IPQ-R FM-Dlv.

The original IPQ-R English language version consists of nine domains. The first domain is the illness identity scale, which consists of 14 commonly experienced symptoms. Subjects are asked to rate whether or not they have experienced each symptom since their illness. They are then asked whether or not they believe the symptom to be specifically related to their illness. The score on the identity domain is the sum of the yes-rated items on this second question. The following seven domains of the IPQ-R are scored on a 5-point Likert type scale (1–5): strongly disagree, disagree, neither agree nor disagree, agree and strongly agree. These domains include timeline acute/chronic (perceptions of likely chronic duration of the health problems); timeline cyclical (perceptions of likely variability of the health problems over time); consequences (beliefs about illness severity and impact on physical, social and psychological functioning); personal control (belief in personal control over the illness); treatment control (belief in cure through treatment); illness coherence (how much patients comprehend or understand their illness); and emotional representations (perception of negative emotions generated by the illness) (see Table 2). High scores on the identity, timeline, consequences, and cyclical domains represent a negative view of the illness. High scores on the personal control, treatment control and coherence domains, represent positive beliefs about the controllability of the illness and a personal understanding of the condition. Finally, the causal domain is presented as a separate section. It consists of 18 attributional items, which are scored on the same Likert type scale. The causal domain can be divided into 4 sub domains: psychological attributions, risk factors, immunity and accident or chance [28].

The IPQ-R English language version was shown to give good internal reliability of the domains, good short and longer term retest reliability and sound discriminant, known group and predictive validity in a study population consisting of patients with a variety of diseases (asthma, diabetes, rheumatoid arthritis, acute pain, chronic pain, myocardial infarction, multiple sclerosis (all from Auckland, New Zealand) and HIV (from Brighton, United Kingdom)) [28].

For constructing the IPQ-R FM-Dlv Moss-Morris's IPQ-R was adapted by changing 'my illness' into 'my fibromyalgia'. The English language version for rheumatoid arthritis and the Dutch language version for diabetes were used as examples [www.uib.no/ipq].

### 2.3. Statistical analysis

Data were analyzed using SPSS-11.5.0. For the first objective of this study, to assess psychometric properties of the Dutch language version of the IPQ-R for fibromyalgia, internal consistency, domain structure and inter domain correlations were calculated. To express the internal consistency of the different items in the domains of the IPQ-R FM-Dlv, Cronbach's alphas were calculated. Cronbach's alpha expresses the association between the different items in a certain domain. A Cronbach's alpha above 0.70 is considered to be acceptable for the use of questionnaires on group level [34].

The Multiple Group Method (MGM) [35], a simple type of confirmatory factor analysis, was used to validate whether the data supported the categorization of items into the domains identified for the original English language version of the IPQ-R. In the MGM, domain scores were created by taking sums of the items that were a priori assigned to the domains. Next, correlations were computed between the items and the domains of the IPQ-R. For items included in a domain, the correlation coefficients were corrected for "self-correlation", that is, the fact that items automatically correlate high with components in which they take part. Also a correction for test-length was included. Finally, we verified that the items indeed correlated strongest with the domain to which they were assigned to on theoretical grounds. It was assumed that factor structures are supported when items correlated strongest with the domain they were assigned to in the original version of

the questionnaire. This MGM was performed twice; first for the 38 items in the 'beliefs domains' and second for the items in the four attributional domains of the questionnaire.

Validity of the range of symptoms included in the Illness identity domain was investigated by assessing the frequencies with which the different symptoms were endorsed as part of patients' illness identity. All the symptoms should at least be endorsed once for acceptable validity [28].

Inter domain correlations were investigated by computing Pearson's correlation coefficients between the domains of the questionnaire. Internal consistency, domain structure and the inter domain correlations of the IPQ-R FM-Dlv were compared to scores of the well-validated IPQ-R English language version in a large mixed patient group.

To describe illness perceptions in Dutch fibromyalgia patients and to compare these with illness perceptions in other patient groups, means and S.E.'s on the different domains for Dutch fibromyalgia patients were calculated and compared to data of studies by Moss-Morris and Chalder [32] and Byrne et al. [33] in chronic fatigue syndrome (CFS), rheumatoid arthritis (RA) and coronary heart disease (CHD). Confidence Intervals for the differences between the means were calculated.

## 3. Results

With a response rate of 61%, a total of 196 patients participated in this study. Due to anonymity of data, information of non-responders was not available.

General characteristics of those participating in this study are shown in Table 1. In this group 64% used medication for their fibromyalgia. All participants experienced pain, fatigue and stiffness from their FM at the time they completed the survey.

For the Illness identity domain the frequencies with which symptoms were endorsed as part of FM were investigated. All symptoms were endorsed by at least 6% of the participants, confirming the validity of the range of symptoms included in the identity domain. Table 2 shows the results on the Illness identity domain of IPQ-R FM.

The internal consistency of the IPQ-R FM-Dlv was calculated and compared to the internal consistency of the IPQ-R English language version, see Table 3. On all domains Cronbach's alpha of the IPQ-R FM are $\geq$0.75. Of the four sub domains within the Causes domain only Psychological attributions presents an alpha >0.70. The sub domain Accident or chance shows a very low internal consistency. All Cronbach's alphas of IPQ-R FM are slightly lower than those of the original IPQ-R.

The factors of the MGM analysis of the 'beliefs' items accounted for 55% of the variance. On the two timeline domains, consequences, and illness coherence domains strongest item correlations are as expected, confirming the a priori allocation of the items in these domains of the IPQ-R FM. Four items have a stronger correlation with one of the other domains of the Dutch IPQ-R than with the domain they were a priori assigned to. However, these four items also correlate relatively strong (but not strongest) with the expected domains (Table 3a).

In the second MGM (Table 3b) the observed variance that is explained by the tested item grouping is 50%. The division of the items in the psychological attributions sub domain and the immunity sub domain of the questionnaire are as expected, the categorization of items in the other two attributional sub domains could not be confirmed.

In the comparison of the inter-relationships between the domains of the IPQ-R FM-Dlv to those of the English language version of the questionnaire similarities but also some differences were found, see Table 4 in which the inter domain correlations for the original English version of the questionnaire in a large sample ($N$ = 711) of eight different illness groups is presented above the diagonal. For example, several correlations in the consequences and treatment control domains and in the attributional domains are identical in the two versions. Nevertheless, in 13 out of 66 cases, correlation coefficients differ more than .20 between the two questionnaires. Only a few strong ($r \geq .50$) correlations were found. Strong correlations in both questionnaires were found for personal control and treatment control, consequences and emotional representations and between psychological and risk factor attributions. The other three strong inter domain correlations in the original version of the questionnaire (between timeline acute/chronic and consequences, between personal control and illness coherence and between treatment control and illness coherence) were moderate or even low in the IPQ-R Dlv.

Most relations between domains of the IPQ-FM are as expected in patients with fibromyalgia (Table 4). The belief that the illness is severe and has a strong impact on psychosocial, economic and physical functioning (consequences) is related to the belief that more symptoms are specifically related to FM (illness identity), a stronger belief in the chronic course of FM (timeline acute/chronic) and to more negative emotions generated by the illness (emotional

**Table 1**
General characteristics of the participants with fibromyalgia

| | Study population |
|---|---|
| Number of participants | 196 |
| Men/women (%) | 12/88 |
| Mean (S.D.) age (years) | 49 (11) |
| Marital status (%) | |
| Married | 65 |
| Unmarried | 28.5 |
| Widow/widower | 2.5 |
| Other | 4 |
| Employment status (%)[a] | |
| Paid work | 46 |
| Household | 36 |
| Unemployed | 8 |
| Sick leave | 2.5 |
| Work disabled[b] | 30 |
| Mean (S.D.) years with symptoms | 15 (10) |
| Mean (S.D.) years diagnosed with FM | 7 (6) |
| Median (min–max) VAS pain at this moment (0–10) | 7 (1–10) |
| Median (min–max) VAS stiffness at this moment (0–10) | 9 (1–10) |
| Median (min–max) VAS fatigue at this moment (0–10) | 9 (1–10) |

[a] Sum > 100% because more than one answer was possible.
[b] >1 year of sickness absenteeism.

**Table 2**
Illness Identity domain of the IPQ-R; 14 commonly experienced symptoms

| | I have experienced this symptom since my fibromyalgia (% of participants answering 'yes') | I perceive this symptom as related to my fibromyalgia (% of participants answering 'yes') |
|---|---|---|
| Fatigue | 94 | 95 |
| Pain | 92 | 90 |
| Stiff joints | 87 | 85 |
| Loss of strength | 78 | 82 |
| Sleep difficulties | 68 | 62 |
| Upset stomach | 63 | 46 |
| Headaches | 54 | 32 |
| Sore eyes | 52 | 25 |
| Dizziness | 44 | 29 |
| Breathlessness | 31 | 11 |
| Nausea | 25 | 12 |
| Wheeziness | 21 | 16 |
| Sore throat | 21 | 6 |
| Weight loss | 15 | 12 |

**Table 3a**
Cronbach's alphas and corrected correlations (Multiple Group Method) of the items in the 'beliefs' domains of IPQ-R FM-Dlv

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. |
|---|---|---|---|---|---|---|---|
| 1. Timeline acute/chronic $\alpha$ = *0.89*, $\alpha$ = **0.80** | | | | | | | |
| My FM will last a short time* | **0.390** | 0.053 | 0.133 | 0.027 | −0.110 | −0.017 | 0.118 |
| My FM is likely to be permanent rather than temporary | **0.511** | 0.035 | 0.159 | 0.121 | −0.042 | 0.044 | 0.044 |
| My FM will last for a long time | **0.417** | 0.067 | 0.128 | 0.012 | −0.067 | 0.082 | 0.034 |
| My FM will pass quickly* | **0.397** | 0.083 | 0.131 | 0.030 | −0.056 | 0.021 | 0.086 |
| I expect to have my FM for the rest of my life | **0.420** | −0.001 | 0.165 | −0.034 | −0.110 | 0.074 | 0.053 |
| My FM will improve in time* | **0.339** | 0.022 | 0.073 | −0.174 | −0.269 | 0.008 | 0.110 |
| 2. Timeline cyclical $\alpha$ = *0.79*, $\alpha$ = **0.75** | | | | | | | |
| The symptoms of my FM change a great deal from day to day | −0.041 | **0.375** | 0.022 | −0.037 | 0.053 | −0.047 | −0.012 |
| My symptoms come and go in cycles | −0.019 | **0.477** | −0.027 | 0.089 | 0.108 | −0.026 | −0.009 |
| My FM is very unpredictable | 0.161 | **0.420** | 0.075 | −0.002 | −0.045 | −0.101 | 0.134 |
| I go through cycles in which my FM gets worse and better | 0.072 | **0.425** | 0.021 | 0.082 | 0.115 | −0.058 | 0.008 |
| 3. Consequences $\alpha$ = *0.84*, $\alpha$ = **0.77** | | | | | | | |
| My FM is a serious condition | *0.211* | 0.031 | **0.313** | −0.077 | −0.116 | −0.104 | *0.261* |
| My FM has major consequences in my life | *0.200* | 0.157 | **0.422** | −0.082 | −0.162 | −0.097 | *0.273* |
| My FM does not have much effect on my life* | *0.213* | −0.048 | **0.381** | −0.005 | −0.039 | −0.059 | *0.223* |
| My FM strongly affects the way others see me | 0.082 | 0.089 | **0.358** | −0.094 | −0.180 | −0.105 | *0.277* |
| My FM has serious financial consequences | 0.071 | 0.008 | **0.347** | −0.090 | −0.098 | −0.075 | 0.190 |
| My FM causes difficulties for those who are close to me | 0.011 | −0.102 | **0.355** | −0.146 | −0.161 | −0.015 | 0.279 |
| 4. Personal control $\alpha$ = *0.81*, $\alpha$ = **0.77** | | | | | | | |
| There is a lot which I can do to control my symptoms | 0.091 | 0.035 | −0.137 | **0.353** | 0.273 | 0.150 | −0.166 |
| What I do can determine whether my FM gets better or worse | 0.053 | 0.107 | −0.158 | 0.294 | **0.371** | 0.137 | −0.167 |
| The course of my FM depends on me | −0.140 | 0.050 | −0.166 | **0.309** | 0.273 | 0.033 | −0.123 |
| Nothing I do will affect my FM* | −0.016 | 0.002 | −0.001 | **0.270** | 0.086 | 0.042 | −0.067 |
| I have the power to influence my FM | 0.013 | 0.041 | −0.073 | **0.336** | 0.320 | 0.115 | −0.096 |
| My actions will have no effect on the outcome of my FM* | −0.020 | −0.038 | 0.040 | **0.243** | 0.096 | 0.138 | −0.070 |
| 5. Treatment control $\alpha$ = *0.80*, $\alpha$ = **0.79** | | | | | | | |
| There is very little that can be done to improve my FM* | −0.141 | −0.008 | −0.240 | 0.177 | **0.390** | 0.155 | −0.206 |
| Treatment will be effective in curing my FM | −0.121 | 0.105 | −0.043 | **0.356** | 0.344 | 0.104 | −0.088 |
| The negative effects of my FM can be prevented (avoided) by my treatment | −0.101 | 0.149 | −0.151 | 0.198 | **0.381** | 0.100 | −0.109 |
| Treatment can control my FM | −0.093 | 0.116 | −0.131 | 0.237 | **0.390** | 0.179 | −0.086 |
| There is nothing which can help my FM* | −0.089 | −0.071 | −0.064 | 0.214 | **0.338** | 0.066 | −0.148 |
| 6. Illness coherence $\alpha$ = *0.87*, $\alpha$ = **0.79** | | | | | | | |
| The symptoms of my FM are puzzling to me* | 0.056 | −0.121 | −0.045 | 0.114 | 0.104 | **0.565** | −0.220 |
| My FM is a mystery to me* | 0.085 | −0.039 | −0.059 | 0.156 | 0.153 | **0.581** | −0.244 |
| I don't understand my FM* | −0.026 | −0.092 | −0.098 | 0.050 | 0.113 | **0.525** | −0.199 |
| I have a clear picture or understanding of my FM | 0.027 | 0.021 | −0.101 | 0.091 | 0.114 | **0.418** | −0.152 |
| 7. Emotional representations $\alpha$ = *0.88*, $\alpha$ = **0.81** | | | | | | | |
| I get depressed when I think about my FM | 0.024 | 0.027 | 0.168 | −0.071 | −0.116 | −0.213 | **0.383** |
| When I think about my FM I get upset | 0.004 | 0.062 | 0.216 | −0.174 | −0.097 | −0.162 | **0.468** |
| My FM makes me feel angry | 0.131 | 0.086 | **0.387** | −0.145 | −0.193 | −0.141 | 0.382 |
| My FM does not worry me* | 0.107 | −0.061 | 0.135 | −0.133 | −0.128 | **−0.185** | **0.176** |
| Having this FM makes me feel anxious | 0.084 | 0.043 | 0.299 | −0.067 | −0.114 | −0.273 | **0.497** |
| My FM makes me feel afraid | 0.095 | 0.023 | 0.298 | −0.099 | −0.116 | −0.249 | **0.476** |

Cronbach's alphas in *italic script* are from the IPQ-R English language version in a mixed patient group (Moss-Morris et al. [28]), Cronbach's alphas in **bold script** from the IPQ-R FM-Dlv, *denotes items reverse scored, the highest corrected correlations are presented in **bold script**.

representations). Believing more symptoms to be specifically related to FM (illness identity) is related to the belief that there is not much the person can do to control the illness (personal control) and with less confidence in the effect of treatment (treatment control). Personal control and treatment control are strongly related, and less confidence in the effect of treatment (treatment control) is also related to a stronger belief in the chronic course of FM (timeline acute/chronic) and to not understanding the illness and its symptoms well (illness coherence).

In the first column of Table 5, scores in our study population are presented. Out of 14 possible symptoms, participants with FM endorse almost six as being directly related to their illness (illness identity). The high score on timeline acute/chronic indicates that participants perceive their illness and symptoms to last for a long time or even for ever. FM patients believe their symptoms to fluctuate over time (timeline cyclical) and believe their illness to have a severe impact on physical, social, and psychological functioning (consequences). They think there is a lot they can do themselves to control their symptoms and the course of their illness (personal control). According to the high score on treatment control, participants with FM also think that treatment can be effective in decreasing symptoms and curing their illness. The score on illness coherence is low in participants with FM, indicating that they do not have a clear picture of their condition. They do not report many negative emotions generated by their FM, such as getting angry, anxious or depressed (emotional representations).

From the 24 comparisons made between FM, CFS, RA and CHD patients, 17 are significantly different. Between FM and coronary heart patients no comparable score was found at all. Some of them reflect stronger held beliefs and more positive thoughts in CHD, for example about the chronicity and controllability of the illness, while amongst others their condition is more puzzling to CHD patients and is believed to have more emotional representations. Both CFS and RA patients endorse more symptoms as being part of their illness and belief their condition to have more negative consequences than FM patients, but are more likely to think their symptoms will pass in time. Illness coherence is best in

**Table 3b**
Cronbach's alphas and corrected correlations (Multiple Group Method) of the items in the attributional domains of IPQ-R FM-Dlv

| Total Causes domain $\alpha$ = **0.78** | 1. | 2. | 3. | 4. |
|---|---|---|---|---|
| 1. Sub domain psychological attributions *$\alpha$ = 0.86*, $\alpha$ = **0.82** | | | | |
| Stress or worry | **0.431** | 0.111 | 0.065 | −0.155 |
| My mental attitude e.g. thinking about life negatively | **0.418** | 0.227 | 0.094 | −0.016 |
| Family problems or worries caused my illness (my FM) | **0.516** | 0.204 | 0.134 | −0.074 |
| Overwork | **0.383** | 0.196 | 0.167 | −0.022 |
| My emotional state e.g. feeling down, lonely, anxious, empty | **0.531** | 0.210 | 0.221 | 0.000 |
| My personality | **0.358** | 0.215 | 0.115 | 0.061 |
| 2. Sub domain risk factors *$\alpha$ = 0.77*, $\alpha$ = **0.55** | | | | |
| Hereditary—it runs in my family | 0.097 | **0.104** | 0.001 | 0.042 |
| Diet or eating habits | 0.199 | 0.203 | **0.310** | 0.075 |
| Poor medical care in my past | 0.199 | 0.179 | **0.438** | 0.173 |
| My own behaviour | **0.422** | 0.128 | 0.040 | −0.008 |
| Ageing | **0.165** | 0.135 | 0.154 | 0.065 |
| Smoking | 0.136 | 0.268 | 0.114 | **0.281** |
| Alcohol | 0.139 | 0.255 | 0.143 | **0.263** |
| 3. Sub domain immunity *$\alpha$ = 0.67*, $\alpha$ = **0.62** | | | | |
| A germ or virus | 0.111 | 0.151 | **0.430** | 0.096 |
| Pollution in the environment | 0.150 | 0.269 | **0.387** | 0.174 |
| Altered immunity | 0.136 | 0.094 | **0.344** | 0.081 |
| 4. Sub domain Accident or chance *$\alpha$ = 0.23*, $\alpha$ = **0.14** | | | | |
| Chance or bad luck | **−0.137** | 0.017 | 0.108 | 0.065 |
| Accident or injury | 0.068 | **0.238** | 0.126 | 0.065 |

Cronbach's alphas in *italic script* are from the IPQ-R English language version in a mixed patient group (Moss-Morris et al. [28]), Cronbach's alphas in **bold script** from the IPQ-R FM-Dlv, the highest corrected correlations are presented in **bold script**.

rheumatoid arthritis patients compared to all three other patient groups.

In the causal domain, stress/worries, bad luck, heredity, problems with immune system and personality are the attributions to which FM participants strongly agree. Patients with coronary heart disease think heredity or other biological factors (35%, $n$ = 279), stress (36%, $n$ = 289) and lifestyle (29%, $n$ = 230) are most likely to cause their illness [33]. Both CFS and RA patients think their illness is caused by a germ or immune dysfunction and by psychological factors [32].

## 4. Discussion and conclusion

### 4.1. Discussion

The internal consistency for use of the questionnaire on group level is acceptable. Also the validity of the items in the illness identity domain was affirmed. However, for three sub domains within the causes domain no acceptable internal consistency was found. The sub domain accident or chance presented with a particularly low Cronbach's alpha, in our analysis as well as in the analysis of the IPQ-R English language version. This sub domain consists of only two items, which probably is not sufficient to form a separate domain of the questionnaire. Also the two items may not fit together in a single domain as the content and meaning of chance or bad luck is different to that of an Accident or injury as possible cause for illness.

Although MGM revealed that for most domains a priori assignment of items was supported, the domain structure of the 'beliefs' domains as suggested for the original IPQ-R could not be completely affirmed in our study. In the Dutch IPQ-R the personal control and treatment control domains might represent a single control domain. The strong correlation between these two domains seems to support this assumption. One item that was a priori assigned to the emotional representations domain correlates stronger with the consequences domains, two domains that also have a strong inter domain correlation indicating that these domains have a lot in common or share an underlying dimension. Maybe it would be better to combine high correlating domains or to remove the items of one of these domains.

The expected assignment of the items in the causes sub domains was not supported by our data. Several items that were a priori assigned to the risk factor and accident or chance sub domains correlated strongest with several other sub domains.

Although Pearson's correlation coefficients of the IPQ-R FM appear to show inter-relationships as expected between the domains, not all associations were in accordance with those found for the original IPQ-R. In the Dutch version only 14 interrelationships between the domains were moderate or high ($r \geq .25$), compared to 24 in the English version. Especially in the illness identity and illness coherence, and also in some attributional domains, correlations were found to differ more than 0.20 between the two versions of the questionnaire. These differences might be caused by lacking a known cause and cure and clear symptoms in FM while in most of the illnesses in the mixed patient group pathophysiology and sometimes even treatment strategies are clear.

Moss-Morris et al. [28] calculated psychometric properties of the IPQ-R English language version for a mixed patient group consisting of 711 patients with rheumatoid arthritis, type II diabetes, asthma, chronic pain, acute pain, multiple sclerosis, myocardial infarction and HIV. Comparison of the psychometric properties of the questionnaires should ideally be calculated in a comparable patient group. To our knowledge data for the IPQ-R for fibromyalgia are not available.

**Table 4**
Pearson's correlation coefficients of the original IPQ-R English language version and the IPQ-R FM-Dlv domains

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Illness Identity | | −0.05 | −0.09* | 0.07 | 0.14** | 0.13** | 0.18** | 0.04 | 0.26** | 0.13** | 0.31** | −0.01 |
| 2. Timeline acute/chronic | 0.13 | | 0.14** | 0.51** | −0.29** | −0.42** | −0.29** | 0.21** | −0.01 | −0.07 | 0.25** | −0.06 |
| 3. Timeline cyclical | 0.15 | 0.18 | | 0.24** | −0.11** | −0.10* | −0.16** | 0.30** | 0.24** | 0.16** | 0.25** | −0.02 |
| 4. Consequences | 0.34** | 0.42** | 0.04 | | −0.25** | −0.32** | −0.28** | 0.53** | 0.07 | −0.05 | 0.28** | 0.01 |
| 5. Personal control | −0.36** | −0.10 | 0.04 | −0.19 | | 0.61** | 0.56** | −0.20** | 0.11** | 0.27** | −0.08 | −0.12** |
| 6. Treatment control | −0.24* | −0.37** | −0.03 | −0.26* | 0.63** | | 0.74** | −0.16** | 0.11** | 0.33** | −0.13** | −0.06 |
| 7. Illness coherence | −0.04 | 0.13 | −0.04 | −0.07 | 0.19 | 0.30* | | −0.43** | 0.06 | 0.26** | −0.08 | −0.11* |
| 8. Emotional representations | 0.26** | 0.11 | 0.07 | 0.53** | −0.23* | −0.20 | −0.24** | | 0.21** | 0.09* | 0.13** | 0.16** |
| 9. Psychological attributions | −0.05 | 0.04 | 0.16** | 0.14 | 0.24** | 0.24** | 0.14 | 0.06 | | 0.64** | 0.43** | −0.07 |
| 10. Risk factor attributions | 0.10 | −0.05 | −0.15** | 0.12 | −0.12 | −0.02 | 0.21** | 0.02 | 0.50** | | 0.28** | 0.04 |
| 11. Immune attributions | 0.21** | −0.05 | 0.02 | 0.27** | −0.05 | 0.11 | 0.17* | −0.16 | 0.24** | 0.37** | | −0.19** |
| 12. Chance attributions | 0.12 | 0.04 | −0.18* | 0.04 | −0.19** | −0.20* | 0.16 | −0.20 | −0.05 | 0.30* | 0.20** | |

*$p < 0.05$, **$p < 0.01$; Results of the IPQ-R English language version (from: Moss-Morris et al. [29]) are presented above the diagonal.

**Table 5**
Comparison of Illness perceptions of patients with fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis and coronary heart disease

| Domain (min. –max.) | FM Mean (S.E.) | CFS[a] Mean (S.E.) | 95% CI FM-CFS | RA[a] Mean (S.E.) | 95% CI FM-RA | CHD[b] Mean (S.E.) | 95% CI FM-CHD |
|---|---|---|---|---|---|---|---|
| Illness identity (0–14) | 5.8 (0.2) | 9.3 (0.5) | −4.37 to −2.63* | 7.3 (0.4) | −2.28 to −.723* | 3.23 (0.1) | 2.11 to 2.85* |
| Timeline acute/chronic (6–30) | 25.7 (0.4) | 20.1 (0.7) | 4.14 to 7.06* | 23.4 (0.6) | 1.01 to 3.59* | 22.5 (0.2) | 2.44 to 3.96* |
| Timeline cyclical (4–20) | 14.8 (0.2) | 14.1 (0.5) | −3.31 to 1.73 | 13.8 (0.4) | .117 to 1.88* | 10.5 (0.1) | 3.77 to 4.83* |
| Consequences (6–30) | 19.5 (0.4) | 24.5 (0.7) | −6.58 to −3.42* | 21.4 (0.6) | −3.28 to −.522* | 18.2 (0.2) | .429 to 2.17* |
| Personal control (6–30) | 21.1 (0.4) | 22.1 (0.7) | −2.51 to .514 | 20.0 (0.5) | −.149 to 2.35 | 22.0 (0.1) | −1.51 to −.288* |
| Treatment control (5–25) | 16.4 (0.3) | 16.8 (0.5) | −1.75 to .953 | 16.7 (0.4) | −1.44 to .838 | 17.9 (0.1) | −2.01 to −.990* |
| Illness coherence (5–25) | 15.1 (0.2) | 15.6 (0.8) | −1.58 to .580 | 16.8 (0.6) | −2.66 to −.745* | 12.7 (0.1) | 1.76 to 3.04* |
| Emotional representations (6–30) | 15.2 (0.4) | 17.9 (0.8) | −4.35 to −1.05* | 15.9 (0.6) | −2.08 to .680 | 16.6 (0.2) | −2.22 to −.579* |

FM = Fibromyalgia; CFS = Chronic Fatique Syndrome; RA = Rheumatoid Arthritis; CHD = Coronary Heart Disease; 95% CI = 95% confidence intervals.
* Indicates a statistically significant difference between the means.
[a] From: Moss-Morris and Chalder [32].
[b] From: Byrne et al. [33].

Differences in the domain structure and inter domain correlations of the questionnaires found in our study could be caused by these disease differences. A high correlation between personal control and treatment control was found; as there is no known cure for fibromyalgia, treatment should focus on self-management and self efficacy of patients instead of curation of the disease. This could explain the strong relation between personal control and treatment control in FM patients. For the attributional items this may play an even bigger role, as attributions are probably disease specific. Heredity or diet for instance may be adequate as possible cause in some illnesses but not in others, and therefore be likely to result in different sub domains.

Other studies that used the IPQ suggest labeling of factors in the causal domain as: psychological stress cause, biological cause and behavioral cause. Possibly this distribution, or a division in internal and external attributions might fit better in patients with fibromyalgia. In future research the psychometric properties of the questionnaire should be studied more closely.

The first column of Table 5 shows the illness perceptions of the FM participants. In the description of the original IPQ-R English language version the interpretation of scores is presented as 'high scores on the identity, timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition. High scores on the personal control, treatment control and coherence dimensions, represent positive beliefs about the controllability of the illness and a personal understanding of the condition'.

The description does not include when scores should be interpreted as being high or low, no cut off point is provided. This makes it difficult to draw conclusions about the illness perceptions of our participants. Comparing results of our study with results of patients in other groups, can make it easier to interpret illness perceptions in patients with fibromyalgia.

In the last couple of years, researchers have been discussing whether or not fibromyalgia and chronic fatigue syndrome are interrelated or even interchangeable syndromes. Chronic fatigue syndrome and fibromyalgia are clinical conditions characterized by a variety of nonspecific symptoms including prominent fatigue, pain, and sleep disturbances. There are no diagnostic studies or widely accepted, pathogenic, explanatory models for either illness. Despite remarkably different diagnostic criteria, fibromyalgia and chronic fatigue syndrome have many demographic and clinical similarities [36–39]. The results of our study may represent that illness perceptions of patients with fibromyalgia and patients with chronic fatigue syndrome are comparable on the timeline cyclical, personal control, treatment control and illness coherence domains, but that patients with FM attribute less symptoms to their illness, perceive their illness to be more chronic, and attribute less negative consequences to their illness compared to patients with chronic fatigue syndrome.

As in fibromyalgia, patients with rheumatoid arthritis and coronary heart disease also present with pain, fatigue and physical disability. The diseases differ in that for RA and CHD pathophysiological backgrounds and pathologic processes are better understood. Therefore, one might expect more negative perceptions and attributions of their illness in patients with FM, where etiology is unclear. Our study did show statistically significant different scores on most domains of the questionnaire, but some scores of FM participants are higher and some are lower than in the other illnesses, not confirming this expectation. Apparently, what is known about pathology, etiology and consequences in literature and by health professionals does not strongly relate to patients' illness perceptions. This is of importance as Gassner et al. [40] found that in myocardial infarction patient models of their illness are different from those used by health professionals, and that participation and adherence to rehabilitation programs are likely to be improved by strategies that take into consideration patients' beliefs about their illness.

The differences in illness perceptions found in the comparison between patients with FM, CFS, RA and CHD might be confounded by several factors. The illness perception scores of Dutch patients with fibromyalgia were compared to the scores of English (CFS and RA) and Irish (CHD) patients. Language difference could be a confounding factor, as well as cultural differences, climate differences, and differences in health care systems between the countries. In a Dutch study by Botha-Scheepers et al. [41] the IPQ-R was used in patients with osteoarthritis. In their study, median scores on the domains were calculated. Compared to median scores in our study, their scores are higher on illness coherence, identical on timeline cyclical, and lower on all other domains of the questionnaire. This indicates that patients in our study reported less understanding of their illness, see the course of their illness as more chronic, report more symptoms as being related to their illness, see more negative consequences and emotional representations because of their FM, but report also more expected control of treatment or personal interventions in managing the illness. Validity of the questionnaire should be confirmed in the different languages and patient groups to be able to draw conclusions.

There are some weaknesses in the design of this study. First, it is possible that a selection-bias occurred. Patients were selected from a treatment center, so all participants have been seeking help in the past. From 322 patients, 196 agreed to participate. Patients who agreed to participate may be different in some aspects to those who did not agree. Unfortunately, it was not possible to compare respondents and non-respondents. Also all fibromyalgia patients in our study received some kind of treatment for their fibromyalgia. The contents, frequency, duration, intensity and effects of this treatment and when it was received is unknown. Finally, results

were post hoc compared to results from Moss-Morris and Chalder [32] and Byrne et al. [33]. For gender, age and length of illness we were able to calculate 95% confidence intervals between the different groups. The proportion females in the other three study populations differed significantly from the FM group; our study population consisted of 88% female participants, which is comparable to other FM studies. Some of the other characteristics were significantly different as well, not all relevant socio-demographic and illness related variables were known and it was not possible to control for in the analyses. These factors might have influenced illness perceptions and make the scores difficult to interpret.

### 4.2. Conclusion

The internal consistency for most of the domains of the Revised Illness Perception Questionnaire for Fibromyalgia Dutch language version (IPQ-R FM-Dlv) is good and appears to show inter-relationships as expected in FM. Domain and sub domain structure as presented in the original IPQ-R English language version in a mixed patient group is largely comparable but could not be affirmed completely.

Participants with FM have negative beliefs about the consequences of FM on daily living and a lack of understanding of FM and associated symptoms, and a strong belief in the chronic and cyclical nature of the condition. FM patients and patients with chronic fatigue syndrome and rheumatoid arthritis show similarities in their beliefs about the controllability of their illness, but overall more statistical significant differences than similarities were found between the illness perceptions of patients with FM as assessed with the Dutch questionnaire and the illness perceptions of CFS, RA and CHD patients as assessed with the original English questionnaire.

### 4.3. Practice implications

This study confirmed that the IPQ-R English language version can be adapted and used in a sample of fibromyalgia patients. The Dutch language version for fibromyalgia showed acceptable internal consistency of the domains, validity of the symptoms in the illness identity domain and inter-relationships as expected between all domains of the questionnaire. Future research should address the factor structure of the control domains and sub domains within the causal domain, and also internal consistency of these sub domains.

The illness perceptions in patients with fibromyalgia were shown. These are of particular importance since effective self-management programs aim at helping patients understand and reframe the thoughts, beliefs, and expectations about their symptoms [42–44]. The IPQ-R FM could be a useful instrument to assess FM patients' illness perceptions, before addressing them in treatment.

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