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A systematic review of patients’ drawing of illness: implications for research using the Common Sense Model

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ABSTRACT
Recent research has examined patients’ drawings of their illness as a means to identify patients’ illness representations. The aim of this systematic review was to examine which representations are evident in patients’ drawings, and whether drawing assessments are associated with patient outcomes. Ten electronic databases were searched for published journal papers in English up to 1 July 2017. Narrative synthesis summarised findings by participant characteristics, study design, illness representations, and associations with outcomes. There were 101 eligible studies, published across 29 different countries, with 27 different disease categories; 54 of the studies were with adults and 80 were cross-sectional. All core illness perception domains were evident; the most common being identity and related concepts (including symptoms, anatomy, pathophysiology), and emotional representations (including fear, denial, stigma). Perceptions of treatment and the clinical and social environment were evident. More organ damage drawn and larger drawing size were associated with worse perceptions and health outcomes, and drawings distinguished between patient groups. Limitations include the inability to conduct meta-analysis. In conclusion, patients’ drawings reveal additional domains of illness representations, specifically perceptions of pathophysiology, treatment and social environments, as well as illness pre-occupation. These findings expand theories of self-regulation and suggest image-based intervention strategies.

The Common Sense Model of Self-Regulation was developed to describe the ways in which people think and feel about health threats and how they respond (Leventhal, Meyer, & Nerenz, 1980). The experience of symptoms, such as coughing, triggers an evaluation of the nature and cause of the coughing, and what to do about it – drink some water, take a pill, or seek medical treatment. It has been found that people try to make sense of symptoms by likening them to their existing schemata developed from previous experiences (Bishop, 1991). By likening the experience of symptoms to prior knowledge, people can identify which illness they have, what it is caused by, and what to do about it. Aspects of the surrounding environment (for example, smells in the air, the temperature, or advice from other people) can influence interpretations, attributions, and actions.

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The structure and content of illness schema (mental representations) was defined through the analysis of patient interviews. Illness cognitions (or perceptions) were grouped into five core domains: identity (name of the illness and its symptoms), timeline, consequences, cure or control, and cause (Lau & Hartman, 1983; Leventhal, Nerenz, & Steele, 1984). An analysis of personal accounts of illness in medical anthropological literature found corroborating evidence for this structure (Kleinman, 1988). The dimensions have also been confirmed in studies asking people to describe their experiences in relation to provided symptom descriptions (Bishop, Briede, Cavazos, Grotzinger, & McMahon, 1987). The structure appears to be common across cultures, although the specific content may differ (e.g., perceived to be caused by a virus or by an evil spirit) (Baumann, 2003).

The methods used to elicit patients’ illness perceptions may influence patients’ answers, and therefore influence the conclusions formed about illness perception domains. Table 1 summarises the evolution of methods used to assess illness perceptions from 1956 to 2006 (Kaptein, Scharloo, & Weinman, 2001). A clear aspect in this evolution is the shift in theoretical background from psychoanalytic to public health to health psychology. Health psychology researchers have developed a number of questionnaires, most notably the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996) and its derivatives – the revised and brief versions (Broadbent, Ellis, Gamble, & Petrie, 2006; Moss-Morris et al., 2002). These questionnaires cover the five core cognitive dimensions identified by Leventhal and his colleagues, as well as emotional responses and overall illness coherence, and have been widely used (Broadbent et al., 2015).

A new idea in this context pertains to how various art forms may be used as sources for identifying illness perceptions. One such art form is the novel, for example, in Cancer Ward (Solzhenitsyn, 2003), illness perceptions can clearly be identified in how the patients, their relatives and health care

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providers made sense of the illness and its treatment (Kaptein & Lyons, 2010). Another art form is film—in *Steel Magnolias* (Stark & Ross, 1989), for instance, the protagonist exhibits denial, poor symptom perception, and poor self-management of type 1 diabetes mellitus. Illness perceptions are also evident in a number of famous paintings, such as those by Frida Kahlo (Courtney, O’Hearn, & Franck, 2017). Kahlo depicts her broken spine, nails in her skin, medical straps, and tears from her eyes; which illustrate her perceptions of identity, pain, and treatment control, as well as her emotional response. It is important to note that these art forms were produced without any explicit instructions to represent an illness. The aim of the artist was artistic or literary and internally motivated. Interpretation of illness representations in such art is strongly influenced by the interpreter.

In contrast, a researcher can explicitly ask a patient to draw their illness. In this case, the aim of the patient is to represent an illness at the request of a researcher in the context of a study with specific instructions. The interpretation of these drawings lends itself more readily to explanations within the frameworks that the instructions were developed. Below, we briefly review the use of drawing tests in psychology, to give a historical context to the development of drawing tests within the Common Sense Model.

A number of drawing tests with explicit instructions have been used in psychological assessment. An example is the projective Draw-A-Person test (Machover, 1949) where either omissions or great detail is interpreted as anxiety. Neuropsychological tests, such as Bender Gestalt test (Bender, 1946), ask patients to copy simple drawings or to draw a house or a square, to identify signs of neuroticism, psychosis, or brain damage. The clock-drawing test is popular for stroke patients to screen for signs of neurological problems (Andrews, Brocklehurst, Richards, & Laycock, 1980). Pain charts, where patients indicate pain by adding shading on a body outline, are often used to identify pain distribution. Figure size has been interpreted as representing the significance of the object to the person, for example research has shown that children’s drawings of Santa Claus get larger as Christmas approaches (Cradick, 1961).

In the 1980s, researchers started to use drawing assessments more frequently outside mental health settings and to use a more content-based approach. This was evident in pain settings, where researchers analysed the ways in which pain was depicted, finding themes such as instruments causing pain, and abstract representations of pain (Jerrett, 1985; Unruh, McGrath, Cunningham, & Humphreys, 1983). One of the first studies to specifically assess how people perceived their illness through drawings was with children with asthma, asking participants to draw their insides when having an asthma attack and revealing perceptions of cause, treatment, emotions, symptoms, and the lungs (Quinn, 1988). The earliest paper to link drawing assessment to the Common Sense Model was with patients with myocardial infarction (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004).

To date, one small scoping review has been published on the use of drawings to explore patients’ perceptions, highlighting the value of drawing-based assessments (Cheung, Saini, & Smith, 2016). However, the review was limited by a restricted date range, a lack of analysis of how drawings relate to illness representations from the Common Sense Model, and no discussion of implications for self-regulation theory or interventions. The aims of the current review were to systematically review research on patients’ drawings of illness and address the following questions: How do illness representations identified from drawings compare to illness representations in the Common Sense Model? How are drawing assessments related to illness perception questionnaires and health outcomes? What are the implications for theory, assessment, and the development of interventions? Studies that used specific instructions to draw an illness, as well as studies that used more general instructions were included to give a comprehensive and historical perspective. Recommendations about instructions and analysis are included in the discussion.

**Method**

Two literature searches were performed in order to identify research papers on patients’ drawings of medical conditions and treatment (defined in Appendix 1). A registered review protocol does
not exist. Inclusion criteria were: empirical papers published in peer reviewed journals, in English up to 1 July 2017; exclusion criteria were: chapters in books, papers where (a) the word ‘drawing’ was used in a different sense than intended here (e.g., drawing the last straw, drawing conclusions, line is drawn, drawing blood, etc.), (b) where the paper described drawing a clock (as a standardised test for in particular patients with neurological conditions), or any other standardised test (e.g., drawing spirals), (c) papers where health care providers made a drawing but patients did not.

Three authors independently extracted data from the papers for Tables 2a and 2b. Data extracted included study population, drawing instructions and scoring, study design, main findings, illness perceptions and emotional representations identified, change over time (Table 2a). Information on associations between drawings, illness perceptions, and demographics was extracted into Table 2b. Where examples of drawings were included in papers, these were also examined for the identification of illness perceptions and emotions.

Results

A Consort Flow Diagram shows the number of studies screened, assessed for eligibility, and included in the review, with reasons for exclusion (Figure 1). The study characteristics of the 101 studies included in the review are shown in Table 2a (see Appendix 2).
Number of papers and countries

Figure 2 shows the number of papers identified within the review per publication year. From 1970 to 2002 the average number of papers per year was 0.5, whereas from 2003 to 2016 the average number of papers was 5.9.

Studies were conducted in 29 different countries across the Americas, Europe, the Middle East, Asia, Oceania, and Africa. Most studies were published in the USA (n = 28), followed by the Netherlands (n = 8), New Zealand (n = 8), the UK (n = 7), and Australia (n = 6). Other countries in which 5 studies or fewer were conducted include: Canada, Cuba, Denmark, Faroe Islands, Finland, Georgia, Germany, Greece, Hong Kong, Hungary, India, Israel, Italy, Mexico, Norway, Pakistan, Singapore, Spain, Sweden, Switzerland, Thailand, Turkey, and Zimbabwe.

Summary of methods employed

The majority of studies (n = 80) were cross-sectional; a minority were longitudinal (n = 15) or case studies (n = 6). Approximately half of the studies were conducted with adults (n = 54) and half with children (n = 47). Twenty-seven different categories of illness were studied, the most common of which were cancer (n = 11 studies), cardiac conditions (n = 9), pain (n = 9), headache/migraine specifically (n = 7), respiratory illnesses (n = 6), mental health (n = 6), and diseases of the nervous system (n = 6). Other illnesses studied included infectious diseases (n = 5); general illness (n = 4); hormonal conditions (n = 4); gynecological conditions, skin conditions, diabetes, kidneys, immune conditions, obesity (all n = 3); arthritic conditions, diseases of the ear, dental conditions, sickle cell anemia, cystic fibrosis (all n = 2); disability, breast biopsy, choking, eye problems, traumatic brain injury, and stroke (all n = 1).

There was a variety of drawing instructions, most commonly asking participants to draw themselves, or to draw the part of their body affected by illness. Variations of this theme included asking participants to draw their illness, to draw how the illness affected them, to draw how they visualised their condition, the meaning of their condition, or how the illness made them feel. Less commonly, participants were asked to draw a person with an illness or a person in a clinical setting, to draw their family, or to draw a free picture. In some cases, participants were also interviewed about their condition and/or about their drawings. In these cases, it was not always clear from the papers whether the results referred to themes identified from the drawings or from the interviews.
In other studies, participants were asked to briefly write what they had drawn in words, or they independently wrote comments on their drawings to indicate specific body parts and/or symptoms.

**Scoring/analysis of drawings**

A number of different methods were used to assess the drawings. A common method was to qualitatively look for themes in the drawings, using content analysis or phenomenology. Another method was to assess aspects of the figures drawn, including omissions, distortions, figure size, and nudity, often to indicate anxiety. Drawing style was examined, including colours used, pen strokes made, shading and darkness of the drawings. Emotions were often assessed from the presence of facial expressions. Many studies assessed the size of the drawings, and since 2004, a number of studies have used image J software (Rasband, 1997) to measure the size/area/height of drawings, as well as the percentage of the body part drawn as affected by the condition (e.g., the amount of damage).

In some studies where participants drew body parts, accuracy and detail of their diagrams were scored. In longitudinal studies, changes in the drawings over time were assessed, such as change in size, changes in perceptions of the disease, or changes in facial expressions.

**Illness representations identified from drawings**

Figure 3 shows how often the core dimensions of illness perceptions were identified in the drawings (identity, timeline, consequences, control, and cause). Overall, it can be seen that all 5 dimensions of illness perceptions could be identified in at least some of the drawings (see Figure 4 for examples of drawings showing each kind of dimension).

Illness identity was the most commonly depicted perception in 82/101 studies. Within this category, the anatomy of the illness, its pathophysiology, and/or its symptoms were included. Pathophysiology is illustrated, for example in Figure 4(b) from Broadbent et al. (2004), where some patients drew damage to the heart following a heart attack, and/or drew blockages in the cardiac arteries, and in Figure 4(f), an adult patient with vestibular schwannoma has drawn a detailed picture of the anatomy of the ear and surrounding tissue along with a list of symptoms he has experienced.

![Figure 3](image_url). Frequency of each illness representation in the drawings.
Figure 4. Examples of drawings showing illness representations. 4a shows timeline and identity perceptions of pain by adults, from Phillips, Ogden, & Copland, *British Journal of Occupational Therapy*, 78(7), 404–411, copyright © 2015 by The Author(s). Reprinted by Permission of SAGE Publications, Ltd. 4b shows an adult’s perceptions of how the heart has been affected by damage and blockages following a heart attack (illness identity). Reprinted from *Journal of Psychosomatic Research*, 57, Broadbent, Petrie, Ellis, Ying & Gamble, A picture of health – myocardial infarction patients’ drawings of their hearts and subsequent disability A longitudinal study, 583–687, 2004, with permission from Elsevier. 4c shows an adult’s perceptions of control through reduced protein in the kidneys after treatment for lupus compared to before. from Daleboudt, Broadbent, Berger & Kaptein, Lupus, 20, 290–298, copyright © 2011 by The Authors 2010. Reprinted by Permission of SAGE Publications, Ltd. 4d shows lost occupations as a consequence of pain drawn by an adult, from Henare, Hocking, & Smyth, *British Journal of Occupational Therapy*, 66(11), 511–518, copyright © 2013. Reprinted by Permission of SAGE Publications, Ltd. 4e shows a child’s causal perceptions of HIV through his father’s promiscuity and the consequences for himself from Campbell et al. 2012. Reprinted with permission from WILEY. 4f shows an adult’s drawing of his/her vestibular schwannoma, showing both anatomy and a symptom list from van Leeuwen, Herruer, Putter, van der Mey, and Kaptein (2015). Reprinted with permission from WILEY. 4g shows an image of the qualitative experience of symptoms in an adult with headache. Reprinted from *Journal of Psychosomatic Research*, 66; Broadbent, Niederhoffer, Hague, Corter, & Reynolds, Headache sufferers’ drawings reflect distress, disability and illness perceptions, 465–470, Copyright (2009), with permission from Elsevier.
Emotional responses to the illness were the second most commonly depicted representation in the drawings \((n = 60, 59\%)\), most often through drawn facial expressions (for example Figure 5(a)). Treatment representations were the third most commonly depicted, as illustrated in Figure 6(a–c). Drawings of treatment included a wide range of content from medical professionals, to hospital beds and clinic waiting rooms, and from changes to body parts after surgery, to syringes and medications.

**Other perceptions identified in the drawings**

Some aspects went beyond existing illness perception questionnaires. For example, evident in some of the drawings were aspects of the individual’s social environment, such as family support, other patients, or the clinical environment (see Figure 7(a,b)). Other aspects that could be identified were depictions of individuals performing activities that were restricted due to their illness, or with disability aids, such as a study of children with cerebral palsy (Chong, Mackey, Stott, & Broadbent, 2013). Another theme was the use of metaphor in drawings, for example a participant drew her experience of Ebola as a bird to express her ability to fly out of danger; drawn with a man and a woman to show that everyone is at risk (Locsin, Barnard, Matua, & Bongomin, 2003).

**Associations with outcomes**

Many papers, especially those published since 2003, reported correlations between aspects of the drawings and other outcomes, as summarised below and reported in Table 2b (Appendix 3).

**Anxiety scored from drawings**

Validity for detecting anxiety from drawings was evident in two studies with children attending the dentist; fear and distress scored from drawings were correlated with child behaviours and self-reports indicating anxiety (Aminabadi, Ghoreishizadeh, Ghoreishizadeh, & Oskouei, 2011; Pala, Nuvvula, &

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Child anxiety detected from drawings in hospitalised children was correlated with other outcomes, including mothers’ lower use of coping strategies, and number of procedures (Burns-Nader, Hernandez-Reif, & Porter, 2014).

Kamath, 2016).
Pathophysiology of illness

Drawings revealed patients’ perceptions of organ damage, which traditional interview or questionnaire assessments do not. In several studies with cardiac patients, the size of damage drawn on the heart was associated with scores on illness perception questionnaires and health outcomes. For example, the area of damage drawn by patients with myocardial infarction was associated with perceived recovery timeline, perceived control, medical indicators of damage, and time to return to work (Broadbent et al., 2004). In a similar study, drawn heart damage was associated with consequences, illness concern, emotional representations, and posttraumatic stress three months later (Princip et al., 2015). In patients with heart failure, drawing heart damage was associated with depression and poor physical functioning (Reynolds, Broadbent, Ellis, Gamble, & Petrie, 2007).

The same findings regarding damage or pathophysiology were evident in other conditions. Greater damage drawn on the brain after traumatic brain injury was associated with more consequences, lower personal control, longer timeline, stronger identity and more symptoms, more concern, more emotions, and worse quality of life (Jones et al., 2016). Greater reductions in drawn damage over time were associated with fewer symptoms and consequences in patients with lupus (Daleboudt, Broadbent, Berger, & Kaptein, 2011). In another study of lupus, more skin lesions drawn were associated with worse disease severity (Chen, Broadbent, Coomarasamy, & Jarrett, 2015). The number of blood cells drawn by people with sickle cell disease was associated with lower perceived personal control (Ramondt, Tiemensma, Cameron, Broadbent, & Kaptein, 2016).

Drawing size

Larger size of the drawing itself was associated with worse perceptions and health outcomes across many conditions. Larger drawings by people with headache were associated with perceptions of worse consequences, worse symptoms, worse emotional representations, lower vitality, higher pain, more days of restricted activity, lower vitality, and more days of restricted activity (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009). An increase in the size of the heart drawings of patients with myocardial infarction over time was related to slower return to work, higher cardiac anxiety, more activity restriction, less exercise, more alternative medicines use, and more calls to the doctor (Broadbent et al., 2006). In patients with heart failure, height and area of heart drawings were associated with anxiety (Reynolds et al., 2007). The heart can become enlarged with worsening heart failure, and this may be communicated by clinicians to patients. Larger drawings of the heart may therefore reflect patient’s accurate perceptions of more severe disease; this was supported by associations between drawing size and biological indicators of more severe disease (Reynolds et al., 2007).

Larger figure size was associated with less walk test distance, and smaller drawings of the self were associated with more pain in children with cerebral palsy (Chong et al., 2013). Kidney transplant patients who drew larger kidneys had worse kidney function as well as higher anxiety and lower personal control beliefs (Látos et al., 2012). Larger post-operatively drawn transplanted kidneys predicted depression 3 years later (Látos et al., 2015). Larger drawings were associated with more worry and longer timeline beliefs in patients with lung cancer (Hoogerwerf, Ninaber, Willems, & Kaptein, 2012). Drawing two kidneys was associated with stronger identity perceptions than drawing one kidney in patients with lupus (Daleboudt et al., 2011), and a bigger drawn face was associated with depression in another study of lupus patients (Chen et al., 2015).

Patients with Cushing syndrome drew themselves as larger when in an active state and after treatment compared to when healthy, and larger drawings were related to higher disease severity (Tiemensma et al., 2012, 2015). Greater drawing width was associated with perceived consequences, personal control, and mental health. Larger figures after treatment were associated with more perceived symptoms, cyclical timeline, consequences, and emotional representations as well as impaired quality of life. The only study in which findings were contrary to this was in children with sickle cell
disease, whereby self-portraits with pain were significantly smaller than their self-portraits without pain (Stefanatou & Bowler, 1997).

Recovery over time
Some drawing studies showed perceptions of recovery over time. For example, patients with mild traumatic brain injury drew less damage after one month compared to baseline (Jones et al., 2016). The majority of patients with lupus drew less damage after treatment compared to before (Daleboudt et al., 2011), and patients with vestibular schwannoma drew smaller drawings after treatment (Kaptein et al., 2011). Improved child drawings of headache were associated with improved clinical measures (Stafstrom, Goldenholz, & Dulli, 2005). Amongst children with sickle cell disease, more sophisticated drawings were associated with longer time since their last pain crisis, suggesting pain might impair cognitive skills (Stefanatou & Bowler, 1997).

Accuracy
Another kind of assessment was in regards to the accuracy of the pathophysiology and anatomy drawn. In one study, the size of patients’ drawings of their melanoma was associated with the diameter of their real melanomas from histology reports (Scott et al., 2015), which was an indicator of accuracy. Similarly, in patients with acromegaly, distorted drawings of the right hand were associated with clinicians’ morphometric scores (Imran et al., 2016). Greater accuracy was associated with more knowledgeable written descriptions of cardiac abnormalities by children (Wang, Hay, Clarke, & Menahem, 2011). Written explanations were associated with higher concern, lower control, and fewer illness episodes in patients with lupus (Daleboudt et al., 2011). Drawing accuracy was associated with longer timeline perceptions and lower treatment perceptions in patients with lung cancer (Hoogerwerf et al., 2012).

Other aspects
Several procedural aspects of drawing were associated with outcomes. For example, pen pressure was associated with higher perceived control over stroke, taking longer to write was associated with fewer consequences, and pen speed was associated with greater worry and longer timeline perceptions in patients recovering from stroke (Grünich et al., 2016). Better integrity of drawing at both postoperative and follow-up time points predicted lower risk of kidney rejection in transplant patients (Látos et al., 2015). Earlier artistic stage was associated with severity of Alzheimer’s disease (Lev-Wiesel & Hirshenzen-Segev, 2003a).

Differences in drawings between groups
Fifteen studies presented evidence that drawings could distinguish between different conditions; mostly these were studies with children but some studies were with adults. Studies with children included differentiating headache from migraine based on drawing of symptoms (Stafstrom & Havlena, 2003). Children with musculo-skeletal pain drew fewer pictures of themselves handling the pain compared to children with migraine (Unruh et al., 1983). Hospitalised children drew more actions, procedures, and instruments inflicting pain than healthy children and more hospital settings, less emotional expression of pain, and less actions to manage pain (Kortesluoma, Punamaki, & Nikkonen, 2008). Sick children could be distinguished from healthy children by the absence of other human figures (Bayrakci, Forouz, Sahin, Abali, & Aliyeva, 2009). AIDS-affected children could be distinguished from poverty-affected children from depictions of bedridden people, chores and caregiving, resources, less beauty, more distress and stigma and more compassion (Campbell et al., 2012).
Physical activities were more common in obese respondents’ drawings than in those by normal weight peers from pulmonary rehabilitation (Rudolph et al., 2010).

Amongst adults, acromegaly patients drew more distortion of the right hand, right foot, and height than adenoma patients (Imran et al., 2016). Psoriasis patients were more likely to draw unclothed figures and more sexual overemphasis, and less complete figures, compared to patients with other skin conditions (Leichtman, Burnett, & Robinson, 1981). Drawings of someone without sickle cell disease showed more positive emotions and fewer negative emotions than drawings of someone with the disease (Ramondt et al., 2016). Three studies found differences in drawings in adult patients with mental health conditions. Patients diagnosed with schizophrenia displayed more symptoms in their drawings of anxiety, aggression, hallucinations, disorganisation, and reality distortion than controls (Lev-Wiesel & Shvero, 2003b). Patients with a diagnosis of psychosis who used integration as a coping style used more colour, drew more detail, were more expressive, and depicted more motion than patients with a sealing-over coping style (McGlashan, Wadeson, Carpenter, & Levy, 1977). Drawings by patients with unipolar depression had less colour and development, and more emptiness and amorphousness than other diagnostic groups (Wadeson & Carpenter, 1976b).

Other studies showed differences in drawing style between conditions. Healthy children drew bigger body features, used more colours, and used blue more than hospitalised children with congenital heart disease, whereas hospitalised children more often omitted body parts and clothes than healthy children (Dolidze, Smith, & Tchanturia, 2013). Patients with breast cancer used blue, black and brown more than healthy and benign diagnosed groups, and also drew more depressed drawings (Eskelinen & Ollonen, 2010).

Discussion

Health psychology research has witnessed an increase in the use of patient drawings to assess illness representations especially over the past 15 years. Drawings research has been conducted with a wide array of diagnostic categories from Alzheimer’s disease to ventricular septic defects. This research has been conducted in 28 different countries from Australia to Zimbabwe, and respondents have included both children and adults. The studies have brought new ways to assess and interpret patients’ perceptions. Depictions pertaining to the core illness perception domains of identity, consequences, timeline, control and cause were evident in drawings, supporting already established domains. Patients most commonly drew identity perceptions, and emotional responses. However, some aspects did not fully fit within the core domains as they are currently conceptualised, and this has potential implications for theory, the assessment of illness perceptions, and clinical interventions.

Older studies tended to have more general instructions, whereas more recent studies explicitly asked patients to draw their illness. General instructions produce more variable drawing content and general thematic interpretations. Explicit instructions to draw an illness provide results that can be better interpreted within the framework of the Common Sense Model. It is therefore recommended that explicit instructions, like those of Broadbent et al. (2004) be used. It is also useful to ask patients to briefly describe what they have drawn (in writing), so that drawing content is more easily identifiable.

Drawings provide some advantages and disadvantages compared to questionnaire assessments. Advantages include more open responses, the ability of even young children to draw, and the ability to see a reflection of the patient’s perspective in a visual sense. In terms of disadvantages, some patients are reluctant to draw due to perceived poor ability, so it is important to reassure patients that ability is not assessed.

It is recommended that drawings are examined for content, and if there are sufficient participants then analyses between content and outcomes can be performed. Simple ways to analyse drawings include objective measures of size (height, width, or area), and measures of pathophysiology, such as
the size of damage depicted. How these aspects are linked with illness perceptions and theory is discussed below.

Drawing size is a commonly assessed feature that has been frequently associated with illness perceptions and outcomes. As suggested in a study of drawings of Santa Claus (Cradick, 1961), drawing size appears to reflect the extent to which the object drawn occupies the person’s mind. We theorise that drawing size represents pre-occupation with illness, an aspect of illness representations not often conceptualised within the Common Sense Model. Illness preoccupation may be similar to the concept of acceptance of illness identity, developed by Linkowski (1971) in relation to disability. The self-illness relationship was assessed with regards to illness representations by Kemp, Morley, and Anderson (1999), who asked patients how large a part epilepsy played in their lives. According to Nerenz and Leventhal (1983), how people integrate chronic illness into the self-concept is a central issue. A recent meta-analysis by Hagger, Koch, Chatzisarantis, and Orbell (2017), provided models of how illness representations influence adaptive and maladaptive coping, yet the concept of how much the illness influenced the self (self-identity or pre-occupation with illness) was missing. This review suggests that this concept needs further attention and could be another process through which illness representations influence coping strategies and health outcomes. The importance of the self-concept is also highlighted by Orbell and Phillips (2018) in this issue.

Amongst studies with explicit instructions in particular, patients commonly drew the pathophysiology or anatomy of illness, which could be seen to represent perceptions about illness identity (what the illness is). However, the concept of pathophysiology does not fit clearly within the identity component of illness perceptions, which is commonly defined as the disease label and its symptom indicator (Leventhal, Diefenbach, & Leventhal, 1992). The drawing of pathophysiology could alternatively be seen to represent a form of illness coherence (a coherent understanding of illness; Moss-Morris et al., 2002). However, a patient may feel that his/her illness makes sense, even though their understanding of pathophysiology and anatomy is poor, reflecting differences between the biopsychosocial model (a patient’s coherent lay understanding) and the biomedical model (medical views as objective and correct). The drawing of pathophysiology could therefore be seen to reveal a domain of illness representations that is not currently included in the Common Sense Model or questionnaires assessing its components. In line with this idea, the authors of a study of drawings by patients with long-term Cushing’s disease suggested that drawings may assess representations of illness identity/severity not covered by questionnaires (Tiemensma et al., 2012). Importantly, one aspect of the perception of pathophysiology, damage drawn on body parts, has been repeatedly associated with health behaviours and outcomes. This critical perception is missed by current illness perception questionnaire assessments. Pathophysiology could therefore be added to the current model as an additional domain of illness perceptions. Alternatively, pathophysiology could be seen in some cases as a kind of metacognition that integrates the person’s subjective perceptions of the different dimensions, including identity, coherence and consequences in a more comprehensive and detailed way.

The common depiction of treatment within patients’ drawings of their illness suggests that the experience of treatment is integral to illness representations. Perceptions of treatment control are already identified within the CSM, and these were evident in some of the drawings, for example, a patient’s perceptions of reduced protein in the kidneys after treatment for lupus illustrate perceptions (Figure 4(c); Daleboudt et al., 2011). However, drawings included depictions of medical professionals, wardrooms and clinics, beds, and medical equipment, even more so than images of medications or surgery. Patients’ mental representations of these aspects of treatment are an under-researched area in the Common Sense Model. The most commonly researched treatment representation model to date is the necessity-concerns framework (Horne, Weinman, & Hankins, 1999). Necessity beliefs could be identified in some drawings, for example, the perceived need to have insulin at hand by a girl with diabetes (Isla Pera et al., 2013). Side effects of treatment could be seen in some drawings, for example, the drawings of a woman with breast cancer showed hair loss and surgical scars (Perdikis, Fakhre, Speed, & Griggs, 2011).
Perceptions of the clinical environment and of medical staff are not currently part of assessments of illness or treatment representation models. Such concepts are described by Kleinman (1980), who writes that the healthcare system is integral to patients’ experiences of illness and healing. Kleinman includes illness institutions, social roles, interpersonal relationships, interaction settings, economic and political constraints, available treatments, and type of health problem, in the concept of the healthcare system. The depiction of some of these wider concepts in patients’ drawings suggests that they deserve greater attention. Currently, it is difficult to link these contextual aspects of drawings to existing illness perceptions. However, one might hypothesise that drawings of more sophisticated medical equipment, more competent staff, and nicer surroundings, might be linked with greater perceptions of treatment control, feelings of support, and lower emotional representations. Future research could investigate whether or not such perceptions have additional explanatory power in the Common Sense Model. A recent scale on attitudes towards vaccinations includes beliefs around commercial profiteering and provides further suggestion that such contextual beliefs are relevant (Martin & Petrie, 2017).

A strength of this review is the identification of additional domains within patients’ illness representations, which expands our understanding of Self Regulation theory. The inclusion of studies from many different cultures suggests cross-cultural validity. The review differs from previous systematic reviews on illness perceptions, which were based on questionnaire assessments (Broadbent et al., 2015; Hagger et al., 2017), and triples the number of studies compared to a previous scoping review of drawings (Cheung, Saini, & Smith, 2016).

A limitation of most drawing research to date is that results are not put into a theoretical context, let alone into the context of the Common Sense Model. Many studies have a limited number of respondents and most are cross-sectional. Instructions for drawing often differ between studies and so instructions need careful consideration in future work. Data analysis has quite often been ‘eye balling’ instead of more formal data analysis using reliable measures. In addition, drawings data have seldom been linked to existing, validated illness perception questionnaires. Very few studies have used drawings in a pre–post intervention or control – experimental group design to assess changes over time or after an intervention. A limitation of this review is that due to heterogeneity of studies and limited statistical analysis within the papers, a meta-analysis could not be conducted. In addition, some studies may have been missed by the literature search.

Future research could further explore the domains identified in this review, using alternative means of assessment and assessing predictive validity. In terms of pathophysiological perceptions, the study of whether accuracy predicts outcomes could be informative, as well as whether drawings are the best way to assess these perceptions. However, alternative ways to assess perceptions of pathophysiology, such as questions about anatomy, could be threatening for lay people, and would not reveal idiosyncratic views. In terms of treatment representations, studies could ask patients to specifically draw their treatment to expand knowledge of how patients perceive treatments, and this could be boosted with patient interviews. The concept of pre-occupation with illness could be explored with questionnaires to see whether this construct can be validated against drawing size. Questionnaires might assess, for example, how much time patients spend thinking about their illness.

This work has implications for illness perception interventions. To date, researchers have mostly used questionnaires to assess perceptions and used cognitive behavioural techniques to change these perceptions. It is possible that important opportunities for intervention have been missed by not assessing perceptions of pathophysiology, the treatment environment, and patients’ pre-occupation with illness. Future work could apply the interpretation of drawings to personalise the content of illness perception-based psychological treatments.

Recent intervention studies have incorporated visual aspects. Based on prior drawings research, one study incorporated drawings into assessments before and after an intervention (Jones, Ellis, Nash, Stanfield & Broadbent, 2016). The intervention consisted of an i-pad animation showing the heart and the coronary arteries during a heart attack, and how medication worked to reduce plaques inside the arteries. This 15-minute intervention successfully changed illness perceptions...
and recovery behaviours. This example illustrates how drawings research can inform intervention development and the power of incorporating image-based techniques. Other visual interventions have included visual displays for patients with haemodialysis (Karamanidou, Weinman, & Horne, 2008), an app showing how medication protects immune cells in patients with HIV (Perera, Thomas, Moore, Faasse, & Petrie, 2014), and bone models for patients with osteoporosis (Jones, Fernandes, Grey, & Petrie, 2017). Children’s drawings have been used to help design educational leaflets for patients undergoing treatment (Wigley, Bucknall, & Fleming, 2017). A further application is iTui, a computerised drawing tool used in paediatric assessments to help engage the child and assess their perceptions of the home environment in a safe and informative way (Waitemata District Health Board, 2018). However, this work did not systematically use drawings to personalise interventions, and this is an area for development.

One way in which drawings could be used to personalise interventions is for the person delivering the intervention to discuss the patient’s drawing with the patient. Where misconceptions about pathophysiology are evident, these could be pointed out, and patients’ scans or x-rays, or medical test results could be discussed with the aim to correct misconceptions. Where emotions have been drawn, the drawing could be a good starting point for a discussion about how the patient has been emotionally affected by the illness.

In conclusion, this review has shown that drawings are becoming a more popular way to assess patients’ perceptions of their illness. Illness representations identified from drawings include perceptions of pathophysiology, the treatment environment, and pre-occupation with illness, which are not typically operationalised in the Common Sense Model, and are not covered by popular questionnaires used to assess it. It is recommended that future studies explore questionnaire-type assessment of these constructs; investigate associations with behaviours and health outcomes; and incorporate these perceptions into the design of interventions. Patients’ drawings, especially at the end of life, can be very moving representations of illness (Tsakanas, 2004). We can utilise patients’ drawings to improve our understanding of the illness experience and inform our clinical interventions.

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References

[* indicates studies included in Tables 2a and 2b]


