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Dissonant dementia: neuropsychiatry, awareness, and contradictions in cognitive decline

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This paper presents an analysis of contemporary neuropsychiatric meaning-making regarding dementia, encompassing distinct beliefs, practices and objects, and the peculiarities of its fragmented public manifestations. First, some core neuropsychiatric beliefs are discussed, arguing that the designation of those beliefs as exceptional truths engenders an imperialist ethic whereby the beliefs must be spread into other populations. Second, the enactment of this spread through dementia awareness is considered, whereby people are presented as having wrong beliefs to justify the promotion of alternative correct knowledge. Third, some emerging contradictions within neuropsychiatric dementia are outlined, as moves toward early diagnosis and “living well” sit uneasily beside notions of dementia as a frightening epidemic. The paper concludes that this produces dissonant dementia wherein contradictory meanings are held together. Finally, it is suggested that this dissonance will likely continue, underpinned by specific interests.

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Introduction

In this paper, we analyse neuropsychiatric meaning-making regarding dementia, focusing on awareness initiatives as a key facet. We approach neuropsychiatric meaning-making via a set of distinct beliefs, practices, and objects in which it is manifest. Our argument proceeds in four stages. First, we discuss some core neuropsychiatric beliefs and key characteristics that shape them. We argue that the presentation of neuropsychiatric beliefs as exceptional truths can engender an imperialist¹ ethic whereby those beliefs should be spread to other populations. Second, we analyse the enactment of this spread through practices and materials of dementia awareness, whereby people are presented as having *wrong beliefs* to justify the promotion of *correct knowledge*. Third, we attend to some contradictions within this neuropsychiatric meaning-making, as the advocacy of early diagnosis and “living well” sits uneasily beside the promotion of dementia as a modern epidemic to be feared and fought. We argue that the emergence of (relatively) able public figures diagnosed with dementia seemingly contradicts apocalyptic depictions of dementia that some associated organisations invoke to elicit funding. Consequently, cognitively impaired older adults inhabit an ambiguous conceptual landscape—*dissonant dementia*. Finally, we suggest that contemporary trajectories of dissonant dementia will likely continue, reflecting on the interests underpinning these phenomena.

This paper offers critical comment on recent public outputs of key dementia-related institutions, which we compare with our pre-existing research to explore shared articulations of dementia. The materials discussed herein were selected based on their being targeted at the public and consequently being publicly available, as this was deemed important to the proliferation of meaning. They were also selected based on the relative prominence of the associated organisations (e.g. the NHS, the Alzheimer’s Association), which was similarly judged to be conducive to greater propagation. We acknowledge, however, that size and reputation need not necessarily equate to influence. Our argument is informed by similar existing work on neuropsychiatry more generally, which has delineated key features (e.g. binarism, exceptionalism) (see Abi-Rached and Rose, 2010; Cooper, 2016; Mills and Hilberg, 2019; Pickersgill, 2013; Williams et al., 2012; Vidal and Ortega, 2017 outlined further below). This is not a comprehensive account of all neuropsychiatric responses to dementia based on a systematic review (indeed, it is doubtful that that is possible), but instead is a critical commentary based on grey literature, various dementia stakeholders and our own previous research projects. Therefore, our argument simply pertains to a facet of neuropsychiatric enterprise that warrants critical attention.

We evidence our arguments with contemporary examples from leading British and international institutions, such as the National Health Service, the National Institute of Health, the Alzheimer’s Society and the Alzheimer’s Association. We provide comparable examples from smaller initiatives to emphasise that dissonant dementia is not limited to major organisations, but is also evident in local projects, including social dementia research, which will be of concern to our social scientific readership. Ultimately, we provide a critical interpretation of select phenomena which, while abundantly manifest in mainstream neuropsychiatric institutional endeavours, are one aspect of more diverse issues that are inevitably open to other interpretations. The commentary’s broad scope is intended to provide a framework and provocation for further debate and more minute analysis of specific elements of neuropsychiatric dementia. Our approach reflects the critical tradition’s (Bartlett and O’Connor, 2010; Zeilig, 2014) concern with revealing seemingly neutral portrayals of phenomena in the natural sciences as implicitly politicised, and challenging those

politicisations. Terminologically, then, this commentary mirrors the implicit political labour of neuropsychiatric meaning-making as a means of both highlighting and contesting that labour. Zeilig (2014) notes that “a range of emotionally charged metaphors about dementia pervades the popular imagination, and these are found in newspaper accounts, political speeches, and in both documentary and feature films.” We similarly address literary neuropsychiatric materials, e.g. advertisements and assessment scales, highlighting how neuropsychiatric imaginings of dementia serve certain political ends. Where Zeilig has uncovered the more emotive portrayals of dementia in terms of war and disaster, we attend to the seemingly more impartial neuropsychiatric productions, highlighting similar meaning-making processes within depictions that are often considered neutral, and the ways in which they can become dissonant.

Finally, while pertaining to dementia as a specific example of neuropsychiatric-public meaning-engagements, we hope that social scientists working in other areas will find our arguments relevant to their own interests. In particular, the dementia enterprise that we depict in this paper echoes wider considerations of later life (ill-)health that garner much scholarly, public and governmental attention in the wider context of ageing welfare states. Moreover, those familiar with the wider critical literature dealing with neuropsychiatry as a broad entity will hopefully find an interesting example of the application of those ideas to a specific topic that, while of considerable societal import, is often overshadowed by greater attentiveness to other neuropsychiatric conditions. To some extent, we intend two different payoffs for two different communities—dementia studies scholars appreciating the application of unfamiliar arguments to a familiar topic, and other social scientists appreciating an application of familiar arguments to an unfamiliar topic.

“Neuropsychiatry”—who, what, when?

“Neuropsychiatry” is an elusive term (Sachdev and Mohan, 2013). For clarity, we use Berrios and Marková’s (2002, p. 629) historical analysis of neuropsychiatry as defined by the “foundational claim” that “mental disorders are disorders of the brain.” Building on this claim, core neuropsychiatric beliefs regarding dementia include that it is a syndrome of cognitive decline caused by discrete neuropathologies that are distinct from ageing, and that not enough people are aware of this. Furthermore, because dementia is caused by disease, and biomedical sciences have cured some diseases, dementia is a technoscientific challenge that will be solved through technoscientific endeavours (Manthorpe and Iliffe, 2016). Fletcher (2020a) notes that dementia is cast as “a grave neuropathological problem to be overcome through biomedical research. Suggestions are repeatedly made that such research will eventually produce curative therapeutics.” Associated practices correspond to these beliefs. As with other ways of understanding the world, neuropsychiatry distinguishes the normal (ageing) and the abnormal (dementia) (see Lock (2013) on Canguilhem, normality and Alzheimer’s disease). That intellectual division has typically been enacted numerically (Wilson, 2014), through cognitive batteries that quantify cognitive abilities and establish diagnostic thresholds, e.g. the mini mental state examination, representing objects of neuropsychiatric meaning-making and transfer (Folstein et al., 1975). Beliefs regarding future technoscientific solutions are manifest in practices of science communication and resource accumulation via advertising campaigns (Fletcher, 2021a). Thus, a neuropsychiatric dementia is manifest in beliefs (e.g. future cures), practices (e.g. fundraising) and objects (e.g. cognitive batteries). This is not an exhaustive typology of components, but rather a useful indication of some sociologically

recognisable key factors to facilitate our analysis. Below, we argue that certain tensions within and between these considerations in combination can create forms of dissonance.

The “neuropsychiatric” term requires two important caveats. First, we must acknowledge the genealogy of contemporary neuropsychiatry and its specific relations to dementia. While we are primarily interested in phenomena that emerged during the late-20th century, dementia has garnered neuroscientific and psychiatric interest for over a century. For example, early-19th century anatomical work (Fuller, 1911, 1912) attended explicitly to the question of dementia’s neuropathological genesis. Moreover, the broader history of “neuropsychiatry” stretches back into the 17th century, albeit in several unconnected forms (Berrios and Marková, 2002). Abi-Rached and Rose (2010) have argued that the neurosciences in their current form emerged in the 1960s as a hybrid of earlier psychiatric and neuroscientific endeavours. Of particular relevance to this paper is the proliferation of the “neuromolecular gaze”, an epistemological shift wherein phenomena such as “cognition”, “behaviour” and “memory” became fundamentally molecular matters. This shift catalysed researchers, charities, governments and publics around common notions of the biologic brain as an answer to life itself. The neuromolecular gaze is now widespread in “regular newspaper articles and television programmes... accompanied by vibrant visual illustrations derived from brain imaging of the living brain in action as it thinks, feels, decides, and desires” (Rose and Abi-Rached, 2013). Pickersgill (2013) has similarly charted the historic proliferation of neuroscience in particular as a basis for generating simultaneous societal and self-knowledge. Vidal and Ortega (2017) have charted the post-1990s making of the “cerebral subject”, wherein we are increasingly prone to neuro-centric self-conceptualisation, as well as the concurrent rise of sociological analyses of various neuro enterprises. The phenomena discussed in this paper can be read as a component of this epistemological shift.

We are primarily focused on the post-1970s emergence of what Fox (1989) identifies as the “Alzheimer’s disease movement” (outlined more recently by Lock (2013)), which developed around the promotion of a specific disease-model of dementia, grounded in neuropsychiatric authority. By employing science communication strategies echoing earlier approaches to cancer, a coalition of researchers, charities, advocates and governments have transformed the meaning of dementia over five decades. Beginning with researchers, various social and natural scientists have coalesced around neuropsychiatric dementia as a catalyst for new research programmes. Many research publications open with appeals to the problem of dementia as a neuropsychiatric disorder with global ramifications, emphasising the importance of the work therein. Charities have used similar notions of dementia to campaign for more resources, often later redistributed to research projects. Various notable advocates have supported this enterprise, both popular media celebrities and individuals who have become known for having dementia, using their personal profiles to publicise initiatives. Governments have also propagated neuropsychiatric dementia, politicising it as a major social concern, particularly regarding state welfare (Innes, 2009). British Prime Minister David Cameron instigated a range of dementia-focused initiatives during his time in office, including financially incentivising diagnosis. Finally, it is worth considering the role of the pharmaceutical industry. It is a major material promoter of neuropsychiatric dementia, financing associated drug research (Cummings et al., 2020; Lock, 2013), but is also a victim to some extent, having lost vast sums in pursuit of promissory cures (Lo, 2018). This highlights distinct possibilities for benefitting from neuropsychiatric dementia—both today (researchers, charities, advocates) and tomorrow (governments, pharma). This dementia

movement, broadly conceived, has popularised a distinct set of beliefs, practices and objects that structure contemporary institutional and personal understandings of, and responses to, dementia. Hence, while the professional neuropsychiatric history of dementia stretches back to the 19th century, the particular iteration discussed herein is more recent.

Second, neuropsychiatry is not the exclusive domain of neuroscientists and psychiatrists, but instead includes the various stakeholders mentioned above. Indeed, as Lock (2013) has observed, these diverse stakeholders may not even necessarily agree fully on the precise meaning of dementia and what action that meaning might necessitate. Charities play a particularly important role in sustaining and promoting neuropsychiatric meanings, because their existence depends on persuading donors that neuropsychiatry will provide solutions to dementia, given sufficient donations. Moreover, (Fletcher, 2020b) has noted that many social scientists are embedded within and perpetuate neuropsychiatric dementia, suggesting that “social research often seems to be dancing to neuropsychiatry’s tune.” Similarly, Cohen (1998) argued that social scientists who self-identified as working on “dementia” or “Alzheimer’s”, as opposed to “senility”, contributed to the neuropsychiatric reconstruction of cognitive decline in later life. Therefore, neuropsychiatry is not rigidly institutionalised or unequivocally demarcated, and hence our argument encompasses an assortment of examples.

Moreover, Rose and Abi-Rached (2013) note that, over the past half-century neuropsychiatry has seeped out of the lab, and into public life and popular culture, so that we increasingly conceive of ourselves and our problems in neuropsychiatric terms. It is this spread of neuropsychiatric meanings, beyond related professions and into public life, which warrants critical attention. As Williams et al. (2012, p. 65) note in relation to ageing and cognition:

Neuroculture is not simply a question of the power or persuasive appeal of the neurosciences within the laboratory or clinic, but of their wider social, cultural, political and economic salience and significance about the future of humanity.

Therefore, we do not focus on the machinations of neuroscientific and psychiatric professions within institutional settings. Instead, we are principally concerned with the manifestations and ramifications of an associated amalgam of meanings in the public sphere. To chart this realisation, we will deconstruct some of the beliefs, practices and objects bound up with that amalgam, before considering what it means for the contemporary status of cognitive decline. Ultimately, we argue that it creates a dissonant dementia, simultaneously spanning several seemingly contradictory meanings.

Extending neuropsychiatric “Knowledge” over public “Beliefs”

For the purposes of this discussion, we focus on key neuropsychiatric beliefs that dementia is: (1) a syndrome caused by discrete neuropathologies; (2) distinct from normal ageing; (3) curable by future neuropsychiatric interventions given sufficient public donations to facilitate technoscientific advances; (4) misunderstood by a public in need of education. Related claims populate various charity websites:

There are a large number of underlying conditions which cause the symptoms of dementia, as a result of changes that happen in the brain (ADI, 2020b).

Dementia is not a natural part of ageing (Alzheimer’s Society, 2017).

The path to effective new treatments for dementia is through increased research funding and increased participation in clinical studies (Alzheimer's Association, 2020).

Greater awareness and understanding of dementia is important to challenge the myths and misconceptions that surround the condition (ADI, 2020a).

Neuropsychiatric stakeholders often adopt *exceptionalist* stances toward these beliefs, attributing to them unique merit and hence superiority. Berrios and Marková (2002) have argued that this assertion of exclusive beliefs is a defining characteristic of neuropsychiatry, itself a driver of contradiction given that the presentation of certainty is set against a backdrop of considerable uncertainty regarding the brain and mental disorder (Bosco et al., 2019). This exceptionalism is evident in common proclamations that neuropsychiatric beliefs are the legitimate depiction of reality, in contrast to non-neuropsychiatric beliefs that are presented as misconstruing dementia. Consider the following Alzheimer's Research UK advertisement:

"Dementia is *not* a natural part of ageing. It's caused by physical diseases, most commonly Alzheimer's" (ARUK, 2019b, emphasis original).

This NHS information takes a similar approach:

"It's also important to remember that dementia is not a natural part of ageing. What is dementia? Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning" (NHS, 2020).

This contrast reveals a certain neuropsychiatric *binarism*, evident in the articulation of beliefs through a true/false language, demarcating what dementia is (i.e. neuropsychiatric beliefs) in contrast to what other groups mistakenly believe it to be. Consider the component arguments of the above quote: "Dementia is *not*..." and "It's caused by..." (ARUK, 2019b), creating an absolute contrast between reality and fallacy. The word "belief" can be instrumental here. For instance, Alzheimer's Research UK state that "22% still incorrectly *believe* that dementia is an inevitable part of old age" (ARUK, 2019a, emphasis added). The use of "believe" distinguishes those meanings from factual meanings, creating an epistemic hierarchy within which one group's *knowledge* (i.e. *fact*) is superior to another's *belief* (i.e. *fiction*) (Cooper, 2016). Such strong assertions of truth and falsity correspond strongly with the blurred physiological boundaries between ageing and dementia, which Lock (2013) identifies as one of the key ontological battlegrounds in the recent history of Alzheimer's. As we will show below, the projected truthfulness of neuropsychiatric knowledge can exacerbate dissonance when knowledges become contradictory.

Non-neuropsychiatric beliefs are not limited to relations between dementia and ageing. For example, Berwald and colleagues' (2016) research on "Black African and Caribbean British communities' perceptions of memory problems" found that participants considered dementia to be "a white person's illness." The authors concluded that this non-neuropsychiatric belief was problematic and should be challenged through interventions to teach these communities neuropsychiatric knowledge. The belief/knowledge binary often traces ethnic classifications in this manner. A recent report on dementia and minority ethnic populations by Alzheimer Europe (2018, p. 18) claimed that "in some cultural and ethnic groups, beliefs about fate, evil spirits, the evil eye, lack of faith in or punishment from God are common." Again, the authors argue such "beliefs" should be challenged by improving neuropsychiatric "knowledge" via educational interventions. This positioning of ethnicity in relation to dementia (see Fletcher,

2020c, 2021b; Fletcher et al., 2021) reveals a delineation of different types of person in reference to their purported amenability to neuropsychiatric beliefs.

The knowledge/belief binary can provide justification for epistemic imperialism. The identification of non-neuropsychiatric populations, e.g. minority ethnic people, can demarcate them as targets for intervention. Cooper (2016) has observed that the discursive construction of binary psychiatric issues often reveals power dynamics that permeate the meaning-making practices through which mental health knowledge is targeted at new populations. Indeed, mental health literacy has been criticised for unreflectively accepting neuropsychiatric 'gold standard' knowledge without taking into account alternative perspectives (Holman, 2015). By "imperialism" we mean that the assumed rightness of a belief-system can justify its extension over other purportedly wrong beliefs (Cooper, 2016). Cooper (2016, p. 702) observes of psychiatric research: "Value-judgements are most pertinently revealed in the kinds of recommendations put forward by many of the studies, where it is explicitly asserted that interventions need to focus on "correcting" false cultural beliefs and behaviours so they are more in line with a biomedical system of knowledge." Epistemic imperialism is realised in dementia awareness initiatives, with interventions designed to spread neuropsychiatric meanings to populations considered problematically non-compliant, ranging from the general public (McParland et al., 2012), through to carers (Robinson et al., 2014) and minority ethnic groups (Fletcher, 2020c). Proponents of awareness initiatives contend that awareness deficits impede diagnosis, denying people access to services, treatments and clarity (Watson et al., 2018). It therefore follows that increasing dementia awareness will lead to improvements in related outcomes. While arguments for awareness promotion are contested (Fletcher, 2021a; Fox et al., 2013; Milne, 2010; Samsi and Manthorpe, 2014), we will not evaluate such debates here. Instead, we wish to examine dementia awareness as a neuropsychiatric endeavour that manifests select beliefs, practices and objects.

The belief/knowledge binary, and the contradictions it contains, represent an initial type of dissonance. As with other belief systems, neuropsychiatric meanings offer some imposition of order on a given phenomenon, in this case later life mental disorder. However, the neuropsychiatric ordering of dementia beliefs is at odds with different understandings of ageing and/or evil spirits (though claims regarding the latter's prevalence may be poorly evidenced racialised caricatures). Hence, neuropsychiatric beliefs not only come into tension with public beliefs (Cahill et al., 2015), but also with historical characterisations of dementia in terms of ageing and/or moralities (Ballenger, 2006; Berchtold and Cotman, 1998; Boller and Forbes, 1998). Perhaps more importantly, neuropsychiatric meanings can be at odds with people's experiences given that neuropsychiatric cures are currently promissory. This begets ambiguity regarding "correct" knowledge, and the consequent tensions are emblematic of the discordances that characterise contemporary depictions of dementia. Such ambiguity, driven by the contesting of non-neuropsychiatric beliefs, is explored below regarding "Alzheimerised senility".

Efforts to extend neuropsychiatric meanings to new populations are not simply a matter of ensuring that everybody holds the right belief for its own sake, or some nefarious ploy to con people. Ultimately, while aspects warrant critical analysis, neuropsychiatric imperialism is largely fuelled by sincere commitments to increasing human wellbeing and can point to a substantial evidence base of comparable past successes. The impetus to convert new populations to neuropsychiatric beliefs is based on public health commitments to health literacy stemming from historic successes in combatting disease and improving

countless lives mental health through raising awareness, grounded in laudable convictions that publicising certain knowledge will improve population-level health (Fletcher, 2021a; Cahill, 2020; Rose, 2019). Historic examples of health literacy improving health outcomes engender expectations that improved dementia knowledge will beget better management (Noble et al., 2015). In this vein, Noble et al. (2015, p. 73) claim that “dementia health literacy is low among the public and likely poses a significant barrier to Alzheimer’s disease symptom recognition and treatment.” They argue that improved awareness could “shift cultural perceptions of AD to improve its acceptance, and reduce barriers to early diagnosis. Such a programme could have additional relevance for early AD recognition should time-sensitive pharmacologic and healthy lifestyle risk-reduction measures be proven effective as disease-modifying strategies.” Moreover, from a science communication perspective, neuropsychiatric enterprises (e.g. research projects) often rely on public funding, and therefore must convince the public of their worthiness (Simis et al., 2016). Indeed, (Fletcher, 2020c, p. 708) notes that “the accrual of resources, enacted through the promotion of certain notions and the refutation of others, is woven throughout the dementia awareness agenda.” This is achieved through promissory claims that funding research will produce future cures (Martin, 2015; Petersen and Krisjansen, 2015). Thus, neuropsychiatry can depict a binary future, one fearful—the neuropathologic epidemic; the other hopeful—the neuropsychiatric cure (Williams et al., 2012). The coexistence of these futures in our present further promotes a dissonant dementia, an observation expanded upon below.

Examples of beliefs regarding promissory science communication are abundant in the materials of associated organisations. The National Institute of Health’s “Hope through Research” education page claims: “Discoveries may eventually lead to ways to slow disease progression or even cure and prevent the dementias” (NIH, 2019). The promotion of curative faith is an effective science communication practice because it justifies the accumulation of resources by causally linking today’s sacrifices (e.g. donations) with tomorrow’s utopias (e.g. cures) (Hacking, 1983). It also invokes an impressive intellectual heritage to justify its own potential, highlighting previous examples of technological progress ameliorating human suffering, e.g. smallpox, polio, HIV. Comparisons with cancer are important here because the Alzheimer’s movement was inspired by cancer-related promissory science (Fox, 1989). A recent Alzheimer’s Research UK advertisement promoting an early detection study claimed: “Early detection has transformed the treatment of cancers and heart disease, and we can do the same for dementia” (ARUK, 2020). Such promissory science beliefs, depicting the future fruits of neuropsychiatric enterprise, are hence an instrumental bedrock of neuropsychiatric enterprise.

Likewise, beliefs regarding public knowledge deficits are evident throughout the discursive productions of neuropsychiatric dementia awareness. Alzheimer’s Disease International’s announcement of its 2019 world report opened thus: “Results from the world’s largest survey on attitudes to dementia reveals [sic] a startling lack of global knowledge around dementia, with two thirds of people still thinking the disease is a normal part of ageing rather than a neurodegenerative disorder” (ADI, 2019b). Following its release, this “startling” knowledge deficit was employed as an awareness call-to-arms. The report was circulated via social and news media to emphasise the exceptional importance of neuropsychiatric beliefs in opposition to other illegitimate beliefs (e.g. Andrews, 2019; Templeton, 2019). It is worth stating unequivocally here that we are not treating any knowledge as “correct” or “incorrect”. Instead, we are concerned with how influential systems of meaning conjure notions of (in)correctness, how those meanings are spread and, most

importantly, how they converge in an increasingly dissonant dementia, explicated below.

Exemplifying the capacity for neuropsychiatry to define the parameters of legitimate knowledge negotiation, Mills and Hilberg (2019) have explored the WHO’s mhGAP-Intervention Guide. This tool facilitates the diagnosis and management of common mental disorders in Low- and Middle-Income Countries (LMICs), as an “inscription device” that promotes specific imaginaries of mental disorder in new populations. The authors note that appeals to the superiority of psychiatric and neuroscientific “knowledge” position mental disorder as open to technical, rather than epistemological, debate. Thus, the problem is rendered negotiable, but the parameters of negotiation and the stakeholders who have legitimacy to engage in negotiation are defined in accordance with neuropsychiatric commitments. Mills and Hilberg (2019, pp. 166–167) term this “craft[ing] the epistemological parameters of critique”, which effectively “exclud[es] alternative conceptualisations from different worldviews.” Similar processes are evident in neuropsychiatric dementia whereby, for instance, the nature of specific causative neuropathologies is (somewhat) open to debate, but the notion that dementias are attributable to discrete neuropathologies is not legitimately contestable. Without symbolic credentials (i.e. a doctorate) and languages (i.e. “amyloidogenic A β 42”), various stakeholders in dementia are positioned outside the parameters of legitimate debate, with little power to contribute to, let alone challenge, neuropsychiatric meaning. In line with mhGAP, interventions are now targeting LMICs as a site for the propagation of neuropsychiatric dementia and its distinctive dissonance, discussed further below.

Extending meaning through practices and objects

Besides unpacking the beliefs that permeate them, we can also analyse dementia awareness initiatives as a set of neuropsychiatric practices that centre on core material objects. The enactment of dementia awareness is evident in some substantial institutional endeavours that we explore in this section. Such initiatives promote neuropsychiatric beliefs through binarism. They simultaneously undermine non-neuropsychiatric beliefs and advocate the superiority of neuropsychiatric beliefs (Shinan-Altman and Werner, 2019). These attempts to govern beliefs, suppressing some and promoting others, constitute a notable neuropsychiatric practice (Zhang, 2018). They are typically orchestrated by actors outside of professional neuropsychiatry, e.g. charities, celebrities and government figures, perpetuating the creep of neuropsychiatric meaning into public life.

Exemplifying this neuropsychiatric creep are academic and third sector attempts to quantify the dementia awareness of certain populations. A growing research tradition seeks to measure awareness, representing an intriguing realisation of neuropsychiatric expansion in seemingly mundane practices (Fletcher et al., 2021). Practices of measuring dementia awareness, typically articulated as “literacy”, are reliant on a range of measurement tools to facilitate assessment. Low and Anstey’s (2009) dementia literacy study used a vignette to assess recognition of dementia. The vignette described someone with “the symptoms and behaviours of a person meeting Diagnostic and Statistical Manual [of Mental Disorders], fourth edition (DSM-IV) criteria for Alzheimer’s disease” (Low and Anstey, 2009, p. 44). Further questions were posed about the potential of dementia risk reduction and causal factors. This method aimed to capture key elements of dementia literacy, which are, according to their definition, “knowledge and beliefs regarding dementia that aid recognition, management or prevention” (Low and Anstey, 2009, p. 33). Here, we see many discussed factors at play. Dementia “knowledge” is predicated on formal neuropsychiatric materials

(DSM-IV), and poor outcomes are attributed to poor knowledge. This type of dementia literacy measurement is now a popular research sub-tradition (see Annear et al., 2017; Bond et al., 2005; Hudson et al., 2012; Lüdecke et al., 2016; McParland et al., 2012; Purandare et al., 2007; Rimmer et al., 2005; Roberts et al., 2014).

Dementia literacy scales represent key neuropsychiatric objects, and are instrumental in the extension of knowledge claims. Critiques of dementia literacy studies have touched on the lack of definitions of “literacy” and its measurement tools (Choi et al., 2018), and a lack of consistency across studies, regarding fundamental constructs and how knowledge is operationalized and measured (Cahill et al., 2015; Spector et al., 2012). Less apparent are critiques of the rationales underpinning the creation and proliferation of such objects, and decisions regarding which *facts* are included and which populations they are practiced upon. As a result, these assessment scales, comprising key material objects of dementia awareness and embodying some key neuropsychiatric beliefs, are often treated as neutral measures of external phenomena rather than influential tools that constrain the nature of the entity to which they attend (Fletcher, 2020c).

Perhaps the most notable example of awareness-measurement is the Alzheimer’s Disease International world report (ADI, 2019a), asking questions regarding whether dementia is a normal part of ageing and whether it is caused by neurophysiological changes. It was a sizeable global endeavour, incorporating almost 70,000 participants across 155 countries, evidencing a powerful mobilisation of neuropsychiatric meaning through certain practices. This particular mobilisation may prove fundamental to the prosperity of neuropsychiatric dementia over coming years, providing statistical foundations for various arguments in support of spreading awareness, which, as we explicate below, contributes to dementia’s dissonance. In this manner, (Fletcher, 2020c) has noted that assessing the awareness of various populations, and invariably finding their beliefs wanting, is an important precursor to secondary practices of awareness-raising. Fletcher (2020c, p. 712) concludes that that “awareness is used to justify the proposed governance of minority ethnic conduct through interventions explicitly seeking to re-educate and hence improve them.” As such, “dementia awareness research can be understood as the neuromolecular governance of life.”

As highlighted by Rose and Abi-Rached (2013), the extension of neuropsychiatric meaning into public life creates new ways of understanding ourselves and others in relation to our brains, their molecular composition and associated diagnostic categories. These practices of meaning-making are perhaps most strongly evident in direct awareness-raising initiatives, that is, enterprises that explicitly seek to ensure that more people hold neuropsychiatric beliefs regarding dementia. One of the most high-profile contemporary awareness initiatives is Alzheimer’s Research UK’s #ShareTheOrange campaign. High-production audio-visual materials, the core objects of awareness-raising practices, are shared across various platforms promoting the legitimacy of neuropsychiatric knowledge and the likelihood that it will eradicate dementia if given sufficient resources. It encourages audiences to spread its messaging through reposting advertisements, hence the “#Share” component. At the time of writing, over two million people have shared the content (ARUK, 2019b).

Another popular British awareness initiative is the Alzheimer’s Society’s “Dementia Friends” scheme (Dementia Friends, 2017). Dementia Friends aims to improve the everyday lives of people with dementia through making the general population more understanding of their impairments and requirements. While the in-depth initiation involves a face-to-face session of 45 min, there is a briefer online process whereby a person watches a short video and subsequently receives a badge. This online option likely goes

some way toward explaining the creation of three million Dementia Friends (Dementia Friends, 2019). This is an unusually explicit form of neuropsychiatric expansion to new populations because those targeted are quite literally (re)labelled and (re)badged. The Dementia Friends scheme has five core messages, including “dementia is not a normal part of ageing” and “dementia is caused by diseases of the brain”. Thus, fundamental neuropsychiatric beliefs are central to the initiative, despite a purported focus on creating a society that is more accommodating toward those living with dementia. The implication here is that people’s actions toward people with dementia are improved when they believe that dementia is abnormal and pathological, a logic returned to below in our discussion of dissonance.

Not all awareness campaigns entail nationwide programmes underpinned by largescale institutional infrastructures. Various smaller endeavours also exist, with an emerging focus on young people and minority ethnic groups. The “Kids4Dementia” programme is designed to change children’s dementia beliefs in regional Australian schools (Baker et al., 2018); “Dementia Detectives” is a one-hour awareness session aimed at secondary school students (Parveen et al., 2015); the “Psycho-educational Intervention for African American Caregivers” is comprised of twelve 90-min “modules” of dementia literacy for African Americans (Morano and King, 2010); and the fotonovelas “Unidos en la Lucha” and “Que le Pasa a Abuelito” are small booklets designed to educate Latinos in the US (Valle et al., 2006). As with #ShareTheOrange and Dementia Friends, these smaller initiatives are relatively explicit in their attempts to spread neuropsychiatric meanings to populations deemed potentially non-compliant. They seem to be broadly successful on their own terms, having reported improved concordance with neuropsychiatric beliefs among recipients.

In light of the self-reported success of awareness initiatives in combatting certain beliefs and promoting others, it is important to qualify commonplace claims regarding the binarism of beliefs, whereby people either subscribe to neuropsychiatric beliefs or do not. Various authors have sought to characterise dementia beliefs along the same categorical lines as those at the heart of neuropsychiatric culture (e.g. Clare et al., 2016; Quinn et al., 2017, 2018). Clare and colleagues (2016) have used cluster analysis to categorise people affected by dementia into distinct groups who consider their dementias to result from *either* illness *or* ageing. Thus, even the methodologies of associated research manifest a type of knowledge binarism, with cluster analysis providing a particularly direct example due to its focus on discrete typification (see Romesburg, 2004).

In response to such claims, it is important to acknowledge that an individual’s beliefs are often more complex in practice. The binary notion that one group holds disease-model beliefs and another group holds senility-model beliefs is misleadingly simple. (Fletcher, 2020a) has observed composite dementia beliefs among people affected by dementia, noting that “their meanings were variable combinations of diffuse aspects of biomedicine, ageing, personality and comorbidity, couched within broader notions of uncertainty and semi-naturalised decline.” These beliefs, labelled *Alzheimerised senility*, resemble longstanding traditional beliefs conflating dementia and ageing, but are articulated through a partially neuropsychiatric language centring on the brain, as well as implicating elements of personality. Fletcher (2020a) suggests that, while the 1970s neuropathological conceptualisation of dementia may represent something of a paradigm shift at an institutional level, in the lives of people affected by dementia, be that in terms of treatments, meanings or lived experiences, “it has been more of a gradual infusion.” The lack of treatment options means that neuropsychiatric institutions are relatively uninvolved

in the lives of people affected by dementia. Fletcher found that, in lieu of neuropsychiatric solutions, participants created their own hybrid systems of meaning for ordering their dementias, based on neuropsychiatric, lay and personal meanings. These findings echo Pickersgill's (2013) work on neuroscience more broadly, arguing that, while from certain perspectives neuroscience has become a dominant engine of public understanding, for many groups the effects are not so pronounced. Hence, neuropsychiatry "neither hegemonic nor monolithic and serves various, sometimes incompatible interests and values" (Vidal and Ortega, 2017, p. 4). Recognition of potential uneven and contradictory developments of neuro-creep highlights the ambiguous terrains of meaning that can emerge from neuropsychiatric creep when its knowledge claims are somewhat at odds with people's experiences, and it is to this ambiguity that we now turn.

Dissonant dementia

So far, we have outlined a seemingly coherent and rather neat neuropsychiatric iteration of dementia that exists as a notable component of the wider dementia landscape. In this section, we discuss what neuropsychiatric creep into the public sphere means for cognitive decline in later life today, before considering how it might shape the future. It is here that the neat dementia meanings described above are contaminated by, and themselves contaminate, a mass of plural, fragmented and often contradictory dementias. The process described herein hence mirrors a growing recognition across medical social science of complex gradual syntheses occurring between technical and lay understandings of health and illness (Weiner et al., 2017). We argue that, through the expansion of certain beliefs and practices, neuropsychiatry can transform dementia into an ambiguous entity, a dissonant dementia, one that is several seemingly contradictory things at the same time, the British public's most feared condition, yet one with which people are living well. We suggest that these contradictions are likely to continue in the immediate future. Finally, we pay critical attention to some of the political implications of this dissonant dementia. We ask why related endeavours focus on legitimising and promoting a symbolism of normality and abnormality, rather than advocating for changes that could improve people's lives more immediately and practically. Throughout, we use "dissonance" literally to denote a lack of harmony between different things.

The first neuropsychiatric contribution to a dissonant dementia is the promotion of early diagnosis, bound up with clinical trial setbacks and biomarker research, discussed further below. Over recent years, neuropsychiatric stakeholders have advocated early diagnosis in response to dementia (Brayne and Kelly, 2019). A notable example was the Department of Health's 2014 pledge to pay GPs £55 per dementia diagnosis to increase diagnosis rates, a much derided and ultimately short-lived scheme (Bell et al., 2015). Dementia diagnosis promotion does appear to be working, with the number of people diagnosed in the UK doubling between 2005 and 2015 (Donegan et al., 2017). The spread of earlier diagnosis creates a new population of people with dementia who are relatively young and cognitively able compared with those previously diagnosed at later stages. Consequently, the move toward early diagnosis has produced a younger and well-er dementia, brought into advertising campaigns as a means of presenting a more socially palatable dementia—"a sanitised presentation of dementia... a purer dementia, uncontaminated" (Fletcher, 2021a, p. 421).

A fascinating aspect of this process is the emergence of tensions between expertise by 'lived' experience and expertise by profession. Perhaps the most explicit examples of this are the social media battles between prominent neuropsychiatrists and activists

(Fletcher, 2019). Over recent years, some dementia activist groups have drawn on disability politics to promote their causes, resulting in the creation of well-known people with dementia who are seemingly younger and more able than traditional stereotypes of people with dementia. Their public profile has partially changed the nature of dementia, expanding it to encompass new notions of "living well", and this has prompted aggressive backlash from members of the traditional neuropsychiatric community. Related professionals have publicly denounced people who they consider misdiagnosed (Howard, 2017; Hu, 2017). Such arguments are infused, both explicitly and implicitly, with prescriptions of what dementia *really* is and what *authentic* presentations look like. Fletcher (2019) critiques the exclusivist approaches on display in such clashes, noting that "each side argues as though they are contesting a fixed entity that is not properly understood by the other... Commentators jostle to declare what dementia is and is not, but nobody has such answers." What is especially ironic about this often fractious assertion of (il)legitimacy is that the existence of unusually able dementia activists is partly a product of diagnostic expansion, both generally and specifically into earlier disease-stages. As with Frankenstein and his monster, this particular neuropsychiatric initiative has created its own foe, and in doing so has invigorated traditional sociological questions regarding configurations of power and knowledge when defining and attributing medical conditions (Busfield, 2017).

The emergence of a younger, well-er, and generally more positive dementia, fuels dissonance because diagnostic expansion goes hand-in-hand with promissory science appeals to the gravity of dementia as a problem (Burke, 2017). The post-1970s alarmist publicisation of dementia, as a modern epidemic imperilling societies, has been key to neuropsychiatric self-justification. Based on the National Institute of Health's use of cancer in the post-war period, neuropsychiatric stakeholders in the late 20th century weaponised cognitive decline in later life to substantiate their existence (see Fox, 1989). The traditional argument has been that dementia will be ruinous, but that neuropsychiatry can prevent that fate. As a marketing enterprise this has been successful—the number of dementia researchers in the UK almost doubled between 2009 and 2015 (ARUK, 2017)—but its success has coincided with dementia becoming the British public's most feared illness (Alzheimer's Society, 2016). This trajectory exemplifies the difficulties of raising societal concern about a health condition without scaremongering (Fletcher, 2021a; Devlin et al., 2007). To this end, Fletcher (2021a, p. 422) cautions that well-intentioned "campaigns risk positioning dementia as a substantial societal problem and portraying people with dementia as exceptional, widely abused and in need of special treatment, ultimately othering dementia." Consequently, the increasingly positive dementia of early diagnosis sits alongside an increasingly negative dementia of promissory science.

Neuropsychiatric emphasis on pathological causation may exacerbate these seemingly contradictory dementias. Pathologisation purportedly minimises "stigma", removing blame from the individual in a moralistic sense and attributing it to molecular processes beyond the person's control (Cations et al., 2017). There is ongoing debate regarding whether the attribution of mental illness to discrete pathologies frees the individual from blame and renders them a victim, or whether it leads to those affected being more feared and reviled because they are diseased and beyond salvation (Fletcher, 2020a, 2021a). However, Fletcher (2021a, p. 422) observes that "while this debate remains unsettled, dementia advocates typically take a hard-line approach, championing the pathological model." The case of cognitive decline in later life is even more uncertain, because neuropsychiatric practices often refute notions of dementia as "normal" or "natural."

This leads to difficult questions regarding normality, pathology and stigma in dementia: Does it make sense to approach normalisation as a form of stigmatisation? And can replacing normalisation with pathologisation destigmatise a phenomenon? Such questions are beyond the scope of this paper. We solely wish to highlight that pathologisation is an important (if not the most important) part of the contemporary neuropsychiatric awareness agenda (Fletcher, 2021a), and that commentators dispute whether it increases positive and/or negative imaginings of dementia.

The dementia that emerges from the contemporary maelstrom of early diagnosis, awareness raising, alarmism and pathologisation is a strange hybrid—on the one hand, a disability to be surmounted through friendliness and adaptation; on the other, a modern epidemic with potentially ruinous implications for our societies. Equally complicated is the partial creep of neuropsychiatric meanings into public life, so that people can inhabit worlds of meaning that draw on senility-neuropathology hybrids. Dementia has hence become many different, sometimes contradictory, things. The macro level creation of a dissonant dementia echoes the emergence of Alzheimerised senility within the worlds of meaning of people affected by dementia. This entanglement of the cultural and the individual demonstrates the creeping influence of neuropsychiatry over our comprehension of cognitive decline in later life. While the component meanings of a post-1970s neuropsychiatric dementia are dissonant, one could argue that in sum they position dementia as an increasingly present and potent feature of public life (see Swinnen and Schweda, 2015, p. 10 on the “dementia boom”). The immediate dissonance of a dementia that is simultaneously worse and better than ever before is hence potentially conducive to the general proliferation of a neuropsychiatric dementia.

There is longstanding recognition of the potential contradiction that stakeholders in health-promotion, e.g. charities, must navigate when propagating disease imageries. Dire warnings backed by statistics and depictions of suffering can garner attention effectively, but can also fuel fear and revulsion. Appeals to “friendly” enabling environments and living well can suggest that the problem is readily surmountable, but can also undermine arguments for dedicating resources to pharmaceutical development and diagnosis promotion. Moreover, pathologisation can simultaneously minimise moral blame and exacerbate the severity of the threat posed. Overall, neuropsychiatric meanings can be presented as absolute fact against a backdrop of generally poor scientific understandings of ageing, neurophysiology, cognition and mental disorder. This cacophony of dissonant meanings can also be at odds with the lived experiences of people affected by dementia. A lack of treatments and services renders the practical experience of dementia today ostensibly identical to the experience of senility fifty years ago. This raises questions about making sense of a later life lived with cognitive impairment, when the available meanings for ordering that experience can be tumultuous and contradictory. The interpretive ground beneath our feet is shifting, with (Fletcher, 2019) noting that “dementia may well be unrecognisable in a decade.” The intensification of dissonance will potentially continue in the immediate future for several reasons, an issue to which we will now turn.

Critical reflections on the future

Moving forward through the tangle of neuropsychiatric meanings, we now consider dementia’s possible futures, and offer some critical comment on the interests underpinning these trajectories. Principally, we contend that the dissonant dementia described herein will likely continue given two emerging trajectories. First, the sustained development of a pre-symptomatic dementia will generate more cognitively able people with dementia. Second,

heightened neuropsychiatric attentiveness toward LMICs will expand dementia alarmism into new populations, stoking public fears. Ultimately, dementia scholars must reflect on why this is happening and whether current trajectories might be altered in pursuit of preferable futures.

The younger, well-er dementia may continue through the development of pre-symptomatic dementia classifications. The promotion of early diagnosis as a strategy for addressing dementia is being fuelled by the failure of clinical trials based on the dominant “amyloid cascade hypothesis” model of Alzheimer’s disease (Hardy and Higgins, 1992). In response, neuropsychiatrists have suggested that pathological processes may begin decades before symptoms first become evident, and therefore treatment must begin much earlier to be effective. This conceptual pre-symptomatic shift has driven a race to develop pre-symptomatic diagnostic biomarkers (Apter et al., 2015). Such developments, born of an amyloid cascade hypothesis that some deem “too big to fail”, are incentivised by key stakeholders (Castellani and Smith, 2011). For example, pharmaceutical companies funded studies encouraging the British government to financially incentivise early diagnosis in 2013 (Le Couteur et al., 2013). Substantial financial interests are reliant on the expansion of dementia diagnosis, with the number of people taking anti-dementia medications more than doubling between 2005 and 2015 (Donegan et al., 2017). There is little to suggest that these interests will change in the immediate future. Therefore, as diagnosis expands ever earlier, the population of people diagnosed with dementia but lacking overt symptoms will likely increase.

On the other side of dementia’s ambiguous future, recent increases in public fear will likely continue through the expansion of dementia into LMICs. The success of neuropsychiatric imaginings of dementia during the late-20th century was largely limited to high-income countries (HICs). Of 19 countries with national dementia plans in 2015, 16 were HICs (WHO, 2015). Of 37 countries with prevalence data in 2012, 23 were HICs (WHO, 2012). LMICs now provide fertile terrain for the expansion of a neuropsychiatric dementia into new populations, part of a broader globalisation of neuropsychiatry via the Global Mental Health movement (Kirmayer et al., 2015; Mills, 2014; Rose, 2019). This is evident in the rush to quantify dementia through global epidemiological projects, providing justification for greater neuropsychiatric practice (e.g. Prince et al., 2007, 2016). Such projects have precedents. Neuropsychiatric dementia has always relied on epidemiology to emphasise its importance. Early claims in the 1970s that Alzheimer’s was the 4th biggest killer in the US were grounded in novel uses of epidemiology as a source of statistical justification (Fletcher, 2020a; Fox, 1989). It seems probable that, just as the expansion of neuropsychiatric imaginings of dementia in HICs coincided with rising public fear, so their proliferation in LMICs will be echoed in growing fear throughout those countries.

Considering these potential futures, critical scholars must draw attention to the political interests and associated normative claims at stake in neuropsychiatric trajectories. In particular, this requires a focus on powerful stakeholders who define and benefit from producing certain types of meaning and practice. As discussed, much dementia awareness-raising centres on spreading neuropsychiatric beliefs—that dementia is caused by discrete neuropathologies, is distinct from normal old age, etc. (e.g. WHO, 2019). Critical attention should be focused on which groups are best served by this portrayal. It is telling that awareness raising campaigns reiterate that dementia is a physical disease (and by extension that donating money to certain organisations will yield cures) but are far less concerned with informing people about their legal entitlements to services. We might ask which *awareness* would be more useful to those affected by dementia—

knowing that Alzheimer's is caused by protein aggregation, or knowing how to access financial transfers for care provision? We might also ask which of these literacies is more conducive to encouraging research and charity donations, while limiting state welfare expenditure. Such questions also warrant reflection on issues of agency. The history of neuropsychiatric dementia certainly contains some suspect actions. For instance, Fox (1989) has documented intentionally alarmist lobbying tactics, purposefully orchestrated in the interests of resource accrual (though one could argue that even the explicit pursuit of resources is often principally motivated by commitments to using those resources for laudable ends). However, it is important to recognise that the processes outlined in this paper are generally not directly attributable to any particular agents, but rather emanate from a cacophony of actors and activities under the influence of multifaceted motivations and an overarching commitment to improving the circumstances of people affected by dementia.

A final point for reflection, provoked by this paper, is whether a dementia counterculture might be desirable, and if so, what it might entail? In answer, it is first worth noting neuropsychiatric dementia's detrimental ramifications. Exploring the power of neuropsychiatric dementia, Burke (2015, p. 24) observes:

The way we talk and think about dementia today is inseparable from the assimilation of a disease model... [T] his shift in thinking, buttressed by a nexus of institutional practices, research agenda, and economic pressures and interests, has profound effects upon the perception of experience of living with this condition.

This generative capacity of neuropsychiatric meanings has created a range of "new problems", including the legitimization of ethically dubious practices, the commodification of affect (and perhaps of "life itself", or even "love itself"), the positioning of dementia as a complex expert concern from which experiential expertise is excluded (Burke, 2015), and a basis for predictions of societal collapse (Falcus and Sako, 2019). We therefore suggest that some conceptual push-back is desirable.

Considering these problems, Falcus and Sako (2019) have called for novel representations of dementia that challenge mainstream imageries. Their recent book details a collection of scholarship that already does so, albeit on the peripheries of dementia research and the public imaginary. Meeks (2020) has charted contemporary "neuro-crime fiction" which engages with and subverts the neuropsychiatric turn through narratives that emphasise its inherent tensions and lead audiences to question mainstream neuropsychiatry. This approach offers a potential strategy for effective resistance, and certainly warrants further concerted academic attention. A critical dementia scholarship must nurture a dementia that readily encompasses experiential tensions, such as jointly respecting suffering and living well, while avoiding the dissonance evident in simultaneous alarmism and celebration. To achieve these ends, it is vital that scholars challenge spurious neuropsychiatric truth claims, binary knowledge/belief appeals, and imperialistic engagements with alternative meanings. It is perhaps this exclusivity above all else that renders contemporary neuropsychiatric dementia dissonant, wherein the assertion of what dementia is and is not leaves little room for the real-world ambiguities that characterise mental disorder in later life.

Conclusion

In this paper we have shone a light on several facets of a contemporary neuropsychiatric dementia to explore the multi-dimensional issue of its potential dissonance. We have shown how neuropsychiatric beliefs are treated as exceptional truths,

engendering a binary epistemic hierarchy whereby correct neuropsychiatric knowledges are contrasted against incorrect non-neuropsychiatric beliefs. Those assessed as holding non-neuropsychiatric beliefs are typically presented as knowledge-deficient, in need of educational interventions, justifying an imperialistic approach to expanding neuropsychiatric meanings. Efforts to measure these inadequate beliefs, and to promote superior neuropsychiatric beliefs, permeate numerous dementia awareness initiatives. Such endeavours are facilitated by assessment scales and high-production advertisements, and are underpinned by promissory science appeals to better futures. Thus, in dementia awareness we can perceive the beliefs, practices and objects of a distinct neuropsychiatric system of meaning.

We have argued that the creep of neuropsychiatric meaning into public life creates new modes of understanding ourselves and others, but that associated efforts to instil certain types of meaning are only partially successful in generating ardent neuro-enthusiasts. This partiality is indicative of the dissonant dementia that has emerged from contemporary neuropsychiatric endeavours, a dementia that is several seemingly contradictory things simultaneously. The dissonance of this novel dementia will likely continue because of contemporary trends in the expansion of neuropsychiatry. Though problematic in several respects, this trajectory of expansion is partially supported by the substantial interests of various powerful stakeholders. Ultimately, neuropsychiatric treatments of dementia warrant greater critical analysis given the increasing influence that they exert in public life, the interests that underpin their proliferation, and the range of possibilities that they open up and shut down.

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Note

¹ We use "imperialism" not as a derisory critique, but rather to denote the moral impetus to extend power.

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Author contributions

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Competing interests

The authors declare no competing interests.

Additional information

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