The psychosomatics of distress: case study insights into lived experience and therapeutic change

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Before beginning psychotherapy, Q went to see his GP complaining about tremors in his upper body that he was feeling increasingly self-conscious about. There was no question of the original cause of the tremors - Q had gone through complications at birth that had left him with permanent nerve damage. However, now in his forties, Q was becoming acutely aware that other people might see these tremors and pass their own judgements on him. In a vicious cycle, he recognised that the more self-conscious he became, the more exaggerated became the tremors. The GP suggested a course of diazepam but Q thought: 'I'm not going down that road' and instead sought out therapy. It was in that context that I began working with Q and during our time together he discovered he was not fated to fall into that vicious cycle, and that he could continue to feel in charge in those situations that had been so uncomfortable for him. Q did not regret his decision to decline diazepam. This article will consider the contentious and often stigmatised position that people find themselves in when physical symptoms appear to be associated with psychosocial distress. Deeply ingrained public misunderstanding about what might be described as the psychosomatic can have powerful influences over a person's relationships and sense of self. I will consider the role that psychotherapy

can play in working with clients who present with bodily symptoms, and introduce my own research, presently underway: a multi-case study of 12 months of clinical practice, concerned with two key questions: what does change look like, and how is change facilitated?

History and terminology

The word psychosomatic - literally a union of psyche and soma - originated in the romantic period of the late eighteenth and early nineteenth century when poets and naturalists alike pushed back against a dominant mechanistic worldview that appeared to reduce human beings to mere biological machines (Schoenberg, 2007). First associated with the work of German physician JCA Heinroth, psychosomatic conditions were those which had an emotional as well as a physical aspect. That idea predates the naming of it however. Heaton (2012) observed throughout the entirety of Shakespeare's plays frequent reference to physical malady associated with the distress of the characters, including ten symptoms of grief such as panting, vomiting, toothache, and hair turning white. In 1688 as the last English Catholic King James II saw his support haemorrhaging in favour of the arriving William of Orange, famously his nose began to bleed heavily, in what

is understood by contemporary historians to have been a psychosomatic event, and he fled to France (Starkey, 2006). In the 20th century and in popular culture psychosomatics are most typically associated with the work of Freud and those who carried his work forward. Freudian thought typically considers psychosomatic symptoms to perform a symbolic role – the body converting intense emotional distress into a physical form in order to protect oneself from experiencing the distress directly. The legacy of the term, though literally meaning the unity of psyche and soma, is that it is considered to mean that physical symptoms are 'all in the mind', with no organic cause for them (Kornelsen et al., 2015).

Because of the potential stigmatising effect of such an idea, the word is not now normally used by health professionals and psychotherapists to describe physical expressions of distress. The preferred contemporary term is medically unexplained symptoms or MUS - meaning symptoms for which an organic explanation is absent or inadequate. The subtext to the use of the term is typically to indicate the presence of emotional or social factors, however the use of the term is as such controversial, with examples of serious organic illnesses being missed following a MUS diagnosis (Wilshire and Ward, 2016). Common MUS include chronic pain; irritable bowels; dermatological conditions such as eczema or alopecia; cardiac expressions such as ectopic or racing heart beats; or neurological events such as numbness, blackouts, or seizures. In studies conducted across the USA, UK, The Netherlands and Denmark, MUS presentations have been found to feature in between 15-40% of all General Practitioner appointments, with even greater frequencies observed in presentations to secondary care (Konnopka et al., 2012; Zonneveld et al., 2013; JCPMH, 2017).

However increasingly it is being recognised that the boundaries between conditions that can be described as medically unexplained and those with an organic aetiology are becoming blurred. Subjective experience of all physical symptoms

may be modulated by psychological factors (e.g. Kirmayer et al., 2004; Wiech et al., 2008; Figuieredo & Griffith, 2016). Creed (2016) observes that in cases of common functional syndromes such as irritable bowel and chronic fatigue syndromes that both organic and psychological causal factors can be discerned. Shoenberg (2007) identifies amongst the many physical symptoms of depression: fatigue, constipation, loss of appetite, and loss of libido. Likewise sufferers of chronic anxiety may experience tremors, diarrhoea, nausea and vomiting, and palpitations (ibid). The position taken in this article is that because psyche and soma are inextricably associated, all physical symptoms are real, regardless of uncertainty about their aetiology. The suggestion that some sufferers of bodily distress may be funnelled into a psychological category has had a profound impact on relationships and sense of self as will now be considered.

The lived experience and social consequences of diagnostic uncertainty

There can be serious social consequences for those of us whose physical conditions lack a tangible and socially accepted diagnosis. Being diagnosed with conditions such as cancer, heart disease, chronic lung disease, or renal failure provide a tangible and socially acceptable label for one's illness. A medically unexplained diagnosis can leave people anxious that a serious condition may be being missed (Gask et al., 2011), and even that they are to blame for their condition (Anderson et al., 2012). People can strongly resent the implication of stress or emotional factors in their physical conditions, in some cases precipitating an ambivalent relationship with physicians, psychiatrists or psychotherapists (Shoenberg, 2007; IAPT, 2014). Those that seek repeated consultations and investigations may be suspected of seeking secondary gains, for example access to disability payments or opioid prescriptions (Wilbers, 2015). GPs and other health professionals can feel demoralised and deskilled when working with people suffering with these conditions (Burton, 2014), and patients in turn may

resort to tactics such as deliberately looking unwell e.g. arriving for the consultation in their dressing gown in order to be taken seriously (as in Neville-Jan, 2003).

Kornelsen et al. (2015) conducted a phenomenological study on the lived experience of 38 Canadians living with MUS. The study found that some of the participants in Kornelsen et al.'s study did believe that a MUS diagnosis was satisfying in comparison to no diagnosis at all, and did at least have some practical functions, for example in being able to fill out disability benefit forms and apply for travel insurance. However almost all of the participants expressed the anxiety that once such a diagnosis had entered their medical records that it would prejudice all future consultations towards psychiatric interpretations and against further medical investigations. The study also found that most participants, despite holding to a belief that their conditions had a biological basis, nonetheless had fleeting moments of self-doubt - when their experience was of being told that their physical problems were all in their head, occasionally they would wonder whether a psychological root cause was possible.

Rossen et al. (2017) performed an ethnographic study accompanying 13 Danish people who had lived with MUS from periods ranging from just a few months to fourteen years. One of the participants had complained of sensory disturbances in a circular region around his leg. His GP had understood that such a presentation did not indicate an organic cause as a circular pattern would not correspond to the nerve pathways, however agreed to refer him to a multiple sclerosis clinic to 'protect the trusting relationship' (ibid, p8). The participant explained that his illness career had affected his marriage - whilst he held to the idea that he had a 'legitimate' disease, his wife had 'lost faith' in his symptoms being caused by a 'real disease'. Another participant, after seeking continual repeat consultations and investigations, was eventually diagnosed with multiple sclerosis (MS). She described this as a turning point: not only was she now 'legitimately ill', but 'she had a right to

be ill', which for her meant that health professionals would now take some responsibility for the management of her condition, and she would now be able to cancel engagements citing physical pain, something she'd not felt able to do before (ibid, p12).

Living with a chronic physical condition can challenge and redefine a person's sense of self, as Patel (2016) demonstrated. Describing her own experience of living with chronic pain, Patel's physical condition soon became central: 'my world and self-concept was all about pain'. Patel goes onto describe successful therapeutic work with a client living with chronic pain. Through the therapy the client's relationship to her pain gradually transformed. She discovered that she could feel independent and strong, and eventually negotiated with her GP a withdrawal from pain medication and anti-depressants. We shall now consider the existent contemporary literature on how psychotherapists have helped clients who suffer with physical conditions.

Psychotherapeutic approaches

Typically in the UK people with persistent medically unexplained symptoms will be referred by their GP for psychological therapies whilst continuing to receive support from other professionals such as physiotherapists, occupational therapists and specialist nurses. Challenging illness beliefs and personal cognitions about symptoms is the aim of cognitive behavioural therapies in this area (Van Dessel et al., 2014). Interventions include targeting vicious cycle effects such as a person responding to a symptom flare-up by excessively reducing their physical activity, thus exacerbating physical problems, or preoccupation with them, further. However people with MUS may also be referred for, and derive benefit from psychodynamic, interpersonal and humanistic therapies. The alleviation of or recovery from medically unexplained symptoms may also involve the production of illness narratives, through which the person is able to make sense of their symptoms (Kirmayer et al., 2004; Deary et al., 2007). People presenting with MUS who are able to narrate

their distress, and appreciate its characteristics and context, feel more confident in terms of self-management of their symptoms than those who continue to be mystified by their condition (Kirmayer et al., 2004). Interestingly the benefits of illness narratives held even where they were incongruent with biomedical explanations (ibid), indicating the importance of clients finding their own subjective truths. There is also in some cases a relational dimension to MUS presentations. In Luyten et al.'s (2012) mentalisation approach to working with MUS, the middle sequence of therapy works explicitly on establishing connections between somatic (physical) and interpersonal experience, thus facilitating the client's increasing capacity to understand their bodily experience in terms of their relationships with others.

The contemporary picture of psychotherapeutic work in this area therefore is that recontextualising physical symptoms can have benefits in terms of clients being less frightened by their symptoms and better able to manage affect in situations associated with symptom flare-ups. Where affect becomes more manageable, subjective perceptions of the intensity of somatic symptoms can diminish (as in Flo and Chalder, 2014; Dura-Ferrandis et al., 2017). However the more effective management of affect can also mean the reduction of objective measures of symptom expression, for example in the frequency of non-epileptic seizures (LaFrance et al., 2014) or of irritable bowel symptoms (Kenwright et al., 2017).

As Johnstone and Watson (2017) observe, there is an alternative to the quest to diagnose and thus medically explain a person's condition. Instead psychological formulation, which they conceptualise as 'a process of ongoing collaborative sense-making', is advocated for mobilising the person's own strengths and resources, and orienting in the direction of recovery and renewal. Luyten et al. (2012) addressed the same issue in designing their mentalisation-based approach to working with somatic disorders. Here the first four therapy sessions involve arriving at a 'common, acceptable illness theory' with the client (ibid).

Case study literature – learning from the last ten years

Tprevious decade has seen a small but nonetheless insightful number of case studies written by psychotherapists from different modalities, working with clients presenting with MUS, with potentially transferable accounts of change. In some cases it was clinically significant for the client to experience having the therapist witness the expression of their physical symptoms in session. Atnas (Atnas & Lippold 2013) witnessed her client Rachel, a woman in her twenties, have two non-epileptic seizures during her CBT therapy. Both Atnas and Rachel, who comments on her own case study, reported these as positive experiences. Rachel experienced a feeling of cold immediately before having a non-epileptic seizure. As a result when Rachel felt cold she associated with the danger of having a seizure and associated fears such as having to go into hospital or even dying. Rachel explored those situations in which she became anxious of having a seizure using what she called a 'hot cross bun chart' with the four corners being spaces for thoughts, behaviour, feelings, and body respectively. This helped Rachel to challenge some of the thoughts and beliefs she'd built up around her body signals, and feel less afraid of having a seizure in certain identified situations.

Likewise Bronstein (2014) witnessed her client Annie, whom she saw between the ages of 8 and 11. have an asthma attack in session. Bronstein was able to provide a psychological context to the symptomatic expression. It had been Annie's birthday and she was showing Bronstein her cards. Despite an apparent show of pleasure in receiving these cards, Bronstein observed that she did not look happy and felt sadness for her. Annie covered her face and Bronstein wondered out loud whether Annie was trying not to cry. Annie replied: 'I am not crying, I am rubbing my eyes'. She began to breathe with difficulty and gasp for air. Bronstein felt 'concerned, impotent, hopeless and very sad'. Bronstein told Annie she understood that she could not feel sad and cry; that instead she felt suffocated by her asthma. This was not taken up directly

by Annie but evidently facilitated a subsequent wondering about whether or not her (biological) mummy had remembered her birthday.

Other case studies demonstrated the importance of historical and traumatic origins of physical symptoms – that in response to a present-day trigger the body was recreating the physical experience of an original trauma. Angelo was living with urinary and faecal incontinence (Dimaggio et al., 2014). During his therapy Angelo recalled childhood humiliation and physical abuse at the hands of his father: the encounters were so frightening that as a boy Angelo felt a pressing need to urinate and anxiety about not getting to the toilet in time. Angelo's present day needs to dash to the toilet were evidently triggered in situations where he experienced being under the scrutiny of others.

Minna - a woman in her thirties who presented with tremors and a history of seizures - began to express symptoms in session, including a tick in the eye, back pain, and numbness or spasms in the arm (Vorne, 2011). Her therapist pointed out that when these symptoms appeared in session Minna had just been speaking about her mother or her father, her deceased sister, men or motherhood; Minna herself had not noticed these associations. At seven years old Minna woke one night and saw her five year old sister Hanna 'convulsing in agony' - Hanna died that night from a cerebral haemorrhage. Through her therapy Minna eventually accepted the possibility that her cramps and convulsions were psychic in nature, recognising the similarity between her own twitches and arching of her back, to those of her sister's as she was dying.

The case study literature also reflects instances where the expressions of physical symptoms appear to be associated with certain relationships and the dynamics of those that the client participates within. In Taylor (2008) Anne complained that after the previous therapy session, she woke to find her pelvic pain much worse and extended throughout her body. Anne recognised a feeling of guilt that from the previous session she had disclosed to her therapist how her mother behaved when she was under the influence of alcohol when Anne was a girl. Reflecting on one

instance of when Anne discovered her mother in an inebriated state, Anne recalled how this had triggered a clamping down of her pelvic floor muscles, such that it was understood that Anne would tense these muscles in times of anxiety as a way of 'holding' herself. As the therapy progressed it became clearer that Anne was locked in a 'traumatic' relationship with her mother.

Sara used the first sessions of her psychotherapy to explore her relationships with three physicians (Liotti, 2017). She was particularly angry with one physician who had 'promised' to provide a diagnosis of Chronic Fatigue Syndrome to support her request for sick leave. In the resultant report, instead Sara discovered the diagnosis had been substituted for anxiety and depression, which left her feeling he had betrayed her. Her therapist enquired as to whether she could think of other situations where she felt a significant person went on to betray her trust in them. Sara recalled a significant memory from childhood. She had woken in the night with intense abdominal pain. Her father had entered her room and believing the pain to be psychological 'ordered' her to stop crying as it would only make the situation worse. When Sara did not stop crying he was verbally abusive to her and returned to his room. Later it was discovered that Sara's symptoms were not psychological in nature but instead were caused by a bladder infection.

What is interesting about the existent case study literature is that even given richly contextualised accounts of a client's unique circumstances and experience, nonetheless patterns identified appear to be transferable across cases. It is also notable that those patterns appear to transfer between cases of different modalities e.g. between cognitive behavioural and psychoanalytic therapies. As a practitioner at the beginning of my PhD study I was motivated to understand better what change looks like and how change is facilitated when working with clients who bring physical symptoms. As I became more familiar with the existent case study literature I was inspired by the idea that patterns of change may be observed across cases, and thus the design of my own research project began to take form.

Introducing my own research

My research project is a multi-case study of my own therapeutic work with people who present with somatic symptoms. My supervisors and I settled on the term 'somatic symptoms' because it recognises physical symptoms as real, and also allows for the possibility of an association with psychosocial distress. I consider my project to belong within the Change Process Research tradition (Elliot, 2010). and in particular research seeking out patterns of change across cases. Because the context of physical symptoms is crucial to understanding their parallels in psychosocial experience, it was apparent early on in the designing of my study that a case study design was most appropriate for the aims of the project. A case study design enables a longitudinal analysis of the therapeutic work e.g. the trajectories of the therapeutic experience over time, and of any changes the client experiences in their lives. Furthermore in attempting to go beyond linear theories of cause and effect in psychotherapy - think billiard balls colliding on the table - and capturing that sense of psychotherapy as a complex intervention, the case study enables us to better represent that complexity and provide more realistic accounts of 'soft' or 'enabling' causality (Elliot, 2002; Bohart et al., 2011).

However there is also an unmissable autoethnographic strand to my research. I participate in the research project not simply as a researcher and a practitioner, but also as a sufferer of chronic pain. During my training in counselling and psychotherapy, I had a vague understanding that my pain was associated with certain social situations and decided to explore this possibility in my MA dissertation research project (Hills et al., 2016). In conducting that project I learned that my present day pain flare-ups were associated more particularly with situations in which I feel out of my depth or that otherwise push at the edge of my window of tolerance. Furthermore I developed tangible associations between my pain and a traumatic double bereavement I experienced when I was 18. As well as noticing flare-ups of pain associated with particular client work, I have noticed the experience of other physical symptoms as I work with different clients - for example muscle contractions in my throat and my chest - and these I'm documenting in my project alongside other subjective events as I work with my clients. My research project is then ultimately an analysis of 12 months of counselling practice in which I, as well as the clients I'm working with, develop, reformulate meanings, experience life events and personal change. The clients who participate in my study are able to comment directly on their experiences of the therapy, and to provide their own accounts of whether they experienced change and what they believed helped change to come about. This culminates in the production of a case report, in which I aim to preserve the client's own language as faithfully as possible, that the client themselves then sees and is invited to comment on, and in this way meanings continue to emerge collaboratively.

What I hope to achieve

In my reviewing of the existent case study literature in this area I have found the client's own voice and appraisals of their therapy to be almost universally unrepresented. Furthermore, whilst therapists have provided theories on what they think has been going on in the therapy work, very few case studies explore the therapists' subjective experiences and transferences. In my own research I intend to address these gaps. In my project's emphasis on change and the conditions that promote change there is a pragmatic contribution I intend to make. As the existent case study literature demonstrates, the patterns of change we observe appear not to be determined by the modality of the therapist. As such I hope to provide practical insights that may be beneficial to fellow practitioners, who may be under-confident in what to do when their clients bring physical symptoms. The promise of this project is in demonstrating that psychotherapeutic work with clients who bring physical symptoms can make progress without having to sign up to any idea about the symptoms having a psychological aspect. Rather, whatever the aetiology of a person's symptoms, we start on the basis of their reality

and can do good therapeutic work in addressing the impact of physical conditions on a person's sense of self and quality of life. From chronic physical discomfort and social alienation, clients can and do make the journey back into life. As a psychotherapist my privilege is to champion the client as they chart the way, and as a researcher to document the steps. §



John Hills is in his second year of PhD study at the University of Leeds, whilst continuing clinical practice in the third sector. John holds an MA in Counselling and Psychotherapy from the University

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