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Changes in illness perceptions mediated the effect of cognitive behavioural therapy in severe functional somatic syndromes

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ABSTRACT

Objective: Although there is substantial evidence that cognitive behavioural therapy alleviates symptoms in functional somatic syndromes, the mechanisms of change are less investigated. This study examined whether changes in illness perceptions mediated the effect of cognitive behavioural therapy.
Methods: We analysed additional data from a randomised controlled trial comparing completers of cognitive behavioural group therapy (46 patients) to an enhanced usual care group (66 patients). Proposed mediators (illness perceptions) and primary (physical health) and secondary (somatic symptoms and illness worry) outcomes were assessed by means of questionnaires at referral, baseline, end of treatment, and 10 and 16 months after randomisation. Multiple mediation analysis determined whether (1) changes in specific illness perceptions during treatment mediated the effect of cognitive behavioural therapy (primary analysis), and (2) whether changes in illness perceptions during the whole trial period were associated with improved outcome (secondary analysis).
Results: Improvements in illness perceptions during treatment partially mediated the effect of cognitive behavioural therapy on physical health one year after treatment (sum of indirect effects 1.556, BCa 95% CI (0.006; 3.620)). Improving perceived control was particularly important. Changes in illness perceptions from baseline to 16 months after randomisation were associated with clinically meaningful improvements in physical health, somatic symptoms and illness worry during the same period.
Conclusion: Our results suggest that changing patients' illness perceptions is an important process in cognitive behavioural therapy for functional somatic syndromes. Challenging patients' own understanding of their illness may hence be a key element of successful treatment.

Introduction

Functional somatic syndromes (FSS) are characterized by physical symptoms and impairment in everyday life, which cannot be attributed to verifiable, conventionally defined diseases [1,2]. FSS cover a variety of disorders including chronic fatigue syndrome, fibromyalgia and irritable bowel syndrome, but similarities regarding diagnostic criteria, aetiology, pathophysiology, neurobiology, psychological mechanisms, patient characteristics and treatment response have been documented [1–3]. Treatments for FSS may hence work through similar pathways, regardless of differences in symptom profiles.

Cognitive behavioural therapy (CBT) is the best documented treatment for a wide range of FSS [4–7]. However, it is less investigated how, why and when CBT works, and several studies have called for more mediation research within this area [8–11]. Currently, a limited number of studies have examined mediators of change in FSS treatments, all of which emphasize the role of illness-related cognitions [11–20].

With the common sense model of illness, Leventhal has offered a generic framework to study illness-related cognitions [21]. According to this model, people develop illness perceptions when they are faced with health threats. Illness perceptions can be assessed by the revised illness perception questionnaire (IPQ-R), categorising them into components consisting of the illness label and the symptoms that the person ascribes to it (illness identity), beliefs about the cause (causal beliefs) and duration (timeline perspective), to which extent the illness can be cured or controlled (control beliefs), expectations regarding its consequences (consequences) and the overall understanding of the illness (coherence). In parallel, the person develops emotional representations – that is how he or she responds emotionally to the illness [21–24]. Patients suffering from FSS have been found to have particularly negative illness perceptions [9,10,21,25–29]. One previous study with illness perceptions as proposed mediators of CBT in FSS found that changes in illness perceptions mediated treatment effects in irritable bowel syndrome [19]. However, as this study included patients with irritable bowel syndrome only, no conclusion as to the generalization of these findings to other FSS can be drawn. Furthermore, illness

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perceptions were combined into one dimension, which did not allow analysis of the role of separate components.

Mediation has been defined as the addition of a third variable to a relationship that "transmits the effect of an independent variable on a dependent variable" [30]. A mediation analysis is shown in Fig. 1.A and B. Fig. 1.A illustrates the effect of CBT on change in outcome. Conducting this analysis, the original trial report found that patients with FSS who received CBT experienced improved physical health both immediately and one year after treatment compared to patients who received enhanced usual care [31]. Fig. 1.B illustrates a model in which part of the effect of CBT is mediated by changes in illness perceptions. In the present study, we aimed to investigate whether changes in specific illness perceptions during treatment mediated the long-term effect of CBT in patients with FSS (primary analysis). We also aimed to investigate whether changes in illness perceptions during the whole trial period were associated with improved long-term outcome (secondary analysis). Although this secondary analysis could not establish causality, the longitudinal associations of illness-related cognitions and physical health are still important for a deeper understanding of the role of cognitive processes in FSS. Since we expected further specific changes in illness perceptions to occur during the year after CBT, different components might be associated with improved outcome in these two analyses.

Method

Participants/sample

The original trial was conducted at the Research Clinic for Functional Disorders, Aarhus University Hospital [31]. All primary and secondary care units in western Denmark (Jutland) received information about the trial and were invited to refer patients with FSS or diagnostic analogues. All patients were screened for eligibility and out of 278 referred patients, 147 patients were considered likely to meet inclusion criteria and invited to a clinical assessment to determine eligibility. Adults aged 18–45 years, with one or more FSS were eligible if they satisfied criteria for the novel unifying diagnosis bodily distress syndrome, multi-organ type [3], which requires symptoms from three out of four symptom clusters and moderate to severe impairment in daily living.

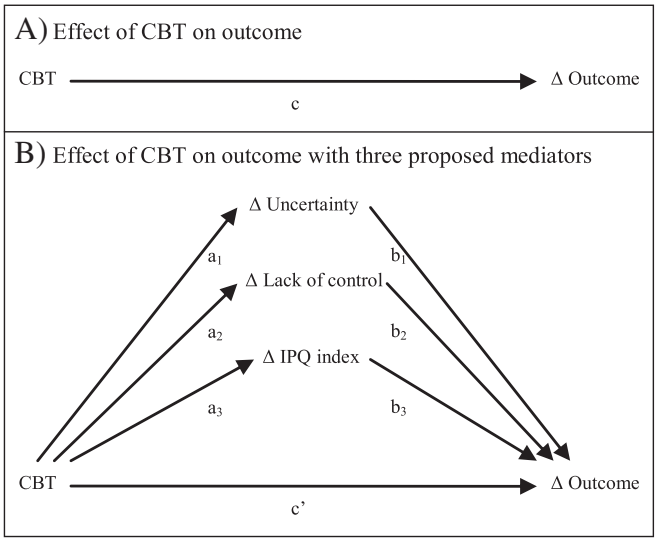

Fig. 1. Proposed mediation model. The effect of CBT A) without and B) with illness perceptions (uncertainty, lack of control, IPQ index) as proposed mediators. c = effect of CBT on change in outcome; a_{1-3} = effects of CBT on specific illness perceptions; b_{1-3} = effects of changes in specific illness perceptions on change in outcome, corrected for the effects of CBT and the other illness perceptions; the product of a and b compose the indirect effect through changes in illness perceptions; c′ = direct effect of CBT on change in outcome corrected for the indirect effects through changes in illness perceptions; CBT = cognitive-behavioural therapy; Uncertainty, Lack of control and IPQ Index (unweighted means of negative consequences and emotional representations) = the revised Danish illness perception questionnaire subscales; Δ = change in.

Exclusion criteria were pregnancy, litigation-claim, non-Scandinavian origin, severe psychiatric morbidity (psychotic or bipolar disorder), and alcohol or drug addiction. Patients with anxiety and/or depression were not excluded. One hundred-twenty out of 125 eligible patients endorsed the trial and were in a block randomisation protocol (six blocks with 20 individuals per block in a 9:11 ratio) randomised to group CBT (n = 54) or enhanced usual care (n = 66). All participants gave written informed consent before enrolment.

In the present study, we used a per protocol analysis in order to investigate mediation. Only patients who actually received CBT were included in the CBT group, and eight patients, who either did not participate or participated in only one module of CBT, were excluded.

Patients completed questionnaires at referral, at baseline (i.e. a few days prior to randomisation) and 4, 10 and 16 months after randomisation. However, illness perceptions were not assessed 10 months after randomisation (Fig. 2). We used corresponding outcome measures as the original trial, while the illness perception data have not been reported previously.

Intervention

Cognitive behavioural therapy (CBT)

The patients allocated to treatment received specialised group CBT for FSS. The group CBT was delivered to groups of nine patients by two psychiatrists. It consisted of nine modules of manualised therapy each of 3.5 hours duration, and was spread over a period of four months. The therapy addressed emotional, cognitive, and behavioural factors known to be involved in the maintenance of FSS and aimed specifically at changing the patients' illness perceptions. At the end of the treatment period, an individualised self-administered rehabilitation plan was given. More details are provided in the original publication [31] and in a detailed description of the treatment [32]. The treatment manual is available at http://funktionellelidelser.dk/en/for-specialists-researchers/psychologists/stress-manual/.

Enhanced usual care (EUC)

All participants underwent a thorough diagnostic assessment, including the semi-structured psychiatric interview Schedule for Clinical Assessment in Neuropsychiatry (SCAN) [33], and received individualised information regarding the nature, course and treatment options for their symptoms. The patients were followed by their general practitioner and there was no restriction on psychological or pharmacological treatments for any of the participants [31]. The assessment might have improved usual care, therefore it was termed 'enhanced usual care' (EUC).

Instruments

Illness perceptions

Illness perceptions were assessed by means of a revised, Danish version of the IPQ-R [26]. The Danish version of the IPQ-R was initially made for primary care use, and a strong correlation between emotional representations and negative consequences (Pearson correlation coefficient = 0.67) was reported in this [26] and other previous studies [24,29,34].

In order to reduce the risk of multicollinearity, we performed a Pearson correlation analysis of baseline data, examining the correlation between the components. We found low intercorrelations (ranging from ±0.10 to 0.25) with exception of a strong correlation between emotional representations and consequences (Pearson correlation coefficient = 0.58, $p < 0.0001$). We therefore combined these two components into an index with unweighted means. The following components were addressed during the group CBT programme and hypothesized key agents of change; lack of control (e.g. I think I have the power to influence my symptoms (reversed)), IPQ index of negative consequences (e.g. I think that my health problem could have major