

Holistic or harmful? Examining socio-structural factors in the biopsychosocial model of chronic illness, 'medically unexplained symptoms' and disability.

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Holistic or harmful? Examining socio-structural factors in the biopsychosocial model of chronic illness, ‘medically unexplained symptoms’ and disability.

Abstract

A particular application of the biopsychosocial model is associated in peer-reviewed literature and patient testimony with harms done to chronically ill and disabled people. These harms derive from an empirically unsubstantiated, neoliberal narrative emphasising the role of personal responsibility and effort in ‘recovery’ from ill-health, ignoring socio-structural contributors to chronic illness and disability. Notably, this biopsychosocial model ignores the health-related impact of welfare and disability insurance reforms which the model has been employed to justify. The model and associated interests can thus be recognised as socio-structural phenomena that should be acknowledged in any truly holistic biopsychosocial approach to chronic illness and disability. A critically informed and reflexive approach to biopsychosocial theorising would allow a more holistic and nuanced understanding of chronic illness and disability, with implications for health and social policy that underline and address what ails society as opposed to what is ‘wrong’ with the individual.

Points of interest

- The biopsychosocial approach suggests that health and illness should be understood ‘holistically’. This means considering not only a person’s biology, but also their psychology (thoughts and behaviour) and social context (for example, social support levels).
- A particular variant of biopsychosocial model, dominant in UK health and social policy, has been associated with political agendas, predominantly: welfare reform, healthcare spending cuts, and creation of profits for the disability insurance industry.
- This variant of the model has also been associated with harms experienced by chronically ill and disabled people.
- Any truly holistic biopsychosocial framework should acknowledge the broader social (here, political) context that has shaped this model and recognise how the model, and associated practices, may contribute to chronic illness and disability.
- Such a framework gives rise to recommendations for health and social policy and practice that address what is wrong with society as opposed to what is ‘wrong’ with the person.

Introduction

The biopsychosocial (BPS) model of health and illness, as discussed in mainstream literature, is typically associated with George Engel (1977, 1992), a doctor who sought to address what he considered a reductionist and dualistic biomedical model through the development of a more holistic and patient-centred approach to healthcare. The BPS model thus ostensibly acknowledges psychological and social factors in health and illness alongside biological considerations. However, Engel's BPS model has been critiqued for a lack of clarity over the precise role of, and relationships between, biological, social and psychological influences: it has been argued that this results in conceptual impoverishment and unbridled eclecticism whereby any influence can be foregrounded, without clinical rationale, as per the biases of whomever applies the model (Ghaemi 2009; van Oudenhove and Cuypers 2014). This point of critique is important, since the term 'BPS model' may carry various connotations and be differentially applied.

Within the healthcare sector, particularly for medically legitimised conditions, a BPS model is applied in many potentially productive ways. Here, 'medically legitimised' (accepted by the medical profession as a legitimate medical entity) stands in contrast to 'contested' conditions, where medical uncertainty predominates (see: Dumit 2006). In the former case, a BPS approach has been applied to, for example, explore correlates of coping with illness, investigate risk factors, develop psychosocial interventions to address side-effects of (biomedical) treatment, and to conceptualise and manage mental health co-morbidities (Grapp et al. 2022; Habtewold et al. 2016; Lauriola and Tomai 2019). In these cases, 'psychosocial' refers to a recognition that social factors (for example, relationships,

social support) and psychological factors (the individual's thoughts, feelings and behaviours) impact on overall health. The BPS model has been argued to add value particularly in the field of mental health (Gask 2018) by offering a less biologically reductive and pathologising alternative to the biomedical model, although some have argued that socio-structural factors continue to be downplayed (Johnstone and Boyle 2018). However, within the UK health and social policy arena, particularly within the context of welfare reform and what the UK National Health Service (NHS) refers to as 'medically unexplained symptoms' (NHS 2021), a BPS model has been applied in a way that, it will be argued, contributes to chronic illness burden and furthers disability. The research presented in this article examines this particular variant of 'the BPS model'.

Disability studies scholars and disabled activists have argued that the BPS model as it dominates health and social policy – sometimes referred to as the Waddell-Aylward BPS model after two of the model's chief architects (Shakespeare, Watson, and Alghaib 2017) - has been manipulated to serve a neoliberal agenda to reduce state health and social expenditure, increase corporate profits, and protect the market and interests of the privileged at the expense of chronically ill and disabled people (Jolly 2012; Berger 2014; Stewart 2019). It is argued that associations and shared interests among actors in academia (predominantly, within psychiatry), the UK government and disability insurance industry underpin a policy of depriving chronically ill and disabled people of welfare provision, appropriate healthcare and/or private disability insurance income protection, ushering them into individualistic psychosocial rehabilitative 'treatments' and thus inappropriately declaring them 'fit for work' (Faulkner 2016; Hooper and Williams 2010; Rutherford 2007a). In this regard, the BPS model downplays biological considerations whilst the 'psychosocial'

dons a mantle of victim-blaming: chronic illness and disability (here understood simply as restricted activity) are considered to be perpetuated by ‘maladaptive’ thoughts and behaviours, alongside over-reliance on or sense of entitlement toward social support such as the benefits system (Waddell and Aylward 2010; Halligan, Bass, and Oakley 2003; Sharpe 2002). Whilst successive welfare reforms and more stringent benefits assessments have been associated with psychological distress, destitution and increased suicides amongst chronically ill and disabled people (Barr et al. 2016; Stewart 2018; Pring 2017), harms are also reported in the healthcare arena. Undue psychologisation of chronic illness through biopsychosocial theorising, largely illnesses that can be framed as ‘medically unexplained symptoms’ or otherwise medically ‘contested’ conditions (Horton-Salway 2002), has been associated with physical, psychosocial and economic harms sustained by chronically ill and disabled people (Geraghty and Blease 2019; Hale et al. 2021a). Lack of medical certainty or consensus around certain chronic illnesses allows political agendas to take centre stage (Dumit 2006; Rutherford 2007a); therefore, although points raised here are of potential relevance to all chronic illness, the focus is on ‘contested’ (highly politicised, stigmatised and medically neglected) chronic illness and associated disability.

BPS theorising and associated agendas under scrutiny in this article can thus be conceptualised as macro- and meso-level phenomena that are doing enormous harm to chronically ill and disabled people. In essence, this application of the BPS model can be understood as a political tool employed to justify welfare and disability insurance policy reforms, reducing welfare provision and biomedical care, whilst facilitating corporate profiteering (Stewart 2019). Interestingly, Engel’s work on the BPS model acknowledged not only individual factors such as the patient, but also “*the social context* in which he [sic] lives,

and *the complementary system devised by society* to deal with the disruptive effects of illness, that is, *the physician role and the health care system*" (Engel 1977, 132, author's italics). These social and structural (socio-structural) influences are curiously missing in the BPS model as it dominates UK policy and practice. That is, the BPS model and associated discourse does not acknowledge how this model, and the agendas of those who promote it, may be adding to the burden of chronic illness and furthering disability.

This article argues that the BPS model and associated interests, as foregrounded in UK health and social policy, can be recognised through a critically informed lens as socio-structural phenomena that should be recognised and addressed in any truly holistic BPS (or rather, bio-psycho-socio-structural) approach to chronic illness and disability. The article draws largely upon myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) as an analogue of broader chronic illness and disability matters, particularly those illnesses and disabilities that are considered medically unexplained or 'contested' and thus susceptible to greater politicisation. ME/CFS appears to have been a prime target of, and blueprint for, state welfare and disability insurance industry reform (Hooper and Williams 2010; Rutherford 2007a; Jackson 1995) and has historically been a prime target of BPS theorising (Sharpe et al. 1997; White et al. 2011; Adamson et al. 2020), despite lack of evidence base for BPS-inspired healthcare interventions (Wilshire et al. 2017; Hughes and Tuller 2022; Geraghty et al. 2019). Points raised in this article are of growing relevance given the emergence of long Covid, where some cases lack diagnostic biomarkers, and which is increasingly subject to BPS theorising (Willis and Chalder 2021; Sharpe 2021; Verveen et al. 2022).

In what follows, key terms are defined and an underpinning theoretical stance is outlined. Next, a detailed explanation is offered as to why the BPS model and associated interests can be considered socio-structural phenomena. Following this, 'social' influences in chronic illness and disability as forwarded by the BPS model are explored, finding them to derive from an individualistic psychology narrative that is employed to justify BPS-inspired policy and practice. Socio-structural influences in chronic illness and disability (ignored by the BPS model) are then examined, noting that these influences arise from or are reinforced by BPS discourse, policy and practice, and qualitative data are drawn upon to demonstrate harms to chronically ill and disabled people. Finally, implications for policy and practice arising from a bio-psycho-socio-structural model of chronic illness and disability are discussed, including a shift from focusing on what is allegedly 'wrong' with the individual to addressing what is wrong with the matrix of social systems in which the individual resides.

Theoretical grounding and definition of terms

This article draws principally on a social relational understanding of disability (Thomas 1999, 2004, 2007), whereby disability is defined as a "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas 1999, 3). In this case, chronic illness, including 'medically unexplained symptoms', can be understood as a form of impairment and, as per the distinction highlighted by the social model (Oliver 1983, 1990), disability is understood as a form of oppression imposed upon people with impairments. The social relational model advances the social model in important ways that are central to points raised here. Notably, acknowledged sources of disability or disablism -

the latter term defined as social practices and assumptions that disadvantage people with impairments (Thomas 2007) - extend beyond the social model's focus on macro- and meso-level social barriers to encompass micro-level (interpersonal) interactions (Thomas 1999, 2007). Such interactions include being stared at and having jokes made at one's expense (Reeve 2004, 2006); in the case of 'medically unexplained symptoms' where impairment might not be immediately apparent, disbelief is a recurrent theme (Blease, Carel and Geraghty 2017; Hale et al. 2020). These micro-level interactions, and broader social discourse, are frequently permeated with ableism (Bê 2019), understood as "a cultural imaginary and social order centred around the idealised able-bodied and -minded citizen who is self-sufficient, self-governing and autonomous" (Goodley 2020, 366-367). Thus, if disablism is analogous to sexism or racism, ableism is analogous to patriarchy or whiteness (Bê 2019): this article will argue that both disablism and ableism, reinforced by and reinforcing a particular application of the BPS model, can increase chronic illness burden and further disability. The self-sufficiency and autonomy valued by ableism is bound up with neoliberalism, a biopolitical-economic ideology discernible in social practices and the social imaginary through an emphasis on competition, consumer-citizens, personal responsibility, free will and self-determination (Adams et al. 2019). Of particular relevance to this article, neoliberalism in the realm of disability policy has been said to create a hierarchy of disabled people whereby only a portion are deemed worthy of state support, whilst the larger portion (perceived to be partially or not really disabled) are re-framed as undeserving and fit to enter the labour market – or invalidated as scroungers and malingerers where disabled people fall short of neoliberal exigencies (Soldatic 2020; Hughes 2015).

A social relational understanding of disability is compatible with feminist, post-structural and phenomenological challenges to the social model (Morris 1992, 1996; Crow 1996; Shildrick 2020; Meekosha and Shuttleworth 2009; Hughes and Paterson 1997), notably recognition that the ‘impairment (biological) – disability (social)’ distinction implied by the social model is problematic. From a feminist viewpoint, the need to link political issues to ‘private troubles’, alongside acknowledgement that removing social barriers will not remove all impairment-related struggles (Crow 1996; Morris 1992, 1996; Thomas 2007), points to a well-recognised need to theorise impairment and chronic illness within disability studies. Of importance for this article, such a viewpoint highlights need for improved chronic illness healthcare, whilst recognising that the medical system is socio-politically situated (Hale et al. 2020), alongside a need to foreground the lived experiences of chronically ill people. The post-structuralist recognition that both impairment and disability are in part constituted through the social imaginary and discourse (Tremain 2001) bears relevance to the role of the BPS model and discourse in constructing particular patient groups as not really disabled. Finally, phenomenology’s emphasis on the interweaving of impairment and disability through lived experience (Hughes and Paterson 1997) is reflected in this article through inclusion of qualitative data and the lived experience of the author, as a disabled person. Tying these theoretically diverse strands together, the article assumes that impairment (here, predominantly, ‘medically unexplained symptoms’) is in part socio-culturally constituted whilst disability (oppression, prejudice, exclusion) can become embodied (Hughes and Paterson 1997; Reeve 2004). In summary, the article takes a pluralist approach underpinned with disability studies’ emphasis on disability as social oppression.

The term 'critically informed' denotes an approach that is consistent with critical theory, as can be found weaving through disciplines such as critical disability studies, critical feminism and critical psychology (Meekosha and Shuttleworth 2009; Lafrance and Wigginton 2019; Teo 2015). The article thus assumes a central role of, and recognises a need to interrogate, socio-structural contexts, power relations and dominant discourse in (re)producing health, healthcare and social inequities and in influencing chronic illness and disability. Consistent with the emphasis on the situated (sociocultural, political and historical context-bound) nature of knowledge, a key tenet of critically informed approaches is that of critical reflexivity (Meekosha and Shuttleworth 2009; Lafrance and Wigginton 2019; Teo 2015), which is a reflexive awareness of this situatedness. Critical reflexivity involves recognising how conceptual frameworks and underpinning epistemologies are products of particular intersected social positionalities, positionalities that limit the ability to appreciate other ways of knowing (Ng et al. 2019). Critical reflexivity thus involves an openness to other epistemologies, whilst questioning who stands to benefit from and be disadvantaged by dominant epistemologies. Of relevance to this article, a critically reflexive approach acknowledges the socio-political context in which the BPS model has evolved, and how a variant of this model represents a detrimental socio-structural influence in chronic illness and disability, whilst engendering a revised, bio-psycho-socio-structural framework.

The term socio-structural, used throughout this article, requires elucidation. In its broadest sense, structure refers to recurrent patterns of social relationships and practices within a social system, patterns that enable and limit individual opportunities (Aragon and Jagger 2018; Link and Phelan 2014). Structures are conceptualised here as economic, political and corporate interests, mainstream institutions (including healthcare systems),

legislation, policies, and associated discourse that privilege some groups whilst disempowering others, partly through policing access to healthcare and welfare provisions and subjecting certain individuals and groups to stigma and epistemic injustice (see Friedman 2020; Hughes 2015; Shakespeare, Watson and Alghaib 2017; Blease, Carel and Geraghty 2017). Whilst the term ‘social determinants of health’ is widely-recognised and refers to the impact of social conditions such as healthcare access, employment or financial support on health (CSDH 2008), the term ‘structural determinants of health’ is increasingly used to highlight the impact of structures such as health and social policy and market forces (Friedman 2020). Importantly for points raised in this article, negative attitudinal contexts can be understood as a structural factor (Link and Phelan 2014) and stigma has been recognised as a structural and social determinant of health (Hatzenbuehler, Phelan and Link 2013; Hatzenbuehler 2016). Moreover, the term ‘structural injustice’ (Young 2003, 2011), has been used to underline the role of structural factors in contributing to social and health inequities.

Whilst recognition of the centrality of structures in (re)producing health and social inequities is crucial, structures are internalised and (re)produced by individuals and groups through social practices (Aragon and Jagger 2018), thereby underlining individual agency. Furthermore, structural injustices are created by the interaction of structures with social categories that result in oppression and privilege, categories such as race, gender, disability, class, sexuality and immigrant status (Gkiouleka et al. 2018; Abrams et al. 2020). Separating the ‘structural’ from the ‘social’ not only risks overlooking downstream (group and individual) costs of structural injustices, but also risks downplaying individual or group responsibility in such a way that the issue of complicity remains unaddressed (see: Aragon

and Jagger 2018). Individual complicity in structural discrimination is well-documented in the case of racism, for example, through allowing discriminatory practices and discourse to go unchallenged (Jones 2021); however, complicity in disablism is less well recognised. Whilst certain actors may be intentionally complicit (or collusive) in the appropriation of BPS discourse for political and professional purposes (Hooper and Williams 2010; Rutherford 2007a), other well-meaning individuals may be unintentionally complicit through lack of awareness or reflection. For these reasons, the BPS model, associated discourse and political-economic interests are arguably best understood as socio-structural phenomena. This can be elucidated more fully through examining the political origins of the model as it dominates policy and practice around ‘medically unexplained symptoms’.

The BPS model as a socio-structural phenomenon

The origins of what has been termed the Waddell-Aylward BPS model (Shakespeare, Watson, and Alghaib 2017), here referred to simply as the BPS model with above-mentioned caveats, can be traced back to the late Gordon Waddell’s conceptualisation of chronic back pain (Waddell 1987; Waddell 1999). The model was, however, largely developed through the work of the Centre for Psychosocial and Disability Research at Cardiff University, for some years sponsored by disability insurance giant Unum (then, Unum Provident). The centre was directed by Mansel Aylward, formerly Chief Medical Advisor, Medical Director and Chief Scientist at the Department of Work and Pensions (DWP) with Waddell as honorary professor, whilst some of the centre’s research was commissioned by the DWP (Rutherford 2007a; Stewart 2019). Although Waddell and Aylward were key architects of the BPS model, a number of other influential academics (largely but not exclusively in the

field of ME/CFS) have been central to the model's development (see: Halligan, Bass, and Oakley 2003; White 2005). The research produced by the Cardiff centre (Waddell and Burton 2004; Waddell and Aylward 2005; Waddell and Aylward 2010) catalysed reform of the state welfare system and disability insurance industry policy on income protection. Of particular note, the 2005 monolith 'The Scientific and Conceptual Basis of Incapacity Benefits' (Waddell and Aylward, 2005) laid the foundations for the 2006 Welfare Reform Bill and the 2007 Welfare Reform Act, and, together with the oft-named Freud report (Freud 2007), set out the design for the 2008 Work Capability Assessment (WCA) (Stewart, 2019). The WCA, which accompanied the transition from Incapacity Benefit to Employment and Support Allowance, is far more stringent than previous assessing, being associated with enormous suffering among chronically ill and disabled people as previously outlined (Barr et al. 2016; Stewart 2018; Pring 2017). Further, 'the biopsychosocial model' was acknowledged, during debates leading up to the 2012 Welfare Reform Act, to inform assessments for Personal Independence Payment (PIP), which gradually replaced Disability Living Allowance (DLA) as part of the Act's provisions (see Faulkner 2016); the profoundly detrimental impact of this transition on disabled people has been discussed elsewhere (Saffer, Nolte, and Duffy, 2018; Roulstone, 2015).

Health conditions that can be framed as primarily psychological or psychosocial in nature, and thus amenable to psychosocial 'treatments', can be exempted from certain welfare provisions, cutting social security and biomedical healthcare spending, whilst creating a role for those involved in the development and provision of 'rehabilitative' interventions (Waddell and Aylward 2010; White 2005; Sharpe 2002). A cluster of these alleged psychosocial conditions are often referred to in the UK NHS and in BPS-inspired

literature as ‘medically unexplained symptoms’ (NHS 2021; Waddell and Aylward 2010; Page and Wessely 2003); however, some BPS literature discourages comprehensive biomedical investigations (Sharpe et al. 1997; Wessely 1996) making ‘medically unexplained symptoms’ a clinically meaningless but politically useful construct that justifies and is justified by BPS narratives. Exemption of such conditions from state support might encourage potential claimants with the means to take out private income insurance, which Unum and other disability insurance companies have been keen to sell, and quick to renege upon, through exploiting mental health exemptions (Hansard 1999; Rutherford 2007a). Mainstream positioning of ‘medically unexplained symptoms’ is therefore a lucrative endeavour from the perspective of the disability insurance industry (Rutherford 2007a; Faulkner 2016). The principal psychosocial interventions advocated, cognitive behavioural therapy (CBT) and graded exercise therapy (GET) have been developed by eminent academics (again, chiefly in the field of ME/CFS), some of whom have played a prominent role in the healthcare sector (Geraghty and Esmail 2020), with known associations as advisors to the UK government and disability insurance industry (Hooper and Williams 2010; Select Committee on Health 2007; Marks 2017). This complex of associations between the UK government, disability insurance industry and certain academics has been referred to as the ‘academic-state-corporate nexus’ (Rutherford 2007b).

The interests of this nexus have arguably been supported by other socio-structural phenomena, including inequitable public research funding, academic publishing biases, inadequate medical education and a largely complicit UK press. The majority of public research funding, particularly in the case of ME/CFS, has historically been allocated to psychosocial research which has been widely critiqued on methodological and ethical

grounds (see: White et al. 2011; Wilshire et al. 2017; Marks 2017). Editors of medical journals have declined to retract and/or re-review studies acknowledged by many within the scientific community to be methodologically and ethically flawed, whilst reinforcing stigmatising narratives around chronically ill and disabled people (Tuller 2018; Tuller 2019; The Lancet 2011; Godlee 2011). The UK mainstream press has, with some exceptions, largely been complicit in such stigmatisation (Briant, Watson and Philo 2013; Anthony 2019), with headlines such as “Always fatigued — yet they never tire of claiming their malady really is a virus” (Liddle 2019); in the case of ME/CFS, some positive coverage has followed the emergence of long Covid (O’Neill 2020). The Science Media Centre (SMC 2020), which provides the UK media with science-related briefings, has established associations with influential BPS proponents (Faulkner 2016; Hooper and Williams 2010) and it has been suggested that broadsheet editors are permitted only to source their ME/CFS-related stories from this centre (Hooper and Williams 2010). Moreover, undergraduate medical education, both within the UK and beyond, accords little curriculum space to biomedical understandings of ‘contested’ illnesses such as ME/CFS, or to structural influences in chronic illness and disability (Jason et al. 2010; Muirhead et al. 2021; Halman, Baker and Ng 2017; Metzl and Hansen 2014). Finally, biases against certain chronic illnesses are reflected in NHS England policy, where the ‘Quality and Outcomes Framework’ (QOF) (NHS Digital 2021) incentivises GPs to provide quality care to people with most medically legitimised conditions, but not to people with ‘contested’ conditions. QOF is a pay-for-performance scheme, introduced in 2004, whereby GP practices receive payments for meeting clinical indicators through accruing ‘points’ (Roland 2004). Whilst conditions such as diabetes, cancer and chronic kidney disease qualify for QOF points, ME/CFS, fibromyalgia, chronic

Lyme and other conditions that could be positioned as ‘medically unexplained’ or otherwise ‘contested’ do not qualify (NHS Digital 2021). Some research suggests that GPs may be disincentivised from caring for ME/CFS patients because such care does not accrue ‘points’ (Hannon et al. 2012). The BPS model and associated discourse as it applies to ‘contested’ chronic illness may thus be understood as being reinforced by broader socio-structural phenomena that position some disabled and chronically ill people as less deserving than others.

‘Social’ factors in the BPS model

According to BPS-inspired research issuing from the Cardiff centre, certain forms of chronic ill-health and disability are heavily influenced by “conscious choice, motivation and effort” (Waddell and Aylward 2010, 21) for which chronically ill and disabled people should take personal responsibility, thus adopting an individualistic perspective consonant with neoliberal, ableist ideology (Stewart 2019; Adams et al. 2019). Here, ‘disability’ does not draw from the social oppression paradigm of disability foregrounded in disability studies, but rather refers to restricted activity, as per a medical sociological understanding of the term (see Thomas 2007) that is dominant in mainstream healthcare settings. Whilst social factors are briefly mentioned, and the social model of disability acknowledged, these factors are significantly downplayed: the social model of disability is said to be lacking scientific basis whilst social factors given greatest emphasis are those of an individualistic flavour (Waddell and Aylward 2005; Waddell and Aylward 2010). Purported reinforcement of ‘illness behaviour’ by clinicians and significant others, alongside ‘secondary gains’ (attention, financial benefits, avoidance of work and other obligations) within a culture of entitlement

are postulated to perpetuate chronic illness and disability (Wade and Halligan 2007; Waddell and Burton 2004). Such theorising arguably crosses the line from clinical judgements to moralising, and promotes a victim-blaming narrative facilitative of stigma. This cherry-picking of social factors justifies the model's existence, since rehabilitative interventions are developed and promoted to target this alleged illness behaviour.

The social model of disability is conceded to retain some relevance in 'severe medical conditions'; these are defined as conditions such as blindness or amputation and are said to be conditions for which social security and work-related compensation were originally designed (Waddell and Aylward 2010). However, again in keeping with a neoliberal and ableist philosophy, the social model, even in the case of 'severe medical conditions', is said to be limited by its lack of recognition of 'personal/psychological' influences in ill-health and disability such as personal responsibility, free will and motivation. Moreover, many debilitating illnesses such as ME/CFS are not classified as severe medical conditions, instead being described as 'common health problems' (Waddell and Aylward 2005, 2010). This construct, used interchangeably in literature from the Cardiff centre with 'medically unexplained symptoms' and sometimes with 'functional somatic syndromes', encompasses mental health, musculoskeletal and cardio-respiratory conditions that are "characterised more by symptoms and distress than by consistently demonstrable tissue abnormality" (Waddell and Aylward 2010, 7) and are thus considered 'subjective health complaints'. As disability studies scholars have argued, this creates a hierarchy of deserving and undeserving impairment or chronic illness (see Shakespeare, Watson, and Alghaib 2017), a socio-politically constituted and subjective divide that fosters stigma and polices eligibility for health and social provisions (Soldatic, 2020). The BPS model has been criticised for

downplaying biological influences in ‘contested’ chronic illness, primarily in the case of ME/CFS (Geraghty and Blease, 2019; Geraghty et al., 2019); this downplaying can be observed in the construct of common health problems.

The case of ME/CFS demonstrates that this politicised form of BPS theorising has found its way into mainstream healthcare research, policy and practice. The same individualistic, victim-blaming narratives can be discerned both in dominant BPS discourse on ME/CFS and in the Cardiff centre’s theorising around implied ‘undeserving’ chronic illness; this is perhaps unsurprising, since these narratives arise from the same nexus of interests (see: Halligan et al. 2003; White 2005). Again, motivation and effort are considered key in improving ME/CFS health outcomes (Picariello et al. 2017), whilst cognitions and behaviours of people with ME/CFS are conceptualised through the same ‘maladaptive’ lens with concomitant recommendations of cognitive-behavioural ‘treatments’ (Wessely et al. 1989; Knoop et al. 2010). Consonant with BPS theorising around so-called medically unexplained symptoms, ME/CFS is considered a sociocultural phenomenon largely without bio-pathological underpinning (Stanley, Salmon, and Peters 2002; Sharpe and Greco 2019). As with Waddell and Aylward’s writing, BPS theorising of ME/CFS only acknowledges social factors as far as they fit a neoliberal, individualistic narrative, thus justifying the model and associated interventions. For example, variables such as receipt of benefits have been associated with – and assumed to be contributing factors toward – poorer treatment and/or health outcomes (Bentall et al. 2002; Turner-Stokes 2002; Deary, Chalder and Sharpe 2007). This posits social reinforcement of ‘maladaptive’ psychology (here, entitlement mindset, secondary gains) as a social factor whilst ignoring critically informed social influences such as healthcare-related prejudice and stigma (Åsbring and Närvänen 2002). In particular, the

structural context of welfare and disability insurance policy reform, alongside the involvement of certain key BPS proponents of ME/CFS in the UK government and disability insurance industry, are ignored as a socio-structural factor. This approach serves to shift the spotlight of scrutiny from the model itself, and motivations of its creators, onto chronically ill and disabled people.

Whilst the BPS model lacks theoretical coherency, it has also been robustly critiqued for a lack of empirical underpinning, both in the case of ME/CFS where the associated cognitive-behavioural model has also been subject of critique (Geraghty et al. 2019; Geraghty and Blease 2019) and within the context of chronic illness and disability more broadly (Shakespeare, Watson, and Alghaib 2017). Whilst the charges against the BPS model in this regard will not be detailed here, it should be noted that criticisms include conflating causation with correlation, strategic and misleading use of terminology, and selective referencing to bolster weak arguments (Shakespeare, Watson, and Alghaib 2017; Geraghty et al., 2019). Perhaps the largest failing of the BPS model is that it has little to no grounding in the narratives of chronically ill and disabled people (Blease, Carel, and Geraghty 2017). These marginalised narratives highlight the role of socio-structural influences in chronic illness and disability (Hale et al. 2020), which will now be explored in more detail.

Socio-structural determinants of health revisited

Whilst the BPS model of chronic illness and disability relies on an individualistic psychology narrative that tips over into victim-blaming, a critically informed approach reveals other influences in health, chronic illness and disability. As previously touched upon, social

conditions such as access to healthcare, education, employment or financial support, food security, housing and community conditions are all recognised as social determinants or influencers of health and are mutually reinforcing (CSDH 2008). These social conditions are impacted by inequitable distribution of resources, money and power, in turn driven largely by structural factors including, as previously mentioned, socio-economic policies, legislation, corporate interests, market forces and negative attitudinal contexts (Friedman 2020; Link and Phelan 2014; Heise et al. 2019). The above discussion has demonstrated that a particular application of the BPS model has arisen from and is reinforced by precisely these structural influences. Such factors, alongside negative media portrayals of disabled people (also associated with BPS discourse as previously discussed), can be conceptualised as contributing to the oppression of disabled and chronically ill people (see: Oliver and Barnes 2012). It is noteworthy that the health and social system, socio-structural factors that could be expected to support chronically ill and disabled people, are largely those that are implicated in harm. Likewise, and in a curious paradox with neoliberal rhetoric, BPS-related narratives and policies of ‘enablement’ (Select Committee on Work and Pensions 2006; Waddell and Burton 2004), which comprise depriving people who cannot work of financial support whilst offering inappropriate, return-to-work focused healthcare, create dependency and disempowerment among those whom such policies aim to enable (Faulkner 2016).

Before moving to a detailed examination of precisely how socio-structural factors increase chronic illness burden and further disability, it is important to note that the injustices associated with the BPS model do not impact equally on all chronically ill and disabled people. That is, variation in terms of intersected social (dis)advantage or socially

constituted identities impact on experience of exclusion and oppression (Gkiouleka et al. 2018; Abrams et al. 2020), including within the healthcare arena (Turan et al. 2019). Further, it has been argued that impairment is bound up with ‘geographies of privilege’ (Sherry 2016) and that social inequality plays an important role in constituting impairment. Limited ‘contested’ illness research drawing from demographically diverse samples suggests that multiply marginalised persons experience extra barriers to healthcare (experience greater disability), notably where racial, ethnic and economic disadvantage intersect with impairment (de Carvalho Leite et al. 2011). Moreover, gender bias has shaped narratives around ‘medically unexplained symptoms’ (O’Leary 2018), whilst the historical (re-)framing of ME/CFS as hysteria, on grounds that most patients in then documented cases were women (McEvedy and Beard 1970), supports the notion that disability and impairment are constructed through “gendered norms and sexist practices” (Goodley 2013, 637). Intersectionality is therefore an important consideration in understanding impairment and disability, yet there is a dearth of literature taking an explicit intersectional approach to ‘medically unexplained symptoms’.

Downstream effects of socio-structural injustices

The downstream impact of injustices associated with BPS discourse, policy and practice can be understood through the lens of the social relational model of disability (Thomas 2007) together with the concept of psycho-emotional disablism (Thomas 1999, 2007), itself interwoven with ableism (Goodley 2020). The social relational model, as previously defined, conceptualises disability as both socio-structural barriers that restrict activity, and the socially generated undermining of chronically ill and disabled people’s psychological

wellbeing. The first form of disablism is the principal focus of the social model and highlights external barriers (Oliver 1983, 1990) whilst the second variant can be understood as psycho-emotional and largely concerns internal barriers. Both these components can be discerned in 'contested' chronic illness and broader disability research within the context of BPS policy and practice. Lack of access to legitimised chronic illness and/or disability identity, largely a consequence of inadequate healthcare, can preclude other (external) social accommodations in environments such as the workplace and education system whilst limiting social security support, all of which can restrict activity, foster exclusion and thus further disability (Bê 2016; Bê 2019). These activity-limiting barriers constrain what chronically ill and disabled people are able to 'do'. Equally, stigma and epistemic injustice underlying lack of legitimised chronic illness or disability identity (Blease, Carel and Geraghty 2017), alongside the psychological consequences of negotiating "landscapes of power and exclusion" (Kitchin 1998, 346), can have a profound (internal) psycho-emotional impact (see: OxCATTS 2019; ME Association 2015; Hale et al. 2020). This can be understood as 'psycho-emotional dimensions of disability' (Thomas 1999) or 'psycho-emotional disablism' (Thomas 2007), which limits who disabled and chronically ill people can be and become (Thomas 1999, 2007; Reeve 2004). Psycho-emotional disablism has been described as "the effects of psycho-emotional pathways of oppression which are sustained through imagery, cultural representations and interactions with others" (Reeve 2004, n.p.) and can be categorised as responses to socio-structural barriers, interactions with others, and internalised oppression (Reeve 2004, 2006).

Responses to socio-structural barriers typically stem from the recognition that a person with chronic illness is not welcome in a particular environment or is positioned as

‘other’, and can be evidenced in research within the context of having access needs ignored or having to navigate numerous obstacles to attain a basic requirement or right (de Wolfe 2012; Bê 2016; Bê 2019). The impact of disconfirming interactions with others are detailed in a wealth of research exploring ‘contested’ illness healthcare encounters, particularly in the field of ME/CFS, which demonstrates recurrent themes of negative stereotyping, stigma and epistemic injustice on the part of clinicians ascribing to BPS discourse, alongside felt stigma and distress on the part of chronically ill persons (Blease, Carel and Geraghty 2017; Chew-Graham et al. 2009; Raine et al. 2004; Dickson, Knussen and Flowers 2007).

Disconfirming and distressing interactions with others in negotiating the arenas of education, the workplace, and the benefits system are also reported (de Wolfe 2012; Bê 2016, 2019); some cases have been explicitly associated with ableist, neoliberal discourse which, like BPS discourse, foregrounds individual effort (Bê 2019). In this regard, it is noteworthy that harms arising from BPS-inspired healthcare interventions (Geraghty and Blease 2019) can be traced to an ableist, neoliberal narrative that infers that positive mindset, effort, motivation and ignoring symptoms can ‘overcome’ chronic illness and disability, understood here as restricted activity (Bavinton, Darbishire and White 2004).

Invalidating and distressing interactions with family and friends, some of whom are noticeably influenced by clinical narratives and attitudes are also documented (Dickson, Knussen and Flowers 2007; ME Association 2015). The impression management strategies associated with ‘contested’ illness require considerable effort (de Wolfe 2012), with consequences for wellbeing (Åsbring and Närvänen 2002). In some cases, such psycho-emotional disablism is reported to be worse than the chronic illness itself (de Wolfe 2012; Åsbring and Närvänen 2002). Finally, internalised oppression can be discerned in the

testimonies of chronically ill people who struggle to ask for reasonable accommodations or communicate their disability experiences to others (thus compounding social and emotional isolation), and suffer identity-related stress and feelings of low self-worth or self-efficacy (Hale et al. 2020; de Wolfe 2012; Edwards, Thompson and Blair 2007). Importantly, this form of disablism can restrict activity just as surely as a physical barrier, but can also restrict psycho-emotional flourishing and challenge ontological security (Thomas 1999, 2007; Reeve 2004). Of particular concern is that psycho-emotional disablism may be associated with reports of increased suicidality among people with ‘contested’ illness (see: Devendorf et al. 2020): some research demonstrates that suicidal ideation follows disconfirming negotiations with the benefits system (de Wolfe 2012), whilst other research indicates that suicidality in ‘contested’ illness may be related to stigma and navigating an unaccommodating healthcare system (Devendorf et al. 2020).

A significant aspect of psycho-emotional disablism, and one that challenges the modernist biological (impairment) – social (disability) binary, is that such disablism can become embodied through a worsening of impairment. Whilst it is clear that structural and physical barriers, such as an excessively steep ramp for a person with mobility impairment, may exacerbate impairment (Crow 1996), it is less clear that psycho-emotional disablism can also become inscribed on the body, biologically as well as psycho-emotionally. Whilst the term ‘impairment effects’ has been used to describe restrictions to activity that are attributable to the body as opposed to societally imposed barriers (Thomas 2007), the term ‘externally imposed impairment effects’ delineates impairment effects (such as pain and fatigue) created or exacerbated by disconfirming interactions with other people or structures (Bê 2016). This emphasises the notion that impairment is ‘bio-social’, determined

by social as well as biological factors (Thomas 2007). Whilst worsening impairment may be related to physically overexerting oneself to meet external demands (Bê 2016), it may also arise from stigma and/or epistemic injustice. Indirectly, epistemic injustice may impact detrimentally on the body and mind via misdiagnosis, delayed diagnosis, or inappropriate healthcare interventions (see Geraghty and Blease 2019), carrying clear risk of worsening impairment. A more direct pathway may be speculated through the biological impact of chronic and uncontrollable stressors (such as stigma and epistemic injustice) on the body over the life course, understood through concepts such as biological embedding and allostatic (over)load, increasing susceptibility to further ill-health (Heise et al. 2019; Metz and Hansen 2014). That is, stigma, epistemic injustice and psycho-emotional disablism may become embodied (see: Hughes and Paterson 1997). In the field of ME/CFS, a bio(psychosocial) model has been forwarded drawing upon immune, inflammatory, oxidative and nitrosative pathways that may be precipitated or perpetuated by biological and psychosocial stressors (Maes and Twisk 2010). It is reasonable to suggest that stigma and epistemic injustice – alternatively understood as psycho-emotional disablism - represent a stressor in such a model. The BPS model, discourse and practice as dominant in UK health and social policy might then be considered to contribute to psycho-emotional disablism and its biological sequelae as well as to socio-structural barriers and associated structural disablism.

Implications for practice, policy and research

When chronic illness is conceptualised through a critically informed framework that includes

a socio-structural understanding of health and illness (as per a bio-psycho-socio-structural framework), implications arise for practice, policy and research. Whilst the following recommendations in no way ignore the value of integrating the 'bio' and 'psycho' elements of a BPS framework, critically informed socio-structural influences require explicit emphasis. Socio-structural injustices can easily go unacknowledged, not only because it is not in the interests of those who benefit from structural inequities to acknowledge them, but also because structural injustices can occur in the absence of (overt) individual discrimination (Link and Phelan 2001; Link and Phelan 2014).

Social policy

A critically reflexive approach involves recognising that the current benefits system is a socio-structural factor that is contributing to chronic illness burden and furthering disability, notably through systematic disempowerment masquerading as 'enabling' policies (Faulkner 2016). Social policies should address socio-structural barriers to the inclusion of chronically ill and disabled people in education and work, whilst supporting and valuing those who cannot engage in work, education or other personally meaningful activity even with adjustments (Hale et al. 2021a; Blattner 2021). Workplace adjustments, commonly refused to those with 'contested' chronic illness (Bê 2019; Hale et al. 2021a), are necessary for those who can benefit, whilst remote-working arrangements, implemented on a large scale due to the covid-19 pandemic, should be developed and maintained for those who are confined to the home (Hale and Allam 2020). The same policies should extend to higher education, where both disablism and ableism represent barriers to inclusion (Bê 2019; Brown and Leigh 2018). A fundamental revision of the social security system is required, moving away from a

disability assessment medicine model (Aylward and Sawney 1999) and towards a more humanistic and holistic model foregrounding the lived experiences of chronically ill and disabled people (Benstead and Nock 2016; Hale et al. 2021a). In particular, greater understanding is required by policy makers and benefits assessors toward impairments that do not fit commonly held 'fixed and clearly visible' stereotypes (Bê 2019); disbelief vis-à-vis impairment, alongside disability denial, has been recognised as a structural barrier in such cases (Hale et al. 2020).

Medical education

The need for better understanding of 'contested' chronic illness, particularly through improved medical education, has been highlighted and, in the case of ME/CFS, is gradually being addressed (ME Research UK 2021). This is necessary but arguably not sufficient: even if health policy and practice were fundamentally revised, prejudice and stigma towards disabled people, deeply rooted in the psychosocial imaginary, would likely be slow to dissipate (Reeve 2004; Shildrick 2020). Thus, a critically reflexive approach to medical education is recommended (Ng et al. 2019). Critical reflexivity, within the context of medical education, would foster sensitivity towards unequal power dynamics in the clinician-patient relationship, alongside recognition of the limitations of dominant (biomedical) ways of knowing. Fostering clinical epistemic humility and honouring the patient's expertise by experience are central to this approach (Thomas et al. 2020). Given that critical reflexivity requires an appreciation of knowledge situatedness, medical students should be appraised of the socio-political context in which the dominant application of the BPS model in the realm of chronic illness (particularly, contested chronic illness and 'medically unexplained

symptoms’) has evolved, and how this application may be harmful to patients. Clinicians should also be trained to be cognisant of how their practice, bound up with personal biases, might render them unintentionally complicit with structural injustices that are perpetuated by BPS discourse.

A critically informed and critically reflexive approach to medical education indicates application of a structural competency framework (Metzl and Hansen 2014). Here, health-related issues and behaviours typically located within the individual (such as guilt, shame, low self-worth, depression, withdrawal from services and suicidality) are conceptualised as a possible result of upstream factors such as negative attitudinal contexts, discriminatory health and social policy that (re)produce health and social inequities (Karadzhov, 2021a). Close reading of ‘contested’ illness research appears largely consistent with this conceptualisation (Edwards, Thompson and Blair 2007; de Wolfe 2012; Devendorf et al. 2020). Such an approach would counter the victim-blaming dynamics found in dominant BPS discourse and practice (Stanley, Salmon and Peters 2002; Horton-Salway 2002; Halligan et al. 2003) and reported by chronically ill people in healthcare contexts (MEA 2015; Hale et al. 2021b).

Healthcare

Healthcare policies and provision should meet the needs of all chronically ill and disabled people, as opposed to privileging the most prevalent conditions, reflecting the needs of more socially advantaged patients, or reflecting the interests of power structures. In the field of long Covid, advocates (notably doctors-as-patients) are foregrounding patient

narrative in pushing for multi-disciplinary services to accommodate multi-system conditions, thorough biomedical investigations, and patient involvement in research and clinical service commissioning (Alwan et al. 2020; Nurek et al. 2021). It is important that any strategies of inclusion for people with long Covid, which may be facilitated by the prevalence of long Covid and relative social power of some advocates, are extended to the wider disability and chronic illness community (see: Hunt, Blease and Geraghty 2022). Current healthcare resource allocation (allegedly needs-based) requires critical scrutiny: there is somewhat of an inverse or disproportionate care law as regards chronic illness provision within many health systems, including the UK NHS, whereby conditions with comparatively low quality of life, such as ME/CFS (Falk Hvidberg et al. 2015), receive amongst the lowest levels of biomedical research funding and appropriate healthcare (Radford and Chowdhury 2016). Systems such as the Quality and Outcomes framework (NHS Digital 2021), which may contribute to the neglect of certain chronically ill and disabled people (Hannon et al. 2012), require scrutiny in this regard.

Health interventions that are currently typically considered biopsychosocial and holistic should include recognition of socio-structural influences in chronic illness and disability (see: Karadzhov 2021b). For example, psychoeducation, psychosocial health management and talking therapies should acknowledge socio-structural injustices, where appropriate 'normalising' (as opposed to pathologising) psychological distress as an understandable response (Johnstone and Boyle 2018). Such interventions should also assist chronically ill and disabled people in asserting their rights, in recognising and addressing internalised oppression and self-stigma, whilst encouraging positive identity-building

through connections with empathetic others (Olkin 2017; Reeve 2002). Patient-centred care is of course crucial, though critically reflexive approaches might shed light onto why hitherto that has been so difficult to achieve. Finally, for people with primarily physical conditions (mind-body interface debates acknowledged), psycho-social-structural interventions should be considered a supportive adjunct to biomedical care, as opposed to a treatment. A bio-psycho-socio-structural approach to chronic illness and disability is thus consistent with bringing the body back into disability studies, whilst integrating disability studies' focus on social oppression into the medical sociological (mainstream healthcare) conceptualisation of disability.

Future research

A critically informed and critically reflexive stance would benefit research, for example, by remaining alert to the potential for reinforcing epistemic injustice and exclusion through research designs and underpinning assumptions (Muhammad et al. 2015). Research on health interventions should acknowledge the impact of socio-structural injustices on chronic illness and disability (Karadzhov 2021a) and recognise how certain interventions might be contributing to such injustices. Critical research examining the psychology of clinicians and other social actors is indicated, with a view to explaining victim-blaming tendencies and disability denial. More research is required into exploring pathways that mediate the impact of socio-structural factors upon burden of chronic illness and furtherance of disability (see: Karadzhov 2021a). In this respect, conceptualising (dis)ablism as a potential socio-structural determinant (influencer) of health, following the example of research into racism and gender inequality (Nonyel et al. 2021; Heise et al. 2019) could prove fruitful. Moreover, as

previously mentioned, there is a paucity of intersectional research, examining the effects of intersected social (dis)advantage on experiences of chronic illness and disability, particularly in the case of ‘contested’ illness. In this regard, more diverse and/or demographically targeted samples are necessary; however, intersectional approaches should guard against separating marginalised identities (or socially constructed categories) from the structural contexts that constitute these identities or categories (Gkiouleka et al. 2018).

Conclusion

Whilst Engel’s (1977, 1992) vision of the BPS model was to counter what was considered a biologically reductionist (non-holistic) biomedical model, the BPS model as it dominates UK health and social policy, in particular regarding ‘contested’ chronic illness and so-called ‘medically unexplained symptoms’, has engendered victim-blaming discourse grounded within individualistic, neoliberal ideology which serves a number of political purposes. These political purposes run counter to the interests and wellbeing of chronically ill and disabled people, creating and reinforcing socio-structural exclusion (disablism as it is typically understood) and contributing to psycho-emotional disablism through stigma and epistemic injustices largely rooted in ableism. This particular application of the BPS model divorces individuals from the broader context in which they live, ignoring how socio-structural factors – including health and social systems, the model itself and associated discourse and practice – can contribute to chronic illness and disability. In fact, this politicised application of the BPS model and interests of the academic-state-corporate nexus can be considered a socio-structural entity that is impacting detrimentally on the health and life chances of

chronically ill and disabled people. The current tendency to cherry-pick and foreground individualistic psychosocial factors within BPS theorising is theoretically incoherent, scientifically unsound, and serves to shift the spotlight of scrutiny away from the model and the interests of its key proponents, whilst facilitating discriminatory policies, practices and attitudes. Socio-structural factors in ('contested') chronic illness and associated disability require further explicit scrutiny in research, and an intersectional lens is indicated.

A critically informed and critically reflexive approach to the BPS model and associated practice would facilitate a more truly holistic and nuanced understanding of chronic illness and disability. This would encourage more structurally competent and inclusive policy development, research and practice, which in turn would encourage more empowering and constructive healthcare and welfare encounters for chronically ill and disabled people. A bio-psycho-socio-structural approach to chronic illness and disability could provide a bridge between medical and social models of disability, the biological (impairment) – social (disability) divide, and historically conflicting paradigms of disability studies and medical sociology disciplines.

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