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### Title

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### Permalink

<https://escholarship.org/uc/item/07x0n19s>

### Journal

Research in Nursing & Health, 43(3)

### ISSN

0160-6891

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### Publication Date

2020-06-01

### DOI

10.1002/nur.22013

Peer reviewed



Published in final edited form as:

*Res Nurs Health*. 2020 June ; 43(3): 241–254. doi:10.1002/nur.22013.

## A systematic review of illness representation clusters in chronic conditions

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### Abstract

A person's beliefs about their chronic condition (illness representations) influence health and treatment outcomes. Recently, researchers have used clustering approaches to identify subgroups with different patterns of beliefs about their illness, with some subgroups having more favorable health outcomes than others. To date, these findings have not been synthesized. The purpose of this systematic review of the literature was to synthesize results of studies that used clustering approaches to analyze illness representation in chronic disease populations, in order to characterize the clusters and their relationship to health outcomes. Using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines we searched CINAHL, PsycInfo, and PubMed. To be included, studies had to be (a) peer reviewed, (b) in English, (c) performing a cluster analysis (CA), latent class analysis (LCA), or latent profile analysis (LPA), (d) using only illness representation (IR) subscales to form clusters, (e) measuring illness representation with the Illness Perception Questionnaire (IPQ-R), (f) in a chronic condition sample, and (g) measuring health-related outcomes. Twelve studies were included. Across studies, the number of clusters found ranged from two to three. In all studies, an association was found between illness representation group and at least one of their health outcomes. Illness representation clusters associated with favorable outcomes usually included lower disease-related consequences, fewer symptoms, less negative emotion, and a more stable disease pattern. The results of this review indicate that the relationship between the patterns of the illness representation profiles and health outcomes transcend diseases. Additionally, some dimensions of illness representation may be more important drivers of group membership than others.

### Keywords

chronic condition; cluster analysis; illness perception; illness representation; systematic review

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#### CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

## 1 | BACKGROUND

Chronic, noncommunicable conditions are an increasing global health concern. Given that chronic conditions are managed rather than cured, finding ways to enhance self-management are critical (Grady & Gough, 2014; Lorig & Holman, 2003). Much of the burden of chronic disease management rests on the patient and their ability and willingness to carry out their prescribed treatment (Sav et al., 2015). While the creation of a good treatment regimen is necessary, it is not sufficient. Vermeire and colleagues argue that a patient's adherence to their treatment program is significantly improved when they are an active partner in treatment planning with the care team, and this relationship has been seen in patient populations from bipolar disorder to diabetes (Brundisini, Vanstone, Hulan, DeJean, & Giacomini, 2015; Chakrabarti, 2016; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Providers who have insight regarding their patients' beliefs about their condition and treatment can more readily engage them as active partners in treatment planning.

Illness representations reflect an individual's beliefs about their condition and treatment. According to illness representation theory (Leventhal, Nerenz, & Steele, 1984), individuals have unique understandings of their condition that can be assessed along several different dimensions, including perceptions about the symptoms, consequences, chronicity, and level of control over the illness. The majority of studies conducted on illness representations to date have treated each dimension as a separate variable and examined the influence of individual dimensions on patient outcomes (Collins & Lanza, 2010). Five meta-analyses of studies employing this type of illness representation analysis have shown that the various aspects of illness representation were differentially related to outcome variables (Aujla et al., 2016; Brandes & Mullan, 2014; Broadbent et al., 2015; Dempster, Howell, & McCorry, 2015; Hagger, Koch, Chatzisarantis, & Orbell, 2017). Treating the illness representation subscales as separate variables makes it difficult to synthesize our understanding of the role illness representations play in health outcomes.

An alternative approach to understanding illness representations is to use clustering approaches like cluster analysis or latent class analysis to identify groups of people who have similar illness representation profiles. Unlike the traditional approach of analyzing subscales individually, clustering approaches may make it possible to identify unique groups of individuals with common illness representations (Collins & Lanza, 2010). Rather than determining the relative influence of each aspect of the illness representation on outcomes for the whole population, individuals are categorized into subgroups based on a similar combination of beliefs about their illness. An advantage of this approach is that assessment and treatment can be tailored to a person's specific beliefs about their illness. This approach is also consistent with the theoretical framework of illness representation, where the components of the illness representation come together in an overall illness perception.

To date, there have been no reviews of the literature focused on analysis of illness representations using clustering approaches. The purpose of this systematic review was to synthesize results of studies using clustering approaches to analyze illness representation in chronic condition populations.

## 2 | METHODS

To facilitate comparison across studies, we included studies that used the Revised Illness Perception Questionnaire (IPQ-R), the most commonly used measurement tool for illness representations (Moss-Morris et al., 2002). The IPQ was originally created in 1996; it was revised into the IPQ-R in 2002 (Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996). The IPQ-R includes nine subscales, each reflecting a different aspect of illness representations including; consequences, identity, cause, emotion, coherence, cyclical timeline, chronic timeline, personal control, and treatment control. See Table 1 for the definitions of each of the subscales. Except for identity and cause, subscales are measured with 4–6 items on a 5-point Likert scale which are averaged together for a subscale score (response options include strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree). The identity subscale has a list of common symptoms and respondents endorse how many symptoms they have experienced and attribute to their condition for a summary score. We excluded the cause subscale from this analysis, because individuals endorse and suggest possible causes, which are expected to vary widely across different chronic conditions. The IPQ-R has been found to have adequate reliability and validity in a variety of populations and languages (Abubakari et al., 2012; Brink, Alsen, & Cliffordson, 2011; Chen, Tsai, & Lee, 2008).

The strategy and criteria used for this search were based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). We conducted a search of the Pubmed, CINAHL, and PSYCInfo databases in February of 2019. Keywords included “illness perception(s)” OR “illness representation(s)” OR “illness cognition(s)” OR “common sense model” AND “cluster” OR “cluster analysis” OR “latent class analysis” OR “latent profile analysis.” The study PI (Dr. Rivera) performed the search in collaboration with Dr. Corte. Once the search was complete, papers accepted by both authors were included.

Inclusion criteria were: (a) published in peer-reviewed journals; (b) in English; (c) in chronic condition populations; (c) measured illness representation with the IPQ-R; and (e) performed a cluster analysis, latent class analysis, or latent profile analysis. Exclusion criteria were: (a) no health-related outcomes; (b) other variables used to form clusters; or (c) use of change scores to form clusters. We used the study quality assessment method developed by Hagger and colleagues, which is based on the Quality Assessment Tool for Observational Cohort and Cross-sectional Studies to determine the risk of bias in the individual studies (Hagger et al., 2017; National Heart Lung and Blood Institute, 2014). This method assesses reported study design components that may reveal areas of bias or structural concern, such as ethical study recruitment, validity and reliability of key variables, and methods of data analysis. Drs. Rivera and Corte performed independent quality assessments of each manuscript reviewed, compared their assessments, and came to consensus for the reported quality scores.

Finally, we analyzed the illness representation profiles in each study and compared them to each other. Because not all studies found the same number of clusters and because the values of each IPQ-R subscale can vary widely between study populations with different chronic

illnesses, it is challenging to assess the patterns of illness representation. The traditional method of presenting cluster analysis data, using a profile plot, is useful for just a few profiles. Because we examined the results of numerous different profiles (two or more per study included in the analysis), a profile plot would be cluttered and difficult to interpret. Furthermore, because we would expect the absolute value of the IPQ-R subscale scores to be different in different populations, comparing absolute values across studies would not be the best method of analysis.

To facilitate our analysis, we compared the clusters that were associated with the “best” and “worst” study outcomes directly within each study. This meant that for studies with more than two clusters, we only examined the clusters that had the most extreme associations with study outcomes; middling groups were excluded. For example, if the outcome is treatment adherence, we examined the clusters associated with the highest level of treatment adherence and the lowest level of treatment adherence. *T* tests were performed if the results of that test were not already provided by the authors.

### 3 | RESULTS

The search yielded a total of 183 studies across the three databases, of which 78 were duplicates (Figure 1). Of the 105 unique studies identified, 93 were excluded. Reasons for exclusion were: (a) not peer reviewed (5 studies); (b) not in English (2 studies); (c) study analysis did not include clustering methods (38 studies); (d) variables other than illness representation subscales were used to create groups (27 studies); (e) illness representation was not measured using the subscales of the IPQ-R (change scores 6 studies, Brief IPQ 5 studies, other measures 6 studies, 17 studies total); (f) sample population did not have a chronic disease (2 studies); and (g) outcome variables were not health-related. A total of 12 studies met inclusion criteria (Aujla, Walker, Sprigg, & Vedhara, 2018; Berry, Davies, & Dempster, 2017; Flora, Anderson, & Brawley, 2015; Graham, Rose, Hankins, Chalder, & Weinman, 2013; Harrison et al., 2014; Hobro, Weinman, & Hankins, 2004; Hsiao, Chang, & Chen, 2012; Lin & Heidrich, 2012; Lopes et al., 2018; McCorry et al., 2013; Norton et al., 2014; Turkington, Dempster, & Maguire, 2018).

#### 3.1 | Quality assessment

The full results of the quality assessment are shown in Table S1, with summary information in the rightmost column of Table 2. Five of the 12 studies received scores denoting low quality (Berry et al., 2017; Harrison et al., 2014; Hobro et al., 2004; Lopes et al., 2018; Norton et al., 2014). The most frequent quality issues were: insufficient description of the sample population (8/12 studies), no reporting performance of a priori power analysis (10/12), no reported reliability data (7/12), and analyses that did not account for confounding variables (6/12).

#### 3.2 | Study and sample characteristics

Characteristics of the 12 studies are summarized in Table 2. Eleven of the 12 studies were published within the last 7 years. Sample sizes ranged from 44 to 227. The mean age of participants ranged from 47 to 81 years. Enrollment of women and men varied in the study

samples but tended to align with the condition in question (e.g., the breast cancer population was entirely female). Eight studies were conducted in the United Kingdom, while the remaining four studies were conducted in Brazil, Canada, Taiwan, and the United States. Eight of the studies were cross-sectional and four were longitudinal, that is, cluster groups were identified at baseline with outcomes examined longitudinally. In some studies, investigators omitted specific IPQ-R subscales in their analysis. Identity and emotion were used in 10 out of 12 studies, and the remaining subscales (consequences, coherence, cyclical, timeline, treatment control, and personal control) were used in all studies.

### 3.3 | Type of clustering analysis

In 11 of 12 studies, a cluster analysis was used; Norton and colleagues used a latent profile analysis. Cluster analysis and latent profile analysis are both analytical techniques that sort cases into several groups based on a predetermined set of variables such that there is maximal within-group similarity and maximal between-group difference (Dunn et al., 2018). Table 2 summarizes software and analysis techniques. For cluster analysis studies after 2007, authors often referred to the IPQ-R cluster analysis Monte Carlo study by Clatworthy, Hankins, Buick, Weinman, and Horne (2007) to guide their approach. The authors of the Monte Carlo study identified an optimal strategy for cluster analysis approaches, which was a two-step approach. First, hierarchical agglomerative cluster analysis (Ward's method) was used to determine how many clusters were in the data, and which values those cases clustered around (called centroids). After the cluster number and centroids were determined, *K*-means analysis was used to assign each case to their specific cluster group (Clatworthy et al., 2007). The number of groups found ranged from two to three.

### 3.4 | Cluster labels and association with demographic variables

We assessed whether there were commonalities in the way that clusters were labeled, which is detailed in Table 2. Five studies did not name the clusters at all. Clusters that were labeled were based on IPQ-R composition, identified as either positive or negative illness perceptions, or based on the relationship to outcomes. For example, Lopes et al. (2018) described their clusters as “distressed” and “coping.” All studies identified at least one cluster with an illness representation profile that they considered to be negative, and another with a more positive illness representation profile.

Generally, the cluster groups across studies did not differ in terms of sociodemographic characteristics. The exception to this was age differences reported in two chronic obstructive pulmonary disease (COPD) studies and disabling hand injury; in all three studies the cluster groups with a younger average age were also the groups with worse outcomes and more negative illness representations (Harrison et al., 2014; Lopes et al., 2018; Turkington et al., 2018).

### 3.5 | Cluster associations with health outcomes

Table 2 describes the outcomes studied in each manuscript as well as what relationships were found between cluster groups and those outcomes. All authors in this review identified significant differences in study outcomes between cluster groups, though not always for every outcome studied. Table 3 shows the results of the comparisons between the cluster

groups associated with the best outcomes and the cluster groups associated with the worst outcomes for each study. Though most studies had more than one outcome of interest, none of them had conflicting identification of the groups with best and worst outcomes; that is, there were no instances where cluster groups that were the best for some outcomes were also the worst in others. By looking at the data in this manner, we see that there are patterns in the composition of the clusters for some subscales and not others. Some of the subscales (consequences, identity, emotion, and cyclical) showed highly consistent patterns of association with cluster group membership, while others (coherence, chronic timeline, treatment control, and personal control) often did not differ significantly between the groups at all.

**3.5.1 | Consequences**—In all 12 studies, lower consequences scores were reported in the cluster groups with the best health outcomes. For example, Berry et al. (2017) found that in patients with type 2 diabetes, the group with significantly fewer consequences had fewer complications, lower levels of depression, and lower distress.

**3.5.2 | Identity (symptoms)**—Ten of the 12 studies included the identity subscale. In all 10 studies that included identity, fewer symptoms were reported in the cluster groups with the best outcomes. In a study of patients with chronic muscle disease (different types of muscular dystrophy and other muscle diseases), the group with significantly fewer reported symptoms had higher quality of life, and lower functional impairment, depression, and anxiety (Graham et al., 2013). Two studies did not use the identity subscale (Hobro et al., 2004; Turkington et al., 2018).

**3.5.3 | Emotion**—Ten of the 12 studies included the emotion subscale, and in 9 of 10 studies, less negative emotion was reported in the cluster groups with the best outcomes. In a study of patients with COPD, the group with significantly lower negative emotion had lower anxiety and depression, with higher health status and self-efficacy (Harrison et al., 2014). Only one study showed no significant differences in emotion subscale scores despite differences in the outcomes (Flora et al., 2015). Two studies did not use the emotion subscale (McCorry et al., 2013; Norton et al., 2014).

**3.5.4 | Cyclical**—In nine of the studies, a less cyclical pattern was reported in the cluster groups with the best outcomes. In one study of patients with COPD, the group with significantly lower cyclical scores had better function, self-efficacy, and quality of life (Lopes et al., 2018). However, in another study, a more cyclical pattern was reported in the cluster group with the best outcome. In a sample of patients with cognitive impairment, the group with higher cyclical scores had significantly higher levels of coping behaviors (Lin & Heidrich, 2012). Two studies showed no significant differences (Flora et al., 2015; Hobro et al., 2004).

**3.5.5 | Coherence**—In four studies, a more coherent understanding of the condition was reported in the cluster groups with the best outcomes (Hobro et al., 2004; Lin & Heidrich, 2012; Lopes et al., 2018; McCorry et al., 2013). In patients with breast cancer, the group with significantly higher coherence scores had significantly lower psychological distress (McCorry et al., 2013). In one study of persons with a disabling hand injury, higher

coherence scores were associated with poorer function, more negative coping, poorer quality of life, and higher risk of experiencing depression and trauma symptoms (Turkington et al., 2018). The remaining seven studies showed no significant differences.

**3.5.6 | Chronic timeline**—In six studies, a more chronic perception was reported in the cluster groups with the worst outcomes (Aujla et al., 2018; Graham et al., 2013; Harrison et al., 2014; Hobro et al., 2004; McCorry et al., 2013; Turkington et al., 2018). Aujla et al. (2018) found that the group of post-stroke patients with significantly higher timeline scores had a worse mood and quality of life. The remaining six studies showed no significant differences.

**3.5.7 | Treatment control**—In five studies, a higher degree of treatment control was reported in the cluster groups with the best outcomes (Graham et al., 2013; Hobro et al., 2004; McCorry et al., 2013; Norton et al., 2014; Turkington et al., 2018). Norton et al. (2014) found that the group of patients with rheumatoid arthritis with significantly higher treatment control scores had significantly lower pain and psychological distress. The remaining seven studies showed no significant differences.

**3.5.8 | Personal control**—In two studies, more personal control was reported in the cluster groups with the best outcomes (Hobro et al., 2004; Turkington et al., 2018). Hobro et al. (2004) found that the group of chronic pain patients with significantly higher personal control had significantly higher levels of mood and function. Conversely, Hsiao et al. (2012) found that the group of hypertensive patients with significantly lower personal control had significantly higher levels of medication adherence. In nine studies, there were no significant differences.

## 4 | DISCUSSION

The purpose of this review was to synthesize the findings of studies that used clustering approaches to analyze illness representations in chronic conditions and to characterize the illness representation profiles and outcomes. Two or three profiles were identified in all studies. All studies identified at least one positive and one negative illness perception profile. Most studies (i.e., seven) labeled the profiles to reflect their positive or negative illness perceptions. Due to the nature of illness representation data, it is not possible to make any meaningful conclusions by direct comparison of scores and clusters from different chronic condition populations. That is why our analysis focused on discovering patterns of commonality in the way the clusters were constructed and how they differed from other clusters within the same sample. Clusters with fewer perceived consequences, fewer symptoms, and less negative emotion were consistently related to better health outcomes. The cyclical, coherence, timeline, personal control, and treatment control subscale scores were not consistent in their pattern of association with clusters.

### 4.1 | Quality assessment

There were quality issues with a number of studies in our review. Some issues originated from a lack of sufficient description of study methods in the manuscript, such as no reporting performance of a priori power analysis and no reported reliability data. Some



issues were more fundamental to the study design itself, such as performing analyses that could not account for confounding variables. To broaden our evidence base given the relatively small number of papers that met inclusion criteria, we decided to retain all papers regardless of quality rating. We did examine their results alongside papers with higher quality and found that their findings did not differ substantially or systematically from the higher quality studies.

#### 4.2 | Study/sample characteristics and association with cluster groups

The age and sex of the study samples varied as expected given that some chronic conditions are more prevalent in older or younger populations or in men or women. For example, the mean age of the sample with muscle disease was 47 years old, while the sample with mild cognitive impairment had a mean age of 81 years (Graham et al., 2013; Lin & Heidrich, 2012). Comparing these two studies, we see that chronic timeline and treatment control are important subscales for cluster group identification in the younger muscle disease population but not the older cognitive impairment population. It is not clear whether these differences are related to age or differences in etiology. Several studies reported significant age differences between their cluster groups (Aujla et al., 2018; Harrison et al., 2014; Lopes et al., 2018; Turkington et al., 2018). For all four of the studies that identified age differences between cluster groups, the group with the worse outcomes had a younger average age. The younger groups tended to be less educated, have lower self-efficacy, lower functional status, and poorer mood. This phenomenon should be explored in future study to see if it is causal or confounded by other factors; recent work in hemodialysis patients is consistent with these results (Kim, Kim, & Ryu, 2019). There were large differences in the proportion of females and males in these study samples, ranging from 33% female in the sample with hypertension to 100% female in the sample with breast cancer (Hsiao et al., 2012; McCorry et al., 2013). However, unlike age differences, no studies reported differences in the proportion of men and women between their cluster groups. Gender differences in illness representation subscale scores have been found (Colombo et al. and Wisting et al. are two recent examples), but when using a clustering approach on these chronic condition populations we no longer see that effect (Colombo, Zagni, Ferri, Canonica, & PROXIMA Study Centers, 2019; Wisting et al., 2016).

#### 4.3 | Types of clustering analysis

All investigators except Norton et al. (2014) cited the recommendations of the Monte Carlo study to guide their choices of cluster analysis methods (Clatworthy et al., 2007). While this is clearly the standard approach, Clatworthy et al.'s work is more than 10 years old and there have been advancements in clustering analytic approaches. At this point, it may be worth revisiting the best options for a cluster-based analytic approach to illness representation research to see if the previous recommendation for cluster analysis with hierarchical agglomerative scheduling followed by *K*-means analysis remains the best approach going forward. A first step could be to assess the work done in other fields to create best practices in clustering methods (Bray, Lanza, & Tan, 2015; Dziak, Bray, Zhang, Zhang, & Lanza, 2016; Kimes, Liu, Neil Hayes, & Marron, 2017).

#### 4.4 | Clusters' association with health outcomes

When characterizing the cluster groups found in the manuscripts in this review, we found that fewer perceived consequences, fewer symptoms, and less negative emotion were important subscales that drove the differences between cluster groups. It is possible that the consequences, identity (symptoms), and emotion subscales are the most important aspects of the illness representation, and thus have the greatest impact on determination of group membership. That is, if patients were asked to prioritize the different aspects of illness representation, we may find that these subscales are identified by the patients themselves as the most important. Future study should explore this phenomenon from a qualitative perspective, possibly by using a cognitive interviewing approach. It is also possible that these subscales have stronger psychometric properties. While extensive psychometric testing of the reliability and validity of the IPQ-R has been demonstrated (Moss-Morris et al., 2002; Weinman et al., 1996), several studies have shown that the treatment control subscale has low reliability (Chilcot, Wellsted, & Farrington, 2010; Porkert et al., 2018; Surgenor et al., 2019). Of the studies in this review, five reported Cronbach's  $\alpha$  scores; most scores were above .7 for all subscales indicating good reliability, with the exception of treatment control in Norton et al. (0.64) and Aujla et al. (0.42) (Aujla et al., 2018; Norton et al., 2014). A major modification in the revision of the IPQ to the IPQ-R was to create the subscales of cyclical timeline and negative emotion, as well as to split the control subscale into personal control and treatment control (Moss-Morris et al., 2002). Though the emotion subscale was found to be important in our analysis, the three newer subscales did not consistently distinguish between better and worse outcomes.

Not every subscale showed a consistent pattern of association for group membership. For the cyclical subscale, a perception of the condition as less variable in nature was associated with better outcomes in 9/12 studies, but the study about coping and self-care in a population with cognitive impairment found the opposite (Lin & Heidrich, 2012). Identifying the reason for this difference in the cognitive impairment population is an important question for future research. The other inconsistency was found in the coherence subscale, where a more coherent understanding was associated with better outcomes 4/12 studies, with opposite results in the study about those living with a chronic disabling hand injury (Turkington et al., 2018). It is possible that in the Turkington study, which examined outcomes such as coping, self-blame, and trauma, a more coherent understanding of the condition could be highly related to the nature of the hand injury incident. Someone who had a traumatic injury for which they blame themselves could still feel that they understood their injury very well.

#### 4.5 | Comparison of findings with other reviews

The findings of this review have some differences and some similarities with findings of the five meta-analytic systematic reviews of the IPQ, IPQ-R, and BIPQ. One review showed that personal control and treatment control subscales were the strongest predictors of adherence, with coherence and timeline also playing a role (Brandes & Mullan, 2014). While we also found coherence and timeline to be important subscales in determining group membership, we did not find that personal control and treatment control distinguished groups with better or worse outcomes. This was true even in the three studies in our review that had adherence outcomes (Flora et al., 2015; Harrison et al., 2014; Hsiao et al., 2012). Our findings are more

consistent with the results of other reviews that showed that greater consequences and more symptoms (identity) were related to poorer outcomes (Broadbent et al., 2015) and that perceived consequences and negative emotion were associated with negative outcomes (Dempster et al., 2015). Our results were consistent with those of Hagger et al. (2017) in terms of identifying the consequences, identity, and emotion subscales as being the subscales with the most consistent relationship with outcomes. Additionally, Aujla et al. (2016), whose analysis found an overall very weak relationship between illness representation subscales and self-management adherence, concluded with a call for greater examination of the intercorrelation of illness representation dimensions.

This review is focused only on clustering approaches for analysis, which differentiate groups based on multiple variables. On the one hand, this could weaken the power for finding relationships (similar to making categories from a continuous measure). On the other hand, cluster-based findings could possibly show a stronger relationship for some groups of individuals who are more homogeneous due to the clustering. The associations found in the reviewed clustering studies are, in effect, multivariate, and group-level findings are conditional on other subscales.

This review has implications for nursing practice and research. Assessing the patient's pattern of beliefs about their illness may facilitate treatment planning and intervention. Interventions should be targeted to the individual patient's pattern of beliefs. For example, interventions aimed at decreasing illness-related negative emotion and negative consequences of the illness would be relevant for patients who have high levels of illness-related negative emotion and many perceived consequences of their illness; such interventions would not likely be relevant for patients who do not. Future studies of patients with chronic illness should include all IPQ-R subscales to fully capture patients' beliefs about their illness.

#### 4.6 | Limitations

There are limitations to this review. Some studies did not include all the IPQ-R subscales, and thus, some subscales were not included in the cluster analyses for certain studies (Hobro et al., 2004; McCorry et al., 2013). It is possible that exclusion of some of the subscales fundamentally altered the composition of the cluster groups. We also restricted our analysis in Table 3 to only the two clusters in each study with the best and worst outcomes. While this made it possible to directly compare results across studies, there may be more nuanced information that we lost using this approach. However, the middling groups that were omitted had subscale values between the other two groups and did not indicate a different or unique pattern of perception. A further limitation is the low quality of some of the studies in this review as assessed by the quality assessment tool, which may mean that the results of studies with low-quality ratings are unreliable. For example, the smallest sample size in this review is 49, which may be underpowered; however, study authors did not provide an a priori power calculation (Flora et al., 2015). Methods for powering cluster analysis are not yet well established, though smaller samples have a higher likelihood of type-2 errors than studies with larger samples, which are more generalizable. Work on the best methods of a priori power analysis for clustering methods is ongoing (Galecki, Burzykowski, Chen,

Faulkner, & Ashton-Miller, 2009; Gudicha, Tekle, & Vermunt, 2016; Tein, Coxe, & Cham, 2013).

## 5 | CONCLUSIONS

Across chronic conditions, health perceptions cluster into positive and negative, and for some conditions, moderate, illness perception profiles. Several dimensions of illness representation appear to be more important drivers of group membership than others. These dimensions are consequences, symptoms, and emotion. The illness representation profiles that are associated with positive health outcomes have similarities that persist across studies with different chronic condition populations and study designs. Groups with fewer perceived consequences, fewer symptoms, and less negative emotion had better health outcomes. The cyclical, coherence, timeline, personal control, and treatment control dimensions do not consistently relate to better or worse outcomes. Assessment of patients' illness perceptions offers consistent opportunities for intervention across a range of chronic conditions.

### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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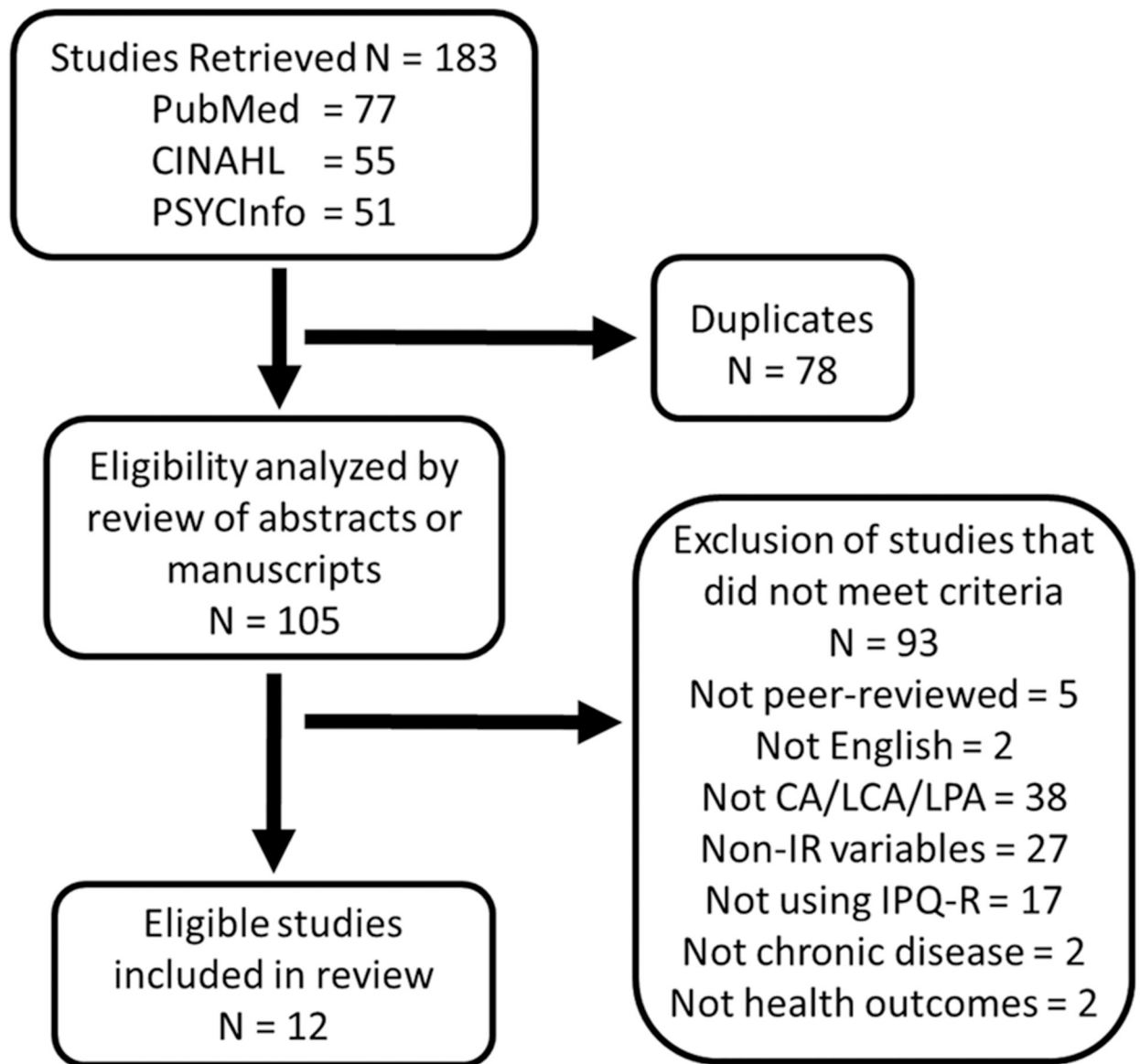
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**FIGURE 1.** Search flow diagram for identification of studies for inclusion in this review. IPQ-R, Revised Illness Perception Questionnaire



**TABLE 1**

Details of the IPQ-R subscales

<b>Subscale</b>	<b>Definition</b>	<b>High score indicates</b>	<b>Number of items</b>
Timeline	Whether an individual perceives their disease to be acute or chronic in nature	A more chronic disease perception	6
Identity	What symptoms the individual attributes to their disease	Each item is a different symptom, summed	Not defined
Cause	Perceived causes of the disease	Factor analysis used to identify causal groups	Not defined
Consequences	The extent of perceived consequences of the disease	More disease consequences	6
Personal control	The amount of perceived control a person has over their disease	More control	6
Treatment control	The amount of perceived control the medical treatments have over the disease	More control	5
Coherence	The perceived level of understanding of their disease	More understanding	5
Cyclical timeline	Whether an individual perceives their disease to have a stable or unstable pattern from day to day	More unstable disease pattern	4
Emotion	Amount of negative emotion an individual attributes to their disease	More negative emotion	6

Abbreviation: IPQ-R, Revised Illness Perception Questionnaire.

TABLE 2

Study and cluster characteristics

Study	Sample; country; n; mean age (standard deviation) years; % female	Outcome variables	Analysis methods	Clusters found	Key findings	Summary of quality assessment (rating out of 10)
Hobro et al. (2004)	Chronic pain; United Kingdom; n = 130; age 53 (SD not reported); 63% female	Function (SF-36), medication beliefs (BMQ), mood (HADS), pain (MPQ)	<ul style="list-style-type: none"> <li>SPSS version 10.0</li> <li>Hierarchical clustering procedure for average linkage</li> <li>Agglomerative scheduling</li> </ul>	Two clusters <ul style="list-style-type: none"> <li>Adaptors (46%)<sup>a</sup></li> <li>Non-adaptors (30%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Clusters did not differ in sociodemographic or disease factors</li> <li>Adaptors had significantly less pain, more energy, higher functioning, and less depression</li> </ul>	<ul style="list-style-type: none"> <li>Weaknesses: cross-sectional design, do not report consent process, reliability and validity of variables not reported</li> <li>Quality rating: 3.85 (low)</li> </ul>
Hsiao et al. (2012)	Hypertension; Taiwan; n = 117; age 54 (±9.5); 33% female	Medication adherence (HPDAQ)	<ul style="list-style-type: none"> <li>SPSS version 13.0</li> <li>Cluster analysis (no further details on clustering methods)</li> </ul>	Three clusters <ul style="list-style-type: none"> <li>Cluster 1 (46%)<sup>a</sup></li> <li>Cluster 2 (12%)<sup>a</sup></li> <li>Cluster 3 (42%)</li> </ul>	<ul style="list-style-type: none"> <li>Clusters did not differ in sociodemographic factors</li> <li>Cluster 1 had the best medication adherence (80%), cluster 2 had the worst (43%)</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: study population well specified</li> <li>Weaknesses: cross-sectional design, reliability and validity of variables not reported</li> <li>Quality rating: 6.15 (high)</li> </ul>
Lin and Heidrich (2012)	Mild cognitive impairment; United States; n = 63; age 81 (±8.3); 52% female	Coping (Brief COPE), self-care behaviors (SCBC)	<ul style="list-style-type: none"> <li>SPSS version 18.0</li> <li>Cluster analysis</li> <li>Hierarchical cluster analysis using Ward's method, dendrogram plot to determine the number of clusters</li> <li>K-means cluster analysis</li> </ul>	Three clusters <ul style="list-style-type: none"> <li>Few symptoms &amp; positive beliefs (29%)<sup>a</sup></li> <li>Moderate symptoms &amp; positive beliefs (43%)</li> <li>Many symptoms &amp;</li> </ul>	<ul style="list-style-type: none"> <li>Clusters did not differ in sociodemographic or disease factors</li> <li>The "few symptoms and positive beliefs" cluster endorsed use of fewer types of coping strategies</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: reliability and validity of variables reported</li> <li>Weaknesses: cross-sectional design</li> <li>Quality rating: 6.15 (high)</li> </ul>

Study	Sample; country; n; mean age (standard deviation) years; % female	Outcome variables	Analysis methods	Clusters found	Key findings	Summary of quality assessment (rating out of 10)
Graham et al. (2013)	Multiple types of muscle disease; United Kingdom; n = 217; age 47 (±16); 49% female	Function (HAQ-DI), mood (HADS), quality of life (INQoL)	<ul style="list-style-type: none"> <li>SPSS version 17.0</li> <li>Cluster analysis</li> <li>Hierarchical clustering with Ward's method</li> <li>K-means clustering, post hoc K-means cluster analysis with a random 50% of the sample</li> </ul>	<p>Three clusters</p> <ul style="list-style-type: none"> <li>Realistic (49%)<sup>a</sup></li> <li>Beneficial (28%)<sup>a</sup></li> <li>Unhelpful (23%)</li> </ul>	<ul style="list-style-type: none"> <li>Clusters did not differ in sociodemographic or disease factors</li> <li>The realistic cluster had the worst functional impairment</li> <li>The beneficial cluster had the highest quality of life and mood</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: reliability and validity of variables reported</li> <li>Weaknesses: cross-sectional design</li> <li>Quality rating: 6.92 (high)</li> </ul>
McCorry et al. (2013)	Breast cancer (new diagnosis); United Kingdom; n = 90; age 57 (±10); 100% female	Coping (CCQ), psychological distress (HADS) [longitudinal]	<ul style="list-style-type: none"> <li>Software not identified</li> <li>Cluster analysis</li> <li>Two-stage approach</li> <li>Ward's clustering method</li> <li>K-mean analysis, squared Euclidean distance, dendrogram and agglomeration schedule</li> </ul>	<p>Two clusters</p> <ul style="list-style-type: none"> <li>Cluster 1 (61%)<sup>a</sup></li> <li>Cluster 2 (36%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>IR remained relatively stable over the first 6 months after diagnosis</li> <li>Cluster 1 had higher psychological distress at diagnosis and after 6 months</li> <li>Coping was not a mediator between IR and psychological distress</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: longitudinal design</li> <li>Weaknesses: reliability and validity of variables not reported</li> <li>Quality rating: 6.88 (high)</li> </ul>
Harrison et al. (2014)	COPD; United Kingdom; n = 128; age 71 (±8.9); 41% female	Health status (CRQ), mood (HADS), self-efficacy (PRAISE), treatment adherence	<ul style="list-style-type: none"> <li>SPSS version 18.0</li> <li>Cluster analysis</li> <li>Two-step approach</li> <li>Hierarchical cluster analysis (Ward's method)</li> <li>K-means cluster analysis, repeated on a random sample (50% of the cases)</li> </ul>	<p>Three clusters</p> <ul style="list-style-type: none"> <li>In control (41%)<sup>a</sup></li> <li>Disengaged (28%)</li> <li>Distressed (31%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Distressed cluster had younger age, worse mood, worse health status, and worse self-efficacy</li> <li>Clusters did not differ in treatment adherence to rehab over a 6-month period</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: study population specified</li> <li>Weaknesses: cross-sectional design, do not report consent process, reliability and validity of variables not reported</li> </ul>

Study	Sample; country; n; mean age (standard deviation) years; % female	Outcome variables	Analysis methods	Clusters found	Key findings	Summary of quality assessment (rating out of 10)
Norton et al. (2014)	Rheumatoid arthritis; United Kingdom; <i>n</i> = 227; age 58 (±15); 76% female	Clinical status, function (HAQ), pain, psychological distress (DAPOS) [longitudinal]	<ul style="list-style-type: none"> <li>Mplus version 5.2</li> <li>Latent profile analysis</li> <li>Bayesian Information Criterion (BIC) and Lo-Mendell-Rubin likelihood ratio test (LMR-LRT) to determine class fit</li> </ul>	Two clusters <ul style="list-style-type: none"> <li>Class 1 (57%)<sup>a</sup></li> <li>Class 2 (43%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Class 2 had higher levels of pain and functional disability at baseline</li> <li>Adjusting for demographic and clinical variables, class predicted pain and psychological distress at 6 months</li> </ul>	<ul style="list-style-type: none"> <li>Quality rating: 5.38 (low)</li> <li>Strengths: longitudinal design, reliability and validity of variables reported</li> <li>Weaknesses: inclusion criteria not implemented uniformly, do not report IRB oversight or consent process, loss to follow-up &gt;20%</li> <li>Quality rating: 5.63 (low)</li> </ul>
Flora et al. (2015)	Cardiac rehab; Canada; <i>n</i> = 49; age 62 (±9.3); % female not reported	Outcome expectations, quality of life (SF-36), self-regulatory efficacy, treatment adherence [longitudinal]	<ul style="list-style-type: none"> <li>Software not identified</li> <li>Hierarchical cluster analysis</li> <li>Follow-up discriminant analysis to determine the weight of each illness perception dimension</li> </ul>	Two clusters <ul style="list-style-type: none"> <li>Weak (37%)<sup>a</sup></li> <li>Strong (49%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Clusters did not differ in sociodemographic factors</li> <li>Strong cluster had more negative expectations, lower quality of life, and lower adherence at 3 months</li> </ul>	<ul style="list-style-type: none"> <li>Strengths: longitudinal design, reliability and validity of variables reported</li> <li>Quality rating: 6.88 (high)</li> </ul>
Berry et al. (2017)	Type 2 diabetes; United Kingdom; <i>n</i> = 162; age 68.3 (±10.8); 34% female	Clinical status (HgbA1C), disease distress (DDS-17), mood (BDI)	<ul style="list-style-type: none"> <li>SPSS version 21.0</li> <li>Cluster analysis</li> <li>Hierarchical cluster analysis (Ward's method)</li> <li>K-means analysis of clusters and centroids</li> </ul>	Three clusters <ul style="list-style-type: none"> <li>Cluster 1 (14%)<sup>a</sup></li> <li>Cluster 2 (42%)<sup>a</sup></li> <li>Cluster 3 (44%)</li> </ul>	<ul style="list-style-type: none"> <li>Cluster 1 had higher diabetes distress, greater diabetes complications, and higher depression scores</li> <li>Cluster 2 had the lowest diabetes distress</li> </ul>	<ul style="list-style-type: none"> <li>Weaknesses: cross-sectional design, do not report IRB oversight or consent process, reliability and validity of variables not reported</li> </ul>

Study	Sample; country; n; mean age (standard deviation) years; % female	Outcome variables	Analysis methods	Clusters found	Key findings	Summary of quality assessment (rating out of 10)
Aujla et al. (2018)	Post-stroke; United Kingdom; n = 44; age 66.9 (±14.5); 32% female	Disability (NEADL), mood (PHQ-9), quality of life (EQ-5D-5L) [longitudinal]	<ul style="list-style-type: none"> <li>• STATA version 13.0</li> <li>• Cluster analysis</li> <li>• Hierarchical agglomerative cluster analysis (Ward's method)</li> <li>• Partitioned into clusters using (-medians</li> </ul>	<p>Three clusters</p> <ul style="list-style-type: none"> <li>• Low adjusters (30%)<sup>a</sup></li> <li>• Moderate adjusters (25%)</li> <li>• High adjusters (45%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• High adjusters were older, more educated, and more likely to have a previous stroke</li> <li>• Low adjusters were more likely to have had a severe stroke, and worse quality of life, mood, and disability during stroke recovery</li> </ul>	<ul style="list-style-type: none"> <li>• Quality rating: 3.85 (low)</li> <li>• Strengths: longitudinal design, performed a priori power calculations, reliability and validity of variables reported</li> <li>• Quality rating: 8.13 (high)</li> </ul>
Lopes et al. (2018)	COPD; Brazil; n = 150; age 68 (±8.3); 33% female	Lung function, physical activity, quality of life (CRQ), self-efficacy (GSE), social support (MOS-SSS)	<ul style="list-style-type: none"> <li>• SPSS version 18.0</li> <li>• Cluster analysis</li> <li>• Two-step approach</li> <li>• Hierarchical cluster analysis (Ward's method)</li> <li>• K-means cluster analysis, repeated on a random sample (50% of the cases)</li> </ul>	<p>Two clusters</p> <ul style="list-style-type: none"> <li>• Distressed (63%)<sup>a</sup></li> <li>• Coping (37%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• The distressed cluster was younger, less educated, had more disability, more symptoms, worse QoL, and worse self-efficacy</li> <li>• Clusters did not differ in social support, activity level, or disease severity</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: study population well specified</li> <li>• Weaknesses: cross-sectional design, reliability and validity of variables not reported</li> <li>• Quality rating: 5.38 (low)</li> </ul>
Turkington et al. (2018)	Disabling hand injury; United Kingdom; n = 62; age 54 (SD not reported); 40% female	Coping (Brief COPE), function (QuickDASH), mood (PHQ-9), quality of life (SF-36), trauma distress (IES-R)	<ul style="list-style-type: none"> <li>• SPSS, version 22.0</li> <li>• Cluster analysis</li> <li>• Milligan's two-stage method</li> <li>• Hierarchical cluster analysis (Ward's clustering method)</li> <li>• Dendrogram and agglomeration schedule</li> </ul>	<p>Two clusters</p> <ul style="list-style-type: none"> <li>• Cluster 1 (48%)<sup>a</sup></li> <li>• Cluster 2 (52%)<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cluster 1 was younger, had poorer function, more negative coping, and more injury selfblame</li> <li>• Cluster 1 also had poorer quality of life and higher risk of experiencing depression and trauma symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Strengths: performed a priori power calculations, study population specified</li> <li>• Weaknesses: cross-sectional design, reliability and validity of variables not reported</li> <li>• Quality rating: 6.92 (high)</li> </ul>

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Note: Further details about quality assessment and rating can be found in Table S1.

Abbreviations: BDI, Beck Depression Inventory; BMQ, Beliefs about Medicines Questionnaire; CCQ, Cancer Coping Questionnaire; CRQ, Chronic Respiratory Disease Questionnaire; DAPOS, Depression, Anxiety, and Positive Outlook Scale; DDS-17, Diabetes Distress Scale-17; GSE, General Self-Efficacy Scale; HADS, Hospital Anxiety and Depression Scale; HAQ, Health Assessment Questionnaire; HAQ-DI, Stanford Health Assessment Questionnaire Disability Index; HPDAQ, Hypertensive Patient's Drug Adherence Questionnaire; INQoL, Individualized Neuromuscular Quality of Life Questionnaire; IR, Illness Representation; IRB, Institutional Review Board; MPQ, McGill Pain Questionnaire; MOS-SSS, Medical Outcomes Study Social Support Survey; NEADL, Nottingham Extended Activities of Daily Living Scale; PHQ-9, Patient Health Questionnaire 9; PRAISE, Pulmonary Rehabilitation Adapted Index of Self-efficacy; QuickDASH, Disabilities of the Arm, Shoulder, and Hand; IES-R, Revised Impact of Event Scale; SCBC, Self-care Behaviors Checklist; SD, standard deviation; SF-36, Short Form-36 Health Survey.

<sup>a</sup>Cluster groups analyzed in Table 3.

**TABLE 3**

Comparison of cluster groups with the best and worst outcomes

Study	Sample	Consequences	Identity	Emotion	Cyclical	Coherence	Timeline	Treatment control	Personal control
Hobro et al. (2004)	Chronic pain	X	-	X	O	Y <sup>a</sup>	X	Y	Y
Hsiao et al. (2012)	Hypertension	X	X	X	X	O	O	O	X
Lin and Heidrich (2012)	Mild cognitive impairment	X	X	X	Y	Y <sup>a</sup>	O	O <sup>a</sup>	O <sup>a</sup>
Graham et al. (2013)	Muscle disease	X	X	X	X	O	X	Y	O
McCorry et al. (2013)	Breast cancer	X	X	-	X	Y	X	Y	O
Harrison et al. (2014)	COPD	X	X	X	X	O	X	O	O
Norton et al. (2014)	Rheumatoid arthritis	X	X	-	X	O	O	Y	O
Flora et al. (2015)	Cardiac rehab	X	X	O	O	O	O	O	O
Berry et al. (2017)	Type 2 diabetes	X	X	X	X	O	O	O	O
Aujja et al. (2018)	Post-stroke	X	X	X	X	O	X	O	O
Lopes et al. (2018)	COPD	X	X	X	X	Y	O	O	O
Turkington et al. (2018)	Hand injury	X	-	X	X	X	X	Y	Y

Note: The letters in each table cell indicate if there were significant differences between the groups authors identified as associated with the best and worst outcomes in their mean scores for a given subscale. X indicates that the group with the best outcomes had significantly lower scores on that subscale than the group with the worst outcomes ( $p < .05$ ). Y indicates the inverse—the group with the best outcomes had significantly higher scores on that subscale than the group with the worst outcomes. O indicates no significant difference in scores for that subscale. Dashes indicate that a given subscale was not included in that study. *T* tests were done for all studies except Harrison et al. (2014) which reported Pearson's *r* differences and Aujja et al. (2018) which reported  $\chi^2$  results.

Abbreviation: COPD, chronic obstructive pulmonary disease.

<sup>a</sup>The authors chose to invert the subscale scores from the direction given by the IPQ-R authors. The letter indicated in this table was chosen to harmonize the inverted values with the majority of the studies to have consistent interpretations.