Illness perceptions in mental health: Issues and potential applications

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Understanding patients’ perceptions of their condition has proved a useful way of predicting behaviour in patients suffering from physical illness or injury. Now more investigators are examining how illness perceptions can be applied to the mental health area by considering how patient views of their mental health problem relate to psychological and treatment outcomes. We believe this work has potential to lead to improved understanding of behaviour in patients with psychological disorders and may offer new applications and approaches to improve patients’ adjustment to their illness.

The work on illness perceptions is based on a self-regulation theory developed by Howard Leventhal. The theory proposes that individuals form common-sense beliefs concerning their illness in order to understand and cope with health threats (Leventhal et al., 1997; Leventhal, Nerenz, & Steele, 1984). Individuals are seen as actively trying to understand their symptoms and illness and it is the nature of this understanding process that drives the patient’s coping and emotional responses to the health threat. The process is a dynamic one where information about the illness or changes in symptoms may cause a re-evaluation of an individual’s perceptions of their illness and a consequent shift in a patient’s coping patterns, help seeking or emotional response.

Research has established that patients’ ideas about their illness coalesce around five main components. These components usually form a logically consistent pattern of beliefs about the illness. These components have been well established in physical illness but it is likely there may be some differences in patients with mental disorders. The first of these components are the personal beliefs patients have about what caused their condition. Causal beliefs are often prominent following the diagnosis of an illness as the individual seeks to understand why they have developed the condition and they are often drawn from shared cultural understandings about a particular illness. Research has shown that psychosocial factors are often identified by the public as the likely cause of depression whereas organic disorders such as a genetic problem or a brain disorder are seen as the most likely causes of schizophrenia (Jorm et al., 1997a; Schomerus, Matchinger, & Angermeyer, 2006). Causal
beliefs tend to also be important as they influence in logical ways the type of treatment patients seek out for their condition and the types of lifestyle changes they make to try and manage or eradicate their illness. Thus psychotherapy tends to be favoured over medication for depression whereas medication is seen as more appropriate for disorders seen as having biological causes (Jorm et al., 1997b Lauber, Nordt, & Rossler, 2005.

Another important dimension of illness perceptions is the identity component that is made up of the symptoms the patient believes are part of the condition as well as the illness label. Often in physical disorders, patients attribute a wider range of symptoms to their condition than the medical staff treating them, but it is not clear whether this is the case in patients with mental health problems. There is evidence that the level of knowledge about the symptoms of mental health disorders in the general population is poor which is likely to lead to a greater misattribution of symptoms (Lauber, Nordt, Falcato, & Rossler, 2003). Furthermore, the diagnoses used for mental health problems are more often associated with negative connotations and it is not clear how this influences the construction of the identity component for mental illnesses (Rose, Thornicroft, Pinfold, & Kassam, 2007).

Perceptions about the time course of the illness make up another component of illness perceptions and patients generally characterize their illness along an acute – chronic dimension. Often it is hard for individuals to conceive of an illness having a chronic course that will last for the rest of their life. A more likely model with mental illnesses is the adoption of an acute or cyclical view of the illness, where the condition appears under a particular set of circumstances such as after stressful life events. Timeline perceptions can have a close association with adherence to treatment in mental illness, especially when the patient does not adopt a chronic timeline perception for their condition and therefore an on-going medication regimen does not make sense (Clatworthy, Bowskill, Rank, Parham, & Horne, 2007).

The beliefs patients hold about how their condition is treated and the effectiveness of the available treatment make up the illness perceptions cure-control component. Patients who have stronger beliefs about the efficacy of treatment and less concerns about the nature of the treatment tend to better adhere to treatment and rehabilitation programmes. Cure-control component beliefs can be divided into perceptions about how much treatment, such as medication, is likely to help their condition and how the patient’s own behaviour can influence the course of the illness. Lay beliefs about the effectiveness of treatments for mental health disorders tends to be negative, particularly for psychopharmacological medication and this is likely to influence the adoption of medication treatment and adherence (Lauber, Nordt, Falcato, & Rossler, 2001; Lauber et al., 2005).

The final illness perception component is called consequences and characterized as the perceived effect of the illness on the patient’s life. The consequences component includes general beliefs about the impact of the illness on the patient’s personal life, family, social relationships and finances as well as how disabling the illness is likely to be. The poor level of knowledge in the general public about mental illness and in some cases the nature of the illness itself, such as depression, may influence some patients to adopt overly negative consequent beliefs which in turn can adversely affect the adoption of more active coping strategies.

Generally the various illness perception components show logical inter-relationships. When illnesses are seen as having large consequences they are usually also perceived as having a longer timeline and poorer treatment efficacy. Symptoms also play a critical role in the development of illness perceptions. When there are no symptoms it is hard for patients to maintain that they have an on-going illness. Perhaps the most interesting aspect of illness
perceptions is how much illness perceptions vary between patients who have similar conditions. It is this individual perspective that lies at the heart of illness perception work. This approach proposes that by understanding the way a patient conceives of their condition can help understand their behaviour and lead to new ways to assist their adjustment to illness (Weinman & Petrie, 1997). A number of researchers have looked at how illness perceptions may be applied in the mental health area.

The first question that arises in this work is whether illness perceptions are relevant to all or only some types of mental illnesses. Initial work suggests that illness perceptions are applicable across a wide range of common mental health disorders, including schizophrenia (Lobban, Barrowclough, & Jones, 2004), non-affective psychotic disorder (Watson et al., 2006), bipolar disorder (Pollack & Aponte, 2001), anorexia nervosa (Holliday, Wall, Treasure, & Weinman, 2005) psychotic or personality disorders (Broadbent, Kydd, Sanders, & Vanderpyl, 2008) depression (Fortune, Barrowclough, & Lobban, 2004; Bhui, Rudell & Priebe, 2006), and anxiety (Bhui et al., 2006). Qualitative research has shown that illness representations are also applicable in the early stages of dementia (Harman & Clare, 2006), although their utility in the later stages of the illness is unclear. The usefulness of illness perceptions in many other conditions such as ADHD, sexual and gender identity disorders, or impulse control disorders, is yet to be established.

Standardized questionnaires commonly used to assess illness perceptions include the IPQ (Weinman, Petrie, Moss-Morris, & Horne, 1996), the IPQ-R (Moss-Morris et al., 2002) and the Brief IPQ (Broadbent, Petrie, Main, Weinman, 2006). The validity and reliability of these questionnaires in people with mental illness has generally been supported. The Illness Perception Questionnaire has been successfully used with patients with psychosis (Watson et al., 2006) and depression (Fortune et al., 2004), the Illness Perception Questionnaire-Revised with individuals with anorexia nervosa (Holliday et al., 2005) and the Brief Illness Perception Questionnaire with patients with psychosis and personality disorders (Broadbent et al., 2008). Lobban and colleagues have also developed a modified Illness Perception Questionnaire for patients with schizophrenia (Lobban, Barrowclough, & Jones, 2004) as well as a relatives’ version (Lobban, Barrowclough, & Jones, 2005).

While these questionnaires have been usefully applied, they may still be missing some domains that are central to mental illness but not physical illnesses. Relatively few qualitative studies have been performed to investigate the underlying dimensions of mental illness beliefs, and more research could be useful in this area. Those studies that have been done have found that, similar to people with physical conditions, patients with mental illness do form cognitive representations of their condition (Pollack & Aponte, 2001; Kinderman, Setzu, Lobban, & Salmon, 2006). The content of illness representations in mental illness is somewhat less certain. Reading the accounts reported in these articles, one can identify the usual illness perception dimensions – identity, timeline, causes, control and consequences, but the authors also identify other domains using content analysis.

Pollack and Aponte (2001) interviewed hospitalized bipolar patients (most admitted with psychotic symptoms and more than half involuntarily) and reported themes of “coming to terms with the diagnosis”, “the importance of personal metaphors”, and “dealing with the medical model”. Other qualitative work with inpatients and outpatients with schizophrenia reported other themes, such as “inseparability of illness from patients’ identity”, “flexibility and uncertainty of beliefs”, “social dimensions of illness labels”, “separation of current self from past experiences”, and “hopelessness and resignation” (Kinderman et al., 2006). Many of these themes seem removed from the dimensions of illness perceptions, yet it should be remembered that the original studies in the late 1970s did not use current thematic analysis techniques, and it could be that if the accounts of patients with mental
illness were analysed using the original methods, the results may align more closely with the illness perception dimensions.

The timing of illness perception assessment is an important consideration in both physical and mental illnesses. Illness perceptions change over time as the distance from acute illness episodes increase. For example, myocardial infarction patients’ perceptions tend to become more positive over the recovery period, and any researcher needs to consider when the most meaningful time is to assess perceptions in their sample. It would be inappropriate to try to assess illness perceptions when someone is in acute pain such as in the middle of a myocardial infarction, and similarly, those currently experiencing acute psychosis may be too confused to offer valid responses (Kinderman, et al., 2006). Illness perceptions may be best elicited in psychosis when the patient is in remission and better able to make sense of the illness.

In past research in physical illnesses, illness perceptions have predicted important outcomes such as return to work, and medication adherence (Petrie, Jago, & Devcich, 2007). Fewer studies have investigated how illness perceptions are related to functioning in mental illness. However, early results are promising. Lobban et al. (2004) found that illness perceptions were associated with quality of life and coping in schizophrenia, with worse consequences scores found to be the strongest predictor of poor functioning and quality of life. Similarly, illness perceptions in patients with non-affective psychotic disorder were associated with levels of depression, anxiety and self-esteem, with the identity dimension a strong predictor (Watson et al., 2006). Causal attributions to poor medical care or external others predicted poorer medication adherence. In high users of mental health services, negative illness perceptions were associated with high unmet needs, low functioning, a poor attitude to medication and doctor visits (Broadbent et al., 2008).

Many studies have used the illness perception paradigm to investigate associations with outcomes. Yet few have investigated how we can use the theory to improve outcomes. The first randomized trial of an illness perception intervention was conducted in myocardial infarction patients, which successfully altered illness perceptions and resulted in quicker return to work and lower complaints of angina at follow-up (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). There is the potential to replicate these findings in other illness groups and also apply an illness perception intervention to mental disorders. Anecdotal reports are promising, with some researchers reporting that interviews assessing illness perceptions are therapeutic in allowing patients to tell their story, consider new issues and clarify aspects of their illness (Pollack & Aponte, 2001).

There are three areas that appear fruitful in terms of applying an illness perception intervention to improve outcomes in mental health conditions. The first is increasing adherence to therapy. Another is reducing inappropriate service use. Many patients are “frequent attenders” or “high users”, which places increased and often unnecessary burden on health services. The third area is improving family and significant other relationships through analysis and therapy around aligning illness perceptions. Similar to findings in physical illnesses, discrepancies in illness perceptions between patients and their families have been related to poorer outcomes in psychosis patients and their family members (Kuipers et al., 2007).

We believe the illness perception approach has a great deal of potential in the mental health area. It puts the patient’s understanding of their illness at the centre of rehabilitation efforts and this opens up a range of intervention possibilities. While considerable progress has been achieved over a short time within the physical illness realm, much work is needed to successfully apply the illness perception paradigm into mental health. Since the mental health field has a stronger history of cognitive behavioural interventions it is hoped that these techniques can be drawn on and expanded to develop effective illness perception interventions designed to improve patient outcomes.
References


