

**Pragmatics of explanation:
creative accountability and ‘medically unexplained symptoms’**

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In the course of the last two decades, health care policy has become increasingly defined by the notion of patient-centredness and by a number of concepts that cluster around it, including those of participation, involvement and empowerment. While the precise scope, meaning and value of these concepts can be a matter of debate (Salmon and Hall, 2003 and 2004; Thompson, 2007; Andreassen and Trondsen, 2010), they now inform a wide range of activities and associated technologies at different levels, from individual doctor-patient consultations to the development of clinical guidelines and research programmes. The same period has seen the conspicuous rise of a multiplicity of patient groups and health social movements, including forms of evidence-based activism that ‘focus on knowledge production and knowledge mobilisation in the governance of health issues’ (Rabeharisoa et al., 2014: 112). These have involved multiple reconfigurations of the traditional lay/expert distinction, in which patients may be constituted as ‘lay experts’ based on their acquisition of scientific and medical knowledge (Epstein, 1995); as possessors of distinct and irreducible forms of knowledge (Arksey, 1994; Rabeharisoa and Callon, 2004; Pols, 2013); or as partners in the process of scientific research and knowledge production (Rabeharisoa, 2003).

The broader context in which these developments are taking place is one characterised by a democratisation of expertise and by the articulation of a number of associated tensions and dilemmas (Liberatore and Functowicz, 2003). One of these dilemmas concerns the relative value of propositions put forward by different types of ‘experts’ in a variety of contexts, and what forms of accountability they should be susceptible to (Jasanoff, 2003; Novotny, 2003;

Collins and Evans, 2002). Against this broad background, in this paper I discuss the problem of explanation, and the value of different explanatory strategies and claims, in the domain of ‘medically unexplained symptoms’ understood as a broad space of problematisation. Rather than evaluating such explanatory strategies and claims in terms of epistemological norms of accountability (e.g. reliability), procedural norms (e.g. transparency), or instrumentalist norms (as in certain versions of pragmatism), I propose to consider them from the perspective of what, following Stengers (2008, p. 53), and in the spirit of a speculative pragmatism, I call *creative accountability*.

The discussion will focus specifically on a set of recent research developments stemming from a series of studies of primary care consultations, which have resulted in the proposition that there is a need for a ‘curriculum of medical explanation for medically unexplained symptoms’, and in at least one programme of research devoted to the development of such explanations as a clinical intervention (Salmon, 2007; see also Burton, 2014). Part of the reason for describing these developments is to argue that they constitute a significant reconfiguration of the discursive space around symptoms – one of which ‘we’, social scientists, should take note for the purpose of reflecting on how it could affect the forms of our own engagement with this issue. This reconfiguration is currently taking place primarily in the context of the UK and northern Europe (particularly the Netherlands and Scandinavia), through clusters of researchers in dialogue with each other, who collaborate in varying combinations. This paper stems partly from my own involvement in one such research team as a participant observer. In the final section of the paper I contrast this case with explanatory strategies evident among participants of self-help groups for illnesses that ‘you have to fight to get’ (Dumit, 2006), and conclude by reflecting on the implications of this contrast for social scientific research in this field.

‘Medically unexplained symptoms’ – first and second order phenomenon

In describing ‘medically unexplained symptoms’ as a space of problematisation rather than as a particular category of illnesses I seek to address the whole range

of theoretical and empirical possibilities involved in forms of discourse that relate to this expression, including those that engage with it specifically in order to reject it. Many illnesses are unexplained, but not all of them fall under the rubric of 'medically unexplained symptoms'. Unlike the term 'idiopathic', this expression is specifically used to indicate physical symptoms that 'are not attributable to any known conventionally defined disease' (Fink et al., 2005: 227), and is discursively related to several other terms and concepts, each with different connotations, that may be used to describe the same phenomenon (or indeed to dispute such sameness – see Greco, 2012 for a review). These include the concept of *somatisation*, the DSM diagnostic categories of *somatoform disorders* (DSM-IV) and *somatic symptom disorder* (DSM 5), the concept of *functional somatic syndrome(s)*, and the multiple diagnoses that – often controversially – are subsumed under it, such as fibromyalgia; chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME) and often as 'ME/CFS'; multiple chemical sensitivity (MCS); irritable bowel syndrome (IBS) and others. This terminological multiplicity and the controversies surrounding the use of many of these terms reflects the fact that basic taxonomic questions – such as 'are we dealing with one or many phenomena when it comes to describing medically unexplained symptoms?' (Deary, 1999: 51) – have not been resolved.

The lack of consensus about nomenclature and classification as well as the supposedly 'unexplained' nature of the symptoms are an empirical phenomenon of sociological, psychological and medical significance in its own right. I propose to regard this as a second-order phenomenon, to be distinguished analytically from the first-order phenomenon of symptoms themselves. Illnesses without a diagnosis, or with a contested or illegitimate diagnosis, involve an additional burden of suffering that stems from profound uncertainty, from social stigma, from the potential denial of access to benefits and services. Much of the sociological and anthropological research on these conditions has focused on making this additional burden visible and discussable (e.g. Cohn, 1999; Clarke and James, 2003; Nettleton, 2006; Dumit, 2000 and 2006; Stenner et al., 2000; Stenner et al., 2015). Any serious discourse about 'medically unexplained symptoms' today must thus take as its point of departure a recognition of this

second order phenomenon, and of a potential dimension of conflict with patients who are thought to reject labels and explanations that suggest their illness may be 'psychological'. This process is reflected in the contemporary preference, in the scientific literature, for expressions like 'medically unexplained symptoms' – over 'somatisation' in particular – not as an ideal choice but as the lesser evil, and therefore often in scare quotes or followed by qualifying statements and disclaimers.¹ Among significant portions of the medical profession the tacit commonsense consensus remains that *medically unexplained symptoms* (or 'MUS') and *somatisation* refer to the 'same', poorly defined, clinical phenomenon, albeit (at least for those specialising in this field) with significantly different theoretical connotations. Pragmatic considerations inform the terminological shift regardless of theoretical ones: while 'somatisation' is a resented and stigmatising term, 'unexplained symptoms' appears, at least in principle, comparatively neutral, un-psychological, and benign.

There is something paradoxical and self-defeating in these terminological shifts in so far as they are perceived as catering to patient 'preferences' (that is, to their psychology) and to be informed by pragmatic concerns (as a form of appeasement, to avoid conflict), rather than attending to the objective reality or truth of their condition. The more care is taken not to offend patients, the more sensitive patients seem to become to the possibility of being duped, infantilised and offended. This is reflected in the notion, expressed colloquially by a senior clinician in this field, that each new expression coming into use has a limited 'shelf life': its utility expires as soon as patients realise that it's 'just a new name for somatisation'.² As I have argued elsewhere (Greco, 2012), this paradox is rooted in the avoidance of the 'psychological' rather than an engagement with its possibilities.

The research developments to which I now turn emerge from and against this background. As we shall see, rather than discarding the concept of somatisation as obsolete or politically unacceptable, they reconfigure it in significant ways.

Turning the tables on 'somatisation': evidencing the iatrogenic vortex

In what is still a standard reference for the definition of the concept, Z. J. Lipowski (1988: 1359) describes somatisation as 'a tendency to experience and communicate somatic distress and symptoms unaccounted for by pathological findings, to attribute them to physical illness, and to seek medical help for them ... despite doctors' reassurances that physical illness cannot account for [the] symptoms'. Lipowski further adds that 'the appraisal, and hence the meaning, of the experienced symptoms needs to be in terms of an actual or threatened disease of or damage to the body for the term to apply' (1988: 1359). Core to the construct of somatisation therefore is the notion that patients who somatise are committed to physical (biomedical) explanations of their condition. By inference, the construct also involves the assumption that patients cannot think psychologically and/or that they resist psychological explanations.

A series of studies published from the mid-2000s has challenged the axiomatic status of these propositions and tested them empirically by analysing consultations for unexplained symptoms in primary care settings, with surprising results (Ring et al., 2005; Salmon et al., 2006; Salmon et al., 2007). One study showed, for example, that patients with unexplained symptoms offered many and varied opportunities for their doctors to address them in a psychological register. Although patients provided unambiguous cues to emotional and social problems, these were blocked by most doctors in a variety of ways: by disregarding the cue, by normalising it ('it's bad luck, isn't it?'), by emphasising the patient's responsibility for the problem, or by reasserting the somatic agenda. 'In responding to patients' cues for explanation by providing symptomatic treatments, investigations or referral', they write, 'doctors effectively "somatised" these patients.' (Salmon et al., 2004: 175). Having thus demonstrated how the clinical consultation can have 'somatising effects' (Ring et al., 2005), they call for further research into the motivations behind doctors' somatising responses to their patients (Salmon et al., 2006).

So why do doctors focus somatically? Suggestions as to the likely nature of their motivations point to multiple sources of doctors' anxiety when faced with symptoms they cannot explain: these vary from reluctance towards using stigmatising diagnoses to fear of overlooking a genuine physical disease, which is linked to fear of litigation and media exposure (Fink et al., 2005), to feelings of inadequacy when faced with manifestations of psychological distress that they do not feel trained or equipped to manage (Wileman et al., 2002; Chew-Graham et al., 2001). What is interesting about this list is that it points to the relevance of the psychology and affective involvement of *doctors* in co-producing the reality of 'somatisation'. Intensely negative emotions were apparent in the accounts of the general practitioners studied by Wileman et al. (2002), including frustration and resentment, with some doctors admitting that these affected their clinical judgment. The authors illustrate this with a quotation from one of their participants, GP10:

You can get yourself into the position where you will never spot an illness in this patient if it was staring you in the face and they were dead on the floor, because you will feel it's just their bloody somatising (GP10, cited in Wileman, et al., 2002: 181).

The changing balance of power within the medical consultation, which some GPs in this study perceived to have become skewed in favour of the patient, is explicitly addressed as a source of doctors' negative emotions. The feeling emerging perhaps most strongly from these accounts, according to Wileman et al. (2002: 181) was a general 'sense of powerlessness ... in the face of apparently intractable symptoms rooted in the realm of the *social*'. These findings were consistent with a series of earlier studies by this team, exploring GPs' responses to manifestations of psychological distress in consultations for chronic lower back pain and depression (Chew-Graham and May 1999; Chew-Graham et al., 2001; Rogers et al., 2001).

Taken all together, these propositions can be read as an emerging problematisation of somatisation that does not simply dismiss the concept either on epistemological

grounds, or on grounds that patients find the term and its connotations unacceptable. This problematisation engages with somatisation as a concrete process, not just as an unfortunate or invalid construct (cf. Crombez et al., 2009), but turns it around, or reframes it fundamentally. It does this by providing the elements for an empirically-based analysis of how patients are 'somatised' in the clinical interaction and by the medical system within which this takes place.

The proposition that somatisation is a systemic product of Western medicine is far from new. The psychiatrist Horacio Fabrega articulated it in the journal *Psychosomatic Medicine* nearly three decades ago, for example (Fabrega, 1990). Until recently, however, this remained an abstract proposition based on a discussion of the features of biomedical epistemology considered, as in Fabrega's case, in a comparative historical and anthropological perspective. Biomedicine, like much of modern science, is predicated on what Alfred North Whitehead described as the bifurcation of nature: a mode of abstraction that makes a fundamental distinction between objective, causal nature (defined as primary) and subjective nature (defined as secondary). In medicine this bifurcation translates into the conceptual distinction between objective 'disease' and subjective 'illness', which is hierarchical in that the truth or reality of an illness is understood to be secondary to the truth of a disease. Fabrega refers to this as the 'postulate of mind/body correspondence': a postulate that prescribes 'how a patient behaves and should behave in the context of specific/measurable disease changes in the body', and that encompasses 'such things as reports of pain, bodily experience and physiological dysfunction', as well as 'culturally appropriate degrees and forms of worry ... modes of social role functioning and health care seeking' (1990: 554). From the perspective of this epistemological orthodoxy, illnesses that are not supported by evidence of disease can in principle be dismissed or explained away as medically insignificant. The endurance of this epistemological orthodoxy, despite the proliferation of conditions that would seem to challenge it or contradict it, can be attributed at least partly to the practical value that this orthodoxy continues to have in relation to problems and functions that are other than strictly medical, such as gatekeeping (Greco, 1998). In other words, evidence of disease offers a baseline discriminating criterion for access to the sick role and a bulwark against moral ambiguity – however questionable and complicated this may have become in a social

context defined by a prevalence of chronic and 'lifestyle' diseases and by the redefinition of patients as 'consumers' (Varul, 2010). In the absence of evidence of disease – as in the case of 'medically unexplained symptoms' – doctors still make gatekeeping decisions that admit patients into the sick role, but these become less transparent and more difficult to account for (Mik-Meyer and Obling, 2012), and in healthcare systems mediated by private insurance they may become legally and politically contentious (Afram, 2004; Dumit, 2006).

In this epistemic context, patients who present with unexplained symptoms can easily find themselves caught in a iatrogenic dynamic well rendered in the famous phrase by the rheumatologist Nortin Hadler: 'If you have to prove you are ill, you can't get well' (1996). This is a dynamic whose elements are now illustrated in rich empirical detail by the sum of the studies that form part of the problematisation addressed here, and it goes something like this: since there is ostensibly 'nothing wrong' with them, patients with unexplained symptoms need to work hard in a clinical context to 'fit in with normative, biomedical expectations' and become a 'credible patient' (Werner and Malterud, 2003: 1409). This effort includes adopting an idiom of explanation that focuses on the physical aetiology of symptoms at the expense of other, more nuanced idioms that are typically employed elsewhere, such as in conversations with family or friends (Bech-Risør, 2009). Patients are encouraged to present in this way by doctors who, as we have seen, themselves tend to focus somatically and to ignore psychosocial cues. This predicament constitutes what Paul Watzlawick and colleagues (1967) called a pragmatic paradox: the efforts made to behave as a credible patient, to the extent that they are perceived as such by others, will tend inevitably to backfire, because a true illness is supposed to be something that befalls us rather than something we 'perform'. Therefore, while adopting a somatic idiom of explanation is facilitated and reinforced by the clinical setting and its structural constraints, doing so when there is 'nothing wrong' actually renders the patient conspicuous from a psychobehavioural (and moral, in a broad sense) point of view, prompting doubt or negative feelings in the doctor, and renewed effort to establish credibility on the part of the patient. The logic of this dynamic tends towards a polemical polarisation of the positions of doctor and patient, and of physical versus psychological explanations.³ This situational (and socioculturally embedded) logic, in other words, sets physical and psychological

explanations up to emerge as mutually exclusive alternatives, regardless of any more complex or nuanced understandings that the parties involved may privately hold.

Although the studies discussed so far mostly refer to clinical interactions in the context of individual doctor-patient consultations, a similar dynamic is fractally reproduced at other levels of analysis, such as in public and cultural discourse. In his study of 'very large scale conversations' (Sack, 2002) among members of online newsgroups for chronic fatigue syndrome and for multiple chemical sensitivity, for example, Joe Dumit (2006; 2000) has shown how sufferers mobilise biomedical facts – or the equivalent of a somatic idiom of explanation – as 'forces' in the struggle to obtain legitimacy. At the same time, within the space of the newsgroup, they may discuss strategies for self-presentation such as how to dress in order to appear convincingly disabled ('sloppy'), and the possibility that this may backfire ('don't you think that all those disability review doctors know perfectly well that anyone faking a disability will be trying to look sick by looking sloppy?') (2006: 586). What this demonstrates is not, of course, these members' collusion in a form of malingering, but rather that the system itself provokes and facilitates the emergence of such tactical behaviours to ensure the legitimisation of illness, and yet treats them as disqualifying evidence as soon as they become conspicuous as behaviours. Another example is offered by Kristin Barker's analysis of discourse around fibromyalgia, with reference to the FDA approval of Lyrica as the first prescription medication specific for the management of the condition (2011). Sufferers initially welcomed Lyrica enthusiastically on internet bulletin boards and other public forums, not only for the promise of relief that the drug offered, but also for its value in legitimating fibromyalgia as a 'real' (i.e. biomedical) disease rather than a mental illness. Seemingly well aware of the importance of this dimension to its target market, Pfizer's advertising campaign for the drug specifically stressed that that it was 'not an antidepressant' (2011: 837). In this case, Lyrica became the proxy for a biomedical explanation for somatic symptoms. In so far as this was the case, however, any failure of the drug to deliver on its promise could also be interpreted as proving that fibromyalgia is not a biomedical condition after all: 'If Lyrica does not restore [sufferers] to health, *as seen on television*, and in the vast majority of cases it will not, this could be used to confirm that their problem is all in their head, that they are hysterical, or that they do not want to get better' (2011: 840).

These examples – both referring to studies based in the United States – illustrate collective efforts to become ‘credible’, both as individual patients and as a category of patients, on the part of members of self-help and discussion groups who share a contested diagnosis. They also show how such efforts can backfire on the larger scale of cultural and public discourse, and not just within the privacy of the consultation.

As Hadler already suggested two decades ago on the basis of his own clinical experience with fibromyalgia, the effort to behave as a credible patient has effects beyond the realm of communication, arguably reaching all the way down to an individual’s physiological capacity for self-regulation. As a result of having to prove they are ill, Hadler wrote, sufferers are ‘likely to lose the prerequisite skills for well being, the abilities to discern among the morbidities, and to cope’ (1996: 2398). A set of normative constraints that include the use of differential diagnostic algorithms, disability determination for social security purposes, and tort law thus collude to draw the patient into a ‘vortex of escalating vulnerability and disaffection’ from which ‘very few recover’ (ibid.). Even when legal and political battles to obtain access to services are not involved, the uncertainty and moral ambiguity associated with the lack of a diagnosis and explanation can leave sufferers in a state of ‘embodied doubt’ and permanent narrative ‘chaos’ (Nettleton, 2006; Frank, 1995). While it is commonsense – within a dualist framework – to suppose that a lack of narrative coherence may have implications for mental health, recent conceptualisations of the immune system suggest that the achievement of narrative coherence may be directly relevant to immune function and thus to physical health as well (Koschwanez et al., 2013; Petrie et al., 2004; Booth and Davison, 2003; Pennebaker et al., 1988). The implication of this is that there is a feedback loop between the psychosocial suffering associated with delegitimation (or what I called the second-order phenomenon) and the genesis of somatic symptoms (the first-order phenomenon).

The polarisation of biomedical and psychological explanations, in a dynamic that makes them present as mutually exclusive alternatives, therefore appears not only scientifically flawed but also performatively *toxic*. In choosing the word *toxic* here I refer to the propositions of Isabelle Stengers in relation to what she calls the ‘efficacy’ of theory. ‘The manner in which something is theoretically characterised’, she writes,

'is part of the milieu of that something, and may empower it or poison it'. (2008: 51). Theories 'are always efficacious, they always add to a situation even when they only aim at diagnosing it', and they can be 'maleficent' even when they are right (2008: 53). Thus theories – like the 'facts' mobilised by the sufferers, doctors and institutions observed by Dumit (2006) – are indeed 'forces', they have the power to produce effects. For Stengers, however, the salient effects are not limited to those that follow from the impact of theories on the organisation of social and discursive practices (e.g. victory in a legal case transforming the conditions of access to services). As part of the *vital milieu* of the 'something' to which they refer, and in combination with its ontological propensities and sensitivities, theories *infect the immanent becoming* of that 'something', they affect its homeostatic capacity and ultimately its health (or 'power') – in this case not only a sufferer's capacity to access health *services* but also their immanent health *status*, independently of the question of access (cf. Greco, 2004).

The turning of the tables on the concept of somatisation – its reconfiguration as the iatrogenic product of a medicine organised around the distinction between disease and illness, objective evidence and subjective experience, and biomedical versus psychological explanations – constitutes an implicit acknowledgment of the potentially maleficent force of abstract propositions, even when they are based on valid (if inevitably partial) knowledge, and even when they are not immediately tied to practical social consequences such as the denial of access to care. As we have seen, the notion that somatisation is a product of Western medicine is not new. The inadequacies of epistemological dualism have been denounced in the name of varieties of 'holism' for more than a century (Lawrence and Weisz, 1998), and they are routinely regretted in editorials and commentaries published in medical journals. In this sense, the problematisation described here is remarkable only in that it challenges empirically some of the assumptions and concrete practices that stem from epistemic dualism, to demonstrate with richness of illustrative detail not just *that*, but *how* Western medicine has 'somatising effects'. In addition to this, however, this reconfigured space of problematisation also involves a *propositive* dimension, and it is to describing this that I now turn.

Taking symptoms seriously

Taken as a whole, what I am calling here the propositive dimension of the new discourse on unexplained symptoms stems from two seemingly contrasting conclusions emerging from different strands of research. The first of these conclusions may be summarised by the injunction: 'forget explanation!', and we find it in the context of debates on classification and nomenclature that intensified as the fifth edition of the APA *Diagnostic and Statistical Manual of Mental Disorders* (DSM 5) was being prepared. Shifting the terms of the debate hitherto, which had focused on problematising specific aetiological assumptions reflected in terms such as 'somatisation', Sharpe et al. (2006) questioned the privilege accorded to aetiology more generally, advocating a research and clinical focus on symptoms 'in their own right'. To the extent that existing diagnostic nomenclature implies hypothetical underlying pathology – whether physical (as in 'myalgic encephalomyelitis') or psychological (as in 'somatoform disorder') – it is misleading and counterproductive, they argued, in that it reinforces the assumption of a linear causal relation between pathology and symptoms. Sharpe et al.'s proposition stems from a developing field of 'symptom research' whose 'possibilities and challenges' (Kroenke and Harris, 2001, p. 801) are only just beginning to be articulated. In this field, symptoms are approached as 'higher order', emergent phenomena 'reflecting the brain's integration of multiple aetiological factors' (Sharpe et al., 2006, p. 355) of which conventionally understood disease may, or may not, be one (Kroenke, 2012). This is in sharp contrast to the conventional approach that regards symptoms (and illness) as epistemologically subordinate or secondary with respect to underlying pathology (or disease). From this perspective, 'medically unexplained symptoms' no longer appear marginal and residual to 'proper medicine', as they are no longer conceived in terms of an absence, or what they are not; on the contrary, they become instances of organic (mal-)functioning of the highest order of complexity, requiring the deployment of sophisticated scientific models that do not lend themselves to the specification of clear or simple causal narratives. For the same reason, the distinction between symptoms that can be attributed to a conventionally defined disease and those that cannot – that is, the distinction

previously articulated as the one between ‘medically explained’ and ‘medically unexplained’ symptoms – appears no longer relevant. In fact, a focus on the qualities of the symptoms alone (including how they are experienced and interpreted) reveals more commonalities than differences between patients with ‘explained’ and with ‘unexplained’ illness (Creed, 2013). This is the rationale behind the revision of the DSM-IV category of *Somatoform Disorder* into the DSM 5 category of *Somatic Symptom Disorder*, for which the presence of ‘unexplained’ symptoms is no longer a diagnostic criterion.

Alongside this proposition, that invites scientists to suspend the question of whether symptoms are biomedically explained and to cease constructing taxonomies around it, we find the sum of social scientific and consultation-based research – some of which I discussed above – which indicates that sufferers nevertheless *need* (good) explanations. A ‘good’ explanation, often implicit in a ‘good’ diagnosis, reassures and legitimates; without it, as we have seen, the interaction with the medical system can easily leave sufferers in the existential no-man’s land of a chaos narrative (Nettleton, 2006). In this sense, explanations and diagnoses can be regarded not merely as more or less accurate representations of the patient’s condition, but as efficacious interventions with therapeutic and social value in their own right. But what can constitute a ‘good’ explanation in this sense? What set of constraints are relevant to defining a ‘good’ explanations in this context? This is a context, let us remind ourselves, defined simultaneously by the ‘proto-professionalisation’ of patients and the public at large, who have learned to adopt biomedical vocabularies and expect biomedical explanations (de Swaan, 1988; Dent, 2006); by multiple claims to epistemological authority in potential tension with each other; and by the ‘problem of whose knowledge *counts* in the medical encounter’ (May et al., 2006: 1028).

The question of what constitutes a good explanation is being asked and researched, as part of the problematisation outlined here, in ways that I argue propose attention to a set of new contrasts: not the familiar contrast between the ‘physical’ (or biomedically explained) and the ‘mental’ (or biomedically unexplained); nor the contrast between ‘evidence’ (and the epistemological

authority of biomedicine) and 'experience' (and the epistemological authority of the patient). Both of these are contrasts that the classic model of somatisation rendered as a polemical contradiction between mutually exclusive alternatives. The new contrasts specifically concern the pragmatic value of the explanations at play, and introduce important differentiations in terms of what it means to be 'pragmatic' in relation to the problem of explaining symptoms that are not susceptible to a linear causal narrative. In what follows I will stage these contrasts to argue that an appreciation of them is important not only in a clinical context, but also for the purpose of defining the value of social scientific representations of, and interventions in, this contested field.

Explanations as a 'wager on an unfinished present'

If it is true that the clinical consultation can have somatising effects it is also true that not all patients are badly managed in the sense of being 'somatised'. On this basis, the same group of researchers who illustrated the somatising effects of the clinical consultation have also studied the communication between doctors and patients with 'medically unexplained symptoms' with a view to articulating what types of explanations are perceived as 'satisfying' and 'empowering', and can as such be considered clinically effective (Salmon et al., 1999; Dowrick et al., 2004). Like the studies reviewed above, these too turn the tables on how the problem has traditionally been posed. Often referred to as an act of 'normalisation' of symptoms, the process of reassurance is conceived as facilitating the 'recognition that symptoms are part of the normal human experience' and do not necessarily represent disease, or even illness (Kessler and Hamilton 2004: 163). This process often fails, and the failure has traditionally been imputed to the psychological characteristics of patients (*'what's wrong with this patient, such that they cannot be reassured?'*). Indeed, the failure to be reassured is a key aspect of the classic definition of somatisation by Lipowski (1988). In contrast to this approach, and focusing on the delivery of reassurance by doctors, Dowrick et al. (2004) found that the explanations that succeed in reassuring patients have three characteristics: first, they acknowledge and validate the patient's sense of suffering, without dismissing the reality or significance of the symptoms; second,

they provide ‘tangible mechanisms’ to explain the symptoms, arising as part of a discussion with the patient as an active interlocutor; and third, they offer patients the opportunity to link the physical symptoms to the psychosocial dimensions of the patient’s life (see also Salmon et al., 1999). At least one programme of research in the UK is currently taking these characteristics as points of departure for the development and testing of explanations as a form of intervention, in the context of a primary-secondary care interface clinic known as The Symptoms Clinic (Burton et al., 2012; Burton et al., 2013). For the present discussion, it is worth dwelling on a data excerpt that Dowrick et al., in their original study, present as an illustration of a successful explanation (2004, p. 168):

Dr: *‘The only thing that fits is, it’s the sort of pain you get with shingles because it comes around in that pattern.’*

P: *‘Yes, yes.’*

Dr: *‘And that’s sometimes irritation of the nerve endings.’*

P: *‘That’s what somebody else, me Nan says, “It could be your nerves”.’*

Dr: *‘I don’t mean your emotional nerves, your actual physical nerves that come round your body – but it could be made worse by stress or things like that.’*

P: *‘I mean, I’m obviously one of them people that are highly strung anyway, I know that. [...]’*

Dr: *‘Have you had any sort of relaxation to see if that would help your pain?’*

What is immediately striking about the content of this exchange – like that of the other excerpts the authors bring as examples – is its distance and difference with respect to the sense in which it might qualify as an ‘explanation’ in any scientific, epistemologically authoritative sense, or even as the rendition of such an explanation in commonsense language. This is a point Dowrick et al. (2004: 169) stress in the discussion of their findings: ‘[w]hat is emerging here’, they write, ‘is a crucial difference between explanations drawn *a priori* from medical knowledge, and those developed by patients and practitioners within shared frameworks that ... are more likely to provide a satisfactory representation of illness, and of the causes and consequences of symptoms.’

In a broader policy and cultural context characterised by values of patient-centredness and democratisation, explanations that are co-constructed rather than unilaterally imposed may appear inherently more desirable or 'better' in so far as they instantiate values of patient involvement and participation. But when there is a conflict of interpretations involved, as often in the domain of 'medically unexplained symptoms', the effort to include patient perspectives can result in seemingly intractable dilemmas and distortions. Forms of professional collusion or acquiescence with biomedical theories proposed by patients, even when these contradict existing evidence and/or the explanatory models favoured by doctors based on such evidence, have been documented both in the context of the consultation and at the level of clinical guideline development (Salmon et al., 1999; Smith and Wessely, 2014). In such cases, we might say that the political value of participation, when it is privileged uncritically with respect to the question of knowledge validity, is allowed to trump the latter, with the potential result of further undermining confidence in the competences of each party and in the process (cf. Jasanoff, 2003). It is therefore crucial to note, in this respect, that what is going on in the proposition of a curriculum of medical explanation for 'medically unexplained symptoms' is something different from the appeal to a form of political (and procedural) accountability in the name of patient-centredness or democratisation. *This proposition instantiates co-construction not primarily as a political value, but rather as a process that is medically appropriate on account of how the nature of the phenomenon it addresses is conceived.* Crudely put, the explanations that are being developed in the context of this problematisation are explanations borne out of a recognition that the nature of the illness – and not just that of the patient as a citizen or consumer – is such as not to be indifferent to what explanations are applied to it. In this sense, it is an approach that foregrounds the importance of *process* not merely in procedural terms, as what occurs between pre-constituted subjects or entities, but in the conception of the nature of the medical entity as an explicitly unfinished, becoming entity, and also as a vital and responsive entity. It is therefore an approach that differs profoundly from the epistemological structure of biomedicine, where diagnostic acts are separated from therapeutic acts, on the assumption that disease is 'a biological reality, independent of any therapeutic

relationship or intervention, that is simply waiting to be discovered and correctly labeled' (Kirmayer, 1994: 184). On the contrary, we may read these explanations, in the vein of a *speculative pragmatism*, as a 'wager on the unfinishedness of the present, ... an intellectual operation whose business is that of making thought *creative of an alternative future* by producing an inventive response to an impending problem' (Savransky, 2016).

Conceived in this way, the explanations resemble forms of psychotherapeutic truth that Kirmayer (1994: 198 and ff.) describes as prospective, proactive and prescriptive: truths whose value relies not on their ability to accurately describe causal mechanisms and predict the future, but on their ability to lure events – and the embodied experience of the patient, in this case – in the direction of new possibilities. Importantly, the *de facto psycho*-therapeutic character of the explanations, in this case, emphatically does not imply an attribution of psychopathology (as distinct from organic pathology) or a psychiatric diagnosis (as distinct from a biomedical one). Again, the reason for this stems less from 'political' concerns as such (e.g. a concern not to offend) than from the specific nature of the problem at hand and the exigencies or obligations this generates in terms of constructing a valid explanation, one that 'satisfies' from a scientific as much as from a clinical and political perspective. These are explanations that take somatic symptoms seriously as such, that is, that do not regard them as proxies for psychological distress; they refer to what goes on in the body and offer suggestions as to how concrete bodily processes may be visualised or imagined, in a conversational framework that relates these closely to the patients' psychosocial reality, in response to specific cues (rather than as the application of an abstract and general theory). The science to which the explanations implicitly refer, as we have seen, is one not of simple causal mechanisms but of complex pathways and feedback loops involving simultaneously biological, psychological and social events. In focusing attention on these processes, rather than on a diagnostic label, the explanations are effectively educating patients (and doctors) into thinking differently about causality. If the explanations 'ring true', and are thereby effective, this is not because they simply confirm pre-existing (and possibly dysfunctional) beliefs but because there is no longer an irreducible

contradiction between the medical (or scientific) ‘truth’ and that of the patient’s experience.

To appreciate the potential achievement of these explanations as a form of intervention does not imply, of course, that their value can be generalised to all patients and all situations. Indeed it is no accident that they are being developed in the context of primary care, where the dynamic leading to a *iatrogenic vortex* arguably begins or at least is found at its earliest stages. My aim here, however, is not to focus on the transportability or otherwise of the intervention – an interesting question that will have to be explored elsewhere – but rather to highlight how they instantiate a form of *creative accountability*, one that ‘dares to speculate about what may come into existence because of the ... intervention’ (Stengers, 2008: 53; see also Puig de la Bellacasa, 2011). In the following and concluding section of this paper, my focus will be on how social scientific research relates to the question of explanation in the field of ‘medically unexplained symptoms’ and of contested illnesses, and briefly on the implications of my discussion for thinking about ‘how “we” [social scientists] are contributing to the construction of the world’ (Puig de la Bellacasa, 2011: 89).

‘Cash-value’ pragmatism and the creative accountability of epistemic neutrality

In a chapter entitled ‘When explanations rest: “good enough” brain science and the new socio-medical disorders’, US-based anthropologist Joe Dumit (2000) illustrates how patient groups involved in advocating the biomedical character of contested illnesses – such as Multiple Chemical Sensitivity or Chronic Fatigue Syndrome – often do so by mobilising brain imaging technologies as sources of factual and objective evidence for their claims. Dumit conducted a multi-sited ethnography: he observed communities of medical researchers in their laboratories and conferences, but he also followed activists, court cases, and popular culture representations. What he found, unsurprisingly, is that brain imaging scans were appreciated and evaluated very differently, as forms of evidence, in different contexts: explanations and evidence that might not satisfy a scientific researcher could be ‘good enough’ in other settings such as courtrooms,

for example, at least temporarily. His research clearly shows that, whether explanations are 'true' or not in a scientific sense, they have pragmatic functions and these are multiple and vary by context. Against this background, Dumit asks: 'Are these preliminary underfunded [brain imaging] studies, which are touted as proof, "bad science"? Are internet groups pressing for specific research agendas biasing otherwise objective work? Or is it possible that there is a *need* for public relations research promoting these disorders as "brain disorders"?' (2000: 227). In other words: since there is a pragmatic value to these explanations, can and should their pragmatic value trump the issue whether they are scientifically 'true'? In asking this question – to which his rhetoric suggests a positive answer – Dumit explicitly refers the pragmatic value of brain-based explanations to the context of the political economy of health in the United States, where access to healthcare services is highly contingent on criteria set by insurance agencies that rely on codified diagnoses and are typically reluctant to treat mental illness. In such a context, arguing for the neurobiological basis of a given disorder is equivalent, in a very concrete sense, to arguing for its recognition as 'real' versus its dismissal as 'unreal'.

The pragmatism exemplified in Dumit's approach tends thus towards a form of relativism or agnosticism in relation to the question of the nature of the illnesses about which he writes. Such agnosticism is not untypical of social scientific research on 'medically unexplained symptoms', much of which has focused on the psychosocial consequences of living with an uncertain illness, while remaining silent on the question of how they might be 'truthfully' characterised other than as 'uncertain' or 'contested'. It is fair to say that, in the approach exemplified here by Dumit, it doesn't matter if the science mobilised by patient activists is 'bad science': what matters is that it facilitates and sustains the mobilisation. But if what matters is the pragmatic value of the explanations at stake rather than their scientific 'truth', it is still possible to put such explanations to the (pragmatic) test of the difference they make to the phenomenon they address. It is still possible, in other words, to consider how different theoretical characterisations of the nature of symptoms, by becoming part of their *milieu*, may infect and affect their possibilities of becoming. In this sense, and to state the matter in the broadest

terms, the pragmatic value of biomedical explanations – in so far as these ‘work’ – is to purchase legitimacy on an immediate and piecemeal basis at the expense of reinforcing a mode of thought that, as we have seen, is an important factor in producing the experience and predicament of ‘medically unexplained symptoms’ at a variety of levels. This ‘cash-value’ pragmatism⁴ stands in sharp contrast with a speculative pragmatism that is characterised by an effort to ‘[vectorise] a transition into ... novel situations’ (Savransky, 2016), and thus by creative accountability.

The reconfiguration of the discursive space around symptoms that we see currently occurring in the UK and northern Europe offers significant points of contrast with respect to the problematisation of ‘contested illnesses’ that we see described in sociological and anthropological literature mostly from North America. The analysis of this contrast – which I leave to a future occasion – can suggest important insights into the possible evolution of these conditions in the context of different political economies of health.

¹ It is significant in this respect that even the most thoroughly argued critiques of ‘medically unexplained symptoms’ – critiques that reject the expression on scientific and epistemological grounds – still retain it albeit in crossed-out form as ~~medically unexplained symptoms~~ (see Creed, 2013). This suggests that, for all its epistemological faults, it remains so far a useful point of departure and entry into the relevant debates.

² In this connection it is worth mentioning that the expression ‘medically unexplained symptoms’ is already well past its sell-by date, with preference given (at least provisionally, in this study) to Persistent Physical Symptoms and Functional Symptoms (Marks and Hunter, 2015). See also Stone et al. (2002) for a study that measures the degree of offensiveness of different expressions that may be used to refer to symptoms.

³ In Greco and Stenner (in press) we describe this dynamic as typical of what we call a ‘liminal hotpot’, and discuss *paradox*, *paralysis*, *polarisation* and the potential for *pattern shift* as generic characteristics of such hotspots.

⁴ I owe the expression ‘cash-value’ to Martin Savransky (in press), who in turn highlights its use by William James in *Pragmatism and the Meaning of Truth* (1907/2011).

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