Frontiers

A qualitative study of the views of patients with medically unexplained symptoms on The BodyMind Approach®: Employing embodied methods and arts practices for self-management.

Introduction

This article reports on original pre-clinical trial qualitative research. It is based on an analysis of the views of patient-participants, with medically unexplained symptoms (MUS), on an embodied arts-based practice called The BodyMind Approach® (TBMA). The aims of TBMA was for participants to develop a changed relationship with their MUS and to enable self-management. These two aspects of this approach to MUS are unique to TBMA.

Principles were derived from a synthesis of research data collected from participants' interviews and questionnaires on the facilitated TBMA groups. These principles explain why TBMA, delivered in the English National Health Service (NHS), demonstrated effectiveness in supporting self-management.

The MUS patient population lacks appropriate, accessible and acceptable interventions (Chew-Graham, et al., 2017). Physiotherapy (pain management) and/or psychological services (mental health, cognitive behaviour therapy/CBT) being the only choices available currently. These are either a physical or a mental health intervention solely. The latter is wholly unacceptable to this population due to their physical experiences in the body which shapes their explanatory model of their condition as being only physical. Additionally, there is a greater stigma associated with psychological/mental health generally. TBMA however, brings both physiological and psychological aspects together in one unique intervention. Furthermore, TBMA for people with MUS has had encouraging outcomes and there is evidence of acceptability for this hard-to-reach population.

Medically unexplained symptoms

Self-management, TBMA, MUS

Previously called 'psychosomatic conditions' now MUS (or Somatic Symptom Disorder/Body Distress Disorder) is defined as chronic bodily complaints for which examinations do not show explanatory structural or other specified pathology (Henningsen, Zipfel & Herzog, 2007), for example, chronic fatigue, headache, chronic pain, fibromyalgia, etc. (Fink & Schroder, 2010; Department of Health, 2008). Patients have recurrent or persistent symptoms or have symptom disorders. Patients with chronic symptoms are extremely common in primary (Steinbrecher et al., 2011; Haller et al., 2015) and secondary care (Nimnuan, Hotopf & Wessely, 2001; Burton et al., 2012) and are a costly (Bermingham et al., 2010) world-wide problem.

Self-management of health conditions

Self-management in health care is defined in different ways, incorporating prevention and decline. It aims to increase the capacity for self-regulation which monitors thoughts, sensations, feelings and behaviours. The impact of self-management groups has the potential to improve health outcomes such as increases in patient confidence, physical functioning, adherence to treatment/medication and reduce anxiety (Challis et al., 2010).

Multiple ways of knowing as in Millar and Crabtree (2005) incorporates a range of activities to engage patients in reflection and self-awareness, memories, body awareness, dance, body maps, to improve body confidence and holistic sensitivity to others to enhance self-care. Body stories of health and illness and the complex relationship of bodies to life histories and context is through the art process rather than solely verbal. As Swartz (2012:21) says when referring to this form of health education 'patients challenge their own situated knowledge and transformation becomes possible'. New and different practices, such as dancing together, result in assumptions about their body being questioned. Written reflections in participant's journals about their changing body

experiences help develop insights and connected knowledge with their own and family/cultural and the collective knowledge. Through becoming more connected with their bodies they can know the meanings of, and respond more appropriately to, bodily messages of pain etc. For example, not rushing to the GP or A&E but valuing, recognising and regulating emotions thus benefiting them and those around them. Furthermore, this helps people to be able to distinguish between the feeling of connection and disconnection with self and others.

Purdy (2010) found reduced unplanned hospital admissions for chronic obstructive pulmonary disease and asthma. Bjørnnes, Parry and Leegard (2018) found (in a meta-summary of qualitative research of self-management for women with cardiac pain) support for an individualized intervention strategy promoting goal setting, action planning, the management of physical and emotional responses, and social facilitation.

TBMA satisfies the above findings through a facilitated group self-management programme with individual goal setting and action plans for people with MUS. It emphasises multiple ways of knowing, social facilitation and managing physical and emotional responses as a solution to the long-term aim of self-managing symptoms in a sustainable manner, thereby reducing the gap between patient needs and funding constraints.

The BodyMind Approach®

The BodyMind Approach® (TBMA) was first researched in 2004 (Payne, 2009a & b; Payne & Stott, 2010) which showed promising outcomes. Further research with larger numbers demonstrated TBMA increased wellbeing, activity levels and decreased depression, symptom

distress and anxiety (Payne & Brooks, 2017). The capital B and M in the term 'BodyMind' emerged from interviews with participants in a previous research study (Payne & Stott, 2010). It emphasises a bottom-up process although both 'body' and 'mind' are important to connect. In TBMA the body is primary, so comes first, connected to the mind (which is not solely the brain - Siegal, 2012). It also counter-balances current trends regarding 'mind-body' concepts (top down).

TBMA, called 'Learning Groups' for patients and GPs, is a biopsychosocial model i.e. is interdisciplinary looking at the interconnection between biology, psychology, and socio-environmental factors all of which play a role in TBMA. It addresses, for example, the stress response (biological), the MUS person's mind-set (psychological), and the social and the body environment (the symptom and the group).

TBMA has been specifically designed to support patients with MUS. It consists of an embodied, enactivist (Gallagher, 2019) model derived from dance movement psychotherapy (Pallaro, 2007; Payne, 2006, 2018) and experimental practices designed to explore the symptom and any meaning through the media of expressive movement, drama (e.g. role play), clay, mark-making and writing. These practices are conducted as large /small groups, in pairs and individually. There is a facilitator, a specialist in dance movement psychotherapy (DMP), adult group work and expressive embodiment models, trained in TBMA, who initiates and co-ordinates the practices and the interactions. A TBMA manual supports the facilitator with examples of practices, values, competencies and mind-set. The content of the TBMA programme is described in detail in Payne, Jarvis and Roberts (2019).

The group in this report is defined as members of the group and interactions and the group experience is defined as the facilitation and/or content of practices, or both.

Self-management, TBMA, MUS

Arts methods in The BodyMind Approach®

The All-Party Parliamentary Group on Arts, Health and Wellbeing (2017) encouraged the use of the arts in health. Arts practices are central and integral to TBMA which is derived from one of the arts therapies i.e. DMP. The methods adopted have been adapted from DMP to suit the MUS population, for example, dancing synchronously together as a group with and without music (Chace, 1975) and authentic movement (Whitehouse, 1999; Adler 2002; Payne, 2006). In TBMA music is used as an emotional induction tool which can accentuate movement qualities and emotions or contrast with them as expressed by the group.

Group dance which is ubiquitous in humans involving exertive synchronised movement to music is employed in TBMA. Research demonstrates there is a link between exertive, synchronous group movement and elevated pain thresholds even with low exertion tasks. Synchrony and exertion have independent effects on this measure which suggests endorphins have been released which reduce pain (Tarr et al., 2015). It may also play a role in social bonding within the group setting. A mixed methods study of group DMP by Shim et.al., (2017) aimed to test and refine a model of DMP for pain resilience. It found improved resilience, less kinesiophobia (fear of movement frequently found in people suffering MUS), increased body awareness, reduced pain intensity, mood, stress, and increased relaxation, 68% of people felt 'moderately to a great deal better' post intervention. Key mechanisms were activating self-agency, connecting to self and others, enhancing emotional intelligence, and reframing. These results have helped to inform the model of TBMA for pain reduction in people with MUS (since many symptoms involve unexplained pain).

Another element borrowed from DMP is mirroring (Eberhard-Kaechele, 2019) which has been shown to foster secure attachment, synchrony and emotional regulation. Mirroring can become synchronous (Vicaria, & Dickens, 2016) and Rennung and Göritz (2016) defined this

interpersonal synchrony as instances when the movements or sensations of two or more people overlap in time. Studies on interpersonal synchrony using manipulated synchronized movement show it has positive, especially prosocial, outcomes (Rabinowitch, & Meltzoff, 2017). Mirroring promotes dyadic resonance, shapes secure attachment experiences and facilitates integration (Bebe, 1998). Nonverbal components give rise to right to right hemisphere resonance affecting attachment relationships, regulation and emotional processing (Schore, 2003). This process of mutual adaptation in mirroring and Chace (1975) group movement can be described as motion co-regulation for the purpose of creating synchrony (Hart et al., 2014). According to Fogel (1993) co-regulation is an intrinsic element of dyadic interactions. With reference to emotional self-regulation there are two modes interactive and auto regulation, mirroring and group synchronous movement supports the former. These findings inform TBMA.

It appears insecure attachment is frequently found in people with MUS (Adshead & Guthrie, 2018). TBMA has been designed to take account of the adult insecure attachment styles (Payne & Brooks, 2019). Attachment is fundamentally a regulatory theory (Fonagy & Target, 2002). Secure attachment involves capacity to shift between the two modes of emotional regulation depending on context (Schore, 2006). Group or dyadic practices using expressive movement provide regulatory opportunities for this adaption between the two modes.

The rationale for including mark-making on paper, clay sculpting, painting with fingers/non-writing hand, and journal writing is that they cultivate a non-threatening environment, there being no right or wrong answers and are inclusive. They stimulate creativity offering symbolic representation of the symptom, thereby encouraging a change in the perception of it and the participants' relationship to it to make meaning. Verbal and nonverbal symbolization narration evolves. This is an experiential means of shifting from a harsh internal mind-set/critic which monitors the threat response to an internal, benign, self-caring, mind-set and

the associated role that compassion (body and self) has on emotional regulation and threat management. From the symptom feeling like the 'enemy' to be 'got rid of', it can change to becoming an 'ally' and to be 'accepted'. People begin to recognise it is their perception of their symptom which is mediating their bodily experience and by relating to it differently they are more able to see ways of managing it. As a result, there is a change in the perception of mind-set, self and agency. The symptom symbolised by movement, marks on paper etc becomes the gateway to self-development and self-management. Arts practices are an ideal vehicle for distancing the symptom from the person making it safer to explore it.

TBMA with its integrated arts bias involves the social model of health where improvements in social inclusion and social cohesion are important indicators. This is in contrast to the medical model, employed by pain management and CBT which separates body from mind. Additionally, CBT uses solely verbal methods. TBMA is also in contrast to other body-oriented groups (Rohricht, Sattel, Kuhn, & Lahmann, 2019) since TBMA, although also working with the body, works with expression through movement and the arts, and has the goal of self-management rather than cure.

TBMA integrates the physical body and its sensations with movement and the arts to inspire cognitive, social, imaginative and emotional intelligence alongside engaging participants with the themes emerging from their experience of ill-health and the NHS.

> Arts activities can involve aesthetic engagement, involvement of the imagination, sensory activation, evocation of emotion and cognitive stimulation. Depending on its nature, an art activity may also involve social interaction, physical activity, engagement with themes of health (Fancourt & Finn, 2019: 14).

This report goes on to claim that psychological (in TBMA this refers to agency, coping and emotional regulation); physiological (in TBMA this refers to less bodily distress from the

symptom); social (in TBMA this refers to reduced isolation, social support) and behavioural (in TBMA this refers to increased physical activity, healthier behaviours, and self-management development) are all vital elements and that ' self-management' is one of the outcomes from these.

The Intervention

Employing a facilitated group, and an embodied, enactive, expressive approach is a novel intervention for MUS sufferers. It is not delivered one-to-one, nor as a group for a specific MUS condition as found in CBT. Instead TBMA is a group for people with a variety of MUS conditions i.e. it is heterogeneous.

TBMA is facilitated by a specialist in TBMA which appears to be crucial according to this study, although it is acknowledged the social support from the group is also essential for efficacy due to the population's extreme isolation. MUS sufferers feel they are the only one for whom their General Practitioner (GP) cannot find a diagnosis and they feel alone due to friends and family having become bored of hearing about their symptoms. In theory a group approach is ideal for MUS sufferers because it can combat this isolation. A group is also helpful because they often have less motivation to be active and go out whereas a group facilitates more engagement in life. They feel helpless and hopeless (due to numerous tests and scans which come back without a diagnosis). Participants in TBMA groups are supported in challenging the notion of hopelessness and helplessness giving a sense of agency. The arts are a perfect medium for combating social isolation and developing group cohesion. A group can generate new experiences and ideas for creativity, support and learning.

The intervention included 15 small groups delivered over 12 x 2 hourly sessions over ten weeks with the first two weeks having two sessions per week. Individual consultations,

before and after the group, took place with the group facilitator. Participants in each group varied between four and ten.

Group work can be challenging for people, especially if already vulnerable, lacking confidence and highly anxious as is often the case for people with MUS. Groups can be destructive and access can be problematic, as group research has shown (Smokowski, Rose & Bacallao, 2001). Consequently, strategies are employed prior to the group commencing to support people to engage and arrive at session one. For example, there is an individual intake meeting for three quarters of an hour with the facilitator at the venue in the week before the first TBMA session. This explores people's fears, questions, provides ground rules/information and clarifies confidentiality. It engages the participant to find rapport /trust with the facilitator. Furthermore, participants only commit to attending six sessions initially and thereafter re-commit to the subsequent six, making it easier to sustain engagement. As a result, most participants attended regularly and completed the TBMA programme (97%). Additionally, the programme was front loaded to have two sessions per week in the first two weeks thereby accelerating group formation and cohesiveness. In the week the programme ended there was an exit meeting, at which face-to-face semi structured interviews or a participant experience form (PEF) were administered.

Methodology

The research question: 'What are participants' perspectives on their experiences of TBMA?' The aim was to establish participants experience of TBMA and if any aspects of TBMA were helpful to developing the self-management of their symptoms.

Design: This was a qualitative methodology design involving semi-structured interviews and open-ended questions on a written PEF post TBMA intervention. Groups were delivered via different facilitators, in geographical areas and at different times. The qualitative findings

reported here, derived from these deliveries, is consistent with the quantitative results previously published (Payne & Stott, 2010; Payne & Brooks, 2018) (improved wellbeing, activity levels, decreased depression, symptom distress and anxiety) and provides rich data illustrating process and understanding of the experience.

Data collection: There was a 65% (24/37) response rate. This research is a synthesis of qualitative data collected from face-to-face semi-structured interviews (which were recorded and transcribed) on participants' experiences of TBMA post intervention (N=18), combined with written qualitative data post intervention from a PEF (N=24). The open-ended questions asked in the PEF were also based on the need to understand participants' experience of TBMA. The rich descriptive narratives describe participants' lived world experience of TBMA. The two sources of data collection (interviews plus PEF, N=42) provide for a method of cross-checking data to search for regularities and/or differences. The point of combining all perceptions was to create a larger number of perceptions.

Ethical approval: This was gained from the local NHS Research Ethics Committee for the data collection 2005-9 (number 05/Q0201/63). For subsequent data collection (2012-16) participants gave written consent to feedback/evaluations being used for research and could withdraw at any time without any reason. All participants agreed the data could be used for research purposes. Permission was gained from the NHS Clinical Commissioning Group to report on data anonymously in published articles. In all cases participants were assured of anonymity and confidentiality in the reporting without names or pseudonyms i.e. only location and year of the group deliveries are referred to in participants' quotations.

Sample: Participants were drawn from patients suffering MUS in primary care in two clinical commissioning groups in the East of England. Recruitment for the groups was via GPs and

self-referral confirmed by GPs. All participants had presented in primary care with MUS for six months plus.

Gender: Of the 18 participants interviewed 15 were female and three were male. Of those participants who were invited to complete the PEF, 24 were returned out of which only 14 answered the question on gender, ten did not. The gender mix, 8% were male and 92% female which reflects the literature whereby more women than men somatise (Barsky, Peekna & Borus, 2001; Sowińska & Czachowski, 2018).

Ethnicity: Of those interviewed all 18 reported being white, although not all British. Out of the 24 PEFs returned seven answered British white, 17 did not answer the question.

Age: Adults of all ages are likely to experience MUS. Of those interviewed ages ranged from 21 – 81 years, of those completing the PEF the biggest age group category was the 46 -57- years. The youngest patient was 24 years and the eldest was 63. One person did not disclose their date of birth.

Types of symptoms: There were 12 different symptoms for this data set of 12/18 patients on these courses. These included:

☐ fatigue
☐ widespread chronic pain
☐ back pain
☐ left side pain
☐ lower back pain
☐ being cold
☐ movement restriction
☐ muscle hardening
☐ pain
☐ tiredness
☐ IBS
☐ anxiety

Employment status: There was data for only eight patients. There was a mixture of unemployed, retired, employed full or part time. For all deliveries most patients remained the same. At the outset 1/8 (12%) of patients were retired; 0/8 (0%) were in full-time employment; 3/8 (38%) in part time employment and 4/8 (50%) were unemployed.

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Educational background: Patients appear to have come from a range of educational backgrounds which reflects that found in previous evidence, for example, none, A levels, degree, post-graduate.

The socio-economic groups were not collected.

Inclusion/exclusion criteria:

Inclusion:
- 18 + years;
- MUS diagnosis for at least six months;
- frequent attender (more than four visits per annum);
- presentation for more than six months;
- co-morbid depression/anxiety;
- fluent English speaker.

Exclusion criteria:
- current relevant physical health problems;
- fewer than four GP consultations in previous year;
- trauma in previous six months;
- current relevant physical disability;
- complex bereavement previous six months;
- learning disability;
- primary diagnosis of psychiatric condition in previous six months;
- current substance misuse;
- a diagnosed eating disorder.

Recruitment: There were two methods of recruitment. Health professionals who made referrals were aware of the nature of the research, and the intervention and inclusion/exclusion criteria having attended a presentation on the project and/or received a handout. They selected appropriate patients to whom to give a flyer and made a referral on their behalf. A second method was self-referral, for example some participants may have seen a notice in the community or GP surgery. In these cases, prospective participants made their

own referral to the project on a form designed to reflect the inclusion and exclusion criteria.

They gave permission for it to be checked with the GP that the referral was suitable.

Procedures: For recruitment to groups, following referral on a first come first served basis, patients received a leaflet about the learning group and then, if they were still interested, attended a half hour screening interview to establish whether they were suitable. Data for this aspect of the research was collected in the week the programme ended post intervention.

Analysis: The subsequent manual analysis of the PEF open-ended questions and the interview data resulted in several themes emerging. Participants recounted narrative examples of their experience of TBMA and ways in which they felt they benefited. For the written responses the authors scrutinised the narratives to identify common themes and /or differences to similar questions. Themes were derived from a step-by-step process of categorising quotations which related to specific content tracking Braun and Clarke's (2006) approach to data analysis. This involved noting specific passages of text from the transcriptions of the interviews and the comments on the PEF linked by, or contrasting with, a common theme. This allowed the indexing of the text into categories to establish a framework of thematic ideas about the phenomena. By systematically interpreting and coding the textual data replicable and valid inferences were able to be made. Braun and Clarke's six steps were followed: familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report. Five themes were identified and there follows a description of each theme in detail. These themes acted as proxy indicators for self-management.

This study employed a form of cross verification to check the credibility of the researchers' interpretation of the data, against the opinions of six different stakeholders engaged with the study (a GP who made referrals to the intervention, TBMA facilitators, the NHS commissioner of the intervention, a researcher-practitioner with similar

qualifications/experience but not directly involved in the study, and one of the participants suffering MUS). In qualitative research truthfulness can be assessed if the reader resonates with the outcomes as believable, consistent, applicable and useful to readers and other researchers. Thus, all stakeholders were invited to comment on the findings. One of the ways of enhancing validity is respondent validation: 'a process whereby a researcher provides the people on whom he or she has conducted research with an account of his or her findings [in order to] seek corroboration or otherwise of the account' (Bryman, 2004: 274). From the stakeholders' point of view there is some evidence for transferability to other settings. The reflexive translation into other contexts is where researchers and practitioners assess the extent to which findings in one context apply (or are transferable) to other contexts which they know (Schofield, 1993). Hence, we also invited a research-practitioner to read the report and assess the extent to which the intervention and findings could be applied to their context of MUS patients in primary care. Their assessment was that TBMA could be applied in such settings with resulting similar outcomes. Furthermore, reliability (i.e. the consistency with which TBMA groups would produce the same findings) can be shown since the findings were derived from 15 groups of TBMA each with different facilitators in different geographical regions and yet were consistent.

Findings

Key for quotations: P=participant, P1=participant1, P2=participant2 in the same group / the initial letter of the venue used for the group and the number of the group in which the participant participated where relevant i.e. 1 or 2/the year in which the group took place

It was clear people enjoyed attending TBMA because 95% said tey would recommend it to family and friends, the attrition rate was only 3% and satisfaction rated good/very good on all aspects. It is noticeable that participants mentioned the elments which they took away from the experece of the intervention without commenting directly on the content of TBMA which involved movement, dance and art-making practices. This is a common finding in similar

interventions examining participants views of an intervention (Payne, 1986; Payne, 1996; Kaimal, et al., 2019).

Categories were repeated, comments were plentiful showing saturation of patterns and repetitions. These were formed into five key principles presented here with one or two examples of participants' comments: 1) TBMA encouraged body with mind connections, 2) the importance of the facilitator, 3) positive benefits, 4) preparedness for change, and 5) self-acceptance/compassion resulting from the experience. It is proposed the interaction between these elements leads to an integration for self-management.

1. TBMA encouraged body with mind connections

Movement and arts practices were designed to help people make connections between body and mind. People said they learned from witnessing others change their relationship with their symptoms/body. The term 'BodyMind' derived from an analysis of participants' comments who, retrospectively, thought the workshop aim was to link the body with the mind - an aim which, they thought, had been met, for example: *"I learned to link my body with my mind"* (P, H3, 2008). This theme continued throughout the analysis, respondents commenting on how the embodied arts practices helped them find a voice and gain insight into their relationship with their body; listen to, and accept their energy levels, and use this monitoring to pace themselves becoming more in touch with their body, "*Able to pace my day*" (P, HH, 2016) and *"Getting down to the root of the problem*" (P2, H, 2016). Links were made between feelings and symptom severity, how mind tuned in with body giving more of an understanding of the relationship between body and mind, for example*,* they liked that "*the group was different in that they did unusual exercises like dancing, walking, breathing which helped me cope with my symptoms* (P, H, 2013).

Participants reported listening to warning signals in the body which helped where symptoms can be addressed to learn how to '*live with the symptoms more easily*' (P, H3, 2008) as well as to '*learn how to cope with the symptoms'* (P, H3, 2008).

2. Importance of the facilitator

The facilitators were all qualified DMPs who had been trained in the methods employing movement and arts-based practices designed specifically for people with MUS. The data analysis led to the conclusion the facilitator was essential to the process engendering an inclusive and collaborative style, safety and support, and challenging participants to take risks. Participants commented the facilitators were very warm and understanding, knowledgeable, patient and helpful. For example: *"I learnt so much, and the facilitator is brilliant, she is patient, understanding and very knowledgeable*" (P, H4, 2016).

Some participants noted the facilitator created a safe environment, for example, for the changes required for self-management: *"I won't trust people easily but trusted the facilitator from day one"* (P, L1, 2015); *"Our leader was a great help in bringing about the group to gel from the start"* (P, H, 2013).

The participants thought the facilitator listened well, facilitated changes, gave freedom of choice/no pushing, helping people to learn how to open up, for example: *"[the facilitator] enforced or found boundaries, encouraging participants to listen to their inner voices"* (P1, H3, 2008). Additionally, they saw facilitators as being approachable, insightful and giving time to each person to be heard and understood. Some facilitators were also seen as nurturers, for example: "*She was nurturing or trying to caress them in a gentle way of exploring something that's quite painful for some people*" (P, H4, 2008); "*by providing safety (physically and emotionally) - nurturing the group"* (P, H3, 2008). It can be argued the non-judgemental, nurturing, kind attitudes demonstrated by facilitators helped people to open-up

to self-compassion which is needed for self-management. The facilitator modelled the practices and joined in to lead dance/movement practices and directed the mark-making for participants to engage with and to link these to their symptom/s. Thereafter the facilitator guided discussion about symptoms and meanings derived from the embodied experience or artwork.

The facilitator was seen to help people learn how feelings are generated from themselves as opposed to from others - another aspect required to be able to self-manage. They explained the relationship with facilitators was profound "*it was a deep relationship*" and enabled people to identify and express feelings giving tools to overcome symptoms: "*the fact we were given time to express our feelings was helpful*" (P, L2, 2015); "*positive encouragement and tools and space to overcome symptoms*" (P, H, 2013).

Facilitators helped participants to attribute new meaning to symptoms i.e. turning bodily symptoms into meaningful information about current emotional states, typically saying: "*Realising my emotional situation is not helping my physical problems* (P, H, 2015). Recognizing these states, participants were guided by facilitators to inform themselves of their needs and ways to self-manage their symptoms: *"I learned new ways of coping"* (P, H, 2013). Facilitators convinced people to become interested in the meaning of their symptoms, and the part the symptom plays in their lives, yet accepting the symptom for what it is without judgement. The reward for learning is the continued capacity for growth, to go forward knowing they can be resilient in the face of adversity when it hits, as it always will: *"[the facilitator] helped me find a way of moving forward"* (P, HH2, 2016).

Facilitator attributes include the ability to model staying in the present moment (Stern, 2004), for example: *"[the facilitator] helped me be more in the present"* (P, H4, 2008); *"[the facilitator] was excellent and always present*" (P2, L1, 2015); "*learned to be more present*

with me and symptoms" (P, H3, 2008) which helped to promote connection with the body and the symptom to bring about self-management. Focusing on bodily sensation aids in the intention to be present as well as focusing on the arts-making or movement process (as in adaptive authentic movement). Furthermore, creative experimentation with reference to the symptom in a safe environment e.g. creative movement with hands, creative, reflective writing in their journal or mark-making, encourages an intention to stay with the present moment.

The facilitator engenders and models a non-judgemental and empathic attitude which is picked up by participants to provide sufficient safety and support to open-up to playing, creativity, risk-taking and exploration etc. for example, "*I liked fact it is free and non-judgemental*" (P, L1, 2015); "*meeting others who had similar problems and not being judged*" (P, H, 2016).

3. Positive benefits

From an analysis of the data it is concluded the positive benefits from the arts practices in TBMA were feelings of: a) belonging, b) support, c) safety, and d) shared purpose all of which are required to help develop the confidence to learn to self-manage. In a group each person brings potential for rich experience whereby numerous perspectives are available. Furthermore, the experience in the group and the group itself was an important vehicle for change for almost all participants', for example: *"[it] worked like a catalyst"* (P, H2, 2008), or as a starting point offering an option: *"This group sort of showed me a road, and I could go down it, or not"* (P, H3, 2008); *"[The] group supported me and helped me to accept the limits of my condition"* (P, L1, 2015).

The experience gave people a sense of belonging: "*Feeling less alone*" (P, H, 2016), support and sharing: *"This course gave me the chance to unite, share experiences and support each*

other and gave a sense of belonging" (P, L2, 2015). Discovering others with similar or other unexplained conditions helped feelings of belonging. Understanding they have had similar NHS experiences and seeing symptoms from new perspectives bonded people: *"being part of a group with people who are in a similar situation and learning to see your symptoms from a different angle"* (P, L1, 2015). Feelings of isolation reduced (i.e. being the only one for whom the GP could not find a diagnosis): *"I found getting other people's feedback and hearing their experiences helpful"* (P, L1, 2015). Participants made friends "*The group and our leader were all very friendly and helped each other, a good experience, I made a number of new friends, the group really gelled from the start"* (P, H, 2013). Participants mentioned they met group members post course on a voluntary basis *"I met people with a similar condition to myself and we are still meeting after it all ended"* (P, H, 2015). Seeing how others changed in their relationship to their body helped participants too *"I have gained from the experience, particularly learning about my relationship with my body, and seeing it reflected in the others in the group"* (P, H, 2013).

4. Preparedness for change

Participants appeared to make changes whereas previously they had resisted this. They reported on changes in their symptoms, lifestyle and mind-set (thinking) resulting from the experience of engaging with embodied experiments with the arts and creative movement. Such change could form the basis for self-management: *"I achieved a return to work and overcoming of fibromyalgia pains and symptoms in an on-going manner"* (P2, H, 2013)*.*

Changes in thinking and habits need to be developed in order to self-manage, for example: "*Changing thinking patterns and habits"* (P, H, 2016), changes in lifestyle: *"I was very set in a pattern, and it sort of acted as a catalyst to start my life changing, and it's changing more now, and quicker"* (P, H2, 2008*).* Changes in mind-sets were also key to self-management:

"a shift in outlook, [I have] a more positive approach" (P, W, 2016)*; "facilitated a shift in how to manage life"* (P, H2, 2008).

Hope for the future became important in the maintenance of new habits, reduced worries and changed mind-sets and in their embedment for sustained self-management: *"I have been able to feel less worried and anxious about the future"* (P, S, 2016); *"I feel more positive in my outlook and look forward to my future* (P, L2, 2015) and mentioned frequently was the phrase: *"I had enough help to go forward* (P, L1, 2015). Other comments on hope for change included: *"I will find life more enjoyable since being involved with the facilitator and the group"* (P, L1, 2015).

Comments concerning change and choices included: *"I do take breaks and do whatever - silly things, but to give pleasure…jogging, listening to music or bubbling around somehow"* (P, H3, 2008); *"I question myself more before I commit myself to do so many things"* (P, H3, 2008).

Some participants referred to the change in reflections on the 'self', these statements concern a deeper knowledge and understanding of self as a pre-requisite to change, for example: *"Taught me a great deal about myself"* (P, L1, 2015); *"Questions I was asked made me look deeper into what was happening to me, making me think deep thoughts I had never realised needed looking into but have helped me very much"* (P, L2, 2015 *"I [learned about] the inner self, to discover what you want and need (and to what extent)"* (P, H2, 2008). Other comments were symptom related such as insight into the meaning or cause, developing coping strategies and learning about their symptoms through the different art forms: *"[I learned] to find out more about the symptoms"* (P, H2, 2008). Flexibility and embracing the possibillity of change in their life emerged, some mentioned reduced anxiety/stress: *"improved stress management, therefore the symptom disappeared!"* (P, H4, 2008).

Participants thought the intervention had affected their lives to change both physically, such as feeling more energetic, relaxed, fitter and in their overall wellbeing: *"My wellbeing has really improved generally"* (P, H1, 2008). Valuing self, indicating improved self-esteem emerged: *"I now value myself and the quality of my life"* (P, H1, 2008) and having more will power and self-reflection. For self-management there needs to be acknowledgement of physical change as well as self-reflection and motivation to sustain it. Ego strength provides the energy for self-agency. The ability to show agency improved: "*I have direction now"* (P, L2, 2015); "*enabled me to help myself"* (P1, H5, 2009).

> *[The] activities taught has enabled me to control my anxiety and be more in tune with what my body needs. The many concepts and strategies taught have made me feel more empowered to tackle this illness and I am noticing a direct correlation between the level of anxiety and the severity of pain felt* (P, W, 2016).

With reference to agency it was not only about managing symptoms but also about facilitating a shift in how to manage life and feeling more in control: "*more control of life, more structure/routine e.g. in family life"* (P, H3, 2008); *"It might give you your independence back from seeking medical advice all the time"* (P, H5, 2009). This would suggest that TBMA may save health service resources.

Other changes involved the management of feelings characterized by comments such as: *"I discovered that I get my symptoms through a lack of expressing how I feel*" (P, H4, 2008); *"to understand how worries can trigger symptoms"* (P, H5, 2009) show participants appear to be learning about repression, the influence of feelings on symptoms and the importance of

expression fostered by the embodied arts practices. Such learning can support strategies for self-management.

Participants found they had changed to be at the start of a journey: *"I feel I am only beginning this journey, as the changes I am putting in place will hopefully have an accumulative effect over time"* (P, H1, 2008). People said they were taking more time for fun things, breaks, changes in diet and how to improve their stress levels. In terms of the sustainability of changes a typical comment was: *"[the course] was life changing"* (P, H4, 2008).

Emphasising the change in positivity more readily appeared from a number of comments: *"friends have commented on how much I have improved with my positivity"* (P, S, 2016) and *"the course brought me to the point of 'I need to start living again'- it has helped me no end"* (P, W, 2016). The latter comment suggests life has been on hold due to the MUS. Participants appeared to feel more empowered to tackle their illness, to start to do things for themselves such as meditation or painting, were more able to take on new things and found a way to move forward with self-care with less dependence on the NHS.

5. **Self-acceptance/compassion**

Self-acceptance and compassion derived from many comments. The symptom is transformed from being an 'enemy' into an 'ally' highlighting tolerance and acceptance - part of what is needed for self-management: "*I have become much more tolerant and understanding of my condition"* (P, S, 2016); "*It was a reminder to make time and space for myself, be more accepting and more relaxed*" (P, H, 2013); "*I have learned to accept it is OK to have limitations on what I can do"* (P, L2, 2015)*; "Whilst I know the sessions won't cure my illness but I have learnt to accept it more, through different ways"* (P, H3, 2016); *"[I] let go of my shame about my condition. [I am] in a much more accepting place which will help me*

achieve my goal of managing my energy better" (P, L1, 2015). Valuing the self is required for self-management: *"[I have] enhanced self-value, self-confidence*" (P, H1, 2008); *"being kinder to self"* (P, W, 2016); *"learning to try and relax more and think about myself*" (P, H1, 2015).

Discussion

All these findings represent participants' take-home experience of the intervention in their terms. The content of sessions was based on arts-practices and embodied approaches to exploring the symptom. Whilst participants have not specifically reported on these approaches, they were the vehicle for experimentation and exploration to learn more about their symptoms in order to provide a platform for self-management.

It is acknowledged MUS sufferers are hard-to-reach perhaps because of the limited treatments acceptable to them; they are hard to define and have varying levels of trust and confidence in the health service. Employing embodied methods and arts practices appears to be a safe and non-threatening pathway to engaging this population.

Mobini (2015: 9) states 'one of the major obstacles of delivering any psychological treatment to this clinical population is that often psychological treatment is considered as irrelevant and so referral to mental health services as unacceptable' referring to patients' views. TBMA appears to be seen by participants as relevant as it is not framed as a psychological treatment but as a course of learning about symptoms and their management.

They may also be hard-to-reach due to the shame attached to being ill and/or sometimes absent from work with symptoms which are unexplained, for example, one participant said: *"I learned to let go of shame about my condition"* (P, L1, 2015). Such feelings of shame can be resolved if meaning can be attributed to the symptom and this provides for a sense of control.

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The themes above (we interpret these as the five key principles) demonstrate several important ingredients and inter-relating aspects for self-management achieved by TBMA. The following discussion for each of the five themes makes links to the literature.

1. Body with mind connections

The body to mind connection concept is a new and emerging area within the world-wide problem of MUS. These conditions are exceedingly costly, very common with few options for treatment; hence TBMA is important for health providers to consider for MUS sufferers. In TBMA the individual is nurtured towards engaging with their body symbolically, to view/experience it not only as a source of pain, discomfort and negative experiences, but also to acknowledge healthy, functioning aspects. Identifying sensations of symptoms, where they are in the body in a mindful way, with kind attention, leads to being able to control the distress. TBMA links sensations (interoception) to feelings and the imagination (via arts practices) and perception of the external environment raising body awareness to find meaning in the symptom.

Seeing others make connections between body and mind and making meaning of their symptoms can stimulate participants to make their own body with mind connections. Making connections between the body and the mind brings an appreciation of the ability to use bodily signals to self-regulate in a positive way, as opposed to previous rather hostile perspectives. TBMA promotes inhibition of old habits, reappraisal of pre-existing assumptions, and possibilities to respond to stress in novel ways offering greater emotional self-regulation. Since emotions and movement are so closely related (Kirchhoff, 2018; Melzer, Shafir & Tsachor, 2019) non-verbal behaviour, as in expressive movement (Krantz & Pennebaker, 2007) and mark-making practices, can encourage reflections on a range of feelings - sadness, fear, anger, joy which some people with MUS find difficult to identify and verbalise (e.g.

alexithymia). This somatic bottom-up intervention removes the focus on verbal language and memory, as it works with implicit elements available in the nonverbal. It appears the creative process, which involves play (Porges, 2015) within the group interactions, can lighten feelings of helplessness and hopelessness (Seligman & Groves, 1970).

By directly speaking to the nature (or purpose) of the symptom, through experimenting with arts practices in relation to symptoms, distance can be created between participant and symptom, allowing meaningful aspects to emerge. Exploring sensorimotor experiences of symptoms, and employing grounding and centring practices, can help reclaim emotional self-regulation and feelings of safety, leading to a greater sense of control.

2. The importance of the facilitator

The group facilitators were perceived as catalysts, crucial for engendering hope for change. They were seen by participants as knowledgeable specialists, role models, and a safe pair of hands, creating a safe, boundaried environment helping people to open-up and feel comfortable, ensuring all were heard and understood. Participants felt safe enough to take risks required to engage with the practices and express feelings since group cohesion (Forsyth, 2010) could be relied upon.

Facilitators honored symptoms, accepting them, and the person, unconditionally without judgement or questioning. Participants did not need to disclose their symptoms, but all were invited to bear their symptom in mind when engaging with a practice. They were perceived as acting as agents for participants to listen to their own inner body-felt voices and address their problems. Facilitators valued participants' lived body experience helping them to look at it afresh and focus on it as opposed to pushing it away as an enemy (some had even had parts of their body cut out). Seeing, feeling and experiencing it 'as is' rather than what they would like it to be i.e. gone forever.

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3. Positive benefits

The benefits were feelings of a) belonging, b) support, c) safety, and d) shared purpose.

These were all present in TBMA groups and seemed important to the efficacy of TBMA

according to participants. Cohesion is a general term for assessing the quality of the whole

group and is based on group integration and on individual attraction to the group

(MacKenzie, 1997; Dion, 2000). It has been found that participation increases in a cohesive

group and in return produces more interactions between members, leading to a more

productive and effective group with better outcomes for its members and the group as a

whole (Tschuschke & Dies 1994; Johnson & Johnson 2000; Marmarosh et al 2005;

Marmarosh, & Van Horn, 2010). Cohesion is regarded by many authors to be the most

important process in a group (Yalom & Leszcz, 2005; Corey, 2004; Delucia-Waak &

Bridboard, 2004; Brown & Lent, 2000). In TBMA cohesion refers to the quality of

relationships that develop between group members and the facilitator (see 2 above) to

promote a sense of 'belonging' reducing isolation (Dirkzwager & Verhaak, 2007).

With reference to 'support' participants commented on the significance of the individual

members of the group, many opting to continue to meet voluntarily after the sessions and

when the programme finished. Most participants commented that the interaction with group

members improved wellbeing and gave a sense of support. For example, many arts practices

took place individually (as in mark-making), in dyads (as in mirroring) or as a whole group

when employing the Chace model of actively moving in synchrony together. After

individually being engaged in an arts practice, participants would pair up to share and support

one another. On other occasions participants would offer support to each other in the manner

of witnessing found in authentic movement (Whitehouse, 1999).

In TBMA group 'safety' is fundamental and the programme is designed with that in mind (Payne & Brooks, 2019). A positive perception of the group can indicate that members view the group as trustworthy and safe to explore and practice new skills (Kivlighan & Tarrant, 2001). It is characterised by participants being active, engaged and seeing the group as beneficial. Orgodinsik and Piper (2003) indicated a correlation between short term group therapy, climate and outcomes, whether positive or negative depending on the level of conflict in the group and the phase of the group's development.

Porges' (2003) Polyvagal Theory concludes that human social interaction combined with taking the mind-set into account in interventions turns off the sympathetic fight/ flight/freeze response. The calming of the sympathetic nervous system, combined with feeling listened to, enables people to feel 'safe' enough to engage in the play required in TBMA arts practices to do the work of self-reflection to achieve self-regulation and self-management (Porges, 2003). There appears to be an attitude of kind, loving acceptance in the group experience where all are equal and respected as individuals adding to 'safety' and experimentation using the arts practices. This is in contrast to their views of previous experiences of unacceptance and disbelief surrounding the symptoms. They may have been regarded as psychosomatic, confirming the symptoms are not genuine and, thus, their illness is 'illegitimate' (Kirmayer, Groleau, Looper, & Dao, 2004) and/or they should be able to fix it by themselves somehow (Kornelsen, Atkins, Brownell, & Woollard, 2016).

Participants perceived members as understanding and non-judgemental as people shared experiences of symptoms and the NHS promoting a sense of 'shared purpose'. They had all joined the programme to learn more about their symptoms which also already gave a shared purpose. It was never mentioned that the programme would cure symptoms but there was

ambition that people could learn to self-manage them. Living with the unknown is extremely stressful, people can begin to imagine the worst, for example; assuming they have the ''big C. They also fear a mental health diagnosis since the assumption is that without a medical diagnosis it is all imagined, one participant said on entering the first session "*If this group is about mental health then I am leaving now!*" Sharing experiences of symptoms normalises such fears and the MUS itself which gives a shared sense of purpose.

The experiences were used by participants to promote change in symptom perception, coping styles, illness beliefs, and personal dynamics necessary to achieve an increase in feelings of agency and control for self-management. Survival as a species is dependent upon the needs and experiences of others (Beckman & Syme, 1979). Hence there is dependence upon connecting. We have 'evolved the capacity to feel social pains and pleasures, forever linking our well-being to our social connectedness. Infants embody this deep need to stay connected, but it is present through our entire lives' (Lieberman, 2013: 10). Furthermore, primates have developed an unparalleled ability to understand the actions and thoughts of those around them, enhancing their ability to stay connected and interact strategically. He goes on to say: 'This capacity allows humans to create groups that can implement nearly any idea and to anticipate the needs and wants of those around us, keeping our groups moving smoothly' (: 10). Although the self may appear to be a mechanism for distinguishing us from others and perhaps accentuating our selfishness, the self operates as a powerful force for social cohesiveness. 'Whereas connection is about our desire to be social, harmonizing refers to the neural adaptations that allow group beliefs and values to influence our own' (: 11). The embodied, expressive movement experiences in TBMA engender the social connectedness/bonds to facilitate the shared purpose of learning more about symptoms.

The TBMA groups share a purpose, practices, values and beliefs and these can influence each member of the group positively. We propose the outcome of self-agency, required for self-management, is derived from the social construction developed from confidence gained from the group's shared purpose, support, sense of belonging and safety experiences. Physiologically, although the intervention did not suggest it would cure or reduce symptom distress, many participants commented on how their symptoms had reduced or disappeared. Particularly pain was reported to have decreased.

4. Preparedness for change

Cohesion in the group leads to more risk taking in giving feedback and establishing interpersonal relationships (Yalom & Leczcz, 2005). Risk taking leads to change in a group setting (Greer, 2012). The practices in TBMA encourage risk taking and therefore opportunities for change in a safe, interactive environment. For example, self-disclosure, feedback, group leader and group members' contributions, all reflect risk taking and increase cohesion in the group (Burlingame, McLendon & Alonso, 2011). Research suggests cohesion plays a role in the outcomes of groups (Brown & Lent, 2000). In TBMA there was a shift, according to participants, to becoming more positive for hope for change for the better and a belief that change was possible (i.e. to self-manage symptoms). Kivlighan, Paquin, Hsu and Wang (2016) found a significant relationship between an individual member's post treatment hope and the aggregated sense of hope of other group members. Participants reported new habits, feelings, routines, lifestyle and mind-set (Wood & Runger, 2016) all required for self-management. Self-understanding and making meaning appeared to be pre-requisites when making changes.

Participants described the group as life-changing such as helping reduce anxiety about the future, improving stress management and regaining interest in past pursuits. Participants reported improved physical and mental wellbeing enhancing self-esteem, willpower and self-

regulation, pacing themselves better and cultivating healthier routines. Recognising feelings, understanding their relationship with symptoms and triggers for their symptoms and emotions were important in the group. Links were made between emotions, thoughts, feelings and the sensation of symptoms.

Change was described as the beginning of a journey and the belief expressed that the improvement can accumulate over time with on-going conscious and/or unconscious impact. Some people felt empowered to tackle their illness noticing a relationship between anxiety and pain. La Cour and Petersen (2015) found an association between anxiety and pain relief. All this points to the capacity to learn hope for the future and take some control, as opposed to their previous state of learned helplessness (Seligman & Groves, 1970).

Role play is both part of the group experience and a practice in TBMA. For example, asking participants to share in pairs how might their symptom move or what posture might it take up? This practice often leads to greater insight into the meaning of the symptoms. The languaging of the feeling state in such a posture for example might contribute to a greater meaning-making of its nature. Furthermore, the feedback received from their partner could add further to this meaning. For example, a participant saw the image of a lion emerge from sensing her symptom through non-directed, expressive bodily movement which she interpreted as anger. During the verbal dyad process her partner also saw features of this animal. The dialogue that followed between them helped this participant to consider how to moderate her anger which she realised tended to trigger her symptoms. The participant dialogued with their symptoms to explore and better understand, re-frame or gain an explanation of meaning, origins, triggers and maintenance of them day-to-day.

Confidence gained in the group enabled the reduction of shame, improved wellbeing, self-esteem and the capacity to believe things could change for the better, promoting the development of a mind-set to embrace change and self-management skills.

5. Self-acceptance/compassion

Through the accepting ethos offered by TBMA participants are afforded the opportunity to learn the value of self and others. Self-acceptance/compassion was concerned with understanding other participants' conditions and having a tolerance of them with kindness. For example, the notion of accepting the symptom non-judgementally appeared often. Being more connected to their body appeared to allow a greater capacity to notice energy limits and for when to rest/relax. Sharing experiences in the group helped participants gain a perspective of their own situation. Journaling provided enforced time to reflect on experiences each session. Participants learned, for example, it was acceptable to have limitations allowing them to accept what their body tells them it needs. Comments on outcomes included enhanced self-value and self-confidence changing the mind-set to one of self-compassion.

The honesty encouraged by the facilitator in the group nurtures people to accept the idea that they have a condition which, whilst not curable, is something they can learn to manage. Finally, acceptance in the supportive group (of their condition) and self-acceptance/compassion appear to be key to starting to self-manage (Gregg, Callaghan, Hayes & Glenn-Lawson, 2007) as opposed to seeking a fix from the health service. The group promoted greater understanding of the condition and the acceptance of the lack of a cure helps with an explanatory model which can kick-start change and obviate the need for more tests and scans. Learning through the group to become kinder to the self reflects an important attitude to developing self-management. Acceptance of self, own needs and symptoms are a pre-requisite for self-managing symptoms changing the mind-set from 'I am not OK' to 'I am OK, despite symptoms and the limitations' (Harris, 1970).

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Conclusion

The research presented here is based on an anlysis of qualitative data and notes five key principles: body with mind connections; the importance of facilitator; positive benefits; preparedness change and acceptance/compassion. These all appear to have kickstarted the self-management process for particpants.

These five key principles in TBMA demonstrate several important ingredients and inter-relating aspects for the self-management of MUS. It is possible to distinguish the success of TBMA from the influence of the facilitator because there were several different facilitators, delivering in different regions, at different times, with different groups of people and yet all groups demonstrated similar outcomes. However, it is impossible to determine whether participants perceptions of the programme result from the group or the group experience, or both. The perceptions arose from open-ended questions about the programme which did not focus on the arts practices per se independent of the group and the group experience. However, because the arts practices were integral to the group experience it is reasonable to infer the perceptions reported connected to these practices. It seems likely, therefore, due to the holistic, integrative nature of TBMA groups, that all these elements may be involved.

We have outlined a model highlighting the interaction between the five key principles in TBMA. It shows how TBMA, with its emphasis on the arts, bodily sensations, creativity and expressive, movement-based embodied contemplative practices, in a facilitated group setting can help to re-establish sensorimotor integration. Furthermore, TBMA can foster non-judgmental, compassionate and accepting attitudes leading towards a reconnection with bodily sensations, improved self and body confidence, functionality, and quality of life. These findings expand the scope of reflection regarding the relationship between the arts,

body awareness and MUS, including interoceptive and emotional aspects of the MUS -

bodymind relationship. It takes further the idea of self-management from its employment

with identified diseases to its adoption as a strategy for management / treatment of MUS,

which currently has poor outcomes. It may be that TBMA might be transferable to other

long-term conditions in health education settings.

The potential benefits of TBMA to support patients with MUS to learn to self-manage could

be that it replaces current treatments (which are unacceptable to patients) and integrates the

body and mind in one holistic social model. Furthermore, it could reduce the high costs for

MUS conditions and free up GP time thus increasing capacity and resources for others. In this

regard the programme is unique in its potential reach, significance and impact since MUS is a

world-wide issue.

Declaration of Conflicting Interests

The Author(s) declare(s) that there is no conflict of interest.

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