This chapter describes the role of illness cognitions and beliefs in guiding patients’ responses to illness and shaping health outcomes. The chapter outlines the historical background of research into illness cognitions, reviews theory and evidence, and sets out directions for future research. The chapter examines illness cognitions and beliefs from a lifespan perspective, describing the views of children, young adults, and older adults. In addition, the chapter outlines similarities and differences in beliefs and cognitions based on ethnicity, both from a US and a global perspective. Finally, an overview of interventions to change illness cognitions and beliefs is provided along with evidence of their effects.

**Historical Background, Theory, and Evidence**

Illness cognitions refer to mental processes involved in understanding illness through thoughts, experiences, and perceptions. A set of illness cognitions or beliefs can be described as an illness representation (Cameron, Durazo, & Rus, 2016). A number of researchers have included illness cognitions and beliefs in theories related to health care and health behaviours, as outlined herein.

**The Health Belief Model**

The Health Belief Model (HBM) was developed in the 1950s to help understand why individuals did not engage in preventative health behaviours, and was later applied to research on responses to symptoms and adherence to medical regimes (Janz & Becker, 1984; Rosenstock, 1974). The model proposes that people have beliefs about their susceptibility to an illness, and the seriousness of that illness, which can motivate them to act. In this theory, the choice of action is determined by the perceived benefits of the health behaviour, such as immunity after getting a vaccination. However, barriers to taking the action include beliefs about negative factors, such as side effects, costs, and inconvenience. Cues to trigger action include both the experience of symptoms and informational messages. Background variables, such as demographics, are also theorised to influence people’s beliefs.

A systematic review of longitudinal research showed that susceptibility beliefs were very poor predictors of health behaviours, and perceived severity had small effects (Carpenter, 2010). The best predictors of health behaviours were perceived benefits and barriers, with moderate effect sizes. The model appears to be stronger for predicting preventative health behaviours than for predicting how people manage already-present illness, which aligns with the original intent of the model. This model is further described in another chapter in this book.
Kleinman’s Explanatory Models

Arthur Kleinman, a psychiatrist and medical anthropologist, described health care systems as social and cultural systems that include the professional sector, popular sector, and folk sector (Kleinman, 1978). Socially legitimised beliefs, roles, relationships, and settings within health care systems can differ between societies. In each sector, explanatory models exist that contain explanations about the aetiology of illness, onset of symptoms, pathophysiology, course of sickness, and treatment. Practitioners, patients, and family members can have markedly different explanatory models for the same illness. Conflicts between explanatory models can cause miscommunication between clinicians and patients. Elicitation of patients’ beliefs is important in the clinical context so that clinicians and patients do not talk past each other.

The Common Sense Model of Illness Representation

This theory was informed by the earlier HBM and Kleinman’s explanatory models. The Common Sense Model describes the psychological and behavioural processes that individuals experience in response to health threats. The theory developed over time from both experimental research and patient interviews. It considers the experience of illness from the perspective of a lay person feeling physical symptoms, such as a rash, fever, or pain (Diefenbach & Leventhal, 1996; Leventhal, Meyer, & Nerenz, 1980). The model proposes five domains in which a person actively tries to make sense of their experience, and forms representations about what is causing their symptoms (causal beliefs), what illness they might have (the identity of the illness), how long the illness will last (timeline perceptions), what can be done to make the symptoms go away or reduce in severity (cure/control), and what effects the illness will have for the individual (consequences). In the model, these illness representations can be automatic and non-conscious. The model incorporates ideas about the self-concept, and how the experience of symptoms triggers illness representations due to differences from the normal self-concept. While illness representations are often initiated through the experience of physical symptoms, they can also be triggered through environmental cues, mass media, and the observation of symptoms in others, which increase the likelihood of benign sensations being interpreted as signs of illness.

The Common Sense Model proposes that individuals also have emotional responses to illness, which can include fear, anger, and distress (Diefenbach & Leventhal, 1996). The emotional responses to the illness operate in parallel to the cognitive representations to influence how the individual acts or copes with the symptoms, such as by making a doctor’s appointment, resting in bed, taking a pain killer, or carrying on with usual activities. These actions (or coping procedures) in turn influence health outcomes in the individual. The model incorporates a feedback loop, whereby people evaluate the effectiveness of their actions on their illness, and revise their representations depending on the results.

Individuals generate action plans based on their experience of symptoms and beliefs. Plans include a specific response, a place for performing the action, and a specific time, as well as a set of expectations regarding the outcomes (Leventhal, Phillips, & Burns, 2016). For example, a plan to take blood pressure pills at breakfast time in the kitchen, or a plan to go for a walk around the park after work with a friend.

Evidence for the theory is consistent. There have been several reviews supporting the model and proposed relationships between illness representations, coping, quality of life, and disease states (Broadbent et al., 2015; Hagger, Koch, Chatzisarantis, & Orbell, 2017; Hagger & Orbell, 2003). Studies have also shown negative illness representations are associated with increased mortality (Parfeni, Nistor, & Covic, 2013; Serlachius et al., 2017). The latest review tested a process model based on the theory that coping strategies mediate the relationship between illness representations and health.
outcomes (Hagger et al., 2017). The review concluded that both direct relationships between illness representations and outcomes occur as well as indirect effects via coping.

The five domains of illness representations can also be applied to treatments (Leventhal et al., 2016). In other words, people have mental representations about the name of a treatment and what it involves (its identity); the timeline for when the benefits of treatment will occur; how well the treatment can control or cure the illness (cure/control); and the consequences of treatment, such as getting better or experiencing side effects. One might think of causal beliefs in this context as involving lay representations of how the treatment works. For example, alcohol kills germs in a wound and is experienced as a stinging sensation, or a coronary stent works by physically holding a coronary artery open to keep it from blocking. Representations about medication have been widely studied in terms of patients’ beliefs about their necessity and concerns about their harms. Beliefs about the necessity of medication have consistently been linked to higher adherence whereas beliefs about medication side effects have consistently been linked to lower adherence (Horne et al., 2013).

The impact of illness extends beyond the patient to family members. Family members try to make sense of the patient’s illness and form their own illness representations. These can influence health behaviours of the patient, for example, spousal attributions to poor health habits in patients with myocardial infarction were associated with improvements in patients exercise levels six months later (Weinman, Petrie, Sharpe, & Walker, 2000). Patients tend to have better outcomes when family members’ have perceptions similar to their own. For example, greater differences in perceptions of identity, timeline, and personal control between patients with head and neck cancer and their carers at diagnosis, lead to poor patient quality of life six months later (Richardson, Morton, & Broadbent, 2016).

It is important to note that patients’ representations of illness can differ substantially from medical professionals’ views. For example, mothers of high risk newborns believed their babies were sicker and that treatment was more helpful than clinicians did, whereas clinicians perceived the consequences for babies as greater than mothers did (Brooks, Rowley, Broadbent, & Petrie, 2012). These differences may lead to misunderstandings and misinterpretations in communication. This aligns with Kleinman’s explanatory model theory.

Research suggests that illness representations are valid in a range of mental illnesses as well as physical illnesses, including depression, schizophrenia, anorexia nervosa, bipolar disorder, and anxiety (Petrie, Broadbent, & Kydd, 2008). Higher identity and treatment control perceptions have been associated with seeking mental health care amongst a distressed community sample (Oexle et al., 2015). Causal beliefs about major depression have been associated with the acceptance of treatment amongst low income African Americans (Murphy & Hankerson, 2017). A systematic review in mental health found that perceptions of timeline, controllability and consequences were associated with coping, and treatment control beliefs were associated with adherence (Baines & Wittkowski, 2013).

Causal beliefs are somewhat understudied compared to other illness beliefs and yet are a critical determinant of coping behaviours (Broadbent et al., 2015). For example, women who attributed their breast cancer to lifestyle behaviours were more likely to change their diet and exercise behaviours (Costanzo, Lutgendorf, & Roeder, 2011). Multifactorial causal beliefs about cancer have been associated with higher cancer screening behaviours, suggesting the importance of health messages around both genetic and behavioural causes (Waters, Muff, & Hamilton, 2014). Causal beliefs are also important in social acceptance of disease. For example, in the general public, biological causal beliefs were associated with greater social acceptance of alcohol dependence and yet lower acceptance of schizophrenia and depression, which was mediated by beliefs about dangerousness and differentness (Schomerus, Matschinger, & Angermeyer, 2013).

In terms of future directions, more research is needed to investigate how illness representations develop, including the involvement of non-conscious processes, and how successful coping strategies occur over time (Leventhal et al., 2016). Many studies are correlational in design and more experimental and interventional studies are needed.
Illness Cognitions and Beliefs

Lifespan Perspectives

Research indicates that children make sense of illness in a similar way to adults, but the sophistication of their ideas develops as they age. Interviews have shown that children as young as five years of age have a reasonably good conceptual understanding of illness, and understanding is more sophisticated in nine-year-olds (Bir & Podmore, 1990). Children’s understanding of illnesses (colds, heart attacks, a broken arm, and chicken pox) includes ideas about symptoms, causal factors, and strategies for prevention and treatment. Children mention personal experience, television, school, and parents as sources of information. Their conceptual understandings appear to be related as much to their experience and access to health knowledge as their cognitive development.

Children also understand psychological states, as suggested by similar research into children’s understanding of depression (Charman & Chandiramani, 1995). Most nine-year-olds understood the term depression although the term had to be explained to most five- and seven-year-olds. Once explained, all children mentioned observable signs of depression, and suggested strategies to help combat depression (such as playing, laughing, cuddling, sharing, support, encouragement, and advice). They also understood causal concepts for depression, including isolation and life events. Research suggests that children as young as five also exhibit implicit understandings of a link between stress and illness (Cheetham, Turner-Cobb, & Gamble, 2016).

Illness representations have been measured in children as young as eight years old using the Brief Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006; Chong, Mackey, Broadbent, & Stott, 2012). This research has demonstrated that similar to findings with adults, children’s illness perceptions are related to their quality of life. Illness perceptions have been shown to be relevant to teenagers as well, with research demonstrating associations between illness perceptions, adherence and metabolic control amongst adolescents and young adults with diabetes (Griva, Myers, & Newman, 2000).

Different forms of assessment may be useful across different age groups. Drawings have been utilised to assess conceptualisations of illness in both adults and children from as young as five years old (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004; Chong, Mackey, Stott, & Broadbent, 2013). Children’s drawings of their cerebral palsy and how it affected their life have been related to walking ability, as well as emotional distress (Chong et al., 2013). Research using drawings suggests that children understand illness with a biomedical explanation (Mouratidi, Bonoti, & Leondari, 2016). Through the use of drawings and questionnaires, research has shown that children and young people have quite a sophisticated knowledge of cancer, and perceive the inner city environment as a causal factor, yet have priorities above health such as employment (Oakley, Bendelow, Barnes, Buchanan, & Husain, 1995). Children with cancer draw good days with happy emotions, sunshine, and outdoor activities, whereas they draw bad days with sad emotions, reclining, and experiencing symptoms (Linder, Bratton, Nguyen, Parker, & Phinney, 2017).

The prevalence of illness and disability increases with age. Not only do illnesses such as hypertension and arthritis increase in prevalence, so do functional impairments including impaired cognition, vision and hearing loss. The experience of illness for older adults may therefore differ to those who are younger. Older adults are more likely to have multiple illnesses, may be living with another older adult who also has illness rather than with young family, and may be retired with less earning power (Clark et al., 1991). Older adults from previous generations may have left school at a younger age so have less formal education than younger adults.

Research indicates that older adults differ in their beliefs and perceptions of specific illnesses compared to younger adults (Prohaska, Leventhal, Leventhal, & Keller, 1985). This is accompanied by differences in health behaviours compared to younger adults; better diet, more regular medical check-ups, more consistent sleep patterns, less alcohol, and deliberate avoidance of negative emotions, but less exercise. Younger adults see exercise as more health protective than older adults do, who
see physical exertion as a risk factor for heart attacks. Older adults have higher susceptibility beliefs than younger adults for hypertension, senility and heart attacks, but lower susceptibility beliefs for colds. Older adults also see colds as more serious and senility as more life-threatening than younger adults do. Older adults are also less likely to perceive aches and weakness as signs of illness than youngest adults are. These differences suggest people do understand that age is a risk factor for illness, and that more education could be provided about the benefits of moderate exercise for older adults.

Similar to research in other age groups, illness representations have been linked to quality of life in older patients (Hampson, Glasgow, & Foster, 1995). Beliefs about treatment effectiveness predicted health behaviours including diet and exercise, although not blood glucose testing, in older patients with diabetes. Lower health literacy has been associated with misconceptions about asthma and its treatment in older adults, with health literacy linked to lower adherence both directly and indirectly via medication concerns (Soones et al., 2017). In Korea, illness perceptions have been linked to depression in hospitalised older adults (Yeom & Shin, 2017), demonstrating the applicability of illness perceptions across cultures in older populations.

US Multi-Ethnic Perspectives

Research to date largely supports the structure of the Common Sense Model and the dimensions of illness representations across multiple ethnicities. Research also supports the idea that people hold beliefs about seriousness and susceptibility, and benefits of treatment. Across ethnicities, people tend to attribute causes, have ideas about the effectiveness of different treatments, and have beliefs about the controllability of illness. The specific content of those beliefs can differ between ethnic groups. For example, research has shown that there are many similarities in beliefs about Alzheimer’s disease amongst African Americans and white Americans, including associated symptoms, causes, and treatments (Roberts et al., 2003). However, African Americans believe more strongly that Alzheimer’s disease is just part of growing older, are less concerned about it, have less knowledge of it, and believe more strongly that a cure can be found in the next five years, whereas white Americans believe more strongly that nursing care is necessary. There are also commonalities and differences between ethnic groups within the USA in causal beliefs about birth defects (Case et al., 2014). Beliefs about drugs, alcohol, and tobacco are common across groups, but compared to non-Hispanic whites, Asian/Pacific women are more likely to mention genetic causes, and Hispanic women are less likely to mention chemicals but more likely to suggest childhood events.

Research with African Americans has demonstrated the utility of the Common Sense Model for hypertension (Hekler et al., 2008). In this study, beliefs that hypertension was caused and controlled by medical factors (diet, age, weight) were associated with lower systolic blood pressure which was mediated by lifestyle behaviours (diet, exercise). Beliefs that stress caused high blood pressure were related to stress reduction behaviours but not to blood pressure. In other research, interviews with African Americans about hypertension revealed some possible cultural differences in home remedies that may be detrimental (Pettey et al., 2016). The research also highlighted that people need guidance as to how to change behaviour (otherwise known as developing action plans in the Common Sense Model).

Place of birth has been shown to be an important factor in determining causal beliefs about Multiple Sclerosis amongst Hispanics in the USA (Obiwuru et al., 2017). US-born Hispanics more commonly perceived stress as a cause of multiple sclerosis, whereas immigrants more commonly perceived susto (fright or surprise in English) as a cause. In a study of Latino immigrants in the USA, religious and psychosocial explanations for depression were prevalent, and causal beliefs about personal transgressions and malevolent forces were associated with perceived stigma (Caplan et al., 2011). Awareness of cultural differences may help to design psychosocial interventions in multicultural societies.
Global Perspectives

Beliefs about health and illness have been studied in many countries and in many languages (Broadbent et al., 2015). Again, the structure of the dimensions in the Common Sense Model and hypothesised relationships with coping and health outcomes appear to hold across many different ethnicities around the world. Nevertheless, ethnicity can influence the specific beliefs that people hold within those dimensions.

Culture and language can influence the recognition of symptoms and labelling of illness (Angel & Thoits, 1987). For example, depression is not a formal diagnosis in China so symptoms of emotional disturbance and fatigue are labelled neurasthenia. Such labels can influence coping actions, such as where people seek help from. Religions too, have rules around behaviours that can influence health outcomes, including alcohol consumption, food preparation, dietary restrictions, and sexual behaviours (VonDraas, 2017).

From an anthropological perspective, many cultures have beliefs about illness that are not based on the biomedical model, and consult healers that are not medical doctors (Pachter, 1994). This can become problematic if the treatment is harmful or if it results in a delay in seeking medical care for serious conditions. Where there are differences in causal beliefs and identity perceptions between patients and medical care providers, a clinician needs to negotiate between the two different belief systems. Eliciting beliefs, respecting them, and engaging in cross-cultural discussion may help to improve patient outcomes. There can be a diverse mix of patient ethnicities within a clinic so the clinician has to be aware of a patient’s knowledge and beliefs. For example, a study of patient beliefs in a TB clinic in London, UK, included patients from Africa, Turkey, Asia, the Caribbean, the UK, India, and Latin America, and highlighted a lack of knowledge about the disease that needed to be addressed before trying to educate patients about the importance of treatment (San Sebastian & Bothamley, 2000).

Within cultures, there can be large individual differences in beliefs based on levels of acculturation. With recent trends in globalisation there are multiple and complex effects on health (Huynen, Martens, & Hilderink, 2005). Communication over the internet, increased mobilisation, changes to the environment, and increased cross-cultural interaction influence health-related knowledge, health services, lifestyle behaviours, and access to healthy water and food.

Differences can also exist between countries in physicians’ beliefs. Research across eight European countries (UK, France, Germany, Spain, Ireland, Sweden, Italy, and Switzerland) has demonstrated similarities and differences in pain beliefs between physicians and patients across countries (Woolf et al., 2004). This study showed patients and physicians had similar beliefs about treatment efficacy. However, physicians (except for those in Italy) were more concerned about the risks of non-steroidal anti-inflammatory medications than patients were. There were differences across countries in patients’ knowledge of side effects, and in patients’ and physicians’ fears of tolerance of medication. More than half the patients (except in Sweden) and more than 60% of physicians (except in Italy) thought that the side effects of treatment could be worse than the effects of the condition itself.

There is evidence that beliefs within the Health Belief Model are relevant for screening in Malaysia, which has a multi-ethnic population. Thalassemia is a serious genetic blood disorder and around 4% of the Malaysian population are carriers. Many people perceive the illness as not serious or very rare, and/or have incorrect beliefs that affected children are mentally retarded, bedridden, and physically abnormal (Wong, George, & Tan, 2011). There are misperceptions, with some believing that carriers also have symptoms and need treatment, and that carriers cannot have normal children.

In Middle Eastern countries, a lack of knowledge and perceptions about control, identity, timeline, and consequences of type 2 diabetes have been identified as contributors to poor patient management (Alsairafi, Taylor, Smith, & Alattar, 2016). This includes beliefs around a cure after a short course of treatment, that diet does not matter if medicines are taken, that herbal treatments are effective,
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and unawareness that diet and exercise can help control diabetes. More accurate knowledge of the symptoms of hypo- and hyper-glycaemia, about potential complications, longer timeline beliefs, and higher treatment necessity beliefs have been associated with better adherence. Religious beliefs, particularly fatalism, can discourage patients from engaging in treatments that are against God’s will. Some patients believe that only God and not doctors and medicines can cure diabetes. Ramadan is also an issue, with patients ceasing their medications due to beliefs that if they were not eating they did not need to take their medication. There are also cultural barriers to adopting healthy lifestyles.

Illness representations have been widely studied in the Pacific, and in New Zealand in particular. Maori, the indigenous population of New Zealand, have been shown to have shorter timeline beliefs about schizophrenia than New Zealand Europeans (Sanders, Kydd, Morunga, & Broadbent, 2011). Similarly, Pacific Islanders and South East Asians had shorter timeline beliefs about diabetes than NZ Europeans (Bean, Cundy, & Petrie, 2007). Pacific Islanders also had worse perceptions of consequences, identity (symptoms), and emotional representations.

**Interventions**

The rationale for interventions to change illness perceptions is that changing perceptions will lead to changes in coping behaviours and hence result in improved health outcomes. An early example of an illness perception intervention is with hospitalised myocardial infarction patients (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). This face-to-face psycho-educational intervention was delivered in three sessions, and content was individually tailored to each patient based on an initial assessment of the patient’s illness perceptions. Patients were given an individualised action plan for recovery and adopting healthy behaviour. The intervention changed patients’ perceptions of control, consequences, timeline, and symptom distress, and resulted in quicker return to work as well as lower angina at follow-up. A subsequent trial included the patient’s spouse in the intervention as well, and found similar patient results along with improved spousal outcomes (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009a, 2009b). Three critical features were an initial assessment, individual tailoring of content, and an action plan.

A number of similar interventions have been developed and tested successfully, for example in patients with diabetes and their families (Keogh et al., 2007). Outcomes included fewer symptoms, lower distress, higher perceptions of control, better coherence, changes to lifestyle causal attributions, as well as higher adherence, and improved blood glucose control (Keogh et al., 2011). Another successful intervention based on these principles and motivational interviewing techniques, increased walking and reduced the need for angioplasty in patients with intermittent claudication (Cunningham, Swanson, O’Carroll, & Holdsworth, 2011). A systematic review of interventions to change cognitions about heart disease found that cognitive behavioural techniques are consistently effective (Goulding, Furze, & Birks, 2010). Other techniques to change perceptions include biofeedback, for example with tinnitus patients (Weise, Heinecke, & Rief, 2008).

Many interventions to change cognitions and beliefs are individually delivered. To reduce costs, interventions do not have to be delivered by a health psychologist and can be delivered by a nurse. For example, a nurse-led intervention based on the Common Sense Model changed control beliefs and increased attendance at cardiac rehabilitation in patients with acute coronary syndrome (Cossette, Frasure-Smith, Dupuis, Juneau, & Guertin, 2012). The length of the intervention can be reduced and technology can be used to enhance efficacy. For example, a 15-minute intervention showing how a heart attack occurs and how medications work to reduce artery blockages using computer graph animation of the heart and cardiac arteries successfully changed patients’ medication beliefs and treatment control perceptions (Jones, Ellis, Nash, Stanfield, & Broadbent, 2015). It also resulted in fewer symptoms, lower cardiac avoidance, greater exercise, and faster return to normal activities.
A cost-effective option may be to deliver interventions in group sessions (Weise et al., 2008), or to use mobile-based technology to achieve much wider dissemination of interventions. These have been successfully delivered using text messages for patients with asthma (Petrie, Perry, Broadbent, & Weinman, 2012), and a mobile app for patients with HIV (Perera, Thomas, Moore, Faasse, & Petrie, 2014).

Conclusions

In conclusion, patients form beliefs and cognitions about illness based on the experience of symptoms, past experiences, health information, environmental factors, culture, and social context. These beliefs and cognitions influence the actions people perform to cope with health threats. In the Common Sense Model, perceived illness identity, consequences, timeline, control, and causal attributions predict changes in health behaviours and health outcomes. Illness beliefs are evident in children as young as five years old and grow in sophistication with age. Beliefs about illness appear to exist along similar dimensions in many ethnic groups but can differ in specific content. Illness representations can differ between health professionals and patients. Interventions to change illness beliefs can be effective in changing perceptions, behaviours, and health outcomes. The challenge for future research is to expand the availability and dissemination of interventions using technology platforms in a cost-effective manner.

References

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Illness Cognitions and Beliefs


