Ignorance Claims as a Call to Action: The Case of Neglected Tropical Diseases

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Abstract: Social scientists are increasingly interested in investigating the social structuring and production of absences, silences and ignorance. Emerging work on non-knowledge and absence highlights that states of 'non-knowing' are themselves socially constructed. This new literature currently concentrates upon examining non-knowing as a device to sustain politically expedient 'strategic ignorance', in keeping certain social problems hidden from the policy and public gaze. However, this paper will present a counter-case – the rise of Neglected Tropical Diseases as a policy problem within global public health. The paper draws upon scoping data that utilises qualitative discourse analysis of global health documentation. It examines the mobilisation of concepts of inaction and unknowing in the social construction of NTDs as a global health issue. The analysis demonstrates that the concept of ignorance/unknowing was coupled with ideas of the risk of inaction to construct NTDs a global health policy problem of immediate concern. The coupling of ignorance claims to particular matters of pre-existing political interest – such as the relationship between diseases of the poor and economic development, and the potential global spread of infectious diseases – further aided the generation of political will. In the case of NTDs, concepts of inaction and non-knowledge underpin discourses of risk and imperative. The case study demonstrates the ways in which claims to ignorance can sometimes serve to promote policy production, rather than hide social problems from the policy gaze.

Introduction

Problems of non-knowledge are currently gaining traction as a site of social scientific investigation. This new area has been described variously as agnotology, ignorance studies, or silence studies, and draws upon various disciplinary and theoretical traditions. At the more sociological end, within which this paper is located, the literature draws on previously under-emphasised aspects of the classics, such as Merton's' (1987) work on the role of non-knowledge in the structure of scientific disciplines or Simmel's (1906) ideas of the social role of secrets. Contemporary ignorance studies is particularly interested in two main areas: the way in which ignorance is passively or actively structured through the practices of scientific and institutional knowledge-making (Kleinman and Suranarayanon 2013; Smithson 1993), and secondly, the active political and policy construction of ignorance (McGoey 2012a; McGoey 2012b; Rappert 2012). This second version is variously referred to as concerted or strategic ignorance. Overwhelmingly, studies of the politics of ignorance emphasise the negative impacts of the social construction of non-knowledge, particularly in relation to suppressing or disrupting knowledge claims and in serving to cover up social problems.

The explicit linking of ignorance studies with the topic of health and illness has been minimal. This is perhaps surprising, given that the problem of unknowing is central to the task of medicine, as evident in issues around the medical encounter including problems of medical uncertainty (Fox 2000; McKinlay 1973; Olsen and Abeysinghe 2014) or particular illness presentations such as Medical Unexplained Symptoms (Nettleton 2006). Studies on the social construction of new diseases show that 'non-knowing' can fundamentally underpin definitional struggles. Examples such as the patient movements

around repetitive strain injury (Arksey and Sloper 1999; Bammer and Martin 1992), premenstrual syndrome (Rittenhouse 1991) and chronic fatigue syndrome (Ware 1992) show that medical issues move from the 'unknown' to the 'known' through acts of recognition and medicalisation. However, such studies tend to focus upon the role of particular agents (e.g. patient or professional communities) or socio-historical constructions (e.g. using Foucauldian and Marxist frames of analysis) in the creation of new illness realities; the issue of non-knowledge is implicit rather than central to this field of research. In interactions between health and policy (i.e. the public health literature) there are a few more examples of the explicit focus upon ignorance, in particular strategic ignorance as employed by corporate and political actors. Within this literature, ignorance is understood to be constructed in ways that hide or minimise health problems. Prominent examples include the way in which the tobacco industry subverted knowledge surrounding the harms of smoking (Proctor 2008; Stocking and Holstein 2008), or in Merck's withholding of the risks surrounding Vioxx (McGoey 2012a). However, as this paper will argue, despite the current focus in ignorance as a device used to hide social problems, in fact, ideas of ignorance can also be employed in highlighting policy issues.

Global health problems are increasingly framed through the concept of neglect, as evident in reference to 'orphaned' drugs, neglected populations or rare diseases (see for example Scheindin 2006; Wästfeld et al. 2006). This mobilisation of 'neglect' is most clearly evident in respect to 'Neglected Tropical Diseases' (NTDs). The term Neglected Tropical Diseases (NTDs) was coined in 2005 to refer to a 'new' category of predominantly parasitic diseases of the developing world. Together, according to the World Health Organization, this category of 17 diseases affects over one billion people worldwide (WHO 2015a). Political interest in NTDs has emerged out of the construction of this new disease category. While the individual diseases that now make up the category of NTDs have been 'known' historically (some of these diseases have even been described in ancient texts) (Hotez et al. 2006), the recent mobilisation of 'neglect' has underpinned the catalysis of global action. 'Ignorance' is fundamental to the construction of this policy problem – as the name Neglected Tropical Diseases itself suggests. The idea of neglect, ignorance and inaction underpin contemporary political orientations towards NTDs. This has led, for example, in highlighting the treatment of NTDs as part of global development, and in overwhelming increases in global funding of these diseases. Since the coining of this term 'Neglected Tropical Diseases', NTDs have moved towards the forefront of the global health agenda, being strongly linked to the Millennium and then Sustainable Development Goals (Molyneux 2014; Smith and Taylor 2013), and facilitating the rise of new coalitions of global actors and institutions (Liese et al. 2010).

The rise of Neglected Tropical Diseases provides an interesting case study of the way in which ignorance claims can be used to support – rather than subvert – policy action. The existing literature within ignorance studies tends to emphasise the strategic uses of ignorance by powerful political actors or institutions to obscure a social problem. Implied within this is the idea that ignorance plays the social role of 'hiding' issues from the public gaze. However, the case study of NTDs suggests otherwise – that claims to ignorance can be used to highlight social problems (here, 'hidden' diseases) and organise political action. This paper draws upon scoping data from documents produced by global health actors managing NTDs. The paper proposes that the case study of NTDs can help to illuminate the way in which discourses of ignorance and non-knowing can be mobilised to achieve political interest. The paper ends with a methodological note on what this case study implies in terms of understanding how scholars can investigate issues of ignorance.

NTDs and Ignorance

The category of Neglected Tropical Diseases refers to a set of infectious diseases that affect under-developed populations. The diseases are exacerbated by the conditions of poverty, including the lack

of clean sanitation and drinking water, as well as the lack of control of disease-carrying vectors (Hotez et al. 2006). The category itself it still undergoing construction in that there remains a large extent of definitional instability and lack of closure around the term. For instance, different global health organisations list vastly different numbers of diseases under the category of NTDs. Various degrees of inclusivity are used, such as the WHO listing 17 diseases (WHO 2015b) versus the specialist scientific journal PLoS Neglected Tropical Diseases listing 37 disease groups (PLoS NTDs 2014). Another example of the definitional looseness around the category is the push for conditions such as snakebite or obstetric fistula to be included as official NTDs (Gutiérrez et al. 2013; Wall 2012), despite the fact that these vary widely from the more archetypical parasitic diseases which the term currently encompasses.

Referencing the WHO's list, clinically, most of the diseases cause high morbidity and disfigurement but not high rates of mortality (though the lack of prior political emphasis on these disease means that these figures are varied estimates) (Fenwick 2012). This fact –the presumed lack of high mortality - has perhaps reinforced the circumstance that the diseases have not become a focus of international and global health until recently. However, what underpins the contemporary definition of this category is not a set of clinical or epidemiological characteristics but rather their binding together of advocacy campaigns. It is the politics of these diseases, rather than the biology, which constitute the category.

What is central to this politics, as the term NTDs itself suggests, is the idea of neglect, ignorance and silence. Ignorance underpins the social construction of the category of NTDs. For example, according to the first WHO report on NTDs, these diseases "cause massive but hidden and silent suffering" (WHO 2010:iii). The hidden and ignored nature of these diseases is fundamental to their current problematisation within global health. In referring to the recent political prominence of NTDs, the WHO DG suggested that "These Cinderella diseases, long ignored and underappreciated, are a rags-to-riches story" (Chan 2012). The idea of a long historical ignorance of NTDs therefore strongly underpins the contemporary global health discourse. As such, social scientific theories of ignorance help us to interrogate exactly what is happening when NTDs are referred to a long-ignored diseases. Particularly, it is clear that ignorance is central to the social construction of this problem, rather than a marginal aspect of this issue. This reflects a key claims of the emerging ignorance studies literature; ignorance can be a defining feature of a policy problem. Conversely, the case study of NTDs also helps provide a counter-point to much of the existing ignorance studies cases. While this literature often focuses upon the role of ignorance in repressing social problems (or at the least in terms of a strategic forgetting), in the case of NTDs discourses of ignorance have been fundamental to the production of political will and interest surrounding these diseases.

Examining this case, it is clear that the concept of 'ignorance' is an important discursive construct in defining the politics surrounding these diseases. The particular mobilisation of the idea of ignorance allows for the linking of 'non-knowing' with other important political frames. Ignorance and silence is embedded in many parts of the global health discourse surrounding NTDs. The way in which neglect or ignorance is deployed in discussions of NTDs serves to highlight the need for action. In particular, references to 'ignored diseases', 'ignored populations' and 'policy absences' prevail. Such ideas are used to highlight the moral duty of the global health community to act against these diseases.

Claims about the neglect of these diseases is also linked to other problems of governance. Here, NTDs are discursively linked to other prominent political issues – problem of global economic development and global security – that are current political priorities. The argument is asserted that ignoring NTDs means ignoring key aspects of these other political issues. While health effects are of course significant, the discourse surrounding NTDs strongly links these diseases to problems of poverty and

security. The linking of NTDs with the Millennium Development Goals was indeed an important moment in gaining political prominence for the issue (Smith and Taylor 2013), and the discursive linking of NTD management and development is a key theme within global health discussions.

NTD advocates proclaim that the global community can no longer ignore these diseases due to their wider socio-political impact. For example, the END Fund – a charity working on the issue of NTDs suggests that "NTDs represent the major stealth cause of poverty among the poorest people in developing nations" (END Fund 2015). In this way, action surrounding NTDs is argued to provide a mechanism to "lift[ing] the 'bottom billion' out of poverty" (END Fund 2015; Hotez 2011:e1134). Discourses of development and health thereby become intertwined within discussions of NTDs. This mirrors the long history of the interweaving of issues of economic development and health, stretching from colonial medicine to current conceptions of global public health, in discussions of illness among the poor of lower income countries (Arnold 1988; King 2002). This linking together of economic and health aims is also evident in relation to the historical management of NTDs, as Farley's (2003) work on bilharzia (schistosomiasis) suggests. What is particularly evident within the quotes above is that disease is often represented as a cause for poverty in affected regions. This reverses dominant social scientific arguments about the link between poverty and disease, where instead poverty is the precursor to ill-health (e.g. Doyal and Pennell 1971). Instead, in mobilising action surrounding NTDs it is suggested that NTD treatment will result in the economic development of affected populations.

The ignorance surrounding NTDs is also suggested to reinforce conditions of violence and war. For example Peter Hotez, one of the key advocate-scientists within the global politics of NTDs suggests that "[i]n addition to the high rates of economic return for the treatment of NTDs…the impact on conflict resolution is potentially enormous" (Hotez and Thompson 2009: e346) and in particular referring to US security concerns that "[w]e now need to examine mechanisms for embracing NTD control as a critical element of US foreign policy" (Hotez and Thompson 2009: e346) in order to moderate the political instability of affected regions. Thus, this particular ignorance surrounding NTDs is placing more important matters – matters of security and economics – at stake. In this way, discourses of neglect are bound up in the wider politics of development and security in demonstrating the need for action around these diseases.

Simultaneously, while the global health discourse of NTDs revolves around the notion of neglect, this discourse serves to conceal other aspects of the NTD story. In presenting action surrounding NTDs as recent and in contrast to previous neglect, this discourse makes little mention of past efforts at the management of these diseases in public health. This historical management occurred at both the local level, for example in respect to the schistosomiasis control campaigns in Egypt and China during national modernisation campaigns (Minggang and Zhang 1999; Sandbach 1976), and also at the level of international cooperation. For example, the Pan-American Health Organisation, often referred to as the first international cooperative public health action, first focused upon the control of onchocerciasis in the region in the 1950s. The control of this disease became a central concern of the PAHO, culminating in the creation of the Onchocerciasis Elimination Program for the Americas in the early 1990s (Banks et al. 1998; Gustavsen et al. 2011). This history seems to be largely forgotten within contemporary global health narratives. Instead, the call to action is made by focusing upon the 'newness' in interest in these diseases and what is represented to be the long history of neglect before the development of the current focus. Thus, in focusing the narrative strongly on assertions of the ignorance surrounding these diseases, the discourse may serve to produce ignorance around the often-deep history of policy action that surrounds individual afflictions.

Further, the discourse on the global level serves to obscure local level actions. Medical anthropologists have been particularly critical of the often perverse effects of international drug distribution

campaigns at the level of local distribution (Allen and Parker 2011). The building of the over-arching category of NTDs to house these diverse diseases has proven a useful advocacy tool but may simultaneously result in the loss of distinctions. What tends to occur – particularly in terms of debate at the global health level – is that the distinctions between affected communities becomes minimised as the diseases become seen as overarching effects of global poverty. In the creation of the broad category of 'Neglected Tropical Diseases' important distinctions between the individual pathologies become blurred. Classification into a single category makes sense as a political strategy, demonstrating the impacts (over 1 billion affected) of this range of diseases. However, such classification may also act as a means of standardisation, given the general tendency of classificatory schema to simplify the explanation of phenomenon and eliminate other potential competing accounts (Freeman & Frisina, 2010; Lewin, 1994). Classificatory schemes which are thought to explain the world are actually a method of constituting it (Bowker and Starr1999; Foucault 1970), and the creation of the disease category of NTDs helps to generate policy action around this category but also minimises the differences between these diverse illnesses.

Within the discourse surrounding NTDs and ignorance, two key points can be drawn out: First, that the problem of NTDs is framed through the lens of silence and ignorance, and second, that these claims to ignorance in themselves serve to ignore important aspects of the history and social reality surrounding particular NTDs.

Implications

Ignorance is a discursive construct as much as it can be an objective reality, and this is clearly evident in the global health narratives surrounding Neglected Tropical Diseases. Much of the existing research in ignorance studies shows the way in which facts have been made hidden, remained unexplored, or subverted. This tends to see ignorance in terms of hiding the objective reality of the 'truth' around a given policy issue. However, locating the problem of ignorance through a strong social constructivist lens shows that – in the case of NTDs – ignorance can be created through discourses of not knowing or neglect.

From this perspective, ignorance can be investigated not in terms of absence but in terms of construction. How do different authors speak about the issues through frames of non-knowledge, and in what ways are narratives of ignorance employed in the creation of a social and policy reality? The case of NTDs appears to demonstrate that the strategic function of ignorance lies not only in covering social problems and subverting 'true' knowledges. Instead, constructions of ignorance can be employed to highlight the need for action.

Necessarily such accounts also serve to construct particular realities and understandings. The scoping data collected around global health discourses of NTDs shows that constructions of ignorance were employed in order to highlight this disease category as a key global health issue. Ideas of ignorance were discursively linked to problems of poverty, economic development and security in constructing NTDs as an issue in need of immediate policy action.

At the same time, the particular formation of the category of Neglected Tropical Diseases may lead to other forms of ignorance. The production of the overarching disease category could lead to the minimising of specific contextual features, such as the nature of individual diseases within this (diverse) category and socio-political factors that determine the experience of particular afflicted populations. Further, in this particular example, it appears that the use of ignorance as a rhetorical and constitutive device also serves to construct NTDs as a 'new' policy problem, even as a long neglect is represented. This carries key political advantages in the form of attracting interest and funding, and

has in part underpinned the co-option of NTD strategy into current global health discussions (in particular, the prominent role of NTD management in the new Sustainable Development Goals). However, this has also potentially led to the minimisation of both local experiences of NTD control and even past international health efforts in dealing with these diseases. In this way, this form of social construction of ignorance has produced its own forms of silences.

Ignorance is a policy problem not merely in the context of the absence of knowledge but also in terms of it centrality in debates. This is clear in the example of NTDs but also other work dealing with health care and health policy, given than uncertainty and unknowing is critical to many aspects of medicine and public health. Ignorance studies may find useful case studies within the sociology of health, and in turn, health sociology can benefit from further focus on forms of ignorance as well as forms of knowing.

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