An evidence-based theory of psychological adjustment to long-term physical health conditions: Applications in clinical practice

Running title: Transdiagnostic model of adjustment in LTCs

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List of Figures*:

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Objective: Around 30% of people with long-term physical health conditions (LTCs) experience comorbid anxiety and depression. For many, comorbid distress is linked to difficulties adjusting to the challenges of the LTC. The aims of this paper are to present a transdiagnostic theoretical model of adjustment to LTCs (TMA-LTC), demonstrate the application of this model in clinical practice, and highlight the distinguishing features of treating LTC-related distress compared to treating primary anxiety and/or depression.

Methods: A systematic review (k=21) was conducted to collate pre-existing evidence-based models of adjustment across LTCs. Models of adjustment for a range of LTCs were extracted and synthesised into a new preliminary TMA-LTC. Two expert consensus meetings were held, where experts rated the relevance and importance of all concepts within the models.

Results: The TMA-LTC proposes that acute critical events or ongoing illness stressors can disrupt emotional equilibrium, and that whether a person returns to equilibrium and achieves good psychological adjustment depends on a number of cognitive and behavioural factors, as well as their interpersonal, intrapersonal, environmental and illness-specific contexts. A case study is presented to demonstrate the clinical application of this model in treating illness-related distress, highlighting how it overcomes roadblocks that may be encountered when working primarily within traditional mental health paradigms.

Conclusions: As an empirically and clinically informed model, TMA-LTC provides a useful guide for assessment, formulation and treatment in the context of psychological adjustment to LTCs. Future studies are needed to test treatments that have been developed based on TMA-LTC.

Keywords: Psychological adjustment, long-term conditions, transdiagnostic

LTC: Long-term physical health conditions

CBT: Cognitive Behavioural Therapy

MS: Multiple Sclerosis

MDT: Multidisciplinary Team

HCP: Healthcare Professional

Using a case study of a woman with multiple sclerosis (MS) as an exemplar, we detail how our new transdiagnostic model of adjustment to long-term physical health conditions (TMA-LTC) can be used to guide assessment, formulation and treatment of illness-related distress. While the purpose of the model is to capture transdiagnostic factors that help and hinder adjustment to long-term conditions (LTCs), and are common in behavioral medicine and psychosomatic clinical practice, we have chosen MS for our case study as it encompasses a range of challenges relevant across many LTCs. MS is an inflammatory demyelinating condition that slows down the transmission of nerve impulses from the brain and spinal cord to the rest of the body. People with MS experience a range of physical and cognitive symptoms, acute symptom exacerbations and chronic symptoms, ongoing treatment and interaction with medical teams, and uncertainty about illness progression [1].

As well as presenting our theory and model of adjustment to LTCs, we also discuss the conceptualisation of psychological adjustment to LTCs, how this differs to formal diagnoses of mental health conditions, and why this distinction is important in clinical practice. This paper focuses primarily on Cognitive Behavioural Therapy as it maps readily onto the proposed model of adjustment. However, we acknowledge that other therapeutic approaches may also be beneficial for supporting people to adjust to LTCs and that intervention choice is often guided by the service context and therapist training. Other therapeutic approaches, such as third wave cognitive behavioural therapies could also be applied to the model.

Case Example

Megan, 35, was diagnosed with MS two years ago. She was understandably distressed following her diagnosis and worried about its impact on her future. Megan has tried to maintain a sense of normality by continuing to work full-time as a teacher, maintain relationships and train with her local running

club. Despite feeling exhausted and under financial pressure, she has attended all medical appointments and engaged with treatment (weekly injections and physiotherapy).

Six months ago, Megan had a severe relapse, which was very frightening for her. She experienced dizziness, visual problems and weakness in her legs that impacted her mobility. She had to take a month off work and felt guilty because she felt she was letting her students down. She needed steroids to alleviate her symptoms as they didn't adequately improve without treatment. Since her relapse, Megan has had ongoing difficulties with fatigue and continued pain and weakness in her leg. Despite this, she has continued working because she worries that people will think she's not doing a good job if she takes time off. She has missed some physiotherapy appointments to avoid missing work, and has doubts about whether physiotherapy will help, since she had thought her previous treatment would prevent relapse.

Megan is very anxious about how MS will affect her quality of life in the future; she worries about relapses, losing mobility and developing new physical and cognitive symptoms. She gave up running because she worried that too much exercise caused her relapse and wants to do all she can to prevent another relapse. Her mood is low, and she has stopped seeing friends from her running club because it makes her sad that she can't do it anymore. She has always considered herself emotionally 'strong'; she hasn't spoken about her feelings because she worries about being treated differently or burdening friends and family.

Epidemiology and clinical features

Thirty percent of the population in England, and 60% of the population in the USA have one or more LTCs [2-4]. People with LTCs are 2-3 times more likely to experience symptoms of depression and/or anxiety than those without [2]. Many will be diagnosed with a mood or anxiety disorder according to the Diagnostic and Statistical Manual for Mental Disorders, 5th Edition (DSM-5) [5]. Others experience subthreshold symptoms that do not meet these criteria, but still cause high levels of distress. When people experience significant distress in

the context of their LTC, but don't meet DSM-5 criteria for an anxiety or mood disorder, they may be diagnosed with Adjustment Disorder. Similarly, people with or without a LTC who experience distress related to persistent physical symptoms (e.g. pain or fatigue) may be diagnosed with Somatic Symptom Disorder [5]. The DSM-5 diagnostic criteria for Adjustment Disorder and Somatic Symptom Disorder are shown in Table 1.

[Table 1 here]

Distinguishing 'psychological adjustment' from psychopathology

We argue that while the diagnostic category 'Adjustment Disorder' has advantages in the context of LTCs, it also has some notable disadvantages. Considering advantages, this diagnosis is helpful in that it recognises the context of a person's distress, by acknowledging that distress can be triggered by the multiple stressors posed by having a LTC. It provides a useful framework for assessing the impact of LTC-related distress by noting the importance of understanding functional impairment across different life domains. Additionally, in some contexts, having this diagnostic label is important as it can facilitate access to care in health systems with limited resources, particularly when people don't meet diagnostic criteria for mood or anxiety disorders [6-8]. Similarly, the term 'Somatic Symptom Disorder' has some advantages as it acknowledges that experiencing ongoing physical symptoms can be highly distressing and cause significant disruption to daily life. It may also facilitate access to services where scoring above clinical thresholds for psychological disorders may be a prerequisite to accessing psychological therapy.

However, the label 'Somatic Symptom Disorder' may be problematic for patients with LTCs as it may be interpreted as suggesting that physical symptoms are solely psychological in nature. Previous qualitative research has suggested that patients prefer the term 'persistent

physical symptoms', as it is less pathologizing and acknowledges the physical experience of symptoms [9].

The term 'Adjustment Disorder' may also be problematic for people with LTCs, as it runs the risk of pathologizing an expected response to a distressing situation. Qualitative studies with patients with LTCs and therapists who work with patients with LTCs have reported that applying diagnostic labels to distress can be experienced as stigmatising by patients [10, 11]. Participants in these studies highlighted the importance of using language that normalises distress, as pathologizing language can have the unintended effect of reducing engagement or satisfaction with care [10, 11]. We therefore argue that the term 'psychological adjustment' is more helpful than the diagnostic label 'Adjustment Disorder'.

This construct recognises that having a LTC poses unique external stressors that disrupt emotional equilibrium and require a degree of psychological adjustment. Based on this conceptualisation, this article outlines how treatments to promote psychological adjustment to LTCs differ from treatments that are applied to people with primary depression and/or anxiety unrelated to living with an LTC.

Biopsychosocial Mechanisms Regarding Etiology and Clinical Consequences

To understand psychological adjustment to LTCs, it is important to consider the biological, cognitive, behavioural and emotional factors that precipitate and perpetuate illness-related distress, as well as the interpersonal and contextual factors that also play an important role. While biological and illness-specific factors differ across LTCs in terms of symptoms, treatment, prognosis and disability levels, there is overlap across illnesses in terms of the psychological challenges and adjustment processes involved in living with a LTC. Therefore, there is value in creating a TMA-LTC, which highlights common factors that precipitate and

perpetuate distress across conditions, whilst also addressing multimorbidity [12, 13]. This allows for the development of a core treatment protocol with the potential to be effective across a range of conditions with minimal adaptation needed, keeping treatment costs low [12]. In the following section we outline the process we used to identify common processes regarding the etiology of illness-related distress, and to develop TMA-LTC.

Developing a transdiagnostic model of psychological adjustment to LTCs (TMA-LTC)

A systematic review of models of adjustment to LTCs was conducted, which was supplemented by key conceptual papers identified by experts in the field, following methodology by Bradbury et al. [14]. The review aimed to identify and collate pre-existing evidence-based models of adjustment in LTCs. Following comprehensive searches, 6142 papers were identified and screened for inclusion. Ten were included in the narrative synthesis. A further 11 key conceptual review papers identified by the research team and/or experts in the field were also reviewed. Eleven papers reviewed chronic illnesses and 10 focussed on specific illnesses; MS (*n*=2), diabetes (*n*=1), kidney disease (*n*=1), IBD (*n*=2), rheumatic diseases (*n*=2), chronic heart disease (*n*=1) and Hepatitis C (*n*=1). Adjustment outcomes largely focused on broad definitions of psychological adjustment including well-being and quality of life (*n*=15), but some were more specific, for example depression (*n*=3), distress (*n*=2) and disorders of adjustment (*n*=1). For more information see Supplementary Digital Content, which presents details on the search strategy and included studies [15-35].

Models of adjustment were extracted from each paper and synthesised into a new preliminary model of adjustment, in an iterative process where changes were made to the model until there was agreement amongst all authors that all key concepts and themes were included.

After developing the preliminary model, two expert consensus meetings were held to identify which factors were relevant to adjustment across different LTCs. Experts were selected to

represent both clinical and academic backgrounds. To participate, clinical experts needed at least 6 months relevant experience and academic experts needed to be working in CBT trials or projects around adjustment to LTCs. Seven experts took part in panel one, and eight took part in panel two. Experts included seven clinical psychologists, four academic psychologists, two health psychologists, one CBT therapist and one psychiatrist. Both meetings lasted three hours. An initial discussion was encouraged to identify factors missing from the model. Participants then privately rated each factor in terms of its importance to adjustment in LTCs. They were asked to think about how often the factor would be relevant to formulation in the LTC they were most familiar with, scoring 3 (*used in almost all cases*), 2 (*used in quite a lot of cases*), or 1 (*used more rarely*). Results were collated and fed back to panellists and unexpected results were discussed. Participants were asked to indicate if any factors should be re-rated. After the meetings, the ratings of both groups were combined and analysed.

Results of the ratings are shown in Tables 2 and 3. Results were relatively consistent across panels. Most factors had an average rating of >2, which indicated importance of the concept across conditions. Ratings of <2 were defined as less relevant across conditions, and were not included in the model, whereas scores above 2.5 indicated particularly important transdiagnostic variables and are highlighted in bold type in the model (Figure 1).

[Table 2 here]

[Table 3 here]

Proposed transdiagnostic model of adjustment to LTCs

The proposed transdiagnostic model of psychological adjustment to LTCs (TMA-LTC) is shown in Figure 1. The model proposes that acute critical events and ongoing illness stressors such as diagnosis, ongoing symptom management and threat to mortality can disrupt a person's equilibrium, and that the process of adjustment involves returning to a state of equilibrium [29]. To define

disruption and return to equilibrium, we draw on the Common-Sense Model of Self-regulation [36]. This model suggests that people's interpretations of illness and symptoms guide their coping mechanisms, and that adjustment is dependent on the helpfulness and appropriateness of the coping mechanism to the situation. Whether or not one returns to a state of equilibrium depends on their ability to evaluate and adapt their coping mechanisms in the context of the health threat they are experiencing. Therefore, returning to a state of equilibrium involves (1) developing accurate interpretations of illness and symptoms, (2) establishing cognitive, behavioural and emotional responses to illness and symptoms that are appropriate to the situation, and (3) being able to evaluate and adapt one's coping mechanisms depending on their how well they work for the individual [37]. The way in which a person responds to diagnosis, ongoing symptoms and treatment will be influenced by their interpersonal, intrapersonal, environmental, and illness-specific contexts, as shown in the four boxes surrounding the dotted line. Considering these factors in assessment, formulation and intervention is key.

Whether or not a person returns to equilibrium and achieves good psychological, physical and social adjustment also depends on a number of cognitive and behavioural factors shown in the boxes to the left and right in the model. These factors help to explain why some people adjust well to LTCs, whereas others experience significant distress or challenges. A key benefit of our model is that it recognises a person's strengths and facilitators of adjustment, as well as factors that make adjustment difficult. By including both helpful and unhelpful cognitive-behavioural factors, it provides a greater number of potential mechanisms to target in therapy. Within these cognitive and behavioural factors, the model also differentiates between *illness specific factors* (e.g. beliefs about illness and treatment) and *generic factors* (e.g. global hopelessness). This distinction helps to show how treatments for primary mental health disorders can be adapted to treat distress in the context of LTCs by focusing on illness-specific factors, whilst elements of treatment related to generic factors remain unchanged.

When considering the helpfulness of patients' cognitive, behavioural and emotional responses, it is important to consider the adaptiveness of the coping strategy within the person's context and the 'goodness-of-fit' between appraisals of different aspects of the LTC and coping strategies [38]. Thus,

the variables in the model should not simply be considered 'helpful' or 'unhelpful', but rather evaluated in relation to their appropriateness and adaptiveness based on the situation. For example, strategies such as denial may be protective and adaptive in the early stages following diagnosis, but prolonged denial is likely to be unhelpful [39]. Similarly, if a person accurately appraises an aspect of illness as controllable, and therefore copes by applying problem-focused coping strategies (e.g. improving diet or exercise, medication management), then the appraisal and coping strategy fit well with the situation and are likely to reduce distress. Conversely, if a person tries to apply similar strategies to aspects of the illness over which they have little control (e.g. progressive disease, trying to prevent relapse), the poor fit between the appraisal, coping strategy and situation is likely to increase distress.

[Figure 1 here]

Authors' perspective: Applying TMA-LTC to the case example (Megan)

A therapist/health care professional's approach to working with Megan may depend on their training and prior experiences. Therapists who are used to working with primary mental health conditions may understand Megan's difficulties within a mental health framework and draw on theoretical models of depression and anxiety. However, working primarily within this paradigm could mean that important nuances that should be considered when working with people with LTCs are missed. This mental health model may be appropriate for some patients whose distress is not related to their LTC. However, when choosing the most appropriate treatment, one should first focus on teasing apart psychopathology from LTC-related distress by carrying out a comprehensive assessment that explores LTC-specific factors. This involves assessing 'general' cognitive and behavioural factors that apply across both LTCs and primary mental health conditions, and supplementing this by collating LTC-specific information, as highlighted in TMA-LTC (Figure 1).

In the sections below, we describe the process of how a therapist could use this proposed model in their work with Megan. We highlight important factors that should be considered in assessment, formulation and intervention, and note potential 'roadblocks' that one might encounter if working primarily within a mental health paradigm.

Assessment

By understanding Megan's presenting problems in the context of mental health conditions such as depression or anxiety, one would likely attune to key processes that maintain low mood and anxiety such as avoidance of activity, social withdrawal, self-critical thinking, having high standards for oneself and catastrophising about the future. These factors may indeed be important for Megan as she withdraws from friends and family, pushes herself in work to avoid others' negative appraisals of her performance, worries about the future, and avoids things she enjoys like running. However, without understanding the MS-specific factors that guide Megan's thoughts and behaviours, it is likely that a therapist will encounter resistance when applying therapeutic techniques to challenge unhelpful thoughts and behaviours.

Table 4 details areas to target in assessment, key assessment points within each domain, and example questionnaires to use in combination with clinical interview to aid assessment. An important first step is to assess 'disrupted equilibrium', which we have defined as clinically significant or ongoing illness-related distress. We recommend using clinical cut-offs on standardised questionnaires to assess clinically significant distress, as previous trials of CBT for adjustment to MS show little change pre and post-intervention for people with lower baseline distress [40]. Regarding duration of distress, it is more challenging to give a specific timeframe for intervention as this is likely to vary greatly between individuals depending on their subjective experience of distress, impact of distress on their ability to function and readiness for intervention. However, to help inform decision making about intervention timing, it may be helpful for therapists to consider clinical guidelines for the treatment of Post-Traumatic Stress Disorder, which recommends active monitoring of patients for a minimum of four weeks before intervention is offered, and bereavement literature which recommends waiting six

months before commencing intervention [41, 42]. As trauma and grief are often relevant in the context of acute illness-related events and ongoing illness-related stressors, considering these timelines in the context of individual assessment may help to guide treatment decisions. For example, immediately after a stressful and potentially traumatic medical procedure, distress may be considered a normal reaction. If the high levels of distress related to this critical event are still there a month or more afterwards, then intervention may well be indicated. If the illness-related events are loss related e.g. loss of mobility, loss of identity as a breadwinner, more time might be needed to grieve and adjust before this is seen as a clinical issue.

We recommend combining psychometric assessment measures of distress with clinical interview to assess whether distress is related or unrelated to the LTC, to guide formulation and intervention. While we have also suggested a range of measures that can be used to guide assessment, the remaining domains could be assessed using clinical interview rather than structured questionnaires, or using a combination of both. We have included a guide to Megan's scores on some of the questionnaires used in assessment. It is worth noting that some of these questionnaires do not have clinical cut-offs (e.g. the IPQ-R and CBRQ), but scores above the mid-point may offer a useful guide to the more unhelpful thoughts, behaviours and perceptions.

[Table 4 here]

Formulation

Following this comprehensive assessment, a collaborative formulation can be developed to guide intervention. The formulation would be guided by the factors included in the TMA-LTC. An example of the formulation that would be collaboratively developed and shared with Megan is shown in Figure 2. Colour coding for thoughts and behaviours shows which thoughts are most likely to link to specific behaviours.

[Figure 2 here]

Current evidence-based treatments and their limitations

Cognitive behavioural therapy (CBT) is recommended for the management of depression in adults with LTCs [53]. Evidence from systematic reviews and meta-analyses have consistently shown CBT is an effective intervention for treating depression in adults with LTCs [54-56]. However, effect size estimates for reductions in symptoms of depression in people with LTCs are lower than those in populations without co-morbid LTCs [57]. One reason for this may be that CBT protocols focused on treating primary mental health conditions do not apply as well to adults with LTCs. We have argued previously that treatments designed predominantly for mental health conditions fail to address the unique context and challenges associated with living with an LTC [58]. Additionally, outcome measures focussed solely on depression or anxiety may not fully capture the breadth of adjustment that is required.

Clinical trials have provided some evidence that tailoring CBT for LTCs improves treatment efficacy over standard CBT protocols designed to treat primary mental health conditions [59, 60]. These trials have tailored treatment protocols to address illness self-management, acknowledge how physical and mental health interact, and explore unhelpful illness perceptions [61-63]. However, none of these interventions appear to have been based on an empirically driven theory of adjustment to LTCs. The Medical Research Council guidance specifies that theory, which helps to define key treatment mechanisms, could be the starting point for the development of complex interventions [64, 65]. Below, we outline the application of our theory-driven model to treating LTC-related distress, drawing on the case example of Megan.

Tailoring treatment: cognitive behavioural therapy based on TMA-LTC

Based on the formulation, adopting a cognitive behavioural approach to therapy with Megan would encompass psycho-education about symptom management and treatment to challenge inaccurate illness perceptions and treatment beliefs, helping Megan to adopt more helpful cognitive and behavioural responses to symptoms, and managing uncertainty. It would also involve drawing on protective factors and strengths that helped Megan to adjust to MS previously (e.g. continued engagement in valued activities, social support network and sense of purpose in her work). Of note, when working in LTCs, it is important to recognise that while patients may hold some inaccurate beliefs about symptoms or treatment (e.g. believing that avoiding activity will prevent relapse), other beliefs will be accurate and realistic (e.g. believing that one will experience more physical and/or cognitive symptoms in the future). This means that therapists often work with beliefs that are realistic and accurate, which differs from working in the context of some mental health conditions such as anxiety, in which predictions about future events are often (but not always) inaccurate (e.g. in the case of panic disorder when physical symptoms are catastrophically misinterpreted as a sign of serious danger).

Table 5 summarises cognitive and behavioural techniques that a therapist could use with Megan and presents suggestions on how to tailor these to LTCs, based on TMA-LTC. With that in mind, working with Megan will likely involve the following components:

1. **Psycho-education about the role of psychological factors in managing symptoms and treatment:** When working with people with LTCs, it's important for therapists to invest time in doing their own homework about the condition. When working outside specialist services, it is unrealistic to expect therapists to have expert knowledge in all LTCs. However, having basic knowledge that can be developed over time through learning from patients and multi-disciplinary healthcare professionals is important. Without understanding the condition, therapists may experience fear or concern about giving the wrong advice (7). In Megan's case, a therapist may have concerns about recommending exercise if they are unsure about whether physical activity and relapse are related. Gaining knowledge of MS and building confidence in one's own understanding of effective symptom management will facilitate the

provision of accurate psycho-education. Moreover, it will help to establish the difference between thoughts that are accurate and helpful, and thoughts that are inaccurate or unhelpful and would benefit from being challenged. Understanding the condition will also help in collaboratively developing goals that are safe and realistic in the context of a person's LTC.

2. **Managing uncertainty:** Many LTCs carry huge uncertainty in terms of unpredictable symptoms and illness progression. Megan expressed concerns about future symptoms and relapses, which are very real concerns as there is high likelihood that she will experience future relapse and worsening symptoms in the future. Therefore, challenging accuracy of these concerns is unhelpful, but exploring the impact of these concerns on her present is important. Rather than challenging accuracy, it is more useful in this context to explore the helpfulness of these thoughts in the context of their current impact on Megan's life.
3. **Challenging unhelpful or inaccurate illness representations:** Having explored illness representations in assessment, a therapist and patient will have developed a shared understanding of the way a person perceives and understands their illness in terms of the symptoms they attribute to the condition (identity), beliefs about occurrence and duration of illness (timeline), impact of illness on life and future (consequences), how much control one feels they have over the course of their illness (personal control), how much control they believe their treatment has over their condition (treatment control) and their overall understanding of the condition (coherence). Megan expressed that she perceives MS to have serious consequences, that she has a low sense of personal control over MS, and that treatment has little control over MS. Therapy with Megan would therefore involve helping her to identify areas in which she has more control over the impact of MS on her life, validating accurate beliefs about serious consequences and exploring consequence beliefs that may be inaccurate or unhelpful, and working with the MDT to explore treatment concerns.
4. **Working with cognitive responses to symptoms:** Like illness representations, it's useful to explore and challenge cognitive responses to symptoms that may perpetuate low mood, anxiety or persistent physical symptoms. For example, therapists should explore factors such as embarrassment or fear that may lead to avoidance of valued activity, inaccurate beliefs

about certain symptoms (e.g. fatigue or pain) being a sign of damage and hypervigilance to symptoms (note: some vigilance is important to guide help-seeking behaviours, but excessive focusing on symptoms can cause heightened anxiety).

5. **Working with behavioural responses to symptoms:** In the context of LTCs, it is important for therapists to understand behaviours that perpetuate anxiety, low mood or persistent physical symptoms, e.g. all-or-nothing behaviour, excessive rest or avoidance behaviours (e.g. avoiding social events because of embarrassment). As therapists traditionally will not have medical backgrounds, it is essential to develop some understanding of the condition by liaising with the MDT and learning from the patient.

[Table 5 here]

Limitations

Considering the process of developing the TMA-LTC, there are some limitations to consider. While we have presented this paper with a focus on cognitive behavioural therapy, we acknowledge that other therapeutic approaches may also be effective in supporting people with psychological adjustment to LTCs (e.g. Acceptance and Commitment Therapy). There are also some limitations associated with the model development process which should be considered. Firstly, because of the very extensive literature looking at every LTC, we reviewed existing reviews rather than individual empirical papers. Secondly, there may have been key papers which were missed by the search. Thirdly, although we believe a strength of the work was adding in expert feedback on the model, due to time constraints in the expert meetings, it was not possible to define each key term prior to rating. Rather, we ascertained feedback through general discussion. Whilst it is possible that expert panellists may have had slightly different interpretations of these terms, the discussion suggested that there was a shared understanding of these constructs so clarification was not required. Therefore, the

discussion instead focused on the relevance of different constructs and how they may be addressed through intervention.

Conclusions

This article has outlined the importance of understanding and conceptualising psychological adjustment to LTCs as distinct from depression and anxiety in a primary mental health model. We have proposed a TMA-LTC which can be used to guide treatment formulations in the context of psychological adjustment to LTCs. This model outlines a number of illness-specific factors that need to be considered, such as the patient's treatment or symptom beliefs, the illness context and the uncertainty associated with living with a LTC.

The transdiagnostic model was developed following an extensive and comprehensive development process; informed both by the empirical literature and by experts working in the field of adjustment to LTCs. This rigorous development process helps to ensure that any treatments based on the model will be grounded both in research and clinical practice. It would be useful to test this model in future studies such as intervention studies which examine process variables in the TMA-LTC which are related to change in outcomes such as illness-related distress. Longitudinal studies which monitor factors within TMA-LTC and how these change in the context of illness-related stressors would also be beneficial to aid our understanding of psychological adjustment throughout the LTC trajectory.

Supplemental Digital Content.doc

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