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EDITORIAL INTRODUCTION

Person-Centered Care as the New Professionalism - Raising the Bar from the Lower Denominator of Legally Acceptable Regulatory Competence to the Higher Numerator of Clinical Excellence

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Introduction

In the current issue of the *Journal* we commence the serialisation of two important new textbooks currently in press by Aesculapius Medical Press, the publishing Imprint of the European Society for Person Centered Healthcare. The first, entitled 'Person Centered Care: Advanced Philosophical Perspectives', edited by Michael Loughlin and Andrew Miles, is the subject of an insightful *Editorial* [1] which introduces this groundbreaking new volume, and which raises important points, particularly in terms of the theory-practice, and practice-theory, relationships. Suffice it is to say here, and as Asbridge [1] comments, the new book brings together 42 distinguished scholars, writing over the course of 28 chapters, divided into 6 definitive sections, spanning some 420 pages of text. The reader will be quick to see how, collectively, these individual works represent outstanding contributions to current thinking in the field, advancing new concepts, and ensuring rigorous philosophical analysis and enquiry.

The second volume, entitled '*Umwelt*', authored by John Pheby with extensive medical commentary by Professor Derek Pheby, is an extraordinary work that is autobiographical and phenomenological in its nature, and which results directly from the author's unremitting experience of 'medically unexplained pain' [2]. Physical symptoms that cannot be explained by objective clinical investigation are typically referred to as *medically unexplained symptoms* (MUS). On occasion they present as intermittent minor complaints, but at the other extreme can manifest as persistent and severe, resulting in major functional impairment and chronic disability [3-10].

Formal definitions of MUS vary, but all in general terms attempt to describe an experience by the patient of physical symptoms in the absence of observable pathophysiological processes and identifiable frank disease [5,9,11-14]. Due to the conceptual, diagnostic and prognostic complexities that these conditions pose, it is perhaps unsurprising that there is an ongoing lack of definitional precision. Indeed, some clinicians argue against the use of the categorisation 'medically unexplained symptoms', preferring, with Marks and Hunter [15], the descriptor 'persistent physical symptoms' [15-17].

In the current article, for the sake of simplicity, and acknowledging the dominant extant terminological usage, I will employ the categorisation 'MUS'. I first set out a summary of current clinical thinking on MUS, before introducing the reader to *Umwelt*, Pheby's important new volume.

Medically Unexplained Pain (MUS)

From an epidemiological standpoint, studies which have investigated the incidence and prevalence of MUS clearly demonstrate that medically unexplained symptoms are common phenomena, being observable throughout every facet of modern healthcare systems [18-24]. In terms of their frequency of clinical presentation, MUS have been estimated to account for approximately 45% of all presentations in primary care [24] and up to a possible 50% of presentations in secondary care [19]. Given the sheer volume of throughput that they therefore constitute, it is less than surprising that economic studies have shown MUS to be associated with substantial healthcare expenditure [cf.25]. In England UK, for example, the costs of adult presentations with MUS have been calculated as being in the order of £2.89 billion (in 2008/2009), with work sickness absence and reduced quality of life for people with MUS (at the time of that sampling) generating costs of £14 billion *per annum* to the UK economy [26].

The management of patients with MUS continues to be normatively undertaken within the primary care setting, where general practitioners exercise the responsibility for the investigation, diagnosis, treatment, referral, and follow-up, of affected individuals [27]. The well-established biopsychosocial (BPS) approach is typically employed in assisting patients to cope with their symptoms and in the hope of some form of resolution and eventual recovery, though controversy continues [28,29]. Clinical recourse to the BPS model does not axiomatically indicate that MUS is a form of mental ill health. On the contrary; take, for example, the observation that depression, co-morbid with generalised anxiety disorder (GAD), occurs in only approximately 33% of patients [30] and that cognitive behavioural therapy (CBT) appears to have little effect on a range of outcome measures in MUS [31]. Nevertheless, it appears clear that the challenge of managing people with MUS requires a multidisciplinary approach, not just a simple primary care-based model, which by its nature thus brings together a wide range of clinicians from primary care, medicine, nursing, psychology/psychotherapy, psychiatry, occupational therapy, and physiotherapy, and which integrates physical and mental healthcare services [30]. This overt multidisciplinarity is, as we shall see below, the essence of person-centered health and social care [cf.32-36].

How do we approach the management of MUS from a person-centered perspective/model?

Are we able to say, from a person-centered perspective, that MUS is not a clinical diagnosis *per se*, but rather an ‘analytical concept’ which acts to unify a diverse group of health problems where no joint cause or biomarker have yet to be identified? After all, a diagnosis is not a fixed entity; rather, it might be considered the ‘product of the scientific, social, economic, and cultural milieu in which both the doctor and patient exist’, being in this sense a ‘shared creation’ that in the real world of clinical practice develops within a context of complex relationships, with ‘continual opportunities for refinement and improvement’ [37].

Malterud and Aamladn [38] dispute the idea that in the context of MUS objective findings are essential to confirm subjective symptoms as disease, and that it is the biomedical model that has insisted on a body-mind duality, where illness is classified, in default mode, as psychological in nature when the search for objective findings yields nothing that is immediately empirically noteworthy [38]. These authors are correct to posit that somatisation is likely to support linear and monocausal explanations, where psychological issues and mental ill health are viewed as the principal drivers of MUS. Of course, and as Malterud and Aamladn [38] concede, in some cases this may well constitute an authentic causal explanation, but experience teaches us that patients typically resist the proposition that their symptoms are emotional in nature, preferring a continued focus on more organic explanations [38,39].

Malterud and Aamland [38] make a salient point when they note that primary care physicians sometimes - or even perhaps often [7] - interpret the ‘U’ in MUS (unexplained) as, instead, *unexplainable*. This is, surely, a position which nods in the direction of a therapeutic nihilism. Where and when identified, it calls for more developed understandings which recognise that MUS in primary care is hardly an exotic rarity, but rather a major challenge to the wisdom and expertise of clinicians, and not only in primary care but in secondary care settings also [7,27].

Returning to the idea, advanced by some, that MUS is indeed a form of ‘exoticism’ in clinical practice, a conundrum, an unwelcome and time-consuming and therefore expensive challenge for many, it is simply not supportable to argue that we have few ways to assist the patients who present with these debilitating and often existentially charged conditions. Consider, for example, the work of Olde Hartman and his colleagues [40], which has relatively recently synthesised, through the use of established modern methodologies, an impressive volume of evidence on the biological basis of MUS, the differing biomarkers of interest in investigation and management, the psychosocial and cultural aspects of MUS, the phenomenology of MUS, potential clinical strategies for rehabilitation in MUS patients, the extent of MUS burden on health and social care services, the economic perspectives and impacts of MUS, and the usefulness of clinical practice guidelines for MUS [40].

We need far more research of the type conducted by Olde Hartman *et al.* [40] if we are to accelerate the development of more person-centered understandings and models of care for the management of MUS. It is surely distressing to observe that patients who are delivered a diagnosis of MUS report that when a biological dysfunction or frank pathology cannot be identified in an explication of their condition, they cease to be seen as a subject of interest, but are then categorised as *difficult patients* who are demanding, psychologically unsound, or even *generally suspect* [41-44]. It is hardly surprising, therefore, to learn that many patients with MUS describe being ‘haunted’ by their medical records, anticipating that the contents of these documents are likely, when consulting new clinicians, to result in immediate prejudices against them, so that such records can feel, as Stone [43] vividly describes, like a ‘criminal record’. Clearly, all this must change - and change urgently.

Umwelt

In *Umwelt* [2], John Pheby, has constructed one of the most comprehensively autobiographical, indeed dramatically phenomenological accounts, of what it is like to labour under, and suffer with, medically explained pain during the entirety of an adult life. Structurally, the volume consists of forty individual chapters by the author, each accompanied by a separate medical commentary by Professor Derek Pheby, constituting, *in toto*, an eighty articles work. The volume is of unquestionable importance and is a very considerable *Opus*. The author describes not only how he has coped - or *not* coped - with the physical trauma of MUS, but how he has also struggled to manage the accompanying psychological and spiritual/existential distress. The book is, from a clinical, and also very human perspective, deeply engaging in its nature. To gain some insight into the sheer breadth of the work, and to provide a rapidly accessible overview of the book's overall direction, its Table of Contents is illustrated in the Appendix.

The 'poetry', as it were, that forms the connecting thread of the volume, becomes clear from the very beginning of the text:

> "I found myself having to meditate on the thorough pointlessness of the chronic pain episode that has become me. Such episodes are entirely separate from any notion of 'useful pain': the child's lesson in not playing with kettles of boiling water, or not texting while crossing the road, or not branding oneself on a still hot hob. I found myself not learning anything at all from a prolonged pain that only hindered living, one so medicated with such ever increasing doses of strong analgesics that a vicious circle became inevitable. Setting out upon a useful day had become increasingly impossible. It is difficult to even distract from such chronic pain, and equally difficult to conceive of any advances in medicine or understanding of related consciousness issues that have made any useful difference. There are times that I would have welcomed the presence of a drummer, in the corner of the pain-filled chamber, engaged in a bludgeoning effort of distraction. A discussion on the matter of pain is the most necessarily subjective subject that we could ever address, where ourselves and our languages meet very real but entirely ill-defined limits. We all have an innate sense of what the meaning involved might be, but we cannot ever precisely elaborate or explain. We cannot define ourselves, when we think about pain. The confusion between physicality and motivation, and a certain ineffable but impossible reality, breaks our language down. And ultimately, all we are left with, untouchable and unknowable, is unmistakable pain".

And consider this section of equally illustrative text from the *concluding* chapter:

> "My body corrupts. I feel this much, at least, though statements regarding this are fairly meaningless in the consulting room. I receive huge numbers of *pain*killers for the *corruption*, but little else. My body is serrated and carved into faulty pieces, each overseen by different microspecialists who do not speak to each other. My consciousness, whatever it is, cannot connect or *re*connect, through the fetid air between my loose limbs. Pain, a black hole, sucks everything in. The event horizon is the enforced state of becoming meaningless. I am no longer allowed to be *whole*.
>
> Every appointment has been shot through with fearful words from the experts: '*We'll call it cancer.*' '*Off the scale.*' '*You must ask someone else.*' '*Not my area, I'm afraid*.' '*Interesting.*' '*Oh my God.*'
>
> I only ever walk out with new scripts, new pills, and chemically-adulterated pain (but pain, nonetheless).
>
> For the last four years, I have been placed on a strict diet of approximately twenty potent pills a day - mostly painkillers of one kind or another. I keep swallowing the killing. At this point, I am undoubtedly an addict. I cannot imagine life without these pills. For me - given the severity of my conditions - the medication is free. But umpteen thousands of pounds have so far been spent, on behalf of the public, on my medicine.
>
> Referrals made by my General Practitioner come to nothing. The microspecialists are her superiors. *They* make the decisions, including decisions to do nothing.
>
> My original General Practitioner told me to leave his practice, seconds after he confirmed my cancer diagnosis. Too much trouble is too much trouble. A few months later, my young daughter reported how she had met him in the park. He had expressed his surprise that I was still alive. He *joked* about my being alive.
>
> Another painkiller. And another. Another.
>
> My head knows no peace, though. I consulted with a neurologist, of course, as previously reported. In pain, as I am, this still preoccupies me. He sent me for a lumbar puncture. He strongly suspected that I had a *high* spinal fluid pressure. But the technician who carried out the test theatrically mopped his brow when he told me that the reading was considerably and '*worryingly*' *below* the accepted range. Something, he said, would have to be *done*. The result, he told me, was clearly indicative of *Cerebral Spinal Fluid Leak*, a condition that would explain most, if not all, of my symptoms.
>
> The neurologist was most put out that the result was the absolute opposite of what he had suspected. He lost the incriminating paperwork and permanently suspended my treatment. I have had *no* neurologist, and no further investigation. Just thousands of pills. And ever worsening pain.
>
> I have continued to black out. I have continued to scream in pain. I have continued to tip tubs of opioids into my battered, shattered being. The neurologist has continued to refuse to see me, the sole reason for his refusal being that the diagnosis (of cerebral spinal fluid leak) refuted his prior supposition. I knew, though, that eventually my ever worsening and unmonitored state could not possibly end well.
>
> Eventually, I had a stroke. For days I could not move. I was quickly taken to a hospital in another county where there were the necessary brain surgery facilities, just in case. And though surgery was not ultimately required, the trauma, in every sense, was significant".

Although I quote above only two brief sections of text from the opening and closing chapters of *Umwelt*, and notwithstanding the fact that there is a hugely detailed and enormously important volume of narrative in between them, the extracts powerfully demonstrate how the volume represents one of the most clinically instructive and deeply personal accounts of what it is like to suffer from medically unexplained pain, and what forms the encounters with healthcare professionals will take.

Overall, the author judges his clinical encounters to be on the whole deeply unsatisfactory, meaning that many lessons are to be learned by physicians and others from what John Pheby himself, as a patient, has been forced to experience at their hands. The current volume can only greatly assist clinical colleagues in addressing their limitations and misunderstandings in dealing with patients who suffer with MUS.

The individual medical commentaries, which accompany each chapter in the book, are not simply immensely insightful; indeed, they are more than that. They are *wise* - demonstrating that precious gift and ability which we easily recognise as *phronesis*, the wisdom that can in the main only be perfected and exercised after considerable clinical experience. If John Pheby's final chapter is staggering in its nature, then Professor Derek Pheby's final commentary is magisterial in its summation, so much so that I have no hesitation whatsoever in presenting it here *in toto*, in advance of its formal publication in the *Journal* later this year, for the earlier benefit of the reader:

> "The author begins with his own experience of being shared out between numerous microspecialists, and of receiving nothing except massive doses of analgesics. The consequence for him, as he sees it, is of entering a state of utter meaninglessness. The growth of microspecialism is a consequence of the expansion of medical knowledge. No longer can most doctors comprehend the entire canon of medical science. Instead, many know more and more about less and less, and lack a common language with which to communicate with colleagues. The holistic approach, which is clearly necessary, is very much a thing of the past, and patients with complex multi-system disorders are seriously let down by the medical profession and the healthcare system. The doctor-patient relationship, which should be so important in pain management, is, paradoxically, undermined by the fact of chronic pain. The doctor is unable to experience the patient's pain directly, and, given the inadequacy of language in expressing the nature of pain, this makes empathy difficult and seriously impedes holistic care.
>
> He writes of the fear he experiences as a result of the words specialists use in relation to his condition. Such a response from experts is the very negation of empathy. Medical language, by raising barriers to communication, does not help, and the modern epidemic of self-harm may be a manifestation of desperation, as sufferers endeavour to get an empathetic response from those responsible for their medical care. A scholarly article by Riess underlines the critical role of empathy, but also reports that empathy declines during medical training. Patients who do not experience empathetic responses from their physicians exhibit lower levels of compliance with treatment. Patients who do not experience empathy often attribute this to discrimination on ethnic, religious or cultural grounds, or to physical differences. She quotes Maya Angelou: "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." While innate empathy appears hard-wired in the human brain, it can nevertheless be taught and learned, and this should be taken into account in designing undergraduate medical curricula and postgraduate training [40-i].
>
> A theme that has pervaded this work throughout is that of inadequacy of language, so that not only may the specialist's words be fearful to the patient, but the patient also may have extreme difficulty in explaining to the specialist what the reality of the pain experience is actually like. Wittgenstein expressed the view that interpretation of language depends on the context within which the message is received [40-ii]. However, the contexts for the patient and for the doctor are quite different, leading to mutual exclusion and incomprehensibility. Despite this, if pain is to be managed effectively, the attempt must be made to find a way to make an objective assessment of the subjective symptom of pain which is meaningful to the physician and at the same time acceptable to the patient.
>
> The author reports swallowing some twenty pills per day prescribed by doctors, and expresses concern at the costs to public funds, to little clinical benefit. His experience of polypharmacy is by no means unique. It has become widespread throughout the Western world [40-iii], and may lead to adverse outcomes, including those associated with drug interactions [40-iv,40-v]. He reports:
>
> "Referrals made by my General Practitioner come to nothing. The microspecialists are her superiors. They make the decisions, including decisions to do nothing. … My original General Practitioner told me to leave his practice, seconds after he confirmed my cancer diagnosis."
>
> In many ways, GPs are in an invidious position, and may feel themselves to be powerless in the face of patients, and also with respect to specialist colleagues. Feelings of powerlessness vis-à-vis patients, whether due to lack of knowledge of the patient [40-vi], insufficient time [40-vii], or the complexity of the patient's needs [40-viii], including clinical complexity [40-ix], may lead GPs to underestimate the severity of symptoms [40-x]. This matters, because, as the author knows from his own experience, it is precisely in such circumstances that empathy is most important in enhancing the capacity for recovery [40-xi].
>
> GP attitudes are by no means the only barriers to care. Other factors contributing to patient vulnerability include socioeconomic position, education, ethnicity and gender, and the patient's symptoms themselves. Chronic pain in itself imposes vulnerability [40-xii], and the end result may be inadequate pain relief [40-xiii] and erosion of the individual's sense of self-worth [40-xiv]. A review of patient-related barriers to cancer pain management found that the quality of pain communication was consistently unsatisfactory [40-xv].
>
> One adverse experience which the author narrates concerns a neurologist who, having received from the technician a report of a lumbar puncture, with exactly the opposite outcome of what was expected, disposed of the report and removed him from his clinic. This is a good example of the way in which the doctor-patient relationship has deteriorated through, as McWhinney pointed out in 1981 [40-xvi], the fragmentation of the medical profession through specialisation, and the growth of microspecialisation, which, it has been argued, is dialectically opposed to holistic care [40-xvii].
>
> The author's conclusion that profligate prescribing of analgesics and holistic care are in opposition to each other is supported by professional opinion. Thus, the

American Association of Nurse Anaesthetists [40-xviii] emphasises the importance of a range of pain management modalities, in order to reduce dependence on opioids, and this is reiterated by the US National Pain Strategy, again with the objective of reducing opioid dependence [40-xix]. Polypharmacy is indeed easy, but carries serious risks, so there have been moves to develop alternative, non-pharmacological interventions in various conditions such as inflammatory bowel disease [40-xx] and arthritis [40-xxi]. All pain is extraordinary, and all pain is subjective. Pain perception has been linked to particular anatomical structures within the brain, including the sensory cortex, the bilateral anterior insulae and the mid-insula [40-xxii]. Much modern human response to pain is unhelpful, when it consists of prescribing ever larger doses of opiates. Uncontrolled use of opioid analgesics is associated with development of deviant behaviour and serious mental health problems [40-xxiii].

What the author is witnessing now, with what he describes as spinal problems, years of chronic pain, malignant stomach tumours, and very unpleasant neurological and gastrointestinal symptoms, is a reawakening of a pattern of symptomatology that he previously experienced at the age of nine. At that time, so-called medical experts attributed his symptoms to psychiatric illness, due to alleged family dysfunction. The family was perceived as inadequate and therefore vulnerable, and the patient himself was subject to serious abuse, as the parents were perceived to be incapable of protecting him. This perception was incorrect, the family blew whistles, and a twenty-five year battle ensued, at great cost to the careers, quality of life and finances of the whole family. Their battle was ultimately successful, and in the meantime medical science has moved on. The underlying pathology is now understood, and the entire pathological chain of causation has been established. The problem is a complex, multi-system disorder. The opinions expressed by the parents many years ago have been vindicated, and the errors perpetrated by those professionals who treated the family with such contempt so many years ago nailed. Meanwhile, the NHS still fails to address the problem, but for different reasons from those evinced a quarter of a century before. Then, the problem was a lack of medical knowledge, compounded by arrogance and ignorance on the parts of some self-styled experts, and errors and misconceptions in medical records being treated as gospel by others without the knowledge to appraise them critically. Now, as stated above, the problem derives from too much medical knowledge, which has led to the growth of microspecialism and the concurrent decline of holistic care.

The compiler of these commentaries drew attention to the problems for medical care, due to misconceptions in medical records, more than thirty years ago [40-xxiv, 40-xxv], and yet the problem remains real and current. Patients are entitled to presume that any medical referral is made with their best interests in mind, and transmitted information should not prejudice those interests. The dangers of transmission of this type of information were spelled out clearly, again more than thirty years ago, by the Committee on Data Protection, whose report (the Lindop report) expressed great concern about records of all types containing data which it described as 'judgemental' [40-xxvi]. This is particularly the case in psychiatry, since in this specialty diagnoses still contain a substantial judgmental element, rather than being objective conclusions from scientific facts, and are thus hypotheses which lack falsifiability. As Karl Popper demonstrated [40-xxvii], the main distinguishing characteristic of a scientific hypothesis is that it is falsifiable. The application of psychiatric labels is particularly likely where underlying pathological processes remain obscure, or outside the knowledge or comprehension of medical professionals. Use of such unscientific labels leads to behaviour being attributed to deviance without proper regard to situational factors, including the concurrence of physical disease. This is termed ‘fundamental attribution error' [40-xxviii].

The fairly widespread view reported by the author, that free will may be nothing but an automated deception, is linked to the ‘zombie’ theory that postulates that there is no such thing as consciousness at all. Anyone who has experienced suffering through chronic pain would reject this theory, as would anyone who has experienced post-traumatic growth. Indeed, the ‘zombie’ theory presupposes that the human brain could exist and function normally but without human consciousness [40-xxix], as the central element of an organism that lacks any form of self-awareness or either experiential and phenomenal consciousness [40-xxx].

The question of ownership of physical symptoms is closely related to that of body-ownership, which in turn is intimately concerned with the sense of agency, or the experience of one’s actions contributing to environmental change [40-xxxi]. This feeling is fundamental to human self-perception [40-xxxii]. The sense of agency is central to human self-consciousness and hence body ownership, and refers to the experience of oneself as the agent of one's own actions [40-xxxiii]. It has been argued that there is a neurological basis for the relationship between agency and body-ownership, and whereas afferent signals provide the distinctive content of one's own body experience, efferent signals seem to structure the experience of one's own body in an integrative and coherent way [40-xxxiv]. The mechanistic approach to pain is opposed to one which sees all lived experience, including experience of chronic pain, as contributing to understanding of oneself. The study of self-understanding is at a very early stage, but it appears that it has a neuroanatomical basis, involving the prefrontal cortex and its links with the rest of the brain [40-xxxv], including the thalamus and brainstem [40-xxxvi].

The question of how those who do not suffer from chronic pain could and should attempt to dialogue with those who do is central to the matter of doctor-patient relationships. How pain is consciously perceived by those who experience is a difficult concept to impart to those who have not experienced it, but the study of the conscious perception of pain is at the heart of the study of self-understanding which is still at a very early stage. It requires a multi-disciplinary approach, involving among other disciplines phenomenology, cognitive science, neuroscience and evolutionary biology [40-xxxvii]. What can be said about self-understanding is that it appears to be something that increases with age, and is related to perception, involving two separate modes of consciousness, one sensory-based and the other memory-based [40-xxxviii].

The argument that pain cannot be labelled as pain unless it can be consciously perceived as such is a circular one, because it is implicit in the whole concept and definition of pain that it is a perceived phenomenon. It is a sad reflection on the semantic muddle of much modern scholarship that it is even necessary to spell out such an obvious truth. The reality is that chronic pain does not have the protective benefits of acute pain. It appears to have no purpose, and is thus essentially meaningless. Inability to live with its meaninglessness may lead to psychopathology [40-xxxix], alienation, low self-esteem [40-xl] and social exclusion [40-xli]. The diagnostic process can help to overcome meaninglessness [40-xlii], though this may be flawed when diagnostic hypotheses fail to fulfil the criteria of scientific hypotheses.

An American report on the use of complementary and integrative medicine has addressed the problem of the epidemic of drug use related deaths, the majority of which involved opiates. It proposed a multimodality approach to chronic pain relief, which would avoid the adverse effects and complications of analgesic treatment [40-xliii]. In the UK, though, the approach has been much more about the organisation of chronic pain management services, through the establishment of local pain management centres, rather than about the content of care provision [40-xliv].

Chronic pain sufferers, like others seen as somehow failing to conform to societal views of physical perfection, may experience discrimination and abuse, and even more commonly complete misunderstanding of their problem, such that there are those who feel they simply have to pull themselves together and, if they are employed, to get back to work. Pain sufferers may be seen as inadequate, and victim-blaming is not uncommon, sufferers being held somehow to be responsible for their own suffering. Similar phenomena have been other in other chronic conditions, for example in ME/CFS, in which a systematic review focusing on support needs identified the importance for patients of making sense of symptoms and obtaining a diagnosis, in order to obtain respect, empathy, positive attitudes and support, and to overcome social isolation [40-xlv]. A study of ME/CFS patients themselves identified a need for personalised, timely and sustained support to alleviate the impacts of ME/CFS, in terms of symptoms, functional limitations, and social consequences including financial ones [40-xlvi]. However, many health professionals felt uncertainty in diagnosing ME/CFS, and indeed many deny its existence, so cannot readily empathise with patients, over either the condition itself or its consequences for life and living [40-xlvii].

It is lack of empathy within the public service as a whole that has led to a benefits system that starts from the premise that all people on benefits are work-shy, and an assessment process, the Work Capability Assessment, that is an entirely mechanistic, tick-box exercise where eligibility is dependent on the accumulation of points. It is imposed by the government on people unable to work because of illness and thus in receipt of benefits, and fails to take account, either of the severity of the patient's symptoms, including invisible symptoms such as pain, or of resultant incapacity, or of any underlying pathology. A review conducted for the Department of Work and Pensions reported that "... emphasising the points scale gives a false impression of scientific validity and appears to drive unhelpful behaviours" [40-xlviii]. The pain of chronic pain sufferers is invisible and may therefore be dismissed as 'psychosomatic'. The reality of pain, and the impossibility of conveying its nature to a third party, is a major problem for benefit claimants. The author writes:

> "Sufferers are … dismissed into the near-extinction of 'desirable employment' (such rarely being employment that the sufferer is desirous or capable of)."

Such errors point to a lack of effective dialogue between patients and doctors, and to a lack of internal quality control within the profession. This threatens professional autonomy, the loss of which, among other hazards, makes the profession vulnerable to the impact of technological change and cost pressures [40-xlix]. Professional autonomy requires physicians to be free to exercise medical judgment, but this does not mean that such judgments are always correct, though patients can demand treatments that the doctor knows to be futile [40-l]. The doctor/patient relationship is unequal because of the patient's vulnerability, and doctors and patients will not always agree on moral issues [40-li]. Patients should be able to exercise autonomy and choice in such matters [40-lii], and the onus is on the doctor to enable the patient to exercise informed consent in a healing relationship [40-liii]. This may be difficult for the physician endeavouring to advise the patient using an evidence-based approach, particularly in complex syndromes such as repetitive strain injury, chronic low back pain and chronic fatigue syndrome, where the research evidence base is itself deficient [40-liv], and the doctor will need to be guided by the core principles of medical ethics. i.e. respect for autonomy; beneficence; non-maleficence; and justice [40-lv]. Bioethics are particularly important in an age of rapid technological and therapeutic advance, especially in the light of recent cases of research fraud [40-lvi]. These four principles, together with the duty of medical beneficence, lead to obligations to respect informed decisions, to maintain competence, to expose incompetence, and to admit errors. The patient's interests must always take priority, but sometimes medical paternalism may be morally justified, e.g. in young children or severely mentally handicapped persons. This comes back once again to the theme of dialogue, which is clearly needed to decide the criteria for determining competence and responsibility for proxy decisions for incompetent patients [40-lvii].

The growth of health technology is an important factor which has limited the autonomy of doctors, placed them under a degree of coercion, and eroded the moral and ethical consensus [40-lviv]. Doctors end up practising defensively, as underlined, for example, by the issue of removal of life support, which underlines the extent to which medical behaviour is motivated by the desire to be protected legally and to avoid prosecution [40-lviii]. Increasing external pressure in the USA, Canada, and the UK is undermining self-regulation and leading to shared regulation between the profession and other stakeholders [40-lix], while the current Australian *Good Medical Practice* code of conduct undermines self-regulation and hence patient protection [40-lx]. Patient autonomy is both ethically appropriate, and a necessary reaction against the medical profession's insistence that it always knows best [40-lxi], though there are disadvantages as well. The growth of patient autonomy and the right to exercise treatment choices means that sometimes doctors may take actions contrary to their own values [40-lxii]. For example, increased patient autonomy and demands have led to an increase in use of radiology services. This change has reduced complaints and litigation, but by reducing paternalism has legitimised and increased unjustifiable actions, adverse side effects, and abuse [40-lxiii].

Organisational change is an important factor limiting medical autonomy, in for example the USA, where its effect has been exacerbated by the growth of and monitoring using IT [40-lxiv]. The medical profession has lost its monopoly of medical knowledge and much of its authority over patients, has failed to establish effective self-regulation, and is vulnerable to changes in healthcare delivery [40-xlv]. The erosion of medical professionalism and autonomy has left the profession with reduced capacity to select and train its own entrants, and the medical knowledge base and professional standards have deteriorated [40-lxvi]. A recent New Zealand judicial inquiry into inadequate treatment of cervical cancer raised questions of professional autonomy (which can lead to misuse of power), patient autonomy, the need for patient advocacy, limits to human moral authority, and questions of agape, incarnation and redemption [40-lxvii].

To sum up, political, technological, and socioeconomic forces in the 20th century have combined to bring medicine under managerial control and undermined the social contract between doctors and the community [40-lxviii]. The growth of health maintenance organisations in the USA has caused the emphasis to move from individual to organisational professionalism, with benefits both for patients and for the organisation [40-lxix]. Over the next fifty years, technological and cultural changes will affect medical practice. This, and acceptance of evidence-based medicine, may well end the role of the physician as an autonomous professional [40-lxx].

Patients who exercise autonomy by challenging medical decisions may wish thereby to achieve a better life, though their choices may at times be irrational. Doctors could help patients to make rational choices [40-lxxi], particularly where there is feedback from patients to clinicians regarding their understanding of treatment options. This benefits both parties, and helps to increase patient's knowledge and reduce patient’s fears [40-lxxii]. However, while internal and external controls are essential to maintain quality of practice, excessive controls may adversely affect quality of care [40-lxxiii].

The author cites examples of pain sufferers finding that the experience of chronic pain added deeper meaning to their lives, and of doctors failing to appreciate this. The failure of doctors either to reach a diagnosis or to empathise with the chronic pain sufferer can only exacerbate, for those pain sufferers who do not find deeper meaning through pain, the existential crisis of meaninglessness. The increasingly popular mechanical approach to pain runs counter to an approach which sees all lived experience, including experience of chronic pain, as contributing to understanding of oneself, states the author. This latter approach, when carried to extremes, may even lead to self-mutilation as contributing to understanding of oneself.

The author asserts that medical conditions without specific physical signs are unlikely to be treated at all, and that this is the position that many chronic pain sufferers find themselves in. Such patients may, all too frequently, attract inappropriate psychiatric labels. Clearly, the reality of pain, and the impossibility of conveying to a third party the nature of that reality, is a major problem. He expresses the view that medicine has replaced the Church as the ultimate source of authority in modern Society. Where scepticism reigns, this authority creates problems for patients, since their relationship with doctors is one of structured inequality. This is all too often the case in chronic pain, and creates a major problem of credibility for patients, the consequences of which may include diagnostic error, and inappropriate and inadequate care. This is true in other conditions too. For example, there is evidence that the severity of post-traumatic headache is frequently disregarded by doctors [40-x], even following traumatic brain injury which can in itself have life-changing consequences, as well as, following repeated head trauma, leading to neurodegenerative diseases, including Alzheimer’s disease [40-lxxiv]. The author writes authoritatively here, through his own experience of a totally unsympathetic GP who, not empathising at all, failed to recognise his severe pain and produced instead a completely capricious and spurious diagnosis, with serious adverse impacts on his ongoing medical care.

The healing approach to chronic pain and the spiritual crises that frequently accompany it is essentially holistic, based on professional expertise, prayer and meditation [40-lxxv], and there is recognition that the spiritual dimension of holistic nursing care is central to patient assessment and meeting patients’ needs [40-lxxvi]. A theology of healing must take into account God’s love for all [40-lxxvii]. Both Hinduism and the Judeo-Christian tradition see humans as primarily religious and spiritual beings, and this is an essential element in holistic health [40-lxxviii]. The Christian concept of the nursing profession’s ministry of healing has essentially a holistic view of needs, physical and spiritual, of people, and should provide hope [40-lxxix]. Spiritual beliefs give meaning to disability for people with disabilities and family members. They may choose to live thankfully and joyfully despite the problems of disability [40-lxxx]. Some patients with pain and disability may with faith turn to God in distress, while others may reject God entirely [40-lxxxi]. Spiritual pain is widespread but difficult to define [40-lxxxii], and the spiritual dimension is an important aspect of pain in HIV or cancer patients, though it is often neglected [40-lxxxiii]. Pastoral care ministers need to understand the nature of suffering and the concomitant feelings of fear, stress, guilt, and emotional distress, to appreciate the patient as a complete, unique, and spiritual being [40-lxxxiv], and to appreciate the close causal relationship between spiritual pain and mental, as brought into focus, for example, as suggested above, by self-mutilation [40-lxxxv]. The chaplain has a crucial role in attending to this spiritual dimension, including the understanding of pain and its religious meanings [40-lxxxvi]. Despite the various rites and liturgies available to them [40-lxxxvii], befriending is often all they can do for patients, though they also have a pastoral role for the staff [40-lxxxviii].

Though Medicine may have replaced the Church as the ultimate source of authority in modern Society, pain cannot be seen as heretical. Medieval mystics, without the possibilities for adequate pain control that modern medicine should provide, endeavoured to see it in a positive light by treating it as a gift from God, and an opportunity to grow in divine grace. The question raised by the author in asking:

> “Was pain divine? Or was it heresy? Is pain worth proper medical investigation and intervention? Or is it creative and malingering?”

.. is in effect asking whether pain is legitimate or not. It is difficult to provide a justification for medical investigation and intervention in respect of pain that is illusory and thus not legitimate. The problem here is that legitimacy is conferred by those other than the patient, and its complement, stigmatisation, again reflects the views and behaviour of others, of third parties other than the patient. Chronic pain sufferers may experience stigmatisation [40-lxxxix], the roots of which may be found in two 19th and 20th century intellectual movements, mechanical objectivity and somaticism [40-xc]. However, other people suffering from chronic illnesses may also experience it, such as patients with familial amyloid polyneuropathy (FAP) [40-xci], type 1 diabetes [40-xcii], vitiligo [40-xciii], those with particular physical traits or perceived character blemishes [40-xciv] or with disabilities of all types, leading to practical difficulties such as lack of accommodation [40-xcv].

Mental illness is particularly stigmatising, is associated with poor life expectancy and physical health outcomes [40-xcvi] and may in young people be a barrier to accessing mental health services [40-xcvii]. Stigmatisation due to physical disabilities may lead to depressive illnesses, and self-stigmatisation is also a problem in mental illness [40-xcviii]. The suggestion that identity destruction, discriminatory behaviour, and non-disclosure of treatable conditions in mental illness may be attributable to stigmatisation may be simplistic [40-xcix], but there is no doubt that stigma due to race, age and sex is a growing problem that impedes the treatment of patients. Interventions to combat are possible at the cognitive, affective, discrimination, denial, economic, and evolutionary levels, and may be educational, psychological, legislative, linguistic, political, intellectual or cultural in nature [40-c]. Nurses and other health professionals have an important role to play in this [40-ci], in line with the seminal work of Irving Goffman on stigma, emphasising the importance of the individual, rather than grand theories about social systems [40-cii].

The other side of the coin of stigmatisation is legitimation. Whatever reduces the stigma attached to a disease increases the chance of it being regarded as legitimate. High on the list of stigma reducing activities is the diagnostic process, particularly when it leads to a positive diagnosis. In chronic back pain, diagnostic tests to identify the cause of the pain are important to patients in legitimising their conditions [40-ciii]. So also is the initiation of effective treatment, so that, for example, the diagnosis of fibromyalgia, initially greeted with relief, proves less welcome when treatment is ineffective, does little to legitimise the condition [40-civ]. Four legitimation principles, autonomy, density, specialization, and temporality, have been identified, and applied for example to academic nursing in Ireland [40-cv]. Some conditions, such as addiction, can only be treated effectively if a legitimising, non-stigmatising approach is adopted [40-cvi]. Legitimation of lifestyles that minimise the risks of cancer and obesity can also lead to positive benefits [40-cvii]. All in all, it can be important, together with acknowledgment, exploration and empathy, in overcoming barriers to the doctor-patient relationship and avoiding conflict [40-cviii].

The author writes of the chronic pain sufferer having to “suffer the ire of the male medical establishment”. Medical scepticism is widespread, particularly in respect of diseases like ME/CFS with no specific symptoms or physical signs. This problem applies also to many chronic pain sufferers, since pain is also invisible and likely therefore to be dismissed all too frequently as ‘psychosomatic’ by doctors who fail to listen to the patient’s narrative and deny him or her credibility. As previously pointed out, the difficulty of conveying to a third party the nature of the reality of pain is a major problem, and this in itself compounds the problem of credibility. Such lack of empathy, which the author himself has experienced, creates a major barrier between the patient and the doctor, when what is needed to enhance recovery is an empathetic approach to encourage on the part of the patient empowerment, self-awareness, motivation, and facilitation [40-cix].

The author points out that, not only is language an inadequate mechanism to convey to the doctor the true nature of the chronic pain experience, but also limits the patient’s own comprehension of his or her pain condition. It is as if patient and doctor are inhabiting different planets. As Tomasi pointed out: “The problem posed by the difference between happy and unhappy worlds – their mutual exclusion and incomprehensibility – reappears as the problem of relating the experience of art to the rest of our experience. There is no identity between the happy and unhappy worlds …” [40-cx]. The author writes “Frozen in pain, it may be that nothing works but language.” However, as a means of communication, language is all that we have, and there is a need to make an objective assessment of the subjective symptom of pain, despite the inadequacy of the means at our disposal, hence the development of template-based approaches such as that of WILDA [40-cxi].

Health professionals should be aware that pain perception is culturally determined, so effective pain management requires sensitivity to cultural differences [40-cxii], and a patient-centred, culturally appropriate approach [40-cxiii] which appreciates the importance of patients’ pain-related beliefs [40-cxiv]. What the author refers to as the ‘Western Tradition’ leaves many chronic pain sufferers to cope with their symptoms entirely on their own. Western Society leaves many people isolated, with physiological consequences including for example increased and prolonged heat pain sensitivity and increased sympathetic tone, activation of the hypothalamic-pituitary axis, decreased inflammatory control, and gene expression regulating glucocorticoid responses [40-cxv]. Isolation is associated with increased morbidity and mortality [40-cxvi].

This underlines again the importance of cultural factors in the management of pain, to which healthcare professionals should be sensitive [40-cxvii, 40-cxviii]. Other societies may manifest different reactions to chronic pain [40-cxix] as may different age groups [40-cxx], and the sexes [40-cxxi]. The impact of such differences may be considerable, so it is important to take ethnic differences into account in pain research [40-cxxii], and to appreciate the importance of cultural considerations in medical philosophy, education, and practice [40-cxxiii]. However, the culture of modern, Western, business-orientated Society remains largely one in which the prevailing view of pain is one in which it is seen as for the most part as a business opportunity, to sell more pharmaceutical products [40-cxxiv]. The author finds this approach problematic, and it is indeed so. There is some light at the end of the tunnel, the need to develop other approaches to care having been expressed, for example, in inflammatory bowel disease [40-cxxv] and sickle cell disease [40-cxxvi].

Despite these straws in the wind, though, there is little evidence that the medical profession as a whole is moving beyond reliance on increasing doses of powerful analgesics, particularly opiates, as the first line of attack in chronic pain. Time pressures may account for much of this; many doctors simply do not have the time to give proper consideration to the needs and wellbeing of the individual patient, or to adopt the holistic approach to an area of clinical practice that is crying out for person-centred care, either in the determination of underlying pathology, or in the appreciation of the patient's human status. The author points out that sedation and analgesia may make it even more difficult to invoke language in order to communicate the reality of the pain symptom. This is in addition to direct impact of pain itself upon mental processes. While some physicians have tended to view both consciousness and pain as epiphenomena, secondary to other processes, and this view has been subject to challenge [40-cxxvii], there is no doubt that difficulty communicating, while in part due to the inadequacy of language, is in itself an epiphenomenon arising from the symptomatology itself.

The author writes about his recent experience of having had a stroke, and the likelihood that this may have been attributable to his having been found some years ago to have cerebrospinal fluid (CSF) hypotension, which in practically all cases is due to a leakage of CSF. CSF leak is a condition that has only recently been recognised [40-cxxviii], and many neurologists appear to remain unaware, both of its existence and of the serious consequences that may follow from it. Recent research has demonstrated that it may cause intracranial hypotension [40-cxxix, 40-cxxx]. CSF leak can damage blood supply to the brain, and can risk direct trauma to the brain due to the loss of the fluid that normally cushions it [40-cxxxi] It also creates a route for the entry of life-threatening infectious diseases such as meningitis [40-cxxxi]. CSF leaks may be in origin spontaneous [40-cxxii], traumatic [40-cxxxiii], or iatrogenic [40-cxxxiii, 40-cxxxiv] for example after cranial surgery [40-cxxxv]. Some spontaneous CSF leaks may be due to problems of connective tissue formation, with ensuing weakness of the dura mater [40-cxxix], for example in Marfan syndrome [40-cxxxvi]. CSF leaks can also occur in idiopathic intracranial hypertension (IIH) [40-cxxxvii]. Other risk factors for spontaneous CSF leaks include obesity and intracranial hypertension [40-cxxxviii]. Spontaneous CSF leaks may also be associated with underlying pseudotumour cerebri syndrome [40-cxxxix].

Orthostatic headache is the main presentation symptom of spontaneous intracranial hypotension [40-cxxix, 40-cxxxviii], but the underlying cause of the headache frequently remains undiagnosed [40-cxl]. It is due to the low CSF pressure producing displacement of pain-sensitive structures, while other symptoms such as tinnitus and vertigo [40-cxxxviii, 40-cxli] may be due to hydrostatic changes occurring at low CSF pressures [40-cxli]. Other symptoms include aural fullness, middle ear effusion and otorrhea [40-cxxxviii]. Among patients, disturbed consciousness may occur in elderly patients with intracranial hypotension due to CSF leak [40-cxlii], while coma is a rare complication [40-cxliii]. Other complications, some of which may be life-threatening, include meningitis, rhinorrhoea, brain abscesses, pneumocephalus [40-cxliii], subdural hematoma [40-cxl, 40-cxliv], subarachnoid haemorrhage, and dural venous sinus thrombosis [40-cxl]. A mortality rate of 9% is reported after one year [40-cxlv].

Computed tomography (CT) myelography has been the mainstay of diagnosis and localisation of CSF leaks [19], but PET cisternography is also recommended [40-cxlvii], and magnetic resonance imaging (MRI) myelography appears to have greater sensitivity [40-cxlviii, 40-cxlix]. Spontaneous intracranial hypotension was unknown until the advent of MRI [40-cxl]. Recognition is increasing, but there are still misconceptions about it which must be dispelled if appropriate investigations and patient care are to be provided [40-cl]. Knowledge of the underlying physiology is increasing, and there are newer non-invasive methods of detection including transorbital ultrasound and serum biomarkers [40-cli]. The treatment of persistent CSF leaks is surgical. Outcomes are generally good, show low recurrence and complication rates with good results. Endoscopic repair of spinal fluid leaks is commonly performed and carries low morbidity [40-clii]. However, long-term follow-up should be made, as recurrences can be delayed [40-cliii]. A retrospective evaluation of 53 patients undergoing surgery for frontal sinus CSF leaks found that all CSF leak repairs were successful at the first attempt, with a mean follow-up of 76.8 months [40-cxxxiii]. In a recent case series, treatment of refractory spontaneous intracranial hypotension with fibrin glue polymers has been shown to be effective [40-cliii].

The author writes: “Science has shown that we are as capable of unlearning as we are of ‘amplifying’ pain.” Pain sufferers, in medieval narratives, seek to regain control over their own bodies. This does not give control over pain, but may open the door to acceptance. This fatalistic approach, marked by acceptance of pain and eschewing excessive analgesic reliance, does not necessarily mean acceptance that pain is uncontrollable. Various non-pharmacological approaches to pain control exist, including mind-body therapies such as relaxation, meditation, imagery, cognitive behaviour therapy [40-cliv], biofeedback, healing touch, progressive relaxation [40-clv], patient positioning, thermal measures, massage therapy and aromatherapy [40-clvi]. Much of it is influenced by Buddhist practice and philosophy [40-clvii].

While the role of pain may be to teach and protect, this cannot be true of chronic pain, and indeed research literature distinguishes nociceptive from maladaptive pain. The sensation of pain plays a critical protective role against tissue damage from mechanical, chemical, and other external exposures, but chronic or neuropathic pain is a serious disease in itself [40-clviii]. It should be noted also that the biological mechanisms for minimising pain can be disrupted by post-traumatic stress disorder. This has been reported, for example, among 1973 Yom Kippur War trauma survivors [40-clix]. It should be noted that pain can both in enhance [40-clx] and constrain [40-clxi] cognitive functioning. The regaining of control over their bodies by pain sufferers does not give them control over pain, but may open the door to an acceptance which embraces pain. The corollary is that such a fatalistic attitude, marked by acceptance of pain and avoidance of excessive reliance upon analgesics, does not necessarily mean acceptance that pain is uncontrollable. The author states:

> “… the body has to learn to listen to itself.”

His approach sees all lived experience, including experience of chronic pain, as contributing to understanding of oneself.

The lack of recognition of pain-associated grief or depression in medical classifications or taxonomies, to which the author refers, may well be an important factor in doctors failing to empathise with or to understand the destructive impact of the conscious perception of chronic pain on their patients. The same is true of other conditions which are still not recognised by substantial sections of the medical profession, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), though this latter is of course to be found in the ICD-10 classification under the code G93.3 [40-clxii]. Many people with ME/CFS experience cognitive disorders [40-clxiii] as well as comorbid depressive illnesses [40-clxiv], though this may not be recognised by the many doctors who, despite its presence in ICD-10, still fail to recognise ME/CFS as a genuine clinical entity [40-clxv].

In conclusion, the emerging themes identified in this work include inadequacy of language, barriers to care, including medical scepticism and unsympathetic doctors, microspecialism among doctors, and stigmatisation. They also include the need to make pain meaningful, and the need to consider cultural aspects of chronic pain, post-traumatic recovery and growth. Pharmaceutical treatment and placebo effect were other matters raised, as well as the consequences of such treatment, being excessive use of analgesics, side effects, and addiction. The distinction between psychological and physical pain was considered at some length, as also were the questions of how medieval mystics made pain meaningful and purposeful in the absence of any effective pain control, and how modern attitudes and the organisation of health services leave many in the world today beyond the reach of pain control services, and therefore faced with the same challenge as the medieval mystics.

Much of what has been written calls into direct question the role and purpose of medicine. In a cogent and well-argued analysis, Dame Margaret Turner-Warwick, a former President of the Royal College of Physicians, came to very similar conclusions [40-clxvi]. She argued that there was increasing recognition of the importance of the contribution of the humanities to good medical practice, and also warned of the extent to which modern medicine "… has been pushed off course from real care of patients". Scientific knowledge is, she asserted, on its own not enough, despite the astonishing advances of science, for human beings have dimensions other than the purely rational, including intuition, sensibilities, and the spiritual dimension. Science itself, and its offshoot in the form of evidence-based medicine, become problematic when they deny the importance of the spiritual dimension. Paradoxically, "… those promoting this sterile caricature of deprofessionalised medicine stress that care must be patient centred, without evidently having the slightest insight about what this actually means".

The priority attached to patient empowerment is a manifestation of patients' desire to be recognised and treated as whole people, and this underlines the need for empathy and mutual understanding between doctor and patient. All too frequently, good doctors, operating in a professional environment where data collection, achievement of clinical and financial targets, and conformity to government directives are the all-important priority, fail to achieve this. Despite this, though, there has been recent recognition of the positive contribution that the arts can make to support the sick. This applies not only to visual arts but also to music and literature, including poetry, and is in no way incompatible with or a distraction from the need for the highest possible standards of medical care based on detailed and accurate scientific knowledge.

She concludes: "The so-called medical humanities are not an add-on, they are central to medical practice because they provide the evidence beyond doubt for that dimension of care reaching beyond the physical of which modern medicine so often loses sight", and, further, that "… medicine must serve patients and it is the responsibility of the profession to know and understand what those needs are and to insist that that is the standard to which we must aspire. It is the maintenance of all these standards both in breadth and depth that defines the profession."

Conclusion

It is my own view that change is indeed coming in the management of MUS, but that there is a need for an acceleration of the pace of development. The experiences reported by John Pheby, and extensively commented upon by Professor Derek Pheby, are not acceptable within any system that elects to describe itself as 'person-centered'. Consider here what Miles and Asbridge [36] have remained resolute in advancing:

> " … PCC acts to raise clinical professionalism from the lower common denominator of legally acceptable, basic technoscientific competence, to the higher numerator of person-centered excellence … Indeed, it has been said, albeit controversially in this very context, that the former can only be understood as 'second, or even third rate' care, while the latter is incontrovertibly first rate and pre-eminent in its nature. We might add, here, with equal controversy, that the provision of second or third rate care is fine - for second or third raters (…) For sure, PCC is here to stay. It is far from an abstract concept, or a 'sentimental' preoccupation with the history of medicine. Neither is it a form of 'virtue signalling', with an associated moral posturing. Rather, it is a new - indeed an entirely radical - proposition, which rests firmly on a rapidly developing ethical justification, a scientific evidence-based justification and an economic justification (…)"

Is the care of patients with MUS generally second, or even third rate? I believe that it is both, specifically depending on the particular clinicians and healthcare institutions involved [cf.7,38]. Are there examples of excellence in the management of MUS? Yes, but they are rare, and not properly communicated, and do not, as they should, form the basis of current undergraduate and postgraduate medical training, even within a crowded curriculum, given their huge complexities and costs to individual patients and healthcare systems [cf.7,38]. Things do not have to be this way, and the resurgence of interest in the patient as a person [33-36,45-48] can only benefit a greater understanding and management of those who present to their clinicians with no pathophysiologically identifiable organic dysfunction, but who nevertheless suffer greatly with the *sequelae* and consequences of 'medically unexplained' illness.

The forthcoming volume, *Umwelt*, will prove, I believe, to be a high impact volume, with the potential to 're-sensitize' clinicians to the need to attend to the 'great depths' of the patient as a person with MUS, and to react and attend accordingly. John Pheby's volume is at once cathartic, but it is much more than that. Its narrative throughout is painful to read, clinically and from a purely human perspective, but it will undoubtedly function to confront those clinicians who deal with MUS, and whose practice is "second or third rate", to address their shortcomings, helping them to understand that MUS is not 'imagined' or 'psychiatric' in its nature, but is, rather, a debilitating condition, of varying and alternating severity, that, with proper skill and purpose, can be assisted with considerable success.

The European Society for Person Centered Healthcare commends *Umwelt*, and strongly recommends the volume to all those clinicians that deal with MUS, and all those patients and their carers who respectively experience and attend to the effects of MUS on a daily basis.

Note to readers

The forthcoming volume by John Pheby [2], preceded by the serialisation of its chapters in the *Journal*, is the second major project on 'medically unexplained illness' undertaken by the ESPCH. The first was in the form of the international conference 'The Person-Centered Care of Medically Unexplained Symptoms', which drew together a range of distinguished experts in the field from across the globe, and which was held by the ESPCH in collaboration with St. George's University Hospital in London UK on 28 September 2016. The relevant link is here: http://pchealthcare.org.uk/sites/pchealthcare.org.uk/files/conference/download/espch_causehealth_st_georges_university_of_london_person-centered_care_of_mus_delegate_brochure.pdf.

Readers who would like to access the individual book chapters of *Umwelt* [2] in advance of the publication of the book are invited to write to Mr. Andrew Williamson, Senior Production Editor of the *European Journal for Person Centered Healthcare*, at: andrew.williamsonprofunit@gmail.com. Pre-orders for '*Umwelt*' as a hardcover text may also be placed *via* these same contact details. The same contact details may also be employed to register interest in the papers from the volume: 'Person Centered Care: Advanced Philosophical Perspectives'. Loughlin, M., & Miles, A. (Eds.). 2020. London: Aesculapius Medical Press [1], or similarly to pre-order the full hardcover text.

Details of the next major publication by the Society, entitled 'Person Centered Care – The New Professionalism', a three volume *Opus* dedicated to an extensive consideration of all major aspects of person-centered care, from concepts, through methodological development, to implementation and measurement of clinical and economic outcomes, will be announced by *Press Release* and within the *EJPCH*, in early 2021.

Acknowledgements and Conflicts of Interest

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References

[1] Asbridge, J.E. (2020). Progress in the conceptual understanding of person-centered health and social care. 'Person Centered Care: Advanced Philosophical Perspectives'. Loughlin, M. & Miles, A. (Eds.). 2020. London: Aesculapius Medical Press. *European Journal for Person Centered Healthcare* 8 (1) 17-19.

[2] Pheby, J. (2020). Umwelt. London: Aesculapius Medical Press.

[3] Wessely, S. (2000). To tell or not to tell? The problem of medically unexplained symptoms. In: Ethical Dilemmas in Neurology. Zeman A, Emmanuel L. (Eds.), pp. 41–53. London: Saunders.

[4] Reid, S., Wessely, S., Crayford, T. & Hotopf, M. (2001). Medically unexplained symptoms in frequent attenders of secondary health care: retrospective cohort study. *British Medical Journal* 322 (7289) 767-771.

[5] Howman, M., Walters, K., Rosenthal, J., Good, M. & Buszewicz, M. (2012). Teaching about medically unexplained symptoms at medical schools in the United Kingdom. *Medical Teacher* 34 (4) 327-329.

[6] Burton, C. (2014). Can we explain medically unexplained symptoms? *Family Practice* 31 (6) 623-624.

[7] Buszewicz, M.J. (2017). Encouraging clinicians to work effectively with people with medically unexplained symptoms - is a change in underlying attitudes required? *European Journal for Person Centered Healthcare* 5 (3) 389-395.

[8] Yon, K., Habermann, S., Rosenthal, J., Walters, K., Nettleton, S., Warner, A., Lamahewa, K. & Buszewicz, M. (2017). Improving teaching about medically unexplained symptoms for newly-qualified doctors in the UK: findings from a questionnaire survey and expert workshop. *BMJ Open* 7 (4) e014720.

[9] Chalder, T. & Willis, C. (2019). Medically Unexplained Symptoms. In: Cambridge Handbook of Psychology, Health and Medicine. C. Llewellyn, S. Ayers, C. McManus, S. Newman, K. Petrie, T. Revenson, *et al.* (Eds.), pp. 78-83. Cambridge: Cambridge University Press.

[10] Lamahewa, K., Buszewicz, M., Walters, K., Marston, L. & Nazareth, I. (2019). Persistent unexplained physical symptoms: a prospective longitudinal cohort study in UK primary care. *British Journal of General Practice* 69 (681) e246-e253.

[11] Sharpe, M., Mayou, R. & Bass, C. (1995). Concept, theories and terminology. In: Treatment of Functional Somatic Symptoms. Mayou R., Bass C. & Sharpe M. (Eds.), pp. 3-16. Oxford: Oxford University Press.

[12] Henningsen, P., Zipfel, S. & Herzog, W. (2007). Management of functional somatic syndromes. *Lancet* 369 (9565) 946-955.

[13] Swanson, L.M., Hamilton, J.C. & Feldman, M.D. (2010). Physician-based Estimates of Medically Unexplained Symptoms: A Comparison of Four Case Definitions. *Family Practice* 27 (5) 487-493.

[14] Fink, P., Fritzsche, K., Söllner, W. & Larisch, A. (2011). Training. In: Medically Unexplained Symptoms, Somatisation and Bodily Distress: Developing Better Clinical Services. Creed, F., Henningsen, P. & Fink, P. (Eds.), pp. 217-235. Cambridge: Cambridge University Press.

[15] Marks, E.M. & Hunter, M.S. (2015). Medically Unexplained Symptoms: an acceptable term? *British Journal of Pain* 9 (2) 109-114.

[16] Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., MacKenzie, L., Warlow, C.P. & Sharpe, M. (2002). What should we say to patients with symptoms unexplained by disease? The “number needed to offend”. *British Medical Journal* 325 (7378) 1449-1450.

[17] Creed, F., Guthrie, E., Fink, P., Henningsen, P., Rief, W., Sharpe, M. & White, P.J.S. (2010). Is there a better term than "Medically unexplained symptoms"? *Journal of Psychosomatic Research* 68 (1) 5-8.

[18] Katon, W., Ries, R.K. & Kleinman, A. (1984). The prevalence of somatization in primary care. *Comprehensive Psychiatry* 25 (2) 208-215.

[19] Nimnuan, C., Hotopf, M. & Wessely, S. (2001). Medically unexplained symptoms: an epidemiological study in seven specialities. *Journal of Psychosomatic Research* 51 (1) 361-367.

[20] McGorm, K., Burton, C., Weller, D., Murray, G. & Sharpe, A. (2010). Patients repeatedly referred to secondary care with symptoms unexplained by organic disease: prevalence, characteristics and referral pattern. *Family Practice* 27 (5) 479-486.

[21] Steinbrecher, N., Koerber, S., Frieser, D. & Hiller, W. (2011). The prevalence of medically unexplained symptoms in primary care. *Psychosomatics* 52, 263-271.

[22] Creed, F., Barsky, A. & Leiknes, K.A. (2011). Epidemiology: prevalence, causes and consequences. In: Somatisation, Symptoms and Bodily Distress. Developing Better Clinical Services. Creed, F., Henningsen, P. & Fink, P. (Eds.), pp. 1-42. Cambridge: Cambridge University Press.

[23] Creed, F.H., Davies, I., Jackson, J., Littlewood, A., Chew-Graham, C., Tomenson, B., Macfarlane, G., Barsky, A., Katon, W. & McBeth, J. (2012). The epidemiology of multiple somatic symptoms. *Journal of Psychosomatic Research* 72 (4) 311-317.

[24] Haller, H., Cramer, H., Lauche, R. & Dobos, G. (2015). Somatoform disorders and medically unexplained symptoms in primary care: a systematic review and meta-analysis of prevalence. *Deutsches Ärzteblatt International* 112 (16) 279-287.

[25] Barsky, A.J., Orav, E.J. & Bates, D.W. (2005). Somatization increases medical utilization and costs independent of psychiatric and medical comorbidity. *Archives of General Psychiatry* 62 (8) 903-910.

[26] Bermingham, S.L., Cohen, A., Hague, J. & Parsonage, M. (2010) The cost of somatisation among the working-age population in England for the year 2008–2009. *Mental Health in Family Medicine* 7 (2) 71-84.

[27] Aamland, A., Fosse, A., Ree, E., Abildsnes, E. & Malterud, K. (2017). Helpful strategies for GPs seeing patients with medically unexplained physical symptoms: a focus group study. *British Journal of General Practice* 67 (661) e572-e579.

[28] Payne, H. & Brooks, D.S. (2019). Medically Unexplained Symptoms and Attachment Theory: The BodyMind Approach®. *Frontiers in Psychology* 10, 1818. doi: 10.3389/fpsyg.2019.01818.

[29] Geraghty, K. & Scott, M.J. (2020). Treating medically unexplained symptoms via improving access to psychological therapy (IAPT): major limitations identified. *BMC Psychology* 8 (1):13. doi: 10.1186/s40359-020-0380-2.

[30] Lamahewa, K., Buszezicz, M., Walters, K., Marston, L. & Nazareth, I. (2019). Persistent Unexplained Physical Symptoms: A Prospective Longitudinal Cohort Study in UK Primary Care. *British Journal of General Practice* 69 (681) e246-e253.

[31] Jones, B. & Williams, C, A de C. (2019). CBT to reduce healthcare use for medically unexplained symptoms: systematic review and meta-analysis. *British Journal of General Practice* 69 (681) e262-e269.

[32] Chew-Graham, C.A., Heyland, S., Kingstone, T., Shepherd, T., Buszewicz, M., Burroughs, H. & Sumathipala, A. (2017). Medically unexplained symptoms: continuing challenges for primary care**.** *British Journal of General Practice* 67 (656) 106-107.

[33] Miles, A. & Asbridge, J.E. (2016). The chronic illness problem. The person-centered solution. *European Journal for Person Centered Healthcare* 4 (1) 1-5.

[34] Miles, A., Asbridge, J.E. & Caballero, F. (2015). Towards a person-centered medical education: challenges and imperatives. *Educacion Medica* 16 (1) 25-33.

[35] Miles, A. & Asbridge, J.E. (2017). Person-Centered Healthcare - moving from rhetoric to methods, through implementation to outcomes. *European Journal for Person Centered Healthcare* 5 (1) 1-9.

[36] Miles, A. & Asbridge, J.E. (2019). The NHS Long Term Plan (2019) – is it person-centered? *European Journal for Person Centered Healthcare* 7 (1) 1-11.

[37] Atkins, C.G.K. & Hodges, B.D. (2010). My imaginary illness: a journey into uncertainty and prejudice in medical diagnosis. Ithaca NY: ILR Press/Cornell University Press.

[38] Malterud, K. & Aamland, A. (2019). Medically unexplained symptoms: are we making progress? *British Journal of General Practice* 69 (681) 164-165.

[39] Burton, C. (2014). Can we explain medically unexplained symptoms? *Family Practice* 31 (6) 623-624.

[40] Olde Hartman, T.C., Rosendal, M., Aamland, A., van der Horst, H.E., Rosmalen, J.G.M., Burton, C.D. & Lucassen, P. L.B.J. (2017). What do guidelines and systematic reviews tell us about the management of medically unexplained symptoms in primary care? *BJGP Open* 1 (3) doi: 10.3399/bjgpopen17X101061

[41] Pohontsch, N.J., Zimmermann, T., Jonas, C., Lehmann, M., Lowe, B. & Scherer, M. (2018). Coding of medically unexplained symptoms and somatoform

disorders by general practitioners - an exploratory focus group study. *BMC Family Practice* 19 (1) 129.

[42] O'Leary, D. (2018). Why Bioethics Should Be Concerned With Medically Unexplained Symptoms. *American Journal of Bioethics* 18 (5) 6-15.

[43] Stone, L. (2014). Blame, shame and hopelessness: medically unexplained symptoms and the 'heartsink' experience. *Australian Family Physician* 43 (4) 191-195.

[44] Steen, L. (2016). The wilderness of the medically unexplained. *BMJ Opinion* Available at: https://blogs.bmj.com/bmj/2016/08/25/lisa-steen-the-wilderness-of-the-medically-unexplained/.

[45] Miles, A. & Asbridge, J.E. (2013). Contextualizing science in the aftermath of the evidence-based medicine era: on the need for person-centered healthcare. *European Journal for Person Centered Healthcare* 1 (2) 285-289.

[46]. Miles, A. & Asbridge, J.E. (2014). Advancing the concepts, epistemology and lexicon of person-centeredness: an essential pre-requisite to the effective operationalization of PCH within modern healthcare systems. *European Journal for Person Centered Healthcare* 2 (1) 1-10.

[47]. Miles, A. & Asbridge, J.E. (2014). Modern healthcare: a technical giant, yet an ethical child? *European Journal for Person Centered Healthcare* 2 (2) 135-139.

[48] Miles, A. (2017). From evidence-based to evidence-informed, from patient-focussed to person-centered – the ongoing 'energetics' of health and social care discourse as we approach the Third Era of Medicine. *Journal of Evaluation in Clinical Practice* 23 (1) 3-4.

Appendix

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