

IMPROVING DISTRESS IN DIALYSIS (iDiD): A TAILORED CBT SELF-MANAGEMENT TREATMENT FOR PATIENTS UNDERGOING DIALYSIS

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Summary

Background: There is significant psychological distress in adults with end-stage kidney disease (ESKD). However, psychological treatments tailored to address the unique challenges of kidney failure are absent. We identified psychological correlates of distress in ESKD to develop a cognitive-behavioural therapy (CBT) treatment protocol that integrates the mental health needs of patients alongside their illness self-management demands.

Methods: Studies which examined relationships between distress and psychological factors that apply in the context of ESKD including: health threats, cognitive illness representations and illness management behaviours were narratively reviewed. Review findings were translated into a CBT formulation model to inform the content of a renal-specific seven session CBT treatment protocol, which was commented on and refined by patient representatives.

Results: Health threats related to distress were grouped into four themes including: acute ESKD events, loss of role, uncertainty and illness self-management. Having pessimistic illness and treatment perceptions were associated with elevated distress. Non-adherence and avoidance behaviours were related to feelings of distress, whereas cognitive reappraisal, acceptance, social support and assertiveness were associated with less distress.

Conclusions: The dialysis-specific CBT formulation identifies the importance of targeting ESKD-specific correlates of distress to allow the delivery of integrated mental and physical health care. The 'Improving Distress in Dialysis (iDiD)' treatment protocol now requires further evaluation in terms of content, feasibility and potential efficacy.

KEY WORDS Anxiety • Cognitive behavioural therapy (CBT) • Common sense model • Depression • End Stage Kidney Disease (ESKD)

INTRODUCTION

Symptoms of depression (Palmer *et al.* 2013) and anxiety (Cukor *et al.* 2008) are common in end-stage kidney disease (ESKD) and are associated with increased mortality (Chilcot *et al.* 2011a; Farrokhi *et al.* 2013), morbidity (Cukor *et al.* 2013) and healthcare utilisation (Hedayati *et al.* 2005). The term

'psychological distress' refers to a heterogeneous set of symptoms (i.e. emotions) and behaviours (Ridner 2004). Distress can include discomfort, change in emotional status and perceived inability to cope effectively (Ridner 2004). Key features of psychological distress include symptoms of depression and anxiety which are detected using either: diagnostic clinical

BIO DATA

Joanna Hudson is a post-doctoral researcher within the health psychology section at the Institute of Psychiatry, Psychology, and Neuroscience; King's College London. Her research focuses on how to support adults in adjusting to the psychological, social, and self-management challenges of living with long-term conditions.

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interviews, continuous self-report symptom checklists or as a manifestation of disease specific distress. In the latter, the experience of negative emotions are contextually dependent on the presence of disease-specific stressors and threats (Hudson & Chilcot 2015). There is a paucity of renal research that has directly investigated 'distress' and no accepted definition exists. Furthermore, most studies have focused on depression and/or anxiety self-report outcomes. Accordingly, this paper draws on this evidence base to develop an ESKD-specific model of distress, but acknowledges that depression and anxiety do not comprehensively capture the heterogeneous nature of distress in people with physical long-term conditions (LTCs).

Cognitive-behavioural therapy (CBT) is an effective treatment for the management of depression in people with LTCs (Coventry *et al.* 2013; Dickens *et al.* 2013). Pilot studies of CBT have also shown positive effects on mood in patients undergoing dialysis (Duarte *et al.* 2009; Cukor *et al.* 2014). Treatment guidelines for the management of depression in people with physical LTCs advise that i) psychological treatments are manualised to the specific needs of the clinical population and ii) the type of intervention offered be determined by the 'course and treatment of the chronic physical health problem' (National Institute for Health and Clinical Excellence 2009). Furthermore,

the provision of integrated mental and physical health care is a key priority for implementation in the UK (Naylor *et al.* 2012; Mental Health Task Force 2016). However, the availability of manualised CBT treatments that appropriately integrate mental health needs alongside LTC-specific self-management regimens is uncommon.

The common sense model (CSM) is a cognitive-behavioural framework developed to explain how people interpret, process and manage threats to their health (Leventhal *et al.* 1980, 1984). Whilst originally developed to understand health behaviours implemented in response to physical ill health, it nonetheless provides a comprehensive framework to identify the illness-specific cognitive-behavioural factors that trigger and sustain distress. The CSM theorises two parallel, partially interacting, processing systems are activated in response to a health threat (Figure 1). The cognitive processing system includes the generation of an illness representation which includes beliefs about: i) symptoms attributed to the illness (identity); ii) illness duration (timeline); iii) cause of illness (cause); iv) the potential impact of the illness on physical and social functioning (consequences); v) efficacy of personal and treatment resources for managing the health threat (control) and vi) perceived overall understanding of the illness (illness

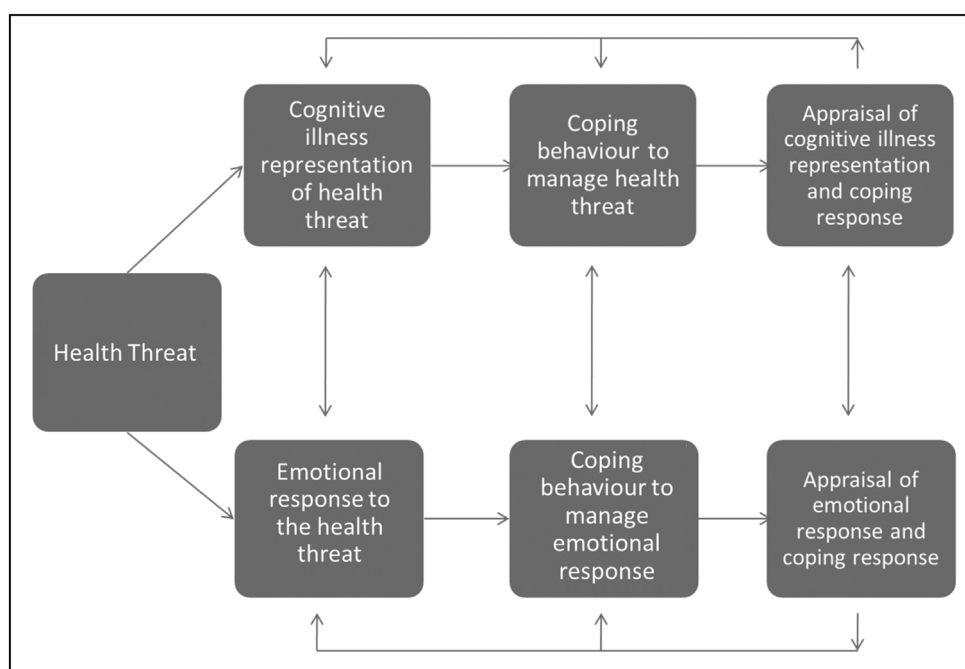


Figure 1: Common sense self-regulation model (Leventhal *et al.* 1980).

coherence) (Moss-Morris *et al.* 2002). These beliefs drive self-management behaviours implemented to manage the health threat, which are then appraised for their efficacy. The interrelated emotional processing system includes emotional responses, which may also trigger behaviours to offset negative emotions. The emotional response and respective behaviours are likewise appraised for their efficacy.

Whilst the cognitive model of depression suggests negative views of the self, world and future are psychological mechanisms for targeting by CBT interventions (Beck *et al.* 1979), the CSM suggests that the way patients cognitively represent and then respond to their illness is associated with their emotional response. Thus, the CSM provides a framework for identifying the specific psychological factors that exacerbate distress in the context of illness. Incorporating elements of the CSM into more traditional CBT approaches may provide a more personally salient method of reducing distress in LTCs and bolster CBT acceptability and efficacy. Studies of treatment interventions using standard CBT protocols for depression and/or anxiety in LTCs report low levels of engagement with these interventions (Ciechanowski *et al.* 2010; Coventry *et al.* 2015). Patients state that traditional CBT treatments fail to take into account the challenges of their illness (Hind *et al.* 2010; Wroe *et al.* 2015). Indeed, greater improvements in mood and quality of life outcomes are observed in primary care mental health treatment settings when standard CBT treatment principles are integrated alongside LTC self-management demands compared with CBT treatment approaches that provide no integration (De Lusignan *et al.* 2015). However, no formalised methodological or theoretical approach was used to develop these integrated mental and physical health treatments. In line with Medical Research Council (MRC) guidance (Medical Research Council 2000), developing a theoretical framework to understand what prognostic psychological factors exacerbate distress in ESKD will identify the specific mechanisms of action that require targeting by CBT approaches. Likewise, once these mechanisms are identified their response to treatment can be formally evaluated in process analyses to prompt further theoretical and treatment refinement and ultimately treatment efficacy once robust targeted treatments are developed (Moore *et al.* 2015).

OBJECTIVES

In this paper, we aimed to (1) generate a CBT self-management formulation model for improving distress in dialysis (iDiD) and

(2) use this formulation to outline a tailored CBT treatment protocol. The CSM was used as a guiding framework to narratively review ESKD-specific health threats (triggers), illness representations (thoughts) and illness management strategies (behaviours) that are associated with psychological distress (depression and anxiety symptoms). A narrative approach was chosen to promote inclusivity of quantitative and qualitative research. We generated the iDiD CBT formulation by mapping illness-specific cognitive-behavioural concepts outlined in the CSM onto a five part CBT treatment formulation, which takes into account the interrelationships between triggers/environmental changes, thoughts, feelings, behaviours and physical reactions (Greenberger & Padesky 2015). Third, we created a seven session CBT treatment protocol by selecting CBT intervention techniques that would target the psychological factors outlined in the five component iDiD CBT formulation found to exacerbate symptoms of depression and anxiety (psychological distress). We incorporated feedback from patient representatives when developing the content of the protocol.

OBJECTIVE ONE-NARRATIVE REVIEW: USING THE CSM AS A GUIDING FRAMEWORK TO IDENTIFY COGNITIVE-BEHAVIOURAL FACTORS RELATED TO THE EXPERIENCE OF PSYCHOLOGICAL DISTRESS IN PATIENTS WITH ESKD

We narratively reviewed articles that quantitatively explored the relationship between self-report measures of depression and/or anxiety and self-reported measures of CSM constructs including: i) health threats both critical illness events (i.e. initiation of dialysis) and ongoing ESKD stressors (i.e. attending for dialysis); ii) illness representations (thoughts) and iii) behaviours relevant to the management of ESKD and/or distress. We also included qualitative analyses that documented the lived experience of people who have ESKD and mapped identified qualitative themes to CSM constructs.

ESKD HEALTH THREATS, DEPRESSION AND ANXIETY SYMPTOMS

The CSM defines health threats as illness related events that trigger somatic and/or functional change (Leventhal *et al.* 2011). Health threats, in the context of chronic illness, may include acute critical events or on-going stressors related to illness management (Moss-Morris 2013). Critical illness events are time limited illness episodes, for example, diagnosis, complication onset. On-going illness stressors include adhering to complex treatment regimens, managing unpleasant symptoms and loss of function.

Meta-analytic review findings indicate that the occurrence of chronic stressors contribute to the maintenance of depression symptoms in ESKD (Chan *et al.* 2011). Identified stressors centred on themes of loss of physical and social function, decreased independence, and increased burden for the patient and others. Other stressors were worry about ESKD progression, anxieties about altered body image/appearance and dealing with diet and fluid restrictions. Furthermore, qualitative reviews show that body image concerns centre around the visibility of dialysis access sites and their potential to provoke stigma (Tong *et al.* 2013; Casey *et al.* 2014). Other themes identified by qualitative research highlight specific concerns about pain and needles, the threat of complications at the dialysis access site, and mistrust of unfamiliar health providers administering painful procedures, uncertainty whilst waiting for a transplant, and the 'unseen burden of ESKD' and its impact on social interactions with others (Moran *et al.* 2011; Tong *et al.* 2013; Casey *et al.* 2014).

Acute critical illness events that are emotionally salient in the ESKD population are less clear. Qualitative reviews emphasise ESKD diagnosis (Tong *et al.* 2013) and procedures used to gain dialysis access (Casey *et al.* 2014) are particularly anxiety provoking. Longitudinal studies are needed measuring psychological distress and the occurrence of acute illness related events (e.g. complication onset, hospitalisation) to identify ESKD-specific illness related events that exacerbate distress. Statistical analyses should also consider the likely confounding role of pre-existing medical co-morbidity and illness severity.

ESKD ILLNESS REPRESENTATIONS, DEPRESSION AND ANXIETY SYMPTOMS

Consistent associations between cognitive illness representation domains and elevated depression symptoms are reported across ESKD studies. Perceiving ESKD as having many symptoms (identity) (Griva *et al.* 2010; Chilcot *et al.* 2011b; Ibrahim *et al.* 2011), that are unpredictable in nature (timeline cyclical) (Chilcot *et al.* 2011b; Ibrahim *et al.* 2011), with serious consequences (Kimmel *et al.* 1995, 1996; Hatchett *et al.* 1997; McGee *et al.* 1998; Griva *et al.* 2010; Chilcot *et al.* 2011b; Ibrahim *et al.* 2011) are associated with increased depressive symptoms. In addition, lower beliefs in the effectiveness of personal capabilities (internal control) (Griva *et al.* 2010; Ibrahim *et al.* 2011) and treatments for managing ESKD, and a perceived lack of overall understanding of ESKD (illness coherence)

(Chilcot *et al.* 2011b; Ibrahim *et al.* 2011) are also associated with lower mood. Personal control beliefs on the other hand have also been shown to correlate with mental health component quality of life scores in haemodialysis patients (HD) (Covic *et al.* 2004).

Prospective analyses indicate that patients on dialysis whose depressive symptoms improve overtime, show a corresponding improvement in their ESKD understanding (illness coherence) (Chilcot *et al.* 2013). In contrast, for those whose depressive symptoms increase overtime, there is a corresponding increase in their beliefs about the degree of negative effects of ESKD on their functioning (consequences) alongside a reduction in beliefs that treatments control kidney disease.

SELF-MANAGEMENT BEHAVIOURS, DEPRESSION AND ANXIETY SYMPTOMS

Unhelpful behaviours, which negatively impact upon health outcomes in ESKD, include non-adherence to diet and fluid restrictions and dialysis treatment regimens. Associations between non-adherence to ESKD self-management behaviours (e.g. skipping and/or shortening dialysis treatments, following diet and fluid restrictions) and elevated symptoms of depression are consistently reported (Clark *et al.* 2014). A qualitative systematic review showed non-attendance at clinical appointments was linked to fears about cannulation and dialysis access site generation (Casey *et al.* 2014). Likewise, avoidance of social situations that had the potential to damage dialysis access sites and repeated checking behaviours for access site functionality, were commonly initiated in response to concerns about future health complications (Casey *et al.* 2014).

Qualitative systematic reviews also offer insight into potentially helpful behaviours implemented in response to ESKD health threats. At the point of diagnosis, peritoneal dialysis patients highlighted the utility of reassessing life values and changing the appraisal of a situation in the management of anxiety (Tong *et al.* 2013). Equally, patients reported the importance of practical and emotional support from friends and family and informational support from medical professionals in managing the daily physical and psychological burden of peritoneal dialysis. Behaviours described by haemodialysis patients as helpful for negotiating the complex self-management challenges of ESKD included: acceptance of their appearance and the potential for health complications to occur and self-assertion with medical professionals (Casey *et al.* 2014).

OBJECTIVE TWO: TRANSLATION OF NARRATIVE REVIEW FINDINGS INTO THE iDiD CBT FORMULATION

To integrate the strengths of the illness-specific health threats (triggers), illness representations (thoughts) and self-management behaviours outlined in CSM with evidence-based CBT treatment principles, we translated the narrative review findings into a CBT treatment formulation. CBT treatment formulations are based on the 'interacting systems principle', which recognise the importance of inter-relationships between thoughts, behaviours, physiological changes and emotions in response to triggers that are appraised by a person as stressful (Westbrook *et al.* 2011; Greenberger & Padesky 2015). Populating a CBT treatment formulation with empirical findings from the CSM allows clearer identification of the types of CBT intervention techniques that map onto the ESKD-specific correlates of distress. Indeed, it promotes the delivery of integrated treatments that recognise the competing demands of managing psychological distress alongside a physical LTC. Furthermore, the shortcomings of the CSM in relation to it not acknowledging the physiological changes that occur in the context of psychological distress are addressed. The CBT formulation gives equal

attention to the importance of physiological changes alongside the cognitive-behavioural correlates of distress. Finally, presenting findings within a CBT formulation model provides a concrete representation of the interactive and cyclical nature of the relationships between illness representations, behaviours, physical symptoms, and emotions. This leads to the generation of interventions that are not linear and focused on one factor but holistic approaches personalised to the needs of a patient.

The iDiD CBT formulation is shown in Figure 2. We grouped ESKD-specific health threats identified from the above review into four trigger themes: i) acute stressors; ii) chronic stressors-change in role/loss/identity; iii) chronic stressors-unpredictability/ambiguity and iv) chronic stressors-illness management. The cognitive model of depression suggests that triggers perceived by the individual as stressful activate maladaptive cognitive schemas (Beck *et al.* 1979). Schemas help people organise and interpret information. Once maladaptive schemas are activated, a person's appraisal of the self, world and future becomes negative and pessimistic. Based on Beck's model we argue that ESKD triggers activate a person's cognitive illness representation

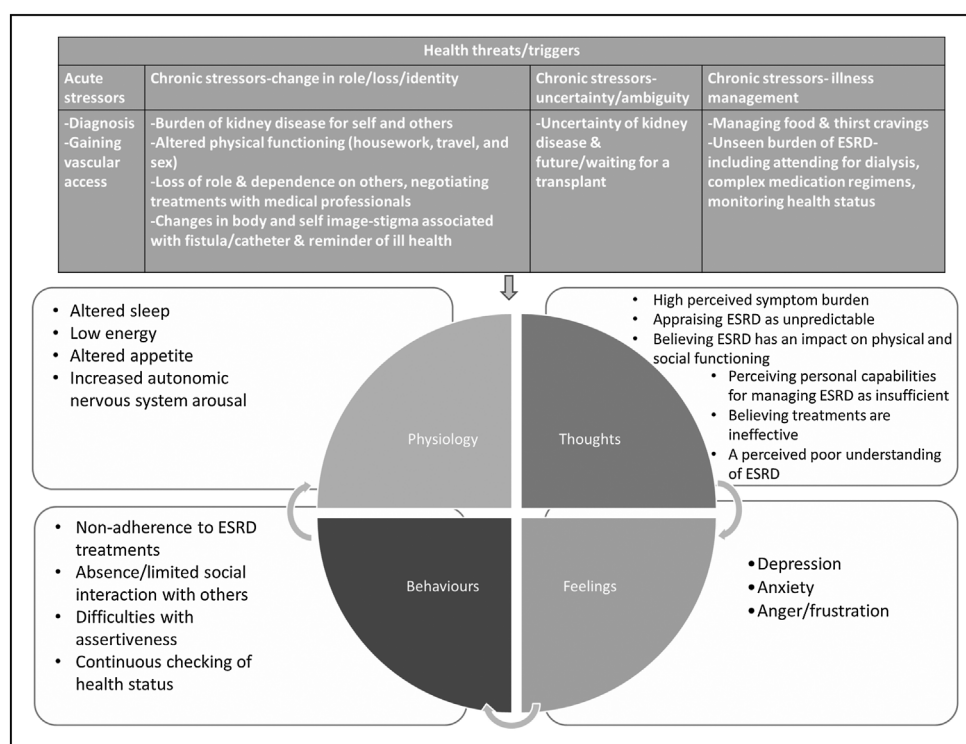


Figure 2: The iDiD CBT formulation.

schema. Indeed, our review findings suggest that a person is more likely to become focused on the symptom burden of ESKD (identity), its unpredictable course (timeline cyclical) and its impact on function (consequences). In addition, a person is more likely to have a pessimistic view of their personal and treatment resources for managing ESKD (control) and believe their overall understanding of ESKD is poor (illness coherence).

The activation of a pessimistic ESKD illness representation and associated emotional response prompts the implementation of illness management behaviours (Leventhal *et al.* 1980, 1984). Our review findings indicated that non-adherence was associated with elevated distress. Non-adherence can be considered a fear-avoidance mechanism (fight/flight response) (Wells 1997). For example, a person becomes fearful of their ESKD because of their negative illness and treatment representation and as a result chooses to avoid situations that provoke more fear and negative illness perceptions. Alternatively, non-adherence may occur because of an absence of motivation in response to feelings of hopelessness (Abramson *et al.* 1989).

Our review also identified the importance of both social interactions and communicating assertively with others in offsetting distress. Avoidance of social contact is commonly observed in people with health and social anxiety (Wells 1997). Indeed, this was frequently identified in the qualitative evidence reviewed above. The reasons for this were related to both disease-specific triggers (such as fluid restrictions) and their effects on body image/social anxiety. A person may retract from social situations for fear of provoking negative appraisal from others, for example, criticism about how they choose to manage their illness or negative comments about their physical appearance. Reduced social contact is also a common behavioural pattern in depression, in response to feelings of hopelessness (Abramson *et al.* 1989) and pessimistic thoughts (Beck *et al.* 1979). For example, a person may feel worthless if they experience a change in their degree of physical and/or social function and as a result withdraw from the company of others. Likewise, the intensive nature of hospital haemodialysis (three times per week for up to four to five hours) alongside a post-dialysis recovery period further impacts on social relationships. Low social support is also associated with a range of clinical and psychosocial outcomes including non-adherence, depression and survival [for a review see Cukor *et al.* (2007)].

Safety behaviours (behaviours implemented by a person to prevent a feared outcome) likely exist to sustain ESKD specific psychological distress. Our review identified repeated checking of dialysis access sites, by some, to maintain a sense of control over health. Whilst preventative health behaviours are beneficial they have the potential to maintain a person's preoccupation with health (Wells 1997) and should be monitored closely during therapy.

OBJECTIVE THREE: A PROPOSED SEVEN-SESSION TAILORED SELF-MANAGEMENT TREATMENT PROTOCOL TO REDUCE SYMPTOMS OF DISTRESS

The iDiD CBT formulation model (Figure 2) provided us with a framework for translation into a seven-session treatment protocol. We mapped evidence-based CBT treatment principles onto the ESKD correlates of distress outlined in the five part iDiD CBT formulation model. The iDiD treatment protocol may be used as a standalone online self- help package, possibly offered whilst patients dialyse, in the context of haemodialysis. However, the efficacy of on-line interventions is increased when therapist support is provided (Spek *et al.* 2007; Richards & Richardson 2012). Below we highlight where attention is needed in the application of CBT intervention techniques when managing distress in the context of ESKD. We draw on the competency framework for the delivery of psychological interventions to people with persistent physical health problems (Roth & Pilling 2015). We also indicate areas for more intensive clinical input from a therapist if resources are available to facilitate this.

The content and design of the seven sessions were presented to renal service patient representatives (two male, four female). Patients were recruited through Guy's and St. Thomas' NHS Trust, London, from a pool of patients who had indicated they had an interest in research. A minimum of two patient representatives commented on the content of each session, whilst two patient representatives commented on the content of all seven sessions. Patient representatives did not receive active CBT treatment from the perspective of a patient in therapy. Specifically, their role was to provide initial feedback on the relevance of the sessions and to contextualise the CBT treatment principles with real-world examples.

Patients either commented whilst on-dialysis with a researcher recording notes or alternatively provided written feedback on paper that was then collated by the researcher. We then applied

a MoSCoW analysis, which is a method used to prioritise content changes when designing digital interventions (Bradbury *et al.* 2014). Content changes were ranked as: 'Must'—essential change to the language and information content for the treatment to demonstrate efficacy and acceptability, 'Should'—important but not critical content change, 'Could'—desirable content changes which may be included and 'Would'—content that has additional features to improve user experience but are by no means essential. Because of the pragmatic nature of this research all 'Must' criteria were incorporated into content revisions. Patient representative comments largely centred on removing psychological jargon about CBT intervention techniques. Likewise, concerns were raised about how we had presented educational information about adhering to dialysis treatment regimens. Initially, we presented information using a health prevention perspective. For example, we listed the negative consequences of non-adherence (e.g. Why should I **not** eat foods high in potassium?). Based on feedback, we changed our focus to highlight the health promoting benefits of adherence and described health benefits (e.g. Why should I limit foods high in potassium?).

The content of the seven-session treatment protocol together with the specific therapeutic techniques relevant to each session is summarised in Table 1. The protocol conformed with traditional CBT session structures (Westbrook *et al.* 2011). The seven sessions were divided into three components:

- Part 1: Socialisation to the CBT treatment model (Treatment sessions 1 and 2).
- Part 2: Active treatment—the application of specific cognitive-behavioural intervention techniques (Treatment sessions 3–6).
- Part 3: Relapse prevention (Treatment session 7).

Parts 1 and 3 of the treatment protocol are best adhered to in the order specified. However, the degree of emphasis placed on the CBT treatment principles outlined in part two will differ on a patient by patient basis, according to their cognitive-behavioural profile (e.g. the nature of their illness representation and their self-management behaviours). Indeed, when therapist support is available the therapist and patient may collaboratively decide to focus their efforts on one particular session and embed it within a treatment structure that comprehensively applies this technique. Based on our clinical experience, we suggest commencing Part 2 with intervention

techniques that target negative emotions using behavioural techniques (described below). We believe this helps to foster engagement as a patient commences 'active treatment' with skills that concretely target their distress and validates their experience of negative emotions. It also provides an opportunity for a degree of relief from distress before moving treatment on to more abstract concepts (Beck 1976), such as illness representations.

PART 1: SOCIALISATION

The first two sessions socialise the patient to CBT treatment. Session 1 is psycho-educational with a particular focus on improving ESKD understanding to foster empowerment (addressing identity, illness coherence, personal control and treatment control illness representations). The content of session 1 was developed from existing patient resources at Guy's and St. Thomas' hospital along with input from the renal consultant (DG) and patient representatives (e.g. adding content for specific contexts that patients noted as misleading, for example, Can I drink alcohol?). Session 2 introduces the links between ESKD-specific triggers and the experience of psychological distress. Session 2 is focused on the development of a model of distress (case conceptualisation), personalised to the needs of the patient. The inter-relationships and vicious cycle that may develop between illness representations (thoughts), emotions, self-management behaviours and physiology in response to a trigger is introduced to the patient. At the end of this session, a patient performs a self-assessment to generate their own vicious cycle model of distress. The iDiD CBT formulation provides the framework for guiding the patient through the self-assessment process (see description of session 2 in Table 1). Two example case conceptualisations generated from the self-help resource are shown in Figure 3a and b.

If therapist support is available for part one of the treatment, then they must have knowledge of the presenting condition, including an awareness of health and social care services available to promote an integrated approach to their care (Roth & Pilling 2015). Knowledge of the presenting condition is vital when non-adherence to treatment has the potential for life threatening health consequences. In the context of dialysis, a patient may disclose dietary and fluid self-management practices that could seriously jeopardise their physical health (e.g. consuming dangerous levels of potassium). Training is needed to ensure that therapists are competent in recognising

Session	Content	CBT intervention techniques
1. What is end-stage renal failure?	Presents information about: - How the kidneys and dialysis treatments work. - Managing treatment efficacy expectations by highlighting common physical symptoms experienced by dialysis patients. Advice is given about the steps patients can take to seek appropriate treatment for these symptoms if not already doing so. - How symptoms of distress can overlap with common physical symptoms that occur in the context of dialysis, for example, tiredness, sexual dysfunction. Patients are informed that subsequent sessions can help patients in managing these symptoms using psychological approaches. - Normalising the experience of distress by highlighting situations that patients on dialysis find stressful (<i>content informed by triggers/health threats from iDiD CBT formulation</i>). - The rationale for specific ESKD treatments and multiple medications. The value of optimal self-management is introduced as a way of lessening the impact of ESKD on physical health (i.e. through adherence, identifying appropriate healthcare professionals for support) whilst also improving psychological wellbeing (i.e. by highlighting adjustment strategies that patients can implement to feel in control, including goal setting and problem solving (addressed more thoroughly in session 5).	• Psycho-education
2. Why do I feel distressed?	- Recap on information in session 1. - Patient performs a self-assessment to generate a case conceptualisation of distress based on the iDiD CBT formulation model. - The vicious cycle metaphor is used to foster an understanding of the reinforcing relationships between: triggers, feelings, thoughts, behaviours and physiology. - First the patient identifies a health threat/trigger that they perceive as being personally relevant to their situation. The list of triggers provided to the patient conform to those presented in Figure 1 of the iDiD CBT formulation. - Second the patient is asked to reflect on the last time they experienced the trigger and how they felt emotionally. - Third the patient is provided with an explanation of how negative emotions can bias a person's cognitive appraisal of the health threat (e.g. their pessimistic cognitive illness representation schema is activated to process and assimilate illness related information). The patient is then asked to select biased cognitive thinking patterns that they recall experiencing in response to the health threat/trigger. The thinking patterns listed for the patient conform to the thinking styles summarised in the iDiD CBT formulation model (see Figure 3a and b for examples). - Fourth, the relationship between pessimistic thinking styles and escape-avoidance behaviours is explained to the patient. The patient is then asked to select behaviours that they recall implementing in response to the trigger. The behaviours listed include the behavioural responses summarised in the iDiD CBT formulation. - Finally, the physiological changes that can occur in response to the trigger and cascade of emotional, cognitive and behavioural responses is described to the patient. The patient then selects physiological changes they recall experiencing when confronted with the health threat/trigger.	• Psycho-education • Guided discovery using education alongside self-assessment • Formulation of the personal model of factors contributing to ESKD distress.

TABLE 1 (Continued)

Session	Content	CBT intervention techniques
	At the end of the session, the patient will have self-generated their own vicious cycle of distress.	
	<i>Between session task:</i> Review content of session 2 by re-reading the session.	
3. Dealing with my negative feelings	- Recaps key information from session 2 and reminds the patient of their personalised vicious cycle of distress. - The rest of the session focuses on behavioural methods used to manage distress. The patient is informed that the session is targeting the emotions section of their vicious cycle. - First examples are provided of potentially unhelpful coping behaviours (e.g. avoidance of threatening situations, suppression of emotions, risky lifestyle) and an explanation is given as to how these exacerbate/maintain distress. - Second the experience of distress is normalised and the different presentations of distress are described, including: low mood, fear and anxiety, and anger and frustration. - Third, the patient selects a particularly salient emotion they would like to focus on and behavioural techniques that they can apply to manage these emotions are outlined to the patient (see techniques in next column). - Fourth, the relationship between poor sleep and distress is introduced. A self-assessment of whether additional support for managing sleep is encouraged. If so sleep hygiene techniques are introduced. - Information provided about acceptance, mindfulness, and relaxation for the patient to access should they wish.	• Psycho-education • Behavioural techniques • Behavioural activation • Emotional expression • Sleep hygiene • <i>Techniques for implementing between session task:</i> SMART goal setting & action planning
	<i>Between session task:</i> The patient is encouraged to select one of the behavioural techniques listed in the next column to implement over the next week. The patient is then introduced to the principles of SMART goal setting and action planning. SMART goal setting includes setting a goal to ensure it meets the following criteria: Specific-stating precisely the goal (behaviour) to be achieved, measurable-defining a metric for evaluating when the goal is complete, achievable-setting a realistic goal, relevant-ensuring the goal is congruent with the ultimate end- point/objective, timely marking an end-point for when the goal will be completed by. A goal is set and recorded by the patient.	
4. Tackling unhelpful thoughts about end-stage renal disease	- Introduction to session 4 outlining its focus on the thoughts component of the vicious cycle. - Recap on information and strategies implemented from session 3. - Review of progress with session 3 goals. After the review, the patient is informed that new goals will be set at the end of the current session. - Introduce the idea of unhelpful thinking patterns related to ESKD. <i>Examples provided are informed by illness representation schema from iDiD CBT formulation.</i> - Introduce the concept of a thought record. - Provide information to equip patients with skills to: i) challenge their thoughts by weighing up the evidence and ii) generate alternative thoughts. - Information is provided to patients about the challenging nature of cognitive techniques to ensure expectations are managed.	• Psycho-education about patterns of cognitive bias in ESKD • Thought elicitation (thought record) • Cognitive reappraisal • Generation of alternative thoughts • <i>Techniques for implementing and reviewing between session tasks:</i> • Progress monitoring and review of goals set from previous session • SMART goal setting and action planning

TABLE 1 (Continued)

Session	Content	CBT intervention techniques
	<i>Between session task:</i> The patient is prompted to remind themselves of the outcome of their goal review from earlier in the session. Based on this review and the information provided in session 4 the patient is prompted to set a new goal and record it. The new goal may include: completion of thought record and thought challenge technique and continuation of behavioural strategies from session 3.	
5. Goal setting and problem solving	- Introduction to session 5 outlining its focus on the behaviours component of the vicious cycle.	• Psycho- education
	- Recap on information and strategies implemented from session 4.	• SMART goal setting
	- Review progress with session 4 goals. After the review, the patient is informed that new goals will be set at the end of the session.	• Action planning
	- The concept of SMART goal setting is outlined in more depth (see above for definition). The term chunking is described to allow the implementation of longer term goals. Examples are provided from dialysis patients who have taken these steps.	• Activity monitoring using diaries
	- The value of completing an activity monitoring diary is introduced. This educates patients in identifying an appropriate time to implement SMART goals.	• Behavioural activation
	- Information on how to implement the seven steps to problem solving approach. Its utility in building self-confidence that the best possible solution is being implemented is emphasised by outlining the difference between controllable (e.g. treatment adherence) and uncontrollable (e.g. worry about future health) health threats/triggers.	• Problem solving
	<i>Between session task:</i> The patient is prompted to remind themselves of the outcome of their goal review from earlier in the session. Based on this review and the information provided in session 5 the patient is prompted to set a new goal and record it. The new goal may include the behavioural techniques introduced in this session including: i) SMART goal setting with chunking; ii) Activity monitoring to inform when to schedule the implementation of a SMART goal or iii) Use of the seven steps to problem solving approach.	• <i>Techniques for implementing and reviewing between session tasks:</i>
		• Progress monitoring and review of goals set from previous session.
		• SMART goal setting and action planning
6. Managing difficult social relationships	- Introduction to session 6 and its focus on social relationships with others.	• Identification of an assertive role model
	- Recap on information and strategies implemented from session 5.	• Preparation of assertive responses to self-identified scenarios
	- Review progress with session 5 goals. After the review, the patient is informed that new goals will be set at the end of the session.	• Mental rehearsal of assertive replies
	- Examples of social situations that people with ESKD find particularly difficult provided (i.e. dealing with medical professionals, asking for help off family and friends, reminding people that they are ill despite looking well).	• Behavioural rehearsal of assertive reply
	- Information on how improving assertiveness skills can foster better social relationships. Concrete examples of people behaving assertively outlined as a prompt for reflection.	• Self-monitoring of assertive behaviour
	- Self-assessment of levels of assertion to prompt the implementation of assertiveness skills training (see techniques used in next column).	• Problem solving to identify sources of emotional, practical and informational support if needed

TABLE 1 (Continued)

Session	Content	CBT intervention techniques
	- If absence of social support is self-identified as an area of need, then information is available for patients to reflect on their social support network and how they can make optimum use of it.	• <i>Techniques for implementing and reviewing between session tasks:</i>
	<i>Between session tasks:</i> The patient is prompted to remind themselves of the outcome of their goal review from earlier in the session. Based on this review and the information provided in session 6 the patient sets a new goal and records it.	• Progress monitoring and review of goals set from previous session
		• Goal setting and action planning
7. Progress recap and preparing for the future	- Recap on information and strategies implemented from session 6.	• Relapse prevention including:
	- Review progress with their session 6 goals.	• Progress review
	- Reflection on progress made over the previous six sessions by identifying new skills learnt and successfully completed between session tasks.	• Self-assessment of new skills
	- Use the principles of action planning to allow the continuation of skills moving forward.	• Action planning to implement new skills
	- Develop a specific action plan to implement when an acute stressful event occurs.	• Preparing for setback

Table 1: Summary of the seven session iDiD treatment sessions

when non-adherence to treatment can be considered a *behavioural risk factor*. Likewise behavioural risk management protocols are needed to ensure appropriate medical advice and support is provided.

PART 2: APPLICATION OF COGNITIVE-BEHAVIOURAL INTERVENTION TECHNIQUES

The structure and emphasis given across sessions 3–6 will vary depending on the needs of the patient (their case conceptualisation). The self-help tool explicitly informs patients that they may find some sessions more relevant and useful than others. This ensures expectations are managed. Session 3 commences with normalising the experience of low mood, fear and anxiety, and anger and frustration in the context of ESKD. Anecdotes used were enhanced by our patient representatives. The patient is prompted to revisit their self-generated model of distress and reflect on a specific type of emotional response they would like to focus on (e.g. low mood). This would preferably occur in collaboration with a therapist (resource permitting). Once selected a patient is then offered a choice of evidenced-based CBT techniques that can address their specific emotional response. Session 3 focuses on the application of three behavioural intervention techniques: i) behavioural activation; ii) emotional expression and iii) graded exposure. Contextual examples of these techniques are described below.

BEHAVIOURAL ACTIVATION

This intervention technique is offered to patients with low mood and/or anger to enhance perceptions of control. This would be an appropriate technique to apply for the case conceptualisation shown in Figure 3a. Behavioural activation allows individuals to gain a sense of mastery and control over their condition by planning and implementing necessary (e.g. dialysis attendance) and pleasurable tasks (e.g. going to the cinema) (Hopko *et al.* 2003). Behavioural activation is a useful intervention technique to apply early on in the therapy process. It allows the patient to experience positive affect and can prompt reflection on why this occurred. More detail of how a patient can build on this technique is provided in session 5 (described below). When behavioural activation strategies are introduced the benefits of exercise for mental and physical well-being is highlighted. If behavioural activation is collaboratively implemented, then the therapist needs to ensure that behaviourally contraindicated treatments are not implemented (e.g. choosing to skip dialysis to improve mood).

EMOTIONAL EXPRESSION

Emotional expression gives the patient an opportunity to process and understand their feelings (Pennebaker 1997). This technique would be useful for the cases shown in Figure 3a and

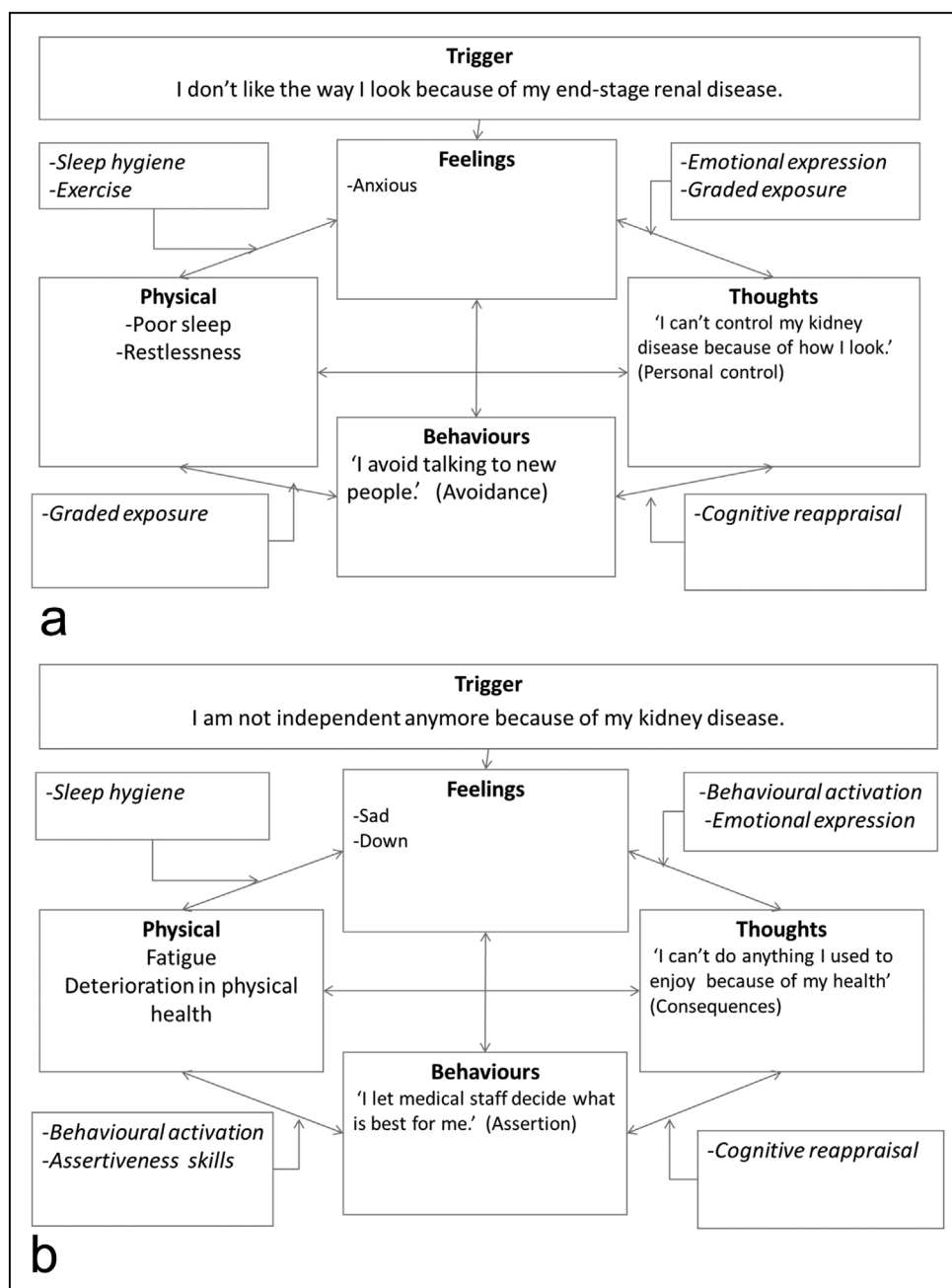


Figure 3: a: Personalised vicious cycles of distress generated from the iDiD CBT formulation: body image. b: Personalised vicious cycles of distress generated from the iDiD CBT formulation: perceived loss of independence. Words in italics represent the CBT intervention components that can be implemented to break a patient's vicious cycle of distress.

b. Expressing emotions prevents inhibition and allows the patient to identify what their needs are. These can then be addressed using CBT intervention techniques introduced later on in the self-help tool. Our protocol encourages written

emotional expression in accordance with the work of Pennebaker (1997). Patients are advised to write about their thoughts and feelings in relation to their emotional trigger for 15–20 minutes per day, for three consecutive days.

GRADED EXPOSURE

For patients who are presenting with fear-avoidance behaviours (fight/flight response), for example, fear of specific ESKD procedures or negative evaluation by others, the principles of graded exposure are introduced (Wells 1997). Graded exposure allows the patient to be introduced to their feared situation in a phased manner. This allows the degree of anxiety experienced to be broken down into manageable phases whilst also allowing the patient to learn how to control their anxiety when exposed to their feared situation (habituation). An explanation is provided to the patient about the process of exposure and habituation to feared situations. The patient is encouraged to think about how they can break their graded exposure hierarchy into manageable steps, using an example of a patient who was fearful of leaving her home in case she became ill. The application of this technique is guided by the work of Wells (1997). There is scope to implement this technique more comprehensively if therapist support is available and the patient is phobic or socially anxious. Indeed, this technique may usefully be applied to the case conceptualisation shown in Figure 3b.

For some patients, poor sleep will exacerbate their distress. Sleep hygiene techniques are also introduced to patients in session 3. A patient can self-assess their sleeping patterns to identify what is disrupting their sleep cycle (if necessary). These are presented to patients in the following format: i) erratic sleep patterns because of irregular sleeping times (common amongst dialysis patients because of co-morbid fatigue (Artom *et al.* 2014); ii) stress or worry preventing sleep and iii) prolonged sleep. Once a patient has selected the cause of their poor sleep appropriate sleep hygiene techniques are introduced (Stepanski & Wyatt 2003).

Session 3 also provides patients with information about mindfulness and acceptance (McCracken 2011). The information is used as means to signpost patients to these treatment principles if they think they are relevant to their specific needs.

Session 4 uses traditional cognitive restructuring techniques (thought challenging) to address unhelpful illness representations about their ESKD. We hypothesise that distressed patients will relate better to the illness-specific thinking styles presented in the self-help resource and therefore engage more with the treatment. Illness representations are often punctuated by thinking styles that commonly occur in depressed and anxious populations (Beck 1964). These thinking patterns are amenable to change using traditional cognitive restructuring techniques.

For instance, our review identified that elevated distress occurs when individuals believe they have a lack of personal control over their ESKD and a poor understanding of it. Some individuals may demonstrate specific biases in the way they appraise their degree of ESKD control and illness understanding. For example, they may think in 'black and white' terms and use absolute statements such as 'I have absolutely no control over my ESKD' or 'I know nothing about my kidney disease'. Session 4, therefore, introduces patients to the concept of biased thinking patterns, self-monitoring of thoughts using thought diaries, thought challenge techniques, and the generation of alternative thoughts.

Likewise, a person may hold erroneous beliefs about ESKD and its management. Our narrative review identified the importance of low treatment efficacy beliefs in the maintenance of distress. Thus, hypothesis-testing/behavioural experiment scenarios (Beck 1995) can be generated whereby patients adhere to specific ESKD treatments over a period of time and monitor its impact on blood test results, for example. This is a useful technique to implement in this context because it provides objective evidence to challenge a patient's unhelpful beliefs. Again, knowledge of the illness and its treatment is needed to ensure appropriate behavioural experiments are implemented.

Session 5 aims to improve a patient's sense of control and empowerment over their ESKD and/or psychological distress. It builds on the behavioural activation concepts introduced in session 3. Session 5 uses principles from problem-solving therapy (D'Zurilla & Goldfried 1971) but also principles of behaviour change applied to the management of physical health, including SMART goal setting and action planning (Michie *et al.* 2011). The worked examples described in this session were informed extensively by our patient representatives' experience with the condition. One problem-solving example describes 'compensatory behaviours' as a strategy to implement when adhering to diet and fluid restrictions, such as limiting diet and fluid intake the day before a meal out with friends. This provides an example of how patients can 'carry forward' their remaining diet and fluid 'balance' to the next day, thus allowing them to 'feel normal' and sustain social contact. These ESKD-specific behavioural skills can usefully be incorporated into traditional problem-solving approaches but collaboration with renal consultants is needed, to ensure that psychological treatments do not conflict with ESKD treatment regimens in some instances.

Given that our review findings identified the importance of social interaction for sustaining emotional well-being, session 6 focuses on improving patients' assertiveness skills and sustaining positive social contact with others. Patients self-identify situations that they find particularly challenging and devise a plan to implement their assertion skills (if necessary) (Wells 1997). Likewise, session 6 includes resources to prompt patients to reflect on the types of social support networks they have available to them. Patients are encouraged to think about the practical, emotional and informational support networks they have. If one area of social support is lacking, then the patient is encouraged to complete the problem-solving section of session 5 to identify a solution for increasing their level of support in this area.

The final session summarises skills learnt and progress made over the preceding six sessions. It also puts in place relapse prevention protocols to sustain improvements into the future.

IMPLICATIONS FOR PRACTICE

Illness representations predict a range of outcomes in patients undergoing dialysis (Chilcot 2012). Furthermore, altering unhelpful illness representations has demonstrated beneficial effects on health outcomes in other physical conditions (Petrie *et al.* 2002; Broadbent *et al.* 2009; Chilcot & Moss-Morris 2013). We have created an iDiD CBT formulation model and seven session CBT protocol to target and improve symptoms of depression and anxiety (psychological distress). Attempts to treat psychological distress as part of routine practice in ESKD are not yet optimised in terms of efficacy, delivery and content. The iDiD CBT formulation and seven session treatment protocol has the potential for low intensity pragmatic delivery, for instance, via self-help manuals or delivery whilst patients dialyse using computerised packages. It may also have utility as an early

stage intervention to help incident patients prepare and adjust to dialysis.

CONCLUSION

Whilst patients were involved in the initial development of iDiD, a thorough evaluation of the treatment content and its acceptability is required [see Hudson *et al.* (2016)]. In addition, the feasibility of different delivery approaches (e.g. self-help manuals, computerised packages) needs to be evaluated in order to better integrate the psychological and physical needs of dialysis patients as part of routine care.

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CONFLICT OF INTEREST

Joanna Hudson, Rona-Moss-Morris, David Game, Amy Carroll and Joseph Chilcot have no conflict of interest with respect to this publication.

AUTHOR CONTRIBUTIONS

JLH: Participated in design and coordination, undertook interviews, drafted the main manuscript, read and approved the final manuscript. RMM: Participated in design and coordination, commented significantly on drafts and added specific components, read and approved the final manuscript. DG: Participated in design and coordination, commented significantly on drafts and added specific components to improve relevance to renal readership. AC: Participated in design and coordination, commented significantly on drafts and added specific components to improve relevance to renal readership. JC: Principal Project Leader, conceived study, participated in design and coordination, read and approved the final manuscript.

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