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Review of the literature

Assessment of illness representations in mental disorders: A mini review

Évaluation des représentations dans les troubles psychiques : une mini revue

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A B S T R A C T

Health beliefs, and especially illness representations, have been widely used to understand clinical outcomes and psychosocial adjustment in people with physical diseases. However, this area of research has been under-explored in the field of mental health, and the few studies that have been conducted have used very different methods. Therefore, the aim of our study was to identify the tools and methods that have been used to evaluate illness representations in psychiatry. To this end, a mini review has been conducted and 58 articles were retained. This mini review highlights that the quantitative method is the most used, and that the scales mobilised are often adapted for the study, but not validated. Indeed, multiple modifications and adaptations have been made by the authors (e.g. deletion of subscales, addition of items), which lead to questions about the reliability of what is measured. In the future, it is essential to have a validated generic tool for mental disorders, which could be based on the Illness perceptions questionnaire for schizophrenia.

R É S U M É

Les croyances en matière de santé, et en particulier, les représentations de la maladie, ont été largement utilisées pour comprendre les issues cliniques et l'adaptation psychosociale des personnes présentant une maladie physique. Cependant, ce domaine de recherche a été sous-exploré en psychiatrie. Pourtant, les premiers résultats dont nous disposons semblent prometteurs. En effet, ils soulignent que dans de nombreux troubles mentaux, les représentations de la maladie sont corrélées aux comportements de santé (comme par exemple, l'adhérence au traitement, l'engagement dans le soin), ainsi qu'à l'adaptation psychosociale (comme par exemple, la qualité de vie). Cependant, les études évaluant les représentations de la maladie en santé mentale se sont confrontées à l'absence d'outils spécifiquement conçus et validés pour les personnes présentant un trouble psychiatrique, conduisant à d'importantes différences méthodologiques au sein de la littérature. Or, pour disposer d'une connaissance fiable des représentations de la maladie en santé mentale, il nous semble indispensable de comprendre comment ces représentations sont mesurées. Ainsi, l'objectif de cette mini revue est d'identifier les outils et les méthodes qui ont été utilisés pour évaluer les représentations de la maladie des personnes atteintes de différents troubles mentaux. À partir des bases de données électroniques PsycINFO, PsycARTICLES, Web of Science et PubMed, nous avons retenu 58 articles scientifiques portant sur les représentations de la maladie de personnes présentant un trouble psychiatrique. Nos résultats indiquent que les outils les plus utilisés sont ceux qui ont été validés auprès de personnes ayant un trouble physique, plus précisément *Illness perception questionnaire revised* et le *Brief illness perception questionnaire*. Afin de les adapter aux troubles mentaux, la plupart des études ont procédé à de multiples adaptations et modifications de ces outils (par exemple, des sous-échelles ont été modifiées ou supprimées, des questions sont ajoutées, des phrases

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reformulées). Il est également important de relever que même les outils qui ont été validés auprès de personnes présentant un trouble psychiatrique ont également l'objet de modifications selon les études, c'est notamment le cas de l'*Illness perceptions questionnaire for schizophrenia*. Ces multiples modifications et adaptations peuvent conduire à s'interroger sur la fiabilité de ce qui est mesuré, et donc des connaissances qui en sont issues. Si l'étude des représentations de la maladie en psychiatrie semble tout à fait essentielle, il est indispensable que les recherches futures adoptent une méthodologie plus rigoureuse et homogène. Pour ce faire, l'utilisation d'un questionnaire transdiagnostique s'inspirant de l'*Illness perceptions questionnaire for schizophrenia* apparaît être tout indiqué.

1. Introduction

Mental disorders are often characterised by low adherence and poor health outcomes [1–5]. Therefore, it is essential to understand the processes underlying health behaviours of people with a mental disorder. Several models (e.g. Health Belief Model [6]; Self-Regulation Model [7]; Theory of Planned Behaviour [8], Capability–Opportunity–Motivation–Behaviour System [9]) have shown that beliefs and attitudes about illness play a central role in health behaviours. More specifically, illness representations, i.e. a set of beliefs about the nature of an illness, may influence an individual's coping with illness, psychosocial adjustment and emotional responses. While these associations have been widely investigated for physical illness (for meta-analysis, see [10,11]), studies in the field of mental health are more rare. They point out that, across a wide range of mental disorders, illness perceptions are associated with health behaviour (e.g. adherence, preference for treatment) and psychosocial adjustment (e.g. quality of life) (for a review, see [12–14]). Thus, despite the small number of studies on the subject, illness representations seem to provide an interesting heuristic framework for understanding the adaptation to illness of people with a mental disorder.

Initially, Weinman, Petrie, Moss-Morris & Horne [15] created the illness perception questionnaire (IPQ) to measure illness representations for various physical illnesses. The IPQ evaluates five dimensions of illness representations: causes (factors believed to be responsible for the illness or condition), identity (overall comprehensibility of the illness), timeline (considering whether the illness is chronic), consequences (assessing its impact on life, including physical, emotional, social and economic outcomes) and cure/control (belief that the illness is cured by treatment or can be controlled by the patient's actions). Thereafter, a revised version was proposed, the Illness perception questionnaire revised (IPQ-R; [16]). The IPQ-R evaluated additional dimensions: emotional representation (emotional impact or emotional response to the illness), coherence (how people understood their illness), chronicity and cyclicality (previously combined in timeline), personal control and treatment control (previously combined in cure/control). More recently, a brief version was created, the Brief illness perception questionnaire (B-IPQ [17]), that measures in nine items, all illness representations, except cyclicality, is today a popular tool [18]. All of these tools have been validated with people with various physical illnesses. As a result, the few studies conducted in the field of mental health have been confronted with the lack of tools specifically validated for mental disorders. Yet, in order to have reliable knowledge about the illness representations for mental disorders, it is necessary to understand how these representations are captured. For these reasons, the aim of the current review is to identify the tools and methods that have been used to evaluate illness representations for people with mental disorder.

2. Method

To identify articles evaluating illness representations in mental disorders, we used the following keywords: self-regulation model OR illness perception* OR illness representation* OR AND mental disorder* OR mental health. We conducted electronic searches on PsycINFO, PsycARTICLES, Web of Science and PubMed to identify both qualitative and quantitative studies published between 1980 and June 2017.

The following inclusion criteria were applied:

- published empirical study (quantitative or qualitative) or research report examining illness representations of people with mental health problems;
- article written in English or French and published in a peer-reviewed journal.

Articles were excluded if they:

- were published as a book chapter;
- were not written in English or French;
- explored illness representations for physical diseases;
- explored illness representations from the perspective of healthy people.

Data were extracted by one reviewer. All titles and abstracts yielded in the initial search were screened by one reviewer to identify articles for full-text retrieval and checked by two reviewers. All full-text articles were independently screened by the three. Data were extracted by one reviewer and checked for accuracy by another reviewer. The extracted data were:

- author;
- year;
- mental disorder studied;
- study design and methodology;
- measures used (See E-component).

The literature searches produced 6384 results, but 2271 papers were excluded because they were duplicates. The screening of titles and abstracts led to a further 2645 being excluded, either because of the type of article (e.g., book, editorial, language) or the nature of the population (physical illness, healthy individuals), or because the articles were not accessible. Full-text screening resulted in the exclusion of a further 1414 articles, because they did not address illness perceptions or psychiatric diagnoses, were reviews, theoretical papers or case studies. In addition, four papers [19–22], published after June 2017, were added, as they were relevant to this review. At the end of this screening process, a total of 58 studies remained. Fig. 1 shows a flow diagram for the study selection process.

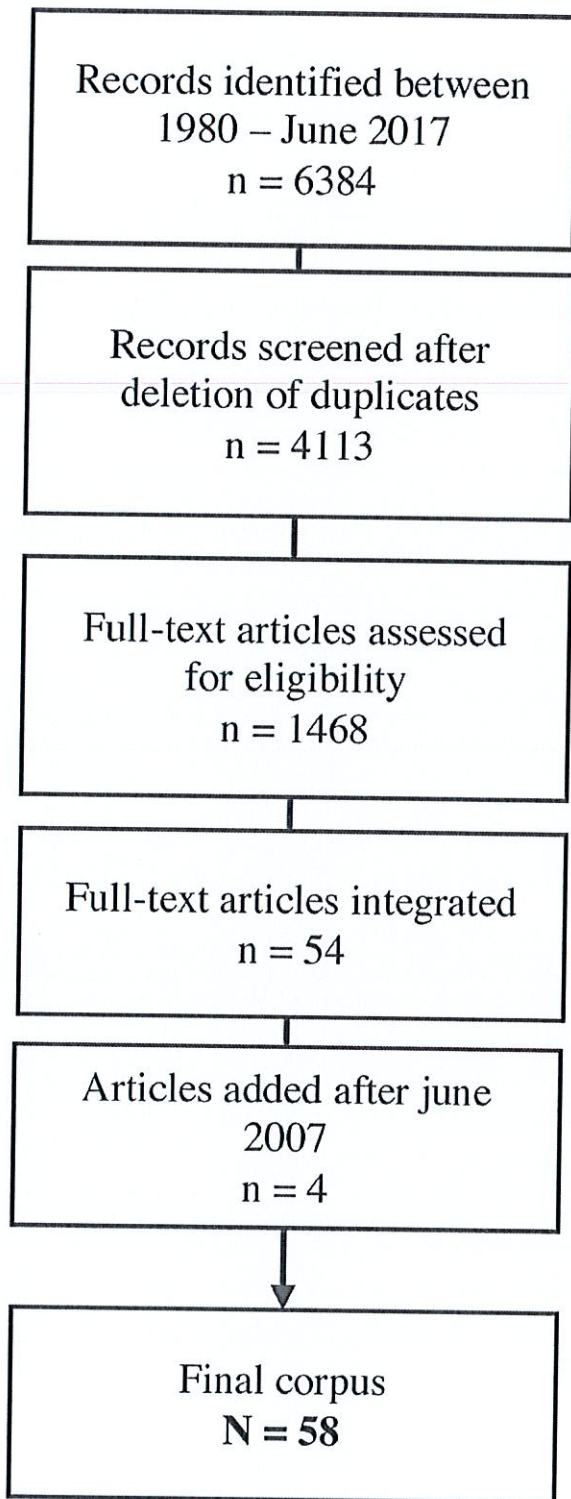


Fig. 1. Flow diagram for the study selection process.

3. Results

Our review showed that in order to evaluate illness representations for people with mental disorders, the quantitative method is mainly used. The main questionnaires used are those that have been validated for physical diseases (IPQ-R and B-IPQ). To a lesser extent, questionnaires have been specifically validated

for mental disorders (Modified-Illness representations questionnaire: M-IPQ; Illness perceptions questionnaires for schizophrenia: IPQ-S). Finally, two studies used qualitative approach. The Table 1 describes the different tools used.

3.1. Illness perception questionnaire revised (IPQ-R)

The IPQ-R was the most used to assess illness representations for mental disorders (Table 2). It was used for people with mixed mental disorders ($n=7$; [23–29]), unipolar disorders ($n=5$; [30–34]), eating disorders ($n=3$; [35–37]), mood disorders ($n=2$; [38,39]), bipolar disorder ($n=1$; [40]), or affective and disruptive disorders ($n=1$; [41]). In order to adapt its use to mental disorders, the authors have made several adaptations and modifications, which are summarised in Table 3. More precisely, seven studies [26–29,31,33,41] replaced the term “illness” in the scale instructions with “depression” [31,33], “mental health problems” [27], “mental illness” [28], “problems” [29] or “behavioural/emotional problems” [26,41]. In addition, seven studies [27–33] changed the subscales of the IPQ-R. The cause subscale is the one that has been modified the most, either by adding items [30], by replacing it with other tools (e.g. Faller’s self-report on perceived causes [27], the causal belief questionnaire [29]), or by creating new categories (e.g. psychological attributions, physical attributions, and social attributions [33], or family-related stress, social stress, alcohol and other drugs [28]). In three studies, the identity subscale was replaced by items of the Symptom Checklist-90 [29], the Brief Symptom Inventory [28], or the Patient Health Questionnaire-9 [31]. In one study [32], the cure/control has been divided into three categories: external control, personal control, and treatment control. The same study also divided the timeline into three categories: acute, cyclical, and chronic. Another used only the strongest-loaded item by dimension [30]. Finally, a total of nine studies deleted items or subscales [25,26,29,31,33,38–41]. Among them, three studies [38–40] removed the cause and identity subscales; two studies [25,33] suppressed the identity or some items from this subscale [29]; and two others [26,41] used only two subscales (timeline and personal control), and deleted all others.

3.2. Brief Illness Perception Questionnaire (B-IPQ)

The B-IPQ has also been used to assess illness representations in various mental disorders as shown in Table 2. Specifically, it was used for bipolar disorder ($n=7$; [20,21,42–46]), psychotic disorders ($n=4$; [47–50]), mixed mental disorders ($n=3$; [51–53]), attention deficit hyperactivity disorder ($n=2$; [22,54]), or unipolar disorders ($n=1$; [55]). As for IPQ-R, in order to adapt its use to mental disorders, the authors have made several adaptations and modifications, which are summarised in Table 3. Among the modifications made, two studies replaced the term “illness” in the scale instructions with “mood swings” [42,43] or “attention deficit hyperactivity disorder” [22]. In addition, nine studies [20–22,42,43,45,46,52,53] changed the subscales of the B-IPQ. The cause subscale is the one that has been modified the most, either because it has been replaced by other tools (e.g. cause subscale of the IPQ-R [52,53], the perceived etiology of bipolar disorder [45,46]), because items have been added [52,53], or because open-ended questions were used [22,42,43]. Concerning other subscales, items have been added concerning personal effort [42,43], self-blame [42,43], or the degree of agreement with diagnosis [20,21]. Furthermore, one study used two items to measure treatment control instead of one [22]. Finally, a total of eight studies [21,44,47–49,52,54,55] deleted items or subscales, especially cause [21,44,47–49,54], coherence, concern [52,55], treatment [52] and emotional representations [55].

Table 1
Description of the different tools used in mental health and the dimensions of the illness representations measured.

Tools	References	Numbers of items	Identity	Causes	Consequences	Dimensions of illness representations measured						
						Chronicity	Cyclicity	Personal control	Treatment control	Emotional response	Coherence	Self-blame
IPQ-R	n = 19 [23–41]	70	X	X	X	X	X	X	X	X	X	
B-IPQ	n = 17 [20–22,42–55]	9	X	X	X	X		X	X	X	X	
IPQ-S	n = 12 [19,56–66]	131	X	X	X	X	X	X	X	X	X	X
IPQ	n = 5 [67–71]	38	X	X	X	X		X	X			
M-IPQ	n = 3 [72–74]	45	X	X	X	X		X	X			
Qualitative studies	n = 2 [75,76]		X	X	X	X	X	X	X	X	X	X

IPQ-R: Illness Perception Questionnaire-Revised; B-IPQ: Brief Illness Perception Questionnaire; IPQ-S: Illness Perception Questionnaire for schizophrenia; IPQ: Illness Perception Questionnaire. The number of items indicated here is that of the original versions of the tools. It does not take into account adaptations made in some studies. These modifications are specified in Table 3.

Table 2
The tools used according to the disorder studied (n).

	IPQ-R	B-IPQ	IPQ-S	IPQ	M-IPQ	Qualitative method
Psychotic disorders	–	4	10	2	3	1
Unipolar disorders	5	1	–	2	–	1
Bipolar disorders	1	7	1	–	–	–
Mood disorders	2	–	–	–	–	–
Eating disorders	3	–	–	–	–	–
Mixed mental disorders	7	3	1	–	–	–
PTSD	–	–	–	1	–	–
ADHD	–	2	–	–	–	–
Affective and disruptive disorders	1	–	–	–	–	–
Total n (%)	19 (33%)	17 (29%)	12 (21%)	5 (9%)	3 (5%)	2 (3%)

IPQ-R: Illness Perception Questionnaire-Revised; B-IPQ: Brief Illness Perception Questionnaire; IPQ-S: Illness Perception Questionnaire for schizophrenia; IPQ: Illness Perception Questionnaire; ADHD: Attention deficit hyperactivity disorder; PTSD: Post-traumatic stress disorder.

Table 3
Mains modifications done according to the different tools (n).

	IPQ-R	B-IPQ	IPQ-S	IPQ	M-IPQ
Changes in terms	7	3	–	–	1
Changes in dimension(s)/item(s)	7	9	2	4	1
Deletions of dimension(s)/item(s)	9	8	8	1	–

IPQ-R: Illness Perception Questionnaire-Revised; B-IPQ: Brief Illness Perception Questionnaire; IPQ-S: Illness Perception Questionnaire for schizophrenia; IPQ: Illness Perception Questionnaire.

3.3. Illness perception questionnaire for schizophrenia (IPQ-S)

The IPQ-S was used primarily to explore illness perceptions of psychotic disorders (n = 10; [56–65]) and more rarely for mixed disorders (n = 1; [66]) and bipolar disorders (n = 1; [19]). Although this scale has been validated specifically for schizophrenia, it has also undergone some changes, which are summarised in Table 3. A total of eight studies [19,56,57,59,61,63,64,66] removed subscales, including personal blame [57,59,61,64,66], identity [19,56,57,64], cause [56,57,59,61,63,64], cyclicity, personal control [57] and emotional representations [59]. In addition, two studies [58,62] modified the subscales, either by replacing the identity subscale with items from the positive and negative syndrome scale [58], or by categorising the cause subscale in three factors: mental health problems, side effects of medication, and other factors [62]. Finally, one study [61] used both the total score and the subscores of the IPQ-S. The IPQ-S is available in E-component (2).

3.4. Illness perception questionnaire (IPQ)

The IPQ was used to measure illness representations in psychotic disorders (n = 2; [67,68]), unipolar disorders (n = 2; [69,70]),

and post-traumatic stress disorder (n = 1; [71]). As with the IPQ-R and B-IPQ, several changes have been made by the authors to adapt these scales to psychiatric disorders. A total of four studies [68–71] changed the subscales of the IPQ. Among them, three studies changed the cause subscale, either by reducing it to two internal causes [68], or dividing it into five factors [69] or two factors [71]. In addition, two studies [70,71] added items to assess perceived consequences; one study [69] added several items to assess emotional reactions; one other [71] reduced the controllability subscale; and one study [68] deleted the consequences and identity subscales.

3.5. Modified illness perception questionnaire (M-IPQ)

The M-IPQ has been used exclusively for psychotic disorders (n = 3; [72–74]). Just like the IPQ-S, although this scale has been validated specifically for mental disorder, it has also undergone some changes, which are summarised in Table 3. Among the modifications made, one study [73] replaced the term “illness” in the scale instructions with “problems/illness”. This same study added items to measure treatment and cure/control subscale. Finally, one study

[74] added items to the cause subscale and reduced the items in the identity subscale to capture only positive symptoms.

3.6. Illness representation/perception interview

A qualitative method was used to explore illness perceptions in psychotic disorders (illness perception interview [76]) and in unipolar disorders (illness representations interview [75]). Among them, one study [76] asked participants to write on a paper "What do you understand by the term schizophrenia?". The second conducted an interview to assess the different dimensions of the illness representations [75].

4. Discussion

Across a wide range of mental disorders, illness perceptions are associated with health behaviour (e.g. adherence, preference for treatment) and psychosocial adjustment (e.g. quality of life) (for a review, see [12–14]). Thus, illness representations seem to provide an interesting heuristic framework for understanding the adaptation to illness of people with a mental disorder. However, illness representations have been studied mainly for physical diseases and much less for psychiatric disorders. In addition, most of the measurement tools have been validated exclusively with people with physical disorders. Consequently, the few studies conducted in the field of mental health have been confronted with the lack of tools specifically validated for mental disorders. Nevertheless, in order to have a reliable knowledge of illness representations for mental disorders, it is necessary to understand how these representations are captured. For these reasons, the objective of this study is to identify the tools and methods that have been used to evaluate the illness representations for people with mental disorders.

This mini review highlights that the main tools used to measure illness representations of psychiatric disorders are those initially created for physical diseases, such as IPQ-R and B-IPQ. However, in order to adapt their use to mental disorders, the authors have made several adaptations and modifications (e.g. subscales are modified or deleted, items are added). Even more surprisingly, even tools validated for mental disorders, such as the IPQ-S, are also widely modified in many studies. These multiple modifications and adaptations lead to questions about the reliability of what is measured. Indeed, the suppression of certain subscales is particularly problematic because illness representations are not necessarily independent [15]. In addition, measurement heterogeneity limits the replication of results and the emergence of reliable knowledge. On the basis of these different elements, we can interrogate whether we have a clear understanding of illness representations of mental disorders. To solve these problems, it is essential that we have a validated generic tool for mental disorders, like what is done in the somatic field with IPQ-R. To this end, the IPQ-S appears to be the most suitable. It has already been validated in English and German [58,60], used in bipolar disorders [19] and in various mental disorders [66]. Only the identity subscale of the IPQ-S, which measures perceived symptoms of schizophrenia, could be specific to the disorder being studied. Finally, the cause subscale is the one that has been most modified or deleted because it is judged to be either irrelevant or too difficult to analyse. Indeed, its analysis is very heterogeneous. Some studies examine each cause independently (e.g. [19]); others categorise causes into different factors (e.g. [33]). In concordance with Moss-Morris et al. [16], we recommend using the causal subscale of the IPQ-S and then performing a principal component analysis.

Beyond issues related to measurement tools, it is important to continue research on the illness representations in the field of psychiatry in order to better understand the processes underlying

health behaviours of people with a mental disorder. To this end, reliable tools are needed. Therefore, in the future, it is essential that new tools be created and validated with people with mental disorders.

Author contributions

PA, EC and LD designed the study and drafted the manuscript.

Disclosure of interest

The authors declare that they have no competing interest.

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