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ORIGINAL RESEARCH

Patients with medically unexplained physical symptoms experience of receiving treatment in a primary-care psychological therapies service: a qualitative study

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Abstract. As a pilot site under the primary-care Increasing Access to Psychological Therapies (IAPT) Long Term Condition/Medically Unexplained Physical Symptoms (MUPS) project, patients with MUPS were offered cognitive behaviour therapy (CBT)-based treatments or attendance at a mindfulness-based stress reduction (MBSR) programme. This study aimed to gain an understanding of the views and experiences of MUPS patients that received CBT-based therapy or MBSR within an IAPT service and to investigate the relationship between their experiences and health outcomes measured on self-report questionnaires. Thematic analysis was used to analyse data gathered via semi-structured interviews with 11 patients. Data collected from three self-report measures were considered in relation to key features of participants' reported experiences and patterns identified. Four main themes emerged: (1) something needs to change; (2) making connections between physical symptoms and mood, thoughts or activities; (3) sharing experiences and feeling understood; and (4) reflections on treatment experience. Participants generally reported a positive experience of treatment and felt better able to cope with their symptoms, although treatment did not necessarily result in reliable change in symptoms as measured by the Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder Scale (GAD-7) and Work and Social Adjustment Scale (WSAS). This novel model of treatment appears to be acceptable for this patient group although evaluation of the pilot should consider the ability of routinely used measures to capture the value of treatment to patients, including improved coping with symptoms.

Key words: CBT, primary care, MBSR, medically unexplained physical symptoms (MUPS), qualitative

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Introduction

Medically unexplained physical symptoms (MUPS) are symptoms that have no currently known pathological cause. Common MUPS include fatigue, dizziness and pain (DoH, 2008). There has been significant debate over the classification of MUPS and the syndromes into which they are clustered (Salmon, 2007), as well as the terminology used to describe them (Creed *et al.* 2011). In this paper MUPS will be used as a broad term describing both medically unexplained physical symptoms and the functional somatic syndromes (FSS) that they are subgrouped into. Although there is significant overlap between the symptoms of different FSS (Dreary *et al.* 2007), there are features which may be considered to define each; irritable bowel syndrome (IBS) is characterized by chronic abdominal pain and bowel disturbance in the absence of structural bowel abnormalities (NICE, 2008) and chronic fatigue syndrome (CFS) by debilitating fatigue (NICE, 2007). Fibromyalgia has been characterized by the American College of Rheumatology by chronic widespread pain and tenderness in 11 of 19 defined tender points (Wolfe, 1990).

There are a number of high costs associated with MUPS. Physical symptoms may cause significant impairment of functioning resulting in time absent from work, and payment of benefits to those not able to work. Because symptoms persist and remain unexplained, patients may engage in an ongoing search for the 'correct diagnosis', resulting in consultation and treatment from a number of healthcare professionals which may include diagnostic tests, hospitalizations, operations and other medical procedures (Nezu *et al.* 2001). Based on 2008/2009 prices, it is estimated that the costs of consultations and care of people with physical problems that are caused by psychological distress in the UK are £3 billion per year (DoH, 2011*a*).

MUPS may cause significant distress to the patient. It is estimated that 70% of patients with MUPS experience depression and/or anxiety (DoH, 2008), although there is debate among researchers and clinicians as to the nature of this association (Henningsen *et al.* 2003). Research has suggested that the majority of MUPS patients attribute their symptoms to physical rather than psychological causes (Nezu *et al.* 2001). Although MUPS patients have generally been considered to be reluctant to undergo psychological help (Shaw & Creed, 1991), other research has indicated that a large proportion of MUPS patients may be willing to participate in psychological or psychiatric treatment (Speckens *et al.* 1995).

Improving Access to Psychological Therapies (IAPT) is an NHS programme rolling out services in England, initially offering interventions, using a stepped care model, approved by the National Institute for Clinical Excellence (NICE) for people with depression and anxiety disorders. One of the priorities identified by the 'Talking Therapies: A Four-Year Plan of Action' document which accompanied the 2011 Government Publication of 'No Health Without Mental Health', was the expansion of the IAPT programme to include people with MUPS. A number of pilot sites were identified (including Southwark/Bexley) and the project rolled out in April 2012. As part of this pilot, patients with MUPS in Southwark were offered, using a stepped-care model, low-intensity guided self-help (GSH), participation in a mindfulness-based stress reduction (MBSR) group or 1:1 high-intensity cognitive behavioural therapy (HI-CBT).

CBT-based treatments offered are based on the cognitive-behavioural model of MUPS, which proposes that an individual's interpretation of physical sensations may bring about a heightened awareness of bodily sensations, increasing emotional distress and triggering self-defeating behaviours such as avoidance of physical activity, reassurance-seeking, inappropriate utilization of medical services which may, in turn, exacerbate physical symptoms and render them chronic (Martin *et al.* 2007). It is this vicious cycle that is targeted in therapy, through interventions that help identify and modify dysfunctional thoughts and behaviours (Speckens *et al.* 1995).

The low-intensity GSH intervention offered involved the patient working through a series of booklets with a psychological well-being practitioner (PWP), typically meeting fortnightly with homework set between meetings. CBT-based GSH has been shown to be an effective form of treatment for IBS primary-care patients (Moss-Morris *et al.* 2010) and for improving fatigue and psychological distress in patients with CFS in a primary-care population (Chalder *et al.* 1997).

Patients receiving HI-CBT were offered weekly, 1-hour appointments with a HI-CBT therapist delivering CBT therapy based on the cognitive-behavioural model of MUPS. There are a number of studies that have demonstrated the effectiveness of CBT for MUPS (e.g. Speckens *et al*. 1995; Escobar *et al.* 2007).

MBSR is a structured group intervention based on the work of Kabat-Zinn (1982) which explores the effects of mindful meditation in alleviating suffering associated with physical psychosomatic and psychiatric disorders (Grossman *et al.* 2004). Participants are taught non-judgemental observation of senses, thoughts, emotions, sensations and external events and, through this, learn to take everyday activities such as breathing, sitting, lying down and turn them into a meditation (Morone *et al.* 2008). Participants practise these mindfulness techniques in the group setting, formally at home and in everyday life, to encourage a sense of non-judgemental awareness of the present moment. At the pilot IAPT site, the intervention was delivered by a trained MBSR facilitator and offered as an 8-week programme for 2 hours per week. MBSR has been found to be of benefit in helping a broad range of individuals cope with their difficulties (Grossman *et al*. 2004) including patients with FSS (Grossman *et al.* 2007; Rosenzeig *et al.* 2010).

Although all of these interventions have shown to be effective with this patient group and are supported by NICE guidance (NICE, 2007, 2008), offering these treatments in a primary-care psychology service, delivered by trained psychological therapists, is a novel model of treatment. The acceptability and effectiveness of this model of treatment in this patient group is unknown. Inquiry into patients' perceptions and experiences of interventions is important and should form part of the evaluation of pilot projects.

There is a very limited existent body of qualitative evidence relating to the experience of patients with MUPS being offered or receiving psychological help. A systematic search of PsychINFO, CINAHL, Web of Science and Medline using relevant key words was undertaken in March 2015. After screening search results, ten studies were identified. Articles were included if they included patients who had been diagnosed or self-diagnosed with MUPS or an FSS, collected the views and experiences of the patient who had been offered or had received the intervention, included the qualitative analysis of data which produced themes in the research findings and were written in English, with their full text accessible. These ten studies were subjected to a quality appraisal using the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006) and the findings of the studies synthesized in a process, which followed the seven phases of meta-synthesis described by Noblit & Hare (1988). The studies were found to be of varying quality, often containing little information about the intervention being offered or by whom it was delivered and none of which explored the relationship between the participants' experiences and the outcomes of their treatment. Four major themes were generated through synthesizing the findings of the studies included in the literature review, each supported by sub-themes. These related to participants' expectations of therapy, feeling believed and understood, their model of understanding of their illness and the impact of the intervention. The generation of these themes suggest that there are common experiences among patients with MUPS who receive psychological therapy. No previous qualitative analyses had explored participants' experiences of receiving a primary care-based intervention for MUPS delivered by trained psychological therapists or explored the relationship between participants' experiences and the outcomes of their treatment. Therefore the current study was identified as addressing a gap in the current literature in providing an understanding of the expectations and experiences of patients with a range of MUPS who received a psychological intervention by a trained psychological therapist in a primary-care psychology service, where the content of the intervention is known and outcome data is compared to reported to participants' experience.

Method

Participants

Participants had attended at least two treatment sessions at the service, were aged ≥18 years and self-identified as experiencing MUPS. Exclusion criteria included not being able to speak English and having been seen by the study researcher in a clinical capacity. Eleven participants took part in the study (eight females, three males). The sample had a median age of 50 years (range 19–60 years) and comprised a range of MUPS: six participants with chronic pain, two with CFS, three with fibromyalgia. Participants had received a range of treatments at the service; three had received MBSR, three GSH only, two HI-CBT only and the remaining three more than one of the interventions. The median number of sessions attended was 17 (range 4–25).

Each participant had completed self-report measures as part of therapy. These measures comprised the Patient Health Questionnaire (PHQ-9; Kroenke *et al.* 2001), a measure of depression severity, the Generalized Anxiety Disorder Scale (GAD-7; Spitzer *et al.* 2006), a tool which facilitates screening for GAD and assessment of its severity, and the Work and Social Adjustment Scale (WSAS; Mundt *et al.* 2002) which measures impairment in functioning across a number of domains.

Eight of the 11 participants had baseline PHQ-9 scores and seven participants had baseline GAD-7 scores high enough to be eligible for reliable change to be shown following treatment (>6 for PHQ-9 and >4 for GAD-7). All of the participants had baseline WSAS scores of >8 (minimum baseline needed to meet criteria for potential reliable change; DoH, 2011*b*).

The study was submitted to the Integrated Research Application System (IRAS), and reviewed by an Ethics Committee. Following their favourable opinion, it was submitted to the local Research and Development Department of the host NHS Trust. Participation was voluntary and all participants gave their written, informed consent.

Design, procedure and analysis

Individuals with MUPS who had received treatment in the service as part of the Pathfinder pilot were invited to take part in a semi-structured interview relating to their experience.

Eleven interviews were carried out by the researcher: nine by telephone and two face-to-face (at the participant's request). All interviews were recorded and transcribed in full. Thematic analysis was chosen as the methodology to evaluate the participants' experiences and perceptions. Thematic Analysis has been used in studies that concern themselves with exploring participants' subjective experience of different therapies, including previous qualitative studies of patients' experience of CBT therapy (e.g. Dennison *et al.* 2010). The interviewer (C.G.) was mindful that as a CBT clinician with experience of delivering these interventions, researcher expectations could influence and bias data collection, analysis and study findings. To minimize this, a 'bracketing interview' (Thomas & Pollo, 2002) was undertaken to elicit the interviewer's expectations, the first transcript was analysed for leading questions and training provided by the other researchers (K.R. and I.J.N.) to ensure even questioning and prompts to unearth evidence contrary to expectations were used in subsequent interviews.

In analysing the data the six phases of Thematic Analysis offered by Braun & Clarke (2006) were followed. The process commenced while data collection continued (after five interviews) and was done using the scissors-and-paste manual method. A coding manual was developed, the reliability of which was checked by one of the other authors (I.J.N.), and used to code remaining transcripts. The coding was an iterative process which involved re-reading transcripts and comparing and organizing excerpts into themes, with care taken to pay attention to any data considered an exception to the themes identified.

Quantitative data relating to symptoms of depression, anxiety and functioning for each participant were collected via self-report measures completed as part of therapy. These data were then considered in relation to key features from each specific participant's interview data, and then qualitative and quantitative findings for the sample as a whole were combined and analysed for patterns of interest.

Results

Thematic Analysis

Four main themes were identified each supported by sub-themes: (1) something has to change; (2) making connections between physical symptoms and mood, thoughts or activities; (3) sharing experiences and feeling understood; and (4) reflections on the treatment experience. Each theme was judged to capture something important about the data in relation to the research questions and, to be counted as a theme, had to occur in a number of instances across the dataset. Each of the following quotes is related to a participant by a number shown within parentheses.

The themes and subthemes are discussed below.

Theme 1: Something has to change

'Something has to change' related to the pre-intervention feeling that something needed to change for the participant regarding their treatment and captured the circumstances that had led participants to the service, their expressed frustration with their previous healthcare experiences, and their expectations of treatment. This theme was reported in the data from nine participants. It comprised five sub-themes.

Frustrating journey

Patients described having experienced a frustrating process of assessment prior to referral to IAPT and an on-going search for answers regarding their symptoms, which often led to frustration and despondency.

> *What I am down about if I am to be totally honest is the fact that they are not getting to the bottom of what's wrong. (11)*

Willing to try anything

Participants shared a sense of desperation and a willingness to try anything to improve their health. One participant described it as follows:

> *I was in a hole just getting deeper and deeper… I knew something had to change but I didn't know what … I'd tried everything. (5)*

Looking for answers

For some participants the search for answers continued as patients reported hoping to gain specialist knowledge and information regarding their condition from the service.

> *I was mainly looking for answers … to see someone who knew what they were talking about. (1)*

Although some patients reported that they had few expectations regarding the content or benefit of the therapy they would receive, other participants had clear hopes and expectations in relation to benefit in terms of pain-management, low mood or anxiety or managing symptoms such as fatigue.

> *I was looking to get some help with my on-going symptoms of low energy, really. (4)*

Wanting strategies

A desire to learn strategies for self-management of symptoms was shared. A number of patients shared a hope to be able to reduce their reliance on medicines:

> *To get back on the track of self-management, away from pharmaceutical management. (8)*

Choice and information

Most participants reported having received very little information regarding our service from their referrer. One participant reported that she did not believe that her GP even realized it was a psychological therapy service. As a result, when these patients came to the service and learnt its remit, they were a little taken-aback.

> *That was really hard … I couldn't see the point in doing something therapy-based when I wanted a solution for the fact my body really hurt. (1)*

Theme 2: Making connections between physical symptoms and mood, thoughts or activities

Making connections between physical symptoms and mood, thoughts and activities was identified as an over-arching theme relating to participants' beliefs relating to the presence or otherwise of any such connection either before or after treatment. It was reported in the data of seven participants and comprised five sub-themes.

Previous beliefs

Most patients reported having recognized some sort of link between their symptoms and mood or thoughts, although there was variation between what they felt came first:

> *It's the pain that triggers off the way I feel, not the other way round. (7)*

or thoughts acting as a trigger for changes in symptoms.

> *Like when my mum died, it was like, bump, and then I'm suddenly not very well, and now I'm on a crutch ... and every time I think about my mum everything hurts. It's absolute madness really, that your brain can make your body feel that way. (10)*

A new model

Most participants were able to express an understanding of the model presented to them during therapy. Participants who had undergone the MBSR course were clear in describing the course's aims and principles, beginning with the vicious cycle of pain:

> *How emotions affect the pain, and the pain affects the emotion ... and it just keeps going round. (5)*

Initial scepticism

A number of participants reported that they were initially sceptical of the model and treatment plan presented to them. One patient described a mismatch between the CBT treatment model and the explanation given for her symptoms by her GP.

> *The doctor says it's a physical illness and then you come here and they talk about your lifestyle. (1)*

For another patient the model sounded too simplistic:

> *Well, it's all because you do stuff and then you get tired and that's it. It's like 'Really?' (2)*

Making sense of the model

Many of the participants accepted the therapy model, sometimes after a few sessions. This acceptance was generally facilitated by experience that fitted the model.

> *Last weekend my cousin came ... she did my massage, my hair, my nails and I feel very nice ... I feeling like a woman, a normal woman. (9)*

However, acceptance of the therapeutic approach did not always predict engagement with treatment. One fibromyalgia patient explained that the MBSR course had not been helpful because of the practical limits and consequences of her condition.

> *The idea of it is great but it didn't work for me unfortunately ... you're sitting there for half an hour ... relaxing different parts of your body. And that's very hard to do when you are in a lot of pain, because I can't sit still for long. (10)*

Another participant did not accept the principles of MBSR presented to her:

> *I don't want any negativity in me, I should be releasing it. So that part of it did not sound right. (11)*

Missing elements

For some participants there were important elements missing from the model: diet, nutrition and the role of faith, particularly prayer, were mentioned.

Theme 3: Sharing experiences and feeling understood

The third theme of sharing experiences and feeling understood related to participants' experiences of feeling able to talk freely to their therapist or other members of their group. This was highly valued and generally in contrast to participants' experiences with friends and family members. This theme was reported by 10 participants and it comprised five sub-themes.

Previously feeling dismissed/a burden

Nearly all participants reported having felt unable to talk freely about their pain or other symptoms to family, friends or colleagues, many believing that others would not understand them if they did not have experience of their condition themselves.

> *I no able to talk with my friend … 'cause you know sometimes it not maybe the person you do not have that condition. They don't understand how my feeling. (9)*

Some participants described having felt that others had dismissed their experience, also reporting that they did not share their experiences openly as they did not wish to burden others with their problems, or risk becoming a nuisance.

> *I've got 3 children but they have got their own lives … when you keep talking to your family they get a bit 'oh, here we go again'. (10)*

Sharing experiences

In contrast to experiences with friends and family, participants reported feeling able to talk freely in sessions, and found simply having the space to talk about their condition to their therapist or members of their therapy group, as someone outside of their social network, to be very helpful.

Participants reported feeling comfortable to freely share with the other participants, even where they might have previously felt unsure about speaking in a group, although one participant did not share this experience, feeling instead that there were not enough opportunities for everyone to speak. This participant also expressed that they would have felt freer to speak in a private setting.

> *There's some things that you don't want to say when there's nine other people sitting there. (10)*

Learning from others

In the group setting of the MBSR course, the experience of being able to hear about others' experiences and perspectives and learn from others was found to be very helpful.

> *It was good to share … one of the ladies had a problem with what I'd already been through. I could say 'have you tried this?' (8)*

Validation

Participants reported feeling understood and validated by their therapist as a result of the knowledge the therapist held about their condition.

> *So just meeting someone that had some knowledge, knew there was something funny going on with pain signals, which isn't just someone who is a bit depressed … that helped. (2)*

Feeling understood by other group members with similar problems helped validate participants' experiences.

Role of the therapist

The role of the therapist in the treatment was emphasized by seven of the participants. One participant described feeling as though they had someone on their journey with them, rather than trying to manage in isolation.

> *Just knowing someone else was on my side … with me every step. It meant I wasn't doing this on my own. (4)*

Theme 4: Reflections on treatment experience

This final theme, which comprised four sub-themes, relates to participants' reflections on their experience of treatment and experiences of 'moving forwards' from therapy. It was reported in the experiences of eight participants.

Impact on symptoms

Some participants reported that there had been some improvement in physical symptoms but many participants reported either no change or a worsening in physical symptoms.

> *In terms of my physical health it has gotten worse … my balance, particularly on my feet. (11)*

However, neither improvements nor worsening in symptoms were attributed to the therapy they had received but seemed to be considered by participants as part of the course of their condition.

A number of participants felt that they had learnt techniques that had helped them to manage their symptoms better even if there had not been an actual improvement.

> *It would not stop the pain, but at least I could try and use how I'm feeling to see if I can redirect it elsewhere. (7)*

A number of participants did report actual improvements in their mood and/or stress or anxiety levels, in some cases explicitly making a link between the therapy received and the improvements.

> *It's definitely had an effect on my mood … I am genuinely happier. (8)*

Even where patients felt there had not been a sustained improvement in their mood, they did report improved coping with stress or depression as a result of utilising techniques learnt; one such technique being the 3-minute relaxation learnt in MBSR.

> *When I get myself in a bit of a state … it helps calm me down … it doesn't help with the pain. (10)*

New ways of coping

Only one participant reported that they did not use any of the techniques learnt in therapy. All other participants reported that they were still regularly putting into practise techniques learnt to help manage their physical symptoms and/or mood.

> *The 3-minute thing I use at least once a day. It seems to clear my head rather than thinking about the pain all the time. (8)*

Participants reported regularly putting into practice cognitive techniques such as recognising unhelpful thinking styles and processes and thought challenging. One participant reporting that since having therapy she was much better at letting go of concerns which she would normally have ruminated and obsessed over. Others reported success in being able to identify and challenge negative and catastrophic thinking.

> *Yeah, as soon as I pick up on the negativity I try and think 'oh no don't think that way, try and look at this differently. (7)*

One participant reported they were now feeling much more accepting of their condition than before therapy,

> *I was less ashamed to tell people I was ill, or I was less prejudiced against having ME, because I knew a lot more about it and because I could explain it to people. (1)*

Reflections on expectations

Participants were mixed in their views as to whether therapy had matched their expectations.

> *Yes, to be honest, I didn't think it was going to be that useful, but it was more useful than I thought it would be. (1)*

> *It did help me in a way, I'm not saying it was a total waste of time … but it wasn't really what I needed. (10)*

Feedback

Participants were generally positive about their experience of therapy, including the relationship with their therapist and most participants said that they would recommend the treatment they had had to someone with similar problems to themselves.

Even where a participant had found an intervention personally unhelpful, she stated that she would recommend the course to others with physical health conditions, although not fibromyalgia.

> *Yes, I would because I think it depends on your needs really … on what kind of physical symptoms you have. A few people were doing great on it. (10)*

Participants made a number of suggestions of how their experience of the service could have been improved. These related to a number of areas, including flexibility in accessing therapy and the number of group-based treatments available as well as the physical environment of the service.

Other findings

Key features from the interview data and key findings from the quantitative data for individual participants are commented on below.

Key features of interview data

Generally participants reported a positive experience of therapy; only two participants reported a mainly negative experience. There was a mix in terms of reported changes in physical and psychological symptoms, with all participants reporting either some improvement or no change in symptoms of anxiety or depression, but only four participants reported improvement in physical symptoms with seven reporting a worsening in physical symptoms. Nine of the participants reported an improvement in perceived coping with both physical and (separately) psychological symptoms. Reported recall of having received information relating to treatment from their referrer was low (three participants). Most participants had positive initial expectations of therapy, with three reporting initial uncertainty or scepticism. All but one participant indicated acceptance of the treatment model presented to them.

Key findings from quantitative data

For the majority of participants, therapy did not result in clinical improvement in terms of depression, anxiety or day-to-day functioning levels, as measured by reliable change in PHQ-9, GAD-7 and WSAS. Of the 11 participants, three participants met criteria for reliable improvement in PHQ-9 score, one for reliable improvement in GAD-7 score and none for reliable improvement in WSAS score.

Relationships between changes in health outcomes and patients' experiences

A number of patterns of interest were identified from considering in combination key features from participants' interview data, quantitative data from individuals' self-report measures completed as part of therapy and characteristics of participants.

Outcome measure scores did not reflect participants' retrospectively reported changes in mood, or stress levels, with only six participants' scores reflecting a reported improvement or deterioration in mood/anxiety and eight participants' scores reflecting a reported improvement or deterioration in physical symptoms. No consistent pattern between participants' reporting of improved coping with physical symptoms and reported actual improvements in these symptoms was found, with four participants reporting the opposite: improved coping but worsened symptoms.

A positive experience of therapy seemed to be related to a reported improved coping with symptoms with all nine participants who reported a positive experience also reporting improved coping. The relationship between a participants' reported experience of therapy and reported changes in symptoms was less clear; although the only two participants who reported a negative experience of therapy reported either a worsening or no change in some symptoms, of the remaining nine participants who reported a positive experience, four reported a worsening of symptoms.

A pattern between participants' expectations of therapy, their reported experience and outcomes was noted with all three of the participants who reported initial scepticism or uncertainty also reporting a positive experience of therapy and improvements in physical symptoms and/or mood. Both participants who reported a negative experience reported positive expectations but a worsening of symptoms.

Discussion

Some of the findings constitute new insights; others echo findings from other MUPS research, or studies of psychological interventions in other contexts. There are a number of implications for clinical practice and future research.

Participants' sense of desperation, willingness to try anything and search for information has been found in previous qualitative studies (e.g. McDermott *et al.* 2011). Participants' mixed expectations of therapy (with three of the 11 participants reporting initial scepticism or uncertainty) are reflected in previous qualitative findings, with some MUPS patients sceptical of benefit of psychological therapy before beginning treatment (e.g. Shaw & Creed, 1991), but many having positive expectations of the potential benefits (e.g. Dennison *et al.* 2010), particularly relating to improved coping with symptoms (Hamnes *et al.* 2011). This finding supports the value of offering psychological treatment to patients with MUPS.

Previous qualitative research has suggested that referral to psychological services are unlikely to be helpful for MUPS patients if pre-treatment patient illness cognitions do not align with those of therapy (Chew-Graham *et al.* 2011). However, in this study all but one participant accepted the model presented to them, despite a lack of knowledge regarding the content of therapy or a previously held explanation of their condition that aligned to CBT principles. These findings suggest that CBT-based therapies are acceptable to MUPS patients, regardless of previously held illness beliefs.

Many participants reported feeling unable to talk openly with friends or family about their symptoms, reflecting previous findings that MUPS patients avoid talking about their symptoms for fear of being seen as 'whining for nothing' (Sallinen *et al.* 2011). The value participants placed on feeling understood or validated either by the therapist or others in the group and sharing experiences and learning from others echoes previous findings in this area (Chew-Graham *et al.* 2011; Hakanson *et al.* 2012) and highlight the need for training IAPT therapists in MUPS and the value of providing group-based treatments that allow time for peer support.

Previous studies including patients with MUPS have linked high openness to psychotherapy to improvements in physical and psychological symptoms (Timmer *et al.* 2006). However, the patterns identified in this study between reported expectations, experience and outcomes seem better explained by research in CBT relating to the role of expectancy disconfirmation. This research found that good-outcome patients frequently report disconfirmation of process expectation and gain more than expected from CBT treatment (i.e. are pleasantly surprised) whereas poor-outcome patients report being disappointed (Westra *et al.* 2010). The research supports the study finding that participants who reported uncertain or sceptical expectations of therapy reported a positive experience and positive outcomes (three participants) and those who had positive expectations but a negative experience reported poor outcomes (two participants). This finding supports the importance of providing accurate information about the process of therapy to patients in order to avoid disappointment. Supporting GPs in providing accurate information to patients prior to referral may be important. That both study participants who reported a negative experience had attended MBSR suggests that providing information regarding this specific treatment is particularly important. Research has shown that a videotape or audiotape of a typical session is considered the best method of doing so (Seligman *et al.* 2009), and should be considered by future services.

The low numbers of participants achieving reliable change in clinical measures (three participants) should be considered in the context of the fact that not all participants had baseline scores high enough for the drops in scores required to indicate reliable change to occur. Although the lack of correspondence between scores on the PHQ-9, GAD-7 and WSAS and patients' retrospective reports of changes in mood, stress and impact of physical symptoms on functioning may be in part explained by the impact of memory effects and other biases, further work is needed to provide an understanding of why reported changes in coping with symptoms and actual reported changes in symptoms by participants do not translate into reliable change on clinical outcome measures.

Nine of the participants reported improved coping with their symptoms following therapy whether or not they reported actual changes in symptoms. All patients who reported improved coping reported a positive experience of treatment. This suggests that symptom change may not be what is most important for the patient and supports previous research findings that therapeutic change can be clinically significant, whether or not symptoms change, if the client feels better able to cope with them (Kazdin, 1999). At the time of the study, no questionnaires that measure coping were routinely used in the service; consequently outcomes used to evaluate the Pathfinder project may not be a true reflection of the impact of and value to the patients of the treatment received. Further work is needed to explore alternative measures and methods that might more accurately capture benefits to patients of therapy, such as improved coping.

Limitations

The limitations of data comprising retrospective accounts are acknowledged. The sample size was small and, consequently, any patterns identified are preliminary, each requiring further exploration with qualitative and quantitative methods. It would be valuable for future research to interview patients before, during and after therapy and to ensure that the sample is as representative as possible. Gathering the views of patients who attended fewer than two sessions of therapy would be valuable in gaining a broader perspective, more likely to include negative experiences.

Conclusions

This qualitative study found that patients with MUPS generally found the psychological interventions to be acceptable, although suggests that further research to establish the acceptability of MBSR is needed. Participants reported a number of benefits of treatment including learning to make connections between physical symptoms and thoughts, mood and activities, feeling understood by other patients and the therapist and improved ability to cope with symptoms. Outcome measures that can demonstrate the value of treatment to MUPS patients, including improved ability to cope with symptoms, are needed within primary-care psychological therapies services.

Summary of the main points

- MUPS are symptoms that have no known pathological cause.
- MUPS may cause significant distress to a patient, and around 70% of MUPS patients will experience anxiety and/or depression.
- Since 2011, the IAPT NHS programme has been expanded to include patients with MUPS.
- Using a stepped-care model, patients in a pilot site were offered guided self-help, HI-CBT or participation in an MBSR group.
- Participants generally reported a positive experience of treatment and felt better able to cope with their experiences, although treatment did not necessarily result in positive reliable change on routinely administered outcome measures.
- Outcome measures that can demonstrate the value of treatment, including improved ability to cope with symptoms, are needed within primary-care psychological services.

Ethical standards

The study was submitted to the Integrated Research Application System (IRAS) and reviewed by the NRES Committee – London (London Bridge). Following approval by this committee the study was then submitted to and approved by the Research and Development Department of South London and Maudsley NHS Trust.

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Declaration of Interest

None.

Recommended follow-up reading

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Learning objectives

After reading this article the reader should be able to:

- Identify the interventions offered by IAPT to patients with MUPS under this pilot.
- Understand common themes in the experience of MUPS patients who received psychological therapy.
- Consider the implications of the findings for the development of future services.