### How can Narrative-Focussed CBT be Adapted for Patients with Medically Unexplained Symptoms? A Discussion Paper and Possible Model

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#### INTRODUCTION

Patients who have somatic complaints which are not fully medically explained, which are sometimes referred to as MUS or Medically Unexplained Symptoms (Nimnuan, Hotopf & Wessely, 2001), or Medically Unexplained Physical Symptoms or MUPS (Burton, 2003) may take up considerable health service resource and time from investigations and other interventions, yet these can have relatively little impact on their presenting symptoms. They can continue to have significant levels of functional impairment and socioeconomic disadvantage and how to best help them poses a major challenge to modern healthcare systems. MUS patients may also have substantial psychiatric co-morbidity, which may not always receive appropriate treatment. Psychological interventions have been studied in this group, with varying results and one of the major therapeutic models that have been studied in MUS is cognitive behaviour therapy (CBT). Although this can be a successful intervention, there may be difficulties in intervention in patients with more chronic and complex MUS problems. A possible modification of the standard CBT models is discussed here, which is influenced by narrative exposure therapy (NET, narrative CBT and trauma-focused CBT models.

#### MEDICALLY UNEXPLAINED SYMPTOMS

### Definition

Who are the patients who have MUS? (Creed, Henningsen & Fink, 2011). Firstly, there can be many different views on how to define (an/or quantify) this problem and this has led some to consider whether this is any longer a useful concept. It can have marked negative connotations of "difficult" and "impossible to help" patients who make a lot of demands on the health system.

Secondly, this term may encompass a range of different syndromes or disorders and may not be a homogeneous entity. (Bridges & Goldberg, 1985; Henningsen, Jakobsen, Schiltenwolf & Weiss, 2005; Wessely, Nimnuan & Sharpe, 1999; Aggarwal et al., 2006; Creed & Barsky, 2004). It is unclear whether this is could represent a "spectrum" of disorders, with milder, less differentiated forms with better outcome presenting in primary care settings e.g. health anxiety related; and more chronic and complex presentations in secondary care such as what used to be termed "somatisation disorder". In the spectrum concept, potentially different intensities of an intervention may be needed. However, this does not explain why certain patients may be more likely to have better outcome and others not respond or even show some deterioration with an intervention. In other words, if this is the case, as say with depression, what determines your particular severity point on the spectrum or moving within the spectrum? Alternative views are that these may be superficially similar, overlapping, but intrinsically different issues e.g. symptom overlap rather than diagnostic overlap (Kroenke

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et al., 1997; Kirmayer & Robbins, 1991). This would imply that certain groups may need different interventions, despite superficial similarities in their presenting complaints.

Thirdly, the formulation may be greatly delayed and the problem may not be correctly identified until many investigations and referrals have been undertaken without benefit. Thus the recognition and diagnosis of an MUS problem can also pose a major challenge to mental health professionals and be the source of professional disagreement (Li et al., 2003)

Fourthly, whether it is thought reasonable to state that symptoms are "unexplained" medically, may be determined partly by how thoroughly these have been investigated and the viewpoint of the practitioner as to how confident they are that there is not likely to be a medical explanation. Patients who are initially termed "MUS" can later have definite physical symptoms explained by previously undetected pathology, although there is some evidence that this is a relatively rare risk (Carson et al., 2002, Stone et al., 2005; 2009). Thus the term can be very much in the eye of the beholder (Heijmans et al., 2011), leading to marked variability in preparedness to consider the term in both non-psychiatrists and psychiatrists. The problem is quite likely to be recognised if chronic and severe, if there have been multiple presentations and specialist referrals. MUS may also encompass what has been termed "functional somatic syndromes" (FSS) and various of these of so-called functional symptoms syndromes have been defined for example:-

- Fibromyalgia
- Irritable Bowel Syndrome
- Chronic Fatigue Syndrome
- Temporo-mandibular Joint (TMJ) dysfunction
- Atypical facial pain
- Non-Cardiac chest pain
- Hyperventilation
- Chronic cough
- Loin Pain haematuria syndrome
- Functional weakness / Movement disorder
- Dissociative (Non-epileptic) attacks
- Chronic pelvic pain / Dysmenorrhoea

These problems have significant comorbidity with depression, anxiety disorders and personality disorders. There can also be increased rates of alcohol and substance use disorders.

### Stigmatising Attitudes to MUS and Uncertainty in Medicine

This lack of consistency can be associated with negative attitudes and therapeutic nihilism e.g. "if we can't even say what it is how we can treat it?" Other issues are how exhaustively somatic complaints are investigated, a low attitude to risk and therefore diagnostic uncertainty, can lead to preparedness to over-investigate i.e. rarer possibilities that are remotely, but theoretically possible are considered, even if highly unlikely. At the other end of the spectrum there can be refusal to consider investigations, even if there is a significant change in presentation, denigration of the patient and complete denial of their needs.

Intolerance of uncertainty in the medical team can be communicated to the patient and escalate unhelpful help seeking behaviours (Henningsen, Zipfel & Herzog, 2007). This can interplay with the patient's own intolerance of uncertainty and escalated safety behaviours (more investigations, fresh opinions) (Howard et al., 2005; Petrie et al., 2007; Salmon et al., 2007).

Patients may have quite marked self-stigma about mental health issues and unwillingness to engage in assessment or treatment. We are not clear whether, or how, they experience any self-stigma about their medically unexplained somatic complaints and the most useful interventions for this aspect of their problems (Stone et al., 2002; Salmon, Peters & Stanley, 1997). Self-stigma may cause delay in help seeking for psychological distress even if this is recognised by the patient and is entirely appropriate clinically.

#### **New Terminology**

Concern about the diagnostic status of "MUS" and what it cannot tell us about the patient, has spurred on the development of newer diagnostic criteria such as "somatic symptom disorder" or SSD in DSM-V (Regier, 2007; Fink & Schröder, 2010). The rationale is that both medically explained and medically unexplained symptoms can increase the risk of psychological morbidity and associated marked functional impairment. Some criticisms have come from the DSM task force itself, that these concepts may be too broad and inclusive (Frances, 2013), but on other hand may be easier to justify in terms of research evidence and to operationalise. As yet it is unclear whether this has any connotations for the most appropriate interventions for each construct.

#### **Health Economic Impact**

The MUS patient group can have significant costs in care, often without marked improvement in health, social or day to day function (Bermingham, Cohen, Hague & Parsonage, 2010; Barsky, Orav & Bates, 2005; Akehurst, 2002). Only part of this cost is direct investigations and procedures, much is from time in consultation, emergency attendances and inpatient care. Opportunity costs in terms of "lost" productivity or capacity that could have been used to care for other patients e.g. On waiting list, has not often been assessed (Hiller, Fichter & Rief, 2003; Hillila, Färkkilä & Färkkilä, 2010; Konnopka, 2012)

#### Interventions

No conclusive evidence is available that any one therapeutic model is superior in MUS to date, but CBT has been more frequently evaluated (Allen et al., 2002; Sumathipala, 2008, Champaneroa et al., 2005; Sumathipala et al., 2008). CBT models have now been proposed for most of the FSS (Suraway, Hackmann, Hawton & Sharpe, 1995; Moss-Morris, Spence & Hou, 2011; Hou et al., 2011; Spence & Moss-Morris, 2007, Williams, Eccleston & Morley, 2012; Zijbendos et al., 2009; Ford et al., 2009). Individual CBT has been extensively evaluated (Nezu, Nezu & Lombardo, 2001; Barsky & Ahern, 2004; Bleichard, Timmer & Rief, 2004; Kroenke, 2007; Kroenke & Swindle, 2000) and group-based CBT (Moreno et al., 2013; Hellman et al., 1990). Some have advocated multimodal or multi-faceted approaches to help MUS e.g. in fibromyalgia (Hauser et al., 2009). Psychodynamic models have been evaluated and have

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some support (Kleinstäuber, 2011; Lackner et al., 2004; Sollner & Schussler, 2001) and some of these have had increasing focus on attachment theory (Taylor et al., 2012; Adshead & Guthrie, 2015; Guthrie, 1999; 2008). Currently, briefer psychodynamically based therapies are being developed and evaluated. There is increasing interest in some other therapy models, but most have so far, involved small studies, such as for CAT (cognitive Analytical Therapy) which has been subject to preliminary study (Jennaway, 2011) and so called "third wave therapies" such as ACT (Acceptance and Commitment Therapy) e.g. Graham et al., (2014) and Mindfulness Based Cognitive Therapy or MBCT (van Ravesteijn et al., 2013).

Many of these studies have been based in secondary care and there have been concerns as to how applicable they are in primary care (Raine et al., 2002), but there are supportive studies emerging (Larisch, 2004; Rosendal et al., 2013). Other briefer interventions have been studied in primary care, such as those based on the reattribution model (Goldberg, Gask & O'Dowd, 1989; Morriss et al., 2010), and psycho-education (Luciano et al., 2011). Briefer CBT interventions may also be effective such as internet-based CBT (Andersson et al., 2011) and CBT guided self-management (Moss-Morris et al., 2010) and one-session interventions (Martin et al., 2007).

#### Present Position of CBT interventions for MUS

CBT has some evidence of effectiveness in MUS, but can have a variable take-up. Some patients can find the reattribution model very challenging and difficult to accept and difficult to engage with, but is this their problem, that of the model, or how it is explained (Roos and Wearden 1999)? It may be initially far more important to understand their own explanatory model of their symptoms and how they feel it can be helped (Moss-Morris & Wrapson, 2003).

These issues of acceptability have been discussed in recent IAPT guidance in the UK (IAPT, 2014). Patients can feel disbelieved "that I am making it all up" and may have difficulty with "dualistic" concepts of illness and of what health should be. Useful CBT models have initially focussed on anxiety cycles and health perfectionism, but more sophisticated cognitive models may be needed (Deary, Chalder & Sharpe, 2007) and some have advocated integrating cognitive with other models (Brown, 2013a,b). A particular thrust of the model proposed by Brown (2013a,b) is on mechansims of dissociation (Holmes et al., 2005) and whether or not these are related to trauma (Brown et al., 2005; 2010; 2012). A briefer, and promising model, which has been shown to be acceptable in hospital patients with health anxiety has been successfully assessed in the CHAMP study (Tyrer et al., 2011; 2014). However, as the MUS group is likely to be heterogeneous it is unclear as yet, if this would benefit all MUS patients.

### Rationale for Narrative Based CBT Approaches in MUS

Some, but not all, MUS patients have significant trauma history in early years or during life and may have ongoing effects from trauma (Creed et al., 2005; Muse et al., 2010). However, it must be emphasised that not all MUS patients have such a trauma history. However, trauma may be affecting MUS patients more subtly; is it possible for instance, that some MUS patients may find repeated investigations and referrals in the "medical" approach to be traumatic? Hence, it is conjectured that even in the absence of earlier trauma history some MUS patients find dealing with health professionals to be 'traumatic". This aspect of patient experience has not so far been systematically explored.

Some trauma-focussed CBT interventions may rely on the traumatic event having finished and the client no longer being under sense of continuing or repeated trauma. CBT models have been introduced for groups where this may the case, the most widely known of which is Narrative Exposure Therapy (Robjant & Fazel, 2010). It could be conceptualised that patients with MUS have considerable sense of ongoing threat to their physical health and therefore safety, thus there would seem to be some rationale for a narrative approach being useful. Other patient groups, such as older people who suffer from depression, may also need modification to the standard CBT case conceptualisation and formulation models. Work by Laidlaw et al., (2003) on this model has emphasised the importance of a narrative account and consideration of intergenerational effects and attitudes to health on engagement and case conceptualisation. This model can encompass traumatic events but is not necessarily focussed on these events. Narrative approaches have been found used in other groups and for other types of problem (Rhodes, 2014) whether or not the focus is trauma-based.

A model is proposed, based on empirical clinical work with this group, which encompasses elements from these various narrative models and which could be developed for work in patients with MUS. It is possible that this could be used as a "stand alone" treatment for patients in whom other CBT models related to health anxiety may not be yet appropriate (Tyrer et al., 2011; 2014) or as a preparatory model to enhance engagement with later CBT based interventions. This is proposed as up to nine sessions (90 minute session as in the NET model).

# Sessions 1-4: Understanding the whole story and what has changed

All forms of narrative therapy will use some type of "Timeline" approach and discuss all of the important past events for the client in their life story, but in this model greater emphasis is also placed on experience of health, illness and the health professions. The model may not need to use the exact methods described in NET (such as the use of the rope, stones or flowers) to illustrate key events, but would use a "timeline" approach and focus on witnessing or experience of life-threatening or limiting illnesses in family and personal experience of health problems, especially if diagnoses have been missed, delayed or there were management issues. The narrative would especially focus on recent experiences of the medical profession and investigations and any sense of threat to physical health or safety.

As with narrative approaches such as NET, the therapist and client work together to summarise the timeline and the client will have time to look at and take in the timeline and fill in "gaps". This may be an important component of therapy as MUS patients may be very concerned that details of their story are not understood and may be vitally important ( the metaphor one could use would be like being their own detective and worrying about missed clues, in case something important is overlooked). This encompasses the facts of exposure to traumatic or potentially traumatic events, but also the sense of therapeutic collaboration and that their narrative is valued and important in helping them deal with their health problems. In the sessions, as in NET, the client can also discuss evidence of their resilience or successes from the timeline, e.g. coping with adversity, how they had enjoyed health and been successful.

This can lead to initial formulations of what has happened as in the standard cognitive models, but it is best that if the client is prepared for this work, it is seen as something that will be inevitably reviewed and modified with further information and understanding of their narrative.

## Sessions 5-8: Dealing with what is known and can be dealt with

A very important part of the model is dealing with uncertainty. This is since it is hypothesised that clients with MUS perceive ongoing threat to their physical health and lack a sense of being safe. An intolerance of uncertainty can affect both the therapist, the client (and their medical team). Acknowledgement that modern medicine is more scientific, but not perfect; and that not everything can yet be easily explained can be helpful. Hopefully, there can be acknowledgement of what important conditions have been excluded, although there will still be uncertainty for the client, so it may be possible to cope with their present problems and have a better quality of life, despite this uncertainty. Discussion of this can be driven by examples of dealing with uncertain situations in life from the client's timeline. This helps the client in moving towards an acceptance model and rehabilitation or recovery. The important aspect of formulation in this model is of the shared discovery of client and therapist to possible solutions and new goals and strategies at this stage.

#### Session 9: Moving forward and reclaiming one's life

The final session will help the client agree their next steps. It is helpful to clarify what has changed and what the client has learnt about their story and themselves. It is hoped that by this stage the clients will have greater sense of safety. This might help them to focus on coping and adaptation, but future goals and possibly may be preparation for more work at a later stage e.g. further CBT or other therapeutic interventions. Work can be done to reformulate present MUS traumatic or quasi-traumatic experiences and and past trauma if relevant. This can range from standard cognitive restructuring approaches, to compassion-focussed approaches (as some MUS clients can be very self-critical of their inability to overcome physical diversity) to initial trauma-focussed work e.g. models of either exposure (Foa, Davidson & Frances, 1999); or reliving (Ehlers & Clark, 2000).

#### DISCUSSION

This may be potentially a more widely acceptable CBT intervention for patients with MUS as it concentrates more on patient's experience and narrative, helps provide understanding of their journey and trauma, but also their resilience. As presented here this model is longer than the standard CHAMP model (Tyrer et al., 2011; 2014), but briefer than most CAT, DBT and psychodynamic models. The approach helps collaboration and the feeling for patients that they have been fully heard and not judged. Also it may not be seen as directive i.e. "done to" by someone in authority, but instead the development of a shared understanding of a difficult and confusing problem. The model possibly helps engagement as with the greater focus on previous experiences and repeated exposure, there is the opportunity for the patient to reflect and scope their story from a distance. This may help them to recognize unhelpful assumptions, but also remind them of resilience.

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