

# PATIENTS' BELIEFS ABOUT THEIR CARDIOVASCULAR DISEASE

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In the recent past it was assumed that knowledge guided health related behaviour. Knowledge in turn was seen as driven by information. This led to a simple model that suggested that patients' health related behaviours are driven by information. The approach implied a somewhat passive role for patients whose behaviours could be easily influenced through providing them with information. This position also resulted in surprise at some patients' health related decisions and behaviours, which appeared counterproductive for their health, contrary to medical advice or sometimes idiosyncratic. However, it is apparent that the behaviours of individuals are affected by the attitudes and beliefs they hold. If individuals think something is appropriate for them they may do it; if not, they don't. With regards to their health or ill health, these beliefs and attitudes may be related to undergoing treatments, taking medications, or performing health maintenance behaviours. Importantly, the beliefs and attitudes that guide patients' behaviours are influenced by more than information provision from health care professionals and may be inconsistent with this information.

Fundamental to this approach is to see individuals as active processors and interpreters of their environment who construct models and hold beliefs about the world. When confronted with symptoms or an illness or a threat to their health, individuals appear to actively construct cognitions and beliefs to conceptualise their condition. These influence how they manage the situation and evaluate their management and potential recovery. Patients' cognitions are important influences at all stages of their experience of an illness, including: the perception of symptoms; searching for attributions for the underlying disease; changing of personal behaviours to affect the course and development of the illness; while undergoing therapy or treatment; during the rehabilitative process; and the decision to return to normal daily activities. Treating patients as active theorists, with models of illness, is not new but is often ignored in the clinical situation.

It is only relatively recently that systematic investigations of patients' beliefs and cognition in relation to their health related behaviours have been performed. The importance of this approach has been strengthened with the shift in clinical practice to a more patient centred approach where the patient's perspective of their illness and the implications this has for the management of their condition is taken into consideration during health care. This article will outline selective health, illness, and treatment cognitions. These cognitions are derived from different, and at times, competing theoretical approaches. To attempt to elucidate these theoretical differences is beyond the scope of this paper but rather the paper will highlight the types of cognitions and beliefs that people hold about their illness and treatment.



## HEALTH RELATED COGNITION

Health and illness related cognitions can be segmented into those that:

- ▶ concern the condition itself—that is, illness representations
- ▶ concern the treatments for the condition—that is, treatment representations
- ▶ concern the patients' attempts and ability to manage or resolve their illness and the circumstances it provokes.

These categories are not mutually exclusive, and it is not surprising that there is a great deal of overlap within the different constructions of these cognitions.

### Illness cognitions

A number of researchers<sup>1–4</sup> following triangulation of methods have come to a general consensus that patients' cognitions concerning their illness can be broadly structured into five major categories of beliefs: identity, causality, consequences, time line, and cure/control (table 1). Different researchers may label these slightly differently.

This structure of illness cognitions provides a useful framework from which to start investigating patients' beliefs and considering how the content of these categories influence

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**Table 1** Example categories of patient cognition

<b>Illness beliefs</b>	
▶ Identity	The bodily symptoms and label associated with the illness
▶ Causality	Beliefs about factors contributing to the onset of an illness
▶ Consequences	The expected outcomes and sequelae of the disease
▶ Time line	Beliefs concerning the moment of onset and expectations about the duration and periodicity of an illness
▶ Cure/control	How one may mediate or recover from a disease and the extent to which this is possible
▶ Helplessness	Evaluation of the illness that emphasises the negative meaning of the illness, focusing on the adverse aspects of the disease as uncontrollable, unpredictable and unchangeable
▶ Acceptance	Perceived ability to diminish, live with and master the aversive consequences of one's disease; recognising the need to adapt to the chronic illness
▶ Perceived benefits	Additional positive consequences of the illness situation, such as changes in life priorities and personal goals, positive personality changes, and strengthened personal relationships
<b>Treatment beliefs</b>	
▶ Concerns	The emotional impact and trepidation patients have at undergoing treatment
▶ Necessity	Beliefs about the necessity of the treatment for maintaining health now and in the future
▶ Treatment value	Patients' beliefs about the positive effects of their treatment in controlling and arresting the progress of their illness
▶ Decision satisfaction	Patients' evaluation of the decision process for choosing their treatment
▶ Cure	Patients' beliefs regarding the ability of the treatment to resolve their illness and return them to their normal life
<b>Patient resources</b>	
▶ Coping strategies	Specific efforts, behavioural and psychological, that individuals employ to master, tolerate, reduce, or minimise stressful events
▶ Self efficacy	The belief in one's capabilities to organise and execute the sources of action required to manage prospective situations

health related behaviours. More specifically in cardiac conditions, there are data regarding how the content of each construct influences both behaviours and emotions. Content may be guided by an individual's current or past personal experiences of the illness, authoritative sources such as doctors or health care professionals, and from cultural knowledge of the illness such as lay information from social sources,<sup>1 w2</sup> such that the conglomeration of sources makes a "common sense" representation of the illness and the situation that the individual finds themselves in. It is important to recognise that the clinical interview is only one of many influences on patients' cognitions. The beliefs patients hold have been consistently related with both health related behaviours and the measures that individuals take to deal with their predicament.<sup>5</sup>

The symptoms (identity) one believes to be associated with an illness may be an important influence on seeking help. If an individual does not believe that the bodily sensations they are experiencing are indicative of an important health problem (for example, tightness in the chest as a result of angina or myocardial infarct) they are likely to delay seeking potentially life saving treatment. At the other end of the spectrum, once labelled as cardiac patients or at high risk of coronary conditions, individuals may become over focused on their internal bodily sensations, interpret them as reflecting their cardiac condition, and become debilitated by heart

focused anxiety.<sup>w3 w4</sup> At its extreme this leads to cardiac invalidism and the adoption of a passive, helpless role, guided by the belief that any form of over exertion will precipitate a myocardial infarction (MI). The identification of symptoms and beliefs regarding their relationship to an illness or an organ emphasises the role of individuals as active processors of information often engaging in hypothesis testing. Hypothesis testing may be more elaborate when some knowledge is present.

A recently published example illustrates the active theorising and hypotheses testing undertaken by a doctor regarding the possible causes his symptoms.<sup>6</sup> On experiencing chest pain he reported using his behaviour to test alternative hypotheses to that of having coronary artery disease. Theorising is not conducted dispassionately as illustrated by the comment in this report that "we do not test hypotheses under circumstances of our own choosing, but according to our hopes, fears and competing demands". This statement emphasises that the attribution of symptoms to one cause or another is influenced by a range of factors and psychological responses.

In cardiac disease, how people interpret and respond to chest pain is influenced by the intensity of the pain, previous experience with the illness (either personal or family history of cardiac conditions) as well as whether they sought advice and support from others. These appear to be among the important influences on the interpretation of symptoms as a serious threat to one's health and in this way influence the speed at which individuals resort to medical treatment.<sup>w5</sup>

The need to have a belief about the cause of phenomena in the world have been claimed to be one of the characteristics of being human.<sup>7 w6 w7</sup> The search for a cause(s) of an illness is a process in which most people engage.<sup>8 w8</sup> What is particularly important is that these causal attributions appear to be factors which guide behaviour in reaction to an illness. For example, if coronary patients believe the cause of their problem to be genetic or hereditary they may hold a fatalistic attitude and continue harmful behaviours (for example, smoking, poor diet). Conversely, a person who believes their illness may have been caused by their poor lifestyle will be more willing to entertain and persist in efforts to change their lifestyle.<sup>w9</sup> Stress attributions (one of the most common attributions for heart disease)<sup>9</sup> may hold patients back from returning to activities which they believe are the cause of stress (for example, work), even though it may be beneficial for them to do so. Patients who believe they can, through their own behaviour, control their condition or the cause(s) of their condition are more likely to engage in exercise programmes and dietary changes.<sup>w10</sup>

Beliefs regarding the degree of seriousness of the condition may also act to encourage or discourage healthy behaviours. For example, if a cardiac patient does not accept that they have a serious problem (that is, belief in serious consequences or chronicity of the illness) they may not be inclined to take appropriate action to attenuate the progress of the disease. However, the likelihood of engaging in these behaviours is also potentially influenced by beliefs that they are capable of influencing their health and that they have the resources to deal with the problem (personal control and self efficacy beliefs—see below).

The notion of being able to exert control over the course of one's illness is an important cognition not only for behaviour but also for mood. The concept of control has been widely

researched and a number of instruments developed (for example, multidimensional health locus of control).<sup>10</sup> It is also enshrined within a number of general measures of illness cognitions (for example, personal and treatment control in the IPQ-R)<sup>11</sup> and applied to cardiac conditions. For example, within heart transplantation patients, personal control was positively correlated with optimism, well being, and satisfaction with life, and negatively correlated with anger and depression.<sup>12</sup> It is also important to differentiate between patients' perception of their own control over the course of their illness and their perception of the control that health care professionals have over the course of their illness. The former is likely to be more important in terms of behaviour change.

Another approach to illness cognitions emphasises the general response to the illness and efforts made to deal with the condition. This is illustrated by the work of Evers and colleagues<sup>13</sup> who use the cognitive dimensions of helplessness, acceptance, and perceived benefits as different beliefs about the illness (table 1).

These beliefs are particularly useful in understanding the individual differences in patients' longer term adjustment to their condition. Over time the inherently aversive nature of the disease is repeatedly re-evaluated on these constructs. Findings on samples with chronic illnesses (rheumatoid arthritis and multiple sclerosis patients) have demonstrated that greater helplessness was related to worse physical and psychological status, and also had a negative impact on daily life.<sup>13</sup> Other studies, which have examined cardiac patients' sense of control (the antithesis of helplessness) over their illness, have found supporting evidence, demonstrating that lower levels of perceived control led to negative health affects.<sup>14</sup> <sup>w11</sup> An opposite pattern emerged for acceptance and perceived benefits beliefs. Higher levels of acceptance and benefits beliefs have been related to better psychological and physical health status (although the benefits beliefs were less consistently related to outcome). Importantly these early beliefs were found to have a longer term impact. Helplessness was related to deterioration in physical health and increase in the impact of condition on patients' lives. In contrast, acceptance related to increases in physical and psychological health, and perceived benefits related to increase in positive mood.

One of the strengths of this schema of beliefs is the acknowledgment that in some cases illness can also have positive effects on people's lives. In addition, these specific constructs appear to have predictive power and thus proffer explicit strategies for developing interventions based on the cognitions (for example, reducing feelings of helplessness and increasing acceptance by training in self behaviours and emotion focused coping strategies). These findings also emphasise the need for an ongoing assessment of patients' cognitions.

It is important to note that in any particular illness, the content and relative importance of each type of illness cognition may vary, and some dimensions may become fractionated, redundant, or merged. Thus the structure of the cognitions should be investigated statistically when examining different samples, different cultural groups, and different conditions.

### Treatment representations

More recent work on patients' illness related cognitions have been supplemented in the research with treatment

representations. Two types of work can be identified with regard to treatment representations. One strand has focused on the beliefs people hold about medication and a second strand has examined beliefs about treatments in general that are offered to patients following diagnosis of an illness (for example, in coronary artery disease: medications, angioplasty, or bypass surgery).

Horne and colleagues<sup>15</sup> <sup>w12</sup> have shown that the beliefs patients hold about their medications are related to their levels of adherence to their medication regimen. They found that patients assess their medication on the basis of whether the specific medications they are to take are necessary (for the maintenance of health), and the concerns they have about the potential adverse effects of taking the medication (which counterbalance the effects of the necessity beliefs). In this way patients undertake a cost-benefit analysis of their treatment. Predictably it has been found that when cardiac patients' beliefs were biased towards concerns, poor adherence was reported; an inclination towards necessity beliefs resulted in greater adherence to their medication.<sup>w12</sup> It is important that these beliefs were stronger predictors of adherence to medication than clinical and sociodemographic factors.

Further work investigating how patients think about their treatments has compared individuals with the same condition, but where alternative treatments are applied.<sup>16</sup> It examined cognitions of individuals with coronary artery disease (CAD) and compared patients taking medication or undergoing revascularisation (angioplasty or bypass surgery). This research recognised that patients evaluate their treatment on the basis of cognitions regarding concerns over the risks of undergoing the treatment. In addition it revealed that cardiac patients also have cognitions about how much they value a treatment, their satisfaction with the treatment decision/option, as well as the ability of the treatment to cure their condition. Patients undergoing these three treatments of very different natures revealed patterns of cognitions that reflected the "drama" associated with their implementations.

These treatment beliefs were closely related to the emotional states of the patients. As expected the patients with the most concerns experienced high levels of anxiety and depression. However, there was a distinct lack of positive emotions despite the patients' satisfaction with the treatment decisions. The known relation between depression and cardiac morbidity and mortality,<sup>w13</sup> and the depression invoking aspects of the treatment indicate that addressing patients' understanding of their treatment may prove an important means of influencing the impact of a treatment and its outcomes.

Both illness and treatment cognitions are influences on patients' health related behaviours as well as their emotions. Work with cardiac patients has found that the treatment cognition of cure is related to beliefs about the illness' timeline; and that illness control beliefs are related to beliefs about the value of the treatment, the ability of the treatment to cure the illness, and satisfaction with the treatment decision.<sup>16</sup> Because of the close relation between the illness and treatment cognitions, the integration of the latter beliefs into models of health related behaviours will further aid understanding of the cognition-behaviour and cognition-emotion relationships. Within the clinical context a consideration of both types of belief in patients will lead to the more patient centred approach and are likely to lead to more effective management and patient care.

### Beliefs regarding the management of the condition

With regards to developing interventions to aid patients to instigate and maintain behavioural change (for example, smoking cessation, dietary recommendations, and increases in exercise levels), patients' perceptions of their resources, skills, and ability to deal with these issues are as important as the illness beliefs they hold. For example, many smokers hold beliefs about the potential impact of smoking on their cardiac condition and health in general, yet are unable to break the habit of smoking.

A further important set of cognitions relates to the manner in which patients regulate and adapt to the illness situation. The initial description of the strategies, both behavioural and cognitive, that patients employ to ameliorate (or attenuate) the condition or its adverse consequences, have often been referred to as "coping strategies". The basic differentiation among coping strategies are those that are focused upon behaviours targeting the direct impact of the stressor—problem focused coping (for example, if the stressor is the illness consequence, a potential strategy is to "pace my activities to fit in with my changing symptoms")—and those focused upon dealing with the emotional consequences of a problem—emotion focused coping (for example, "I seek emotional support from others"). Another way of categorising coping is into adaptive and avoidant strategies. The former attempt to tackle the problems evoked by the illness (for example, "I've been looking for something good in what is happening"), while the latter lead to avoiding dealing with the illness and its consequences (for example, "I'm doing things to take my mind off it").

Coping strategies are considered in some theoretical approaches to be the link between cognitions and outcomes.<sup>1 w2</sup> However, the evidence of this mediator relationship is inconsistent and the evidence concerning the role of coping is not strong, although it intuitively sounds attractive.<sup>5</sup> One suggestion is that current techniques to assess coping are not effective and lack specificity to individual behaviours.<sup>w14</sup>

In contrast, patients' expectancies regarding any behaviour they engage in are found to be consistent predictors of health behaviours as well as health outcomes. These expectancies are often related to specific health related behaviours. In this way they offer greater specificity when developing interventions to influence behaviour through cognitions. Typically a post-MI or coronary bypass graft (CABG) patient holds beliefs as to the potential role of exercise and diet, as well as the value of attendance at rehabilitation, in the amelioration of their symptoms and the prevention of recurrence. Importantly, they also hold beliefs regarding their ability to perform these required actions—that is, self efficacy beliefs.<sup>w15</sup> This set of beliefs can be very specific—for example a patient's confidence in altering their diet to include less fat (dietary self efficacy beliefs) or their ability to engage in the required level of exercise and maintain this behaviour (exercise self efficacy). Measures of confidence in outcomes and ability to perform these behaviours have been found to be related to the actual behaviours in the rehabilitation process and beyond. For example, Sullivan and colleagues<sup>18</sup> found that coronary heart disease (CHD) patients' high self efficacy in their ability to maintain function and control symptoms predicted better physical and role functioning, after accounting for coronary disease severity, anxiety, and depression. Mahler and Kulik<sup>14</sup> found that surgical patients with stronger self efficacy beliefs regarding their recovery led to shorter intensive care unit stays

### Patients' beliefs about their cardiovascular disease: key points

- ▶ Clinicians are encouraged to see patients as active processors and theorists of their condition and to examine the condition from the patient's perspective
- ▶ Patients' beliefs about their illness and treatment have been consistently related with both health related behaviours and the measures that individuals take to deal with their predicament
- ▶ The positive effects an illness may have on people's lives should not be underestimated and may be used as a tool for instigating and maintaining behavioural changes
- ▶ Interventions can be based on an assessment of patient cognitions
- ▶ Addressing patients' understanding of their treatment may prove an important means of influencing the impact of a treatment and its outcomes
- ▶ A patient centred approach leads to more effective management and patient care
- ▶ Patients' expectancies regarding any behaviour they engage in are found to be consistent predictors of health behaviours as well as health outcomes
- ▶ Patients' perceptions of their resources, skills, and abilities to deal with health related issues are important to instigate and maintain behavioural change
- ▶ Simple interventions are able to affect patients' levels of self efficacy (that is, beliefs regarding their ability to perform required actions)
- ▶ Questionnaires to assess specific beliefs and understanding in heart disease have been developed and may be used in clinical settings to investigate patients' beliefs and can easily be completed before the clinical interview with scores available for the clinician, so they can have an appreciation of each patient's perspective
- ▶ A patient's beliefs are frequently influenced and reinforced by family members and thus their beliefs should also be addressed in parallel to the patient's

and shorter hospitalisation. Most importantly, this study found that it was able to affect levels of self efficacy using a simple video intervention on the night before surgery.

### ASSESSMENT OF COGNITIONS AND POTENTIAL ROLE IN GUIDING THE CLINICAL INTERVIEW

The assessment of cognitions is customarily done through standardised questionnaires although some assessments have involved interviews and the analysis of qualitative data. A number of questionnaires have been designed to measure illness cognitions—for example, the illness perceptions questionnaires,<sup>3 11</sup> the illness beliefs questionnaire,<sup>2</sup> and the personal models of illness questionnaire.<sup>4</sup> For assessing treatment representations there is the beliefs about medicines questionnaire (BMQ) that specifically examines beliefs about medications,<sup>15</sup> and the recently developed treatment representations inventory (TRI) for examining beliefs regarding treatments in general.<sup>16</sup>

Questionnaires to assess specific beliefs and understanding in heart disease have also been developed and may be used in clinical settings to investigate patients' illness beliefs—for example, the York angina questionnaire<sup>19</sup> and the cardiac misconceptions scale.<sup>20</sup> These contain items such as "angina is caused by a worn out heart", "it is not advisable for patients with angina to exercise", and "angina pain causes permanent damage to the heart", which along with other beliefs may lead to the development of maladaptive coping



strategies,<sup>w16</sup> undue fear and anxiety with consequent invalidism,<sup>w17</sup> and a greater likelihood of subsequent hospitalisation.<sup>w18</sup> Identification and challenging of specific beliefs is an important aspect of the cardiac care process and a thorough investigation of patients' illness and treatment cognitions is a first step to achieving this. Modification of beliefs, coping, and behaviours may then be achieved through various methods that can involve skills training, role models, or short cognitive behavioural interventions to provide evidence for and against adaptive and maladaptive beliefs respectively. Importantly, patients' beliefs are frequently influenced and reinforced by family members and thus their beliefs should also be addressed in parallel to the patients'.

The above questionnaires can be most easily incorporated into the clinical interview by having patients and family members complete them before the interview. It will then be possible for the clinician to have an appreciation of the patient's perspective by having the scores available at the time of interview.

While questionnaires may be used to gain an understanding of a patient's beliefs in clinical practice, the clinical interview can also effectively be used to elicit a patient's beliefs. Key to this would be to use open ended questions to elicit the beliefs (for example, "What do you think caused you to have a heart attack?") and judicious use of follow up probe questions (for example, "Do you think that you could have controlled this?", "How do you think that you can prevent further problems?"). An understanding of a patient's beliefs, gained in this way may help to understand a patient's seemingly idiosyncratic behaviour, but it also offers the opportunity to challenge the beliefs and thereby potentially alter behaviour. This approach encourages clinicians to see patients as active processors and theorists of their condition and to examine the condition from a patient's perspective. This is inherently a psychological approach which has the potential to provide a greater understanding of what guides patients' behaviour.

## CONCLUSION

This paper attempts to illustrate the types of beliefs that patients hold about their condition and its treatment and how these beliefs relate to behaviour and mood. An appreciation of these beliefs and eliciting them from patients has the potential to further move the patient-clinician exchange onto a more patient centred approach.

Additional references appear on the *Heart* website—<http://www.heartjnl.com/supplemental>

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