

NCDs

Names, sums, and parts

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Abstract

The global burden of mortality and morbidity attributable to noncommunicable diseases (NCDs) now exceeds that of infectious disease. Yet, concern is mounting that global political prioritisation and action have stalled. The failure of NCDs to capture public and political imaginations has been ascribed to a number of reasons, with some recently contending that the very name of the disease classification is to blame. In this piece, I reflect critically on why discourse about NCDs has not compelled global action proportionate to the magnitude of the suffering these diseases cause. Failure to act on NCDs, I argue, is not a failure of terminology alone.

Keywords

NCDs, noncommunicable, chronic, policy, advocacy

Though the term ‘noncommunicable diseases’ (NCDs) is ubiquitous in public health, it remains an unfamiliar construct to almost everyone else. This is common-sense enough: laypeople understand and experience diseases, such as diabetes or cancer, not categories. In effect, they experience and encounter the parts of the NCD category, never the sum. Yet, despite the absence of the term in everyday parlance, NCDs remain central to the language, tools, policy, and advocacy strategies of global and national public health. Indeed, and as medical researchers Blundell and Hine (2018, 5) have recently argued, although NCDs are ‘well known to medical professionals, the jargonistic nature of the NCD acronym has not

caught the imagination of the world at large. . . . It has not become common enough to be featured and understood in the mass media'. This disjuncture between public health ubiquity and lay absence generates the question that animates this think piece: how to generate much-needed political action on NCDs when popular awareness and understanding of the term remain so low?

NCDs cause over 70 per cent of global mortality and 85 per cent of premature deaths in low- and middle-income countries (WHO 2017). The acronym is short for a nosological category comprised of four diseases (cancer, cardiovascular disease, chronic respiratory disease, and diabetes) and four modifiable behavioural risk factors (tobacco, alcohol, diet, and physical activity), commonly known as the '4 by 4'. Mental health is sometimes (but not always) included within this category (WHO 2018). While the NCD category may now be constituted in relatively neat terms, it has not always been so. The circuitous journey to the current '4 by 4', described here, offers crucial context to better understand why the NCD category is failing to deliver political action at a time when it is needed most. NCDs therefore represent a twofold 'crisis': one of magnitude in terms of their health and economic costs, and one of persistent inaction in the face of these costs. Though the magnitude of the crisis is well evidenced and generally agreed upon, this certainty rarely translates into adequate or appropriate political action.

To explore the context of this twofold crisis, I draw on reports by international organisations – the World Health Organisation's *World Health Reports*, key NCD publications, and the World Bank's *World Development Reports* from 1990 onwards – to reflect upon the emergence of the NCD category itself. Briefly describing the conceptual, epidemiological, and etymological evolution of this term, I show that 'NCD' was inserted into a shifting global health landscape where it has been limited in its ability to mitigate and manage the twofold crisis. While some public health researchers have argued that the impotence of NCDs lies with the name itself (Allen and Feigl 2017a, 2017b), I argue that the lack of political prioritisation cannot be resolved simply by changing the terminology. Rather, inaction represents the failure of 'NCDs' to resonate with the public and to create the kinds of meanings, values, and sense of crisis that make people anxious enough to care and politicians accountable enough to act.

Making jargon

The contemporary history of the language of NCDs starts with the first 'global burden of disease' (GBD) study published in the World Bank's 1993 *World Development Report*. This study divided afflictions into three groups: (I) communicable, perinatal, and maternal; (II) noncommunicable; and (III) injuries. This hugely important report was one of the earliest to

tie together the recursive relationship between economic development and health at individual, household, national, and global scales. It also highlighted that while progress had been made in reducing mortality from infectious disease, mortality rates from noncommunicable diseases were climbing. This was especially the case in regions of the world previously thought to be burdened by infectious diseases. But the report also made new geographies of NCD burden visible and, in so doing, tightly yoked together health and development agendas.

The report's significance was not, however, limited to questions of geography. One of the key epidemiological ideas put forward by the authors of the GBD was the 'disability adjusted life year' (DALY). In measuring the contribution of the three disease categories above to years of healthy life lost, DALYs illuminated the scale and scope of the NCD burden. The use of DALYs showed that, contrary to the received wisdom of the period, the burden of NCDs was greater than that of communicable diseases in all regions except for sub-Saharan Africa, India, and the Middle East. The report also predicted that as mortality rates from communicable diseases declined, the population aged, and fertility rates fell, 'the burden from noncommunicable diseases [would] increase sharply, both absolutely and proportionately' (World Bank 1993, 32). This prediction of increasing morbidity and mortality as well as future increases in risk factors cemented a sense of impending public health crisis.

The 1995 *World Health Report* (WHR) expanded on the nature of this crisis, arguing that 'developing countries will increasingly face the *double burden* of continuing to cope with a legacy of the traditional diseases of poverty, while dealing with a growing number of lifestyle diseases' (WHO 1995, 32; emphasis added). The 1997 WHR (WHO 1997, 2) continued this theme, suggesting that NCDs were characteristic of a later stage of development trajectories, citing a 'changing pattern of health in which poor countries inherit the problems of the rich, including not merely illness but also the harmful effects of alcohol, tobacco and drug use, and of injuries, suicide and violence'. This framing of NCDs as part of an inexorable development trajectory solidified the category's identity as relating to the negative externalities of globalisation. It also firmly positioned NCDs as an important problem in, of, and for development.

It is noteworthy that, at that time, NCDs were not yet referred to by their acronym and were defined by what they are not, rather than by what they are. The category began as a repository for the diseases that did not readily fit the other classifications. For example, after defining Group I as 'infectious diseases and maternal and perinatal causes', the WDR's (1993, 197) annex states that 'noncommunicable diseases include *all other causes of death*' (emphasis added). In essence, therefore, it was a residual category whose members could be

combined; taken together, NCDs represented very high levels of disease burden. And yet, although the composition of the category managed to create and convey the *magnitude* of crisis – especially among low- and middle-income countries – the inconsistent adoption of the terminology used to describe it arguably diluted the messaging. Moreover, the lack of a commonly understood name for the problem did little to secure the political will to act.

The WHO and World Bank reports from the mid-1990s continued to oscillate between the use of ‘chronic’ and ‘noncommunicable’ disease. In 1997, the WHR expanded its terminology, referring to ‘non-infectious chronic disease’ or the ‘chronic diseases which strike later in life’ (WHO 1997, 2). The lexical inconsistency continued well into the 2000s: the WHO’s 2004 *Global Strategy on Diet, Physical Activity and Health* used the term ‘noncommunicable diseases’, while the *NCD Action Plan 2008–2013* used the acronym. All the while, other documents still referred to ‘chronic disease’, as many still continue to do. Bernell and Howard (2016), for example, point out that the Centers for Disease Control use the term ‘chronic disease’ in relation to diseases in the United States, but use the term ‘NCDs’ in their global health work, despite dealing with many of the same diseases. But by 2011, when the first UN High Level Meeting (UN HLM) was held, the acronym was in common use by international organisations. The widespread adoption of the term was likely aided by the 2009 formation of the NCD Alliance, an influential lobbying and advocacy group that was instrumental in driving forward the case for the ‘urgency’ of the global NCD burden and, therefore, the need for the UN HLM.

While the terminology might have been inconsistently deployed, it is notable that the term ‘NCD’ was never actively problematised in any of the reports I have cited. Rather, concern coalesced around the problem that, as the WHO (1997, 3) argued, ‘separating infectious and chronic diseases creates something of a false division. It is becoming more and more difficult to establish a firm borderline between them’. As biomedical research has shown, the risk factors for NCDs are innately fluid and cross-cut infectious agents, behavioural risk factors, and manifold life conditions. Medical historian McKeown (2009, 7) notes that ‘not only is it the case that some infectious diseases have chronic disease characteristics, but we have come to recognize the importance of infectious agents and related inflammatory processes in the aetiology of a number of chronic diseases and adverse outcomes’ (see also Seeberg and Meinert 2015).

The inclusion of NCDs within the United Nations’ Sustainable Development Goals (SDGs) in 2015 produced high hopes for swift and effective political action and global health funding. While the NCD agenda has enjoyed clear progress in the form of SDG targets and indicators, this has yet to really dent the upward trends in NCD prevalence, especially across the global South. Funding levels also remain a fraction of those granted to the global health behemoths of malaria, HIV/AIDS, and tuberculosis. In 2013, for example, NCDs

commanded only 1.3 per cent of all Development Assistance for Health funding (Nugent 2016). These funding gaps are inseparable from the ‘malignant neglect’ of NCDs within global health prioritisation (Stuckler and Basu 2013). However, it is significant that recent debate in the *Lancet* sidesteps this economic reality in favour of ascribing inaction to the terminology alone. I want to briefly turn to this debate in order to explore why names alone are less significant than their deployment and popular use.

On names and naming

Over the last decade there was great hope within the public health community that the UN High Level Meetings in 2011, 2014, and 2018 might catalyse much-needed multisectoral action on NCDs. For public health advocates, the 2011 HLM was an unparalleled ‘opportunity to stimulate a coordinated global response to NCDs that is commensurate with their health and economic burdens’ (Beaglehole et al. 2011, 449). Yet, since the 2011 Political Declaration of the United Nations General Assembly on the Prevention and Control of NCDs, hope has been replaced by feelings of panic that the momentum behind the cause is waning (Horton and Sargent 2018). Lurking behind the politics of political prioritisation is the unresolved question of whether NCDs do not readily lend themselves to the kind of stories that ignite public passion and political action because of a fundamental problem of their nomenclature. This debate starts from the supposition that the current name is not working, evidenced by the fact that progress is slow, governments are not sufficiently committed and not meeting their own voluntary targets, funding has not materialised, and the forces of ‘vested interests’ are too strong.

Along these lines, public health researchers Allen and Feigl (2017b, e129) invite public health researchers to reflect on ‘what’s in a name’, arguing that the ‘branding’ of NCDs is underdeveloped and the disease classifications themselves are ‘both outdated and counterproductive’. The authors assert that the word “noncommunicable” propagates confusion, undermines efforts to spur a sense of urgency and deflects attention from effective systems-wide interventions’ in favour of a continued focus on individual behavioural modification (Allen and Feigl 2017b, e129). They propose renaming NCDs as ‘socially transmitted conditions’ to shift attention and action to their upstream commercial and socioeconomic determinants, and away from individuals and their risk behaviours (Allen and Feigl 2017a). The term ‘socially transmitted’, they argue, is ‘vastly more transparent, accurate and tractable’ and offers a ‘coherent and internationally significant narrative’ (Allen and Feigl 2017a, e645).

In response to their paper, researchers have suggested numerous other terms to replace NCDs. These include ‘industriogenic diseases’ (Lincoln 2017), ‘lifelong diseases’ (Rigby

2017), ‘interactional diseases’ (Kozelka and Jenkins 2017), ‘human-made illness’ (Blundell and Hine 2018), and ‘biosocial and development diseases’ (Zou et al. 2017). Two online polls on the topic provide additional suggestions, including ‘avoidable behavioural and chronic diseases’, ‘the major diseases’, ‘proximal disorders’, ‘blue and green diseases’, ‘cardiometabolic diseases’, and, my favourite, ‘insidious killer diseases’. Intended to replace a vague and obtuse acronym, these terms are arguably even more vague and obtuse than ‘NCDs’. ‘Socially transmitted’, ‘interactional’, ‘biosocial’, and ‘industriogenic’, for example, are terms whose meaning even health researchers cannot agree on. More importantly, they are utterly meaningless to a lay audience. It reminds me of when I asked a friend to read my PhD thesis, and they thought I’d made most of the words up. While I thought these ‘made-up’ words were powerful and resonant, my friend thought they were nonsensical. For NCDs, political action is not hindered because the term is inaccurate, but because it has not been infused with enough common meaning, power, significance, and resonance to compel change. What I find remarkable in these critiques is the assertion that institutional failures to mount effective responses can be traced to the label of NCDs, as if with a change of terminology alone – rather than with a fundamental shift in global political economy, a turn to global social justice, and the reduction in the power of lobbyists – apathy will be transformed into action.

So what?

Tackling NCDs in meaningful, effective, and equitable ways goes far beyond words alone. As George Alleyne and colleagues (2011) have argued, NCDs need to incite more fear to galvanise action. The history of public health clearly bears out this argument, with ‘public hysteria’ about infectious disease outbreaks far outstripping any ‘public fear’ of the dangers posed by NCDs (Alleyne, Basu, and Stuckler 2011, 84). This lack of ‘public angst’ or ‘international hysteria’ is important because it means that NCDs have effectively become normalised and routine. Deaths from NCDs are tragic and often premature, but they are not cast with the same tenor of panic that accompany infectious diseases. Interestingly, among the alternative terms mooted in the *Lancet* debate, none would seem to incite fear or hysteria any more than ‘NCDs’. Rather, each term emerges from a different problem frame and requires a slightly different locus of action and set of solutions. However, and crucially, none of these are immediately obvious to anyone other than health researchers.

What then of the NCD term itself? If NCDs have thus far failed to ignite any sense of urgency, then perhaps it is because the term has yet to be infused with meanings sufficient to generate the right sense of ‘crisis’. And even though the metrics of NCDs may convey crisis, this is not translated into any particular sense of crisis. The problem is not so much that the name is deficient, but that it is not in common parlance and has no resonance with the

public. This is not a failure of terminology alone, but a broader failure to connect that terminology to the lives and experiences of laypeople in a meaningful way. When people go to the doctor, they get diagnosed with a disease or diseases, not an NCD. For NCDs then, the power of the sum – regardless of the name – is arguably far less than that of its commonly understood parts. This raises an obvious question ignored in the debate on naming: if individual diseases already have powerful names, frames, and ‘brands’ that resonate and draw in research and advocacy money, how can the sum of these parts be infused with the power and resonance to catalyse change? A first step might be that if people in health care settings talked instead of NCDs (rather than individual diseases) and risk factors were linked to NCDs in the media, then the public might start to recognize the term.

Debates that happen in a public health vacuum will not alter the average person’s experiences of health and illness. But when terms are mainstreamed into popular use and people identify with them and start to identify the broader issues they raise – of social justice, inequality, poverty, political economic systems, industry lobbying, regulation, and social protection – then they might begin to care. And when people start to care, then they will demand change. It is then far more likely that political mobilisation and action will follow. Inspiring care is often about finding the right words, but people must first know that those words exist and what they really mean.

About the author

Clare Herrick received her PhD from University College London and is currently Reader in Human Geography at King’s College London. Her research explores the intersections of risk behaviours for chronic disease, urban development, and governance strategies. She is the author of *Governing Health and Consumption* (Policy Press, 2011) and has published widely in geography, sociology, anthropology, and global/public health journals. She is currently researching the genesis of noncommunicable disease advocacy.

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