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*Published in:*  
Economy and Society

*DOI:*  
[10.1080/03085147.2014.983830](https://doi.org/10.1080/03085147.2014.983830)

*Publication date:*  
2015

*Document version*  
Peer reviewed version

*Document license:*  
[Unspecified](#)

*Citation for published version (APA):*  
Wahlberg, A., & Rose, N. (2015). The governmentalization of living: Calculating global health. *Economy and Society*, 44(1), 60-90. <https://doi.org/10.1080/03085147.2014.983830>

## The governmentalization of living: calculating global health

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# The governmentalization of living: calculating global health

## Abstract

The contemporary 'global health agenda' has shifted emphasis from mapping disease patterns to calculating disease burden in efforts to gauge 'the state of world health'. In this article, we account for this shift by showing how a novel epidemiological style of thought emerged in the closing decades of the 20<sup>th</sup> century. As is well known, the compilation and tabulation of vital statistics – death rates, birth rates, morbidity rates – contributed to the birth of the 'population' in the 18<sup>th</sup> and 19<sup>th</sup> centuries. The population is reformatted from the middle of the 20<sup>th</sup> century by 'modified life tables' made up of disability weightings, health state valuations, quality of life scores, disease burden estimates, etc. The problem of morbid death gives way to that of morbid *living*, made calculable through a metrics of 'severity', 'disability', and 'impairment'. A series of new indices and scales (e.g. the QALY and DALY) has contributed to a governmentalization of living, in the course of which the social and personal consequences of living with disease come to be an object of political concern, and made knowable, calculable and thereby amenable to various strategies of intervention. We conclude by showing how this style of epidemiological thought has generated a new global visibility for brain disorders as their impact on individuals, healthcare systems and nations are calculated in novel ways.

## Key words

Population, quality of life, bio-politics, epidemiology, burden of disease, brain disorders

## Introduction

Epidemiologists and demographers have been grappling with the problem of how to gauge the state or level of a national population's health for over a century. Indeed, the compilation and tabulation of vital statistics, life tables and health indicators to this end has become a comprehensive, painstaking and enduring task spanning the entire globe.<sup>1</sup> Yet, the ways in which aggregated health has been perceived have not remained constant. In this paper, we account for one of the most salient shifts in epidemiological styles of reasoning when it comes to calculating the state of a national population's health on a global scale. It is a shift that has seen disease pattern displaced by disease burden as the most important marker of health in a given population. The epidemiological puzzle at the heart of this shift has been: If diseases are not 'only' something people have and/or die from, but also something that people *live with*, then how can the level of a population's health be adequately measured? And the questions underpinning this are: what are the implications of these variations in population health, what are the social, economic, political consequences of 'the burden' of ill health?

In this paper we ask how it has come about that the health of the population is problematized in this way. We begin by showing how demographers around the early 20<sup>th</sup> century began comparatively assessing the health of a nation's population as something of a by-product when working out their theories of demographic transition. By inversely correlating birth and death rates to levels of modernisation, urbanisation and industrialisation, demographers and later epidemiologists would stabilise a link between disease and developmental processes as a matter of disease pattern differentiation. We will specifically focus on those demographers and epidemiologists who developed hierarchizing classifications for the entire globe under the auspices of theories of demographic and epidemiological transition. Within this style of reasoning, the pattern of disease in a given population is transformed through modernisation processes as "a long-term shift occurs in mortality and disease patterns whereby pandemics of infection are gradually displaced by degenerative and man-made diseases as the chief form of morbidity and primary cause of death" (Omran, 1971, p. 736-7). Importantly, such a style of reasoning fitted well with, and indeed contributed to, the kind of developmental stage-thinking that, by the mid-20<sup>th</sup> century, would rank nations into First, Second and Third worlds (see Escobar, 1994). As demographers and epidemiologists began tabulating, calculating and comparing birth, death and morbidity rates in different parts of the world by compiling so-called 'life tables', populations could be ranked according to their levels of modernisation and associated patterns of disease.

Yet this style of reasoning has not remained unchallenged. In the second part of the paper, we show how these 'old' ways of aggregating health according to a population's mortality and morbidity rates came to be problematized through a series of 'adjustments' in the latter half of the 20<sup>th</sup> century. Those making such adjustments were responding to two distinctive concerns. On the one hand, governments and policymakers, faced with steep rises in health care costs, called for effective tools to help prioritise the use of scarce health care resources. On the other, critics of modern medicine – bolstered by the World Health Organization's 1948 definition of health as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948) – were decrying health care systems' 'reductionist' focus on bodily pathology. As a consequence, a cluster of instruments for measuring aggregated health – Years of Potential Life Lost (YPLL), Quality Adjusted Life Years (QALY), Disability Adjusted Life Years (DALY), Health Adjusted Life Years (HALY) and Health Adjusted Life Expectancy (HALE) – made the health impact of *living with* a particular disease or condition calculable by introducing a metrics, not of incidence and prevalence, but of prematurity, severity and disability in efforts to, on the one hand, prioritise health problems and, on the other, to measure health gains in a given population resulting from specific health interventions.

We suggest that QALYs, DALYs and the like can helpfully be thought of as human technologies – "technologies that take modes of being human as their object" (Rose, 1996, p. 26) – whose development and deployment have played a crucial part in an ongoing *governmentalization of living*. As is well known, population was an exemplary object of *governmental* rationalities and technologies, as it came to be understood as a domain with its own internal laws and regularities, notably those of reproduction, morbidity and mortality, that could not be simply dominated and mastered, but had to be understood and managed (Foucault, 1991). By governmentalization of living, we refer to a mutation in these initial concerns with the brute rates of birth, sickness and death in a national population, in the course of which the social and personal experience and consequences of living (in this case, living with disease) comes to be regarded as objects of political concern, and made knowable, calculable and thereby amenable to various strategies of intervention that aim to improve the 'quality of life' or 'wellbeing' of individuals and populations. What QALYs and DALYs have in common is that they are 'adjustments' of previous forms of epidemiologic calculation which emphasised the mapping of disease patterns in particular populations. In contrast, these tools of calculation emphasise the "burden of disease borne by individuals in different communities" (WHO, 2008, p. 40) when health problems are prioritised and the cost-effectiveness of health interventions are assessed. While morbid patterns continue to be mapped out, within a so-called 'global burden of disease' framework, it is not so much the *distribution of diseases* (and associated mortality) in a given population that characterises its level

of health as the *distribution of the burden of these diseases* in that same population. Population health has become characterisable in terms of the aggregated impact that a particular disease has on the 'quality' of the *lived* lives of its individuals and communities.

In the final part of the paper, we show how DALYs and QALYs have provided new forms of visibility to mental and neurological disorders, notably depression and the dementias, not least as an effect of rendering non-fatal outcomes calculable. Within this new style of epidemiological reasoning, even though disease is first and foremost seen as depriving of life, this is not necessarily because it is deadly. Mortality is only one kind of life that can be lost (albeit the most unambiguous) to disease according to these instruments of adjustment. Also lost to that same disease is both 'potential' life and 'healthy' life. As a result, a new metrics of 'prematurity', 'severity', 'disability' and 'impairment' emerges. Such metrics have given neuropsychiatric conditions a newfound prominence on national life tables and the global health agenda, with international organizations such as the WHO, professional groupings such as the European Brain Council, and movements such as that for Global Mental Health framing that 'burden' largely, though not entirely, in economic terms in order to make the case for increased attention by national governments, international policy makers as well as civil society organisations and businesses.

### **Populations and their diseases – vital transitions**

When Michel Foucault in the late 1970s proposed the concepts of anatomo-politics and bio-politics as two poles of a bio-power that took human life as its object, one of the points was to distinguish between individual and collective forms of vitality. If the 17<sup>th</sup> and 18<sup>th</sup> centuries had witnessed a swarming of disciplinary anatomo-political technologies which sought to secure the spatial distribution and harness the productive capacities of docile bodies through practices of record keeping, monitoring, supervision and observation in workshops, schools and barracks, by the mid-18<sup>th</sup> century this individual 'body as a machine', he suggested, was joined by an entirely different kind of 'species body':

we see something new emerging in the second half of the eighteenth century: a new technology of power... addressed to a multiplicity of men, not to the extent that they are nothing more than their individual bodies, but to the extent that they form, on the contrary, a global mass that is affected by overall processes characteristic of birth, death, production, illness, and so on... What we are dealing with in this new technology of power is not exactly society... nor is it the individual-as-body. It is a new body, a multiple body, a body with so many heads that, while they might not be infinite in

number, cannot necessarily be counted. Bio-politics deals with the population as political problem, as a problem that is at once scientific and political, as a biological problem and as power's problem. (Foucault, 2003, p. 242–5)

Put in another way, the 18<sup>th</sup> and 19<sup>th</sup> centuries saw a proliferation of bodies of knowledge which took the population as its object, from political economy to sociology, demography, epidemiology and public health. Through the collection of vital statistics and the preparation of life tables, the population was rendered calculable in terms of birth rates, mortality rates, morbidity rates, life expectancy, growth rates, genetic load and the like. As a result, this 'global mass' would come to be mapped out in terms of its size, stock, quality, fecundity, fertility, density, mortality, morbidity, mobility, etc.; qualities that made it subject to fluctuation, expansion, contraction, decline, deterioration, degeneration, growth and development.

While there is much to be said about the stabilisation of population as an object of study in the 18<sup>th</sup> and 19<sup>th</sup> centuries, and the different ways in which it was conceptualised and problematized (see Emery, 1993; Etches et al., 2006), for the purposes of this paper we will limit ourselves to asking how economists, demographers and epidemiologists, starting in the early 20<sup>th</sup> century, set about measuring the level of health of a national population on a global scale. As we will see, this task was inherently comparative and teleological, as a national population's health came to be defined in relation to other populations as well as along specific yardsticks of health which allow for the detection of health improvement. Comparisons of the demographics and diseases of populations in different parts of the world have been integral to the development of measures to gauge the level of health of a particular (national) population. Moreover, these comparisons have almost invariably taken the form of rankings, a form of global population categorisation that gained particular currency through the 20<sup>th</sup> century.

[Table 1 here]

In a "brief and sketchy outline of world population movements"<sup>2</sup> published in 1929, demographer Warren Thompson proposed that the world's "countries fall into three main groups" in demographic terms. In this seminal article, he argued that Groups A, B and C could be told apart by looking at birth and death rate combinations in a national population (Thompson, 1929, p. 959). In Thompson's model, health gains could be read out of falls in a population's birth and death rates; as these rates fell, demographic transitions took place – hence a country can move from Group C to B and then A. While, Thompson did not explicitly set out to say anything about the health of a national population, he

directly linked the notion of a demographic transition to “developing modern industry and sanitation” as “the rapidity with which the birth-rate will fall... appears, then, to depend on the speed with which... industrialization takes place” just as he saw death rates as affected by “positive checks, hunger and disease particularly” (Thompson, 1929, p. 970; 973).

Roughly speaking, in Thompson’s model of transition (see Table 1) group A countries are characterised by a “very rapidly declining birth-rate and death-rate”, while in group B countries “death-rate is declining as rapidly or even more rapidly than the birth-rate” and in group C countries “both birth-rates and death-rates are quite uncontrolled and we may expect either a rapid increase or almost a stationary population dependent on the harshness of the ‘positive’ checks to population growth, viz., disease, hunger, war, etc.” (ibid, p. 961-62). Picking up on such correlations, Winslow was among the first to specify not only the demographic but also the morbid characteristics of nations at different “stages of progress” when he suggested that in some countries “control of malaria, tuberculosis and syphilis may be a major objective for many years to come”, compared to “countries where control of communicable diseases has been effectively accomplished, [and] the primary objective for the coming decade may be the care and rehabilitation of an ageing population and the promotion of an effective programme of improving mental hygiene” (Winslow, 1952, p. 194). Myrdal correlated these differences in disease profiles explicitly to the economic level of a country and pointed to dramatic differences in life expectancy: “The general relationship between poverty and disease is illustrated by all health indices. Thus the life expectancy at birth in the small part of the world which can be characterized as developed is more than double that in the much larger part of the world which is underdeveloped. Infant mortality has, as we all know, in countries with a high standard of living been brought down to a mere fraction of that in underdeveloped countries.” (Myrdal, 1952, p. 205).

By the 1960s, developmental stage-thinking had become staple fare among demographers and economists alike perhaps most famously outlined in Rostow’s argument that “it is possible to identify all societies, in their economic dimensions, as lying within one of five categories; the traditional society, the preconditions for take-off, the take-off, the drive to maturity, and the age of high mass-consumption” (Rostow, 1960, p. 4). Building on Thompson’s ideas of an aggregated transition, Rostow proposed that a nation could move through these five stages of economic growth as they adopted and took advantage of modern science and technology. And, although the health of a nation’s population was never explicitly addressed in his taxonomy either, Rostow argued that in traditional societies “population – and, within limits, the level of life – rose and fell not only with the sequence of the



harvests, but with the incidence of war and of plague” while “modern public health and medical techniques are extremely effective and prompt in lowering death-rates” (Rostow, 1960, p. 5, 140).

It was Omran, who in 1971 would bring the likes of Thompson, Winslow, Myrdal and Rostow together in yet another attempt to taxonomise and rank the world’s populations. According to Omran, “an epidemiologic transition has paralleled the demographic and technologic transitions in the now developed countries of the world and is still underway in less-developed societies” (Omran, 1971, p. 732). Omran’s classification was organised around “the complex change in patterns of health and disease” as “a long-term shift occurs in mortality and disease patterns whereby pandemics of infection are gradually displaced by degenerative and man-made diseases as the chief form of morbidity and primary cause of death” (ibid., p. 738). Not only did particular birth-death rate combinations and technological dispositions correspond to levels of socio-economic progress so too did particular disease profiles as “disease patterns change markedly as life expectancy rises” (ibid.). Although Omran is mostly concerned with disease patterns, it is clear that his notion of aggregated health is directly related to the overcoming of mortality through what he calls ‘survival’ as he accounts for the “tremendous improvements in survivorship” that countries gain through their epidemiologic transitions (ibid., p. 747).

And so we can see how, on a global scale, through the 20<sup>th</sup> century, notions of demographic, economic, technologic and epidemiologic transition were mobilised to classify and rank country populations according to patterns of population growth, fertility, mortality, economic growth, technological uptake, life expectancy, and disease. In this style of thought, those countries to be found at the bottom of their taxonomies are the ones most affected by “‘positive’ checks to population growth, viz., disease, hunger, war, etc.” (Thompson, 1929, p. 162), while the ones at the top enjoy longer life expectancies because of lower death-rates and better survivorship. However, while each speaks of levels of life, stages of progress, levels of life expectancy, standards of living or levels of industrial development, there are no explicit definitions of health that would allow for the measurement of the aggregated ‘health’ of a population. Vital statistics in these taxonomies consist of ‘brute’ birth, death and morbidity rates and corresponding life expectancies. The kinds and numbers of diseases a given population *has*, the ways and ages in which people in this population *die* serve as proxy indicators for the health of that population.

### **Adjusting vital calculation**

Around the mid-20<sup>th</sup> century, the outlines of a new form of epidemiological calculation emerged. Notwithstanding the epistemological credibility that had been achieved by demographic, economic and epidemiological transition theory, some epidemiologists began to suggest that it was not enough to map out incidence and prevalence of and deaths caused by particular diseases in a given population to measure the aggregate level of health. Moreover, as practitioners of the emerging discipline of health economics also stressed, equally important was knowledge about the *impact* of a particular disease on that population and on its health care system. This shift from incidence and prevalence to impact, as we will see, has given rise to a new epidemiological style of thought which, not content with tabulating the amount of life lost to particular diseases, would also tabulate the amount of ‘potential life’ and later ‘healthy life’ lost as a way to gauge the impact of different diseases on a given population and in doing so giving form to the challenges faced by those for whom health and health care were becoming vital problems for government on a global scale.

In 1947, Dempsey argued that it would be misleading to dismiss the importance of tackling tuberculosis despite an impressive 53 percent decline in tuberculosis mortality between 1924 and 1944 as compared to steady increases in mortality from cancer and heart disease. “These death rates,” argued Dempsey “while admittedly correct, fail to tell the entire story” (Dempsey, 1947, p. 158). Instead, we need to “demonstrate more vividly the *seriousness* of a disease” (ibid., our emphasis). And so a new form of calculating the impact of disease is proposed: potential years of life lost.

The method used in this computation is simple indeed. For example, the average white woman may expect to live sixty-nine years. If she dies at the age of 24 from tuberculosis, she has lost forty-five potential years of life, whereas if she dies at 62 of heart disease, she has lost but seven potential years. In the aggregate, 1,929,953 potential years of life were lost by all Americans who died of heart diseases in 1944, compared with 1,287,245 potential years lost by those who died of cancer and 1,175,500 by those who died of tuberculosis in that year. (ibid., p. 158-9)

Ever since Dempsey proposed to calculate such aggregations of ‘premature mortality’ as a way to quantify potential years of life lost, epidemiologists, health economists and others have taken up this suggestion that an individual who has died from a disease at an age below that of average life expectancy at birth has not been able to fulfil his or her life because of *premature* death, a point that was not captured in mortality-morbidity rate measurements. With Dempsey’s computation method, the impact of a particular disease could be read out of the total (aggregate) potential years of life lost because of a given disease in a given population. These totals could then be compared across diseases to see which diseases caused the greatest loss of potential years of life in particular populations.

But it was not only this notion of ‘premature mortality’ – potential life lost – that was mobilised to challenge ‘classic’ modes of epidemiological mapping. Calculating years of potential life lost (YPLL) still privileged *biological* life (the fact of being alive or not), with life expectancy estimates in given populations used as a social norm against which to determine the amount of unfulfilled life (understood as a certain aggregated quantity of lost years) that could be attributed to particular diseases (cf. Canguilhem 1994). In the same years that Dempsey was writing, medical doctors began proposing new ways to characterise and classify the *impact* of specific diseases on a patient. In 1949, Steinbrocker and colleagues (1949) proposed a classificatory scheme of functional capacity in rheumatoid arthritis while Karnofsky and Burchenal (1949) proposed a performance scoring system to measure the ability of cancer patients to carry out activities of daily living. Common to their approaches was an attempt to quantify daily living and wellbeing along scales of performance or functional ability. The question of whether individuals were being restricted or limited in the carrying out of routine activities in their daily life became central to the measurement of their individual health states. Karnofsky and Burchenal argued that in the clinical evaluation of chemotherapeutic agents in the treatment of cancer there is a need:

for another criterion of effect. This has been called the performance status... It is a numerical figure, in terms of percentage, describing the patient’s ability to carry on his normal activity and work, or his need for a certain amount of custodial care, or his dependence on constant medical care in order to continue alive. These simple criteria serve a useful purpose, in our experience, in that they measure the usefulness of the patient or the burden that he represents to his family or society. (Karnofsky and Burchenal, 1949, p. 195-197)

We see here the beginnings of impact calculation when it comes to disease. Of course, these changes occurred at a period of major transformations in the logics of healthcare. The mid-20<sup>th</sup> century, following the end of the Second World War, was a time where healthcare was being transformed in multiple ways throughout the world. In Europe and America, nationalised and privatised health insurance systems were being consolidated, raising the complex question of the optimal ways of financing health care. In a newly aggregated ‘developing world’, the WHO was setting global health priorities, not least based on economic calculations of the cost of disease as a burden on nations. Moreover, incipient critiques of modern medicine were insisting that there was more to disease than bodily pathology, a point which, as noted earlier, the WHO would embrace in its broad 1948 definition of health. In a talk entitled “The Economic Values of Preventive Medicine” given at the congress of the World Health Organization in 1952, Winslow made an economic case for public health interventions, arguing, for example, that:

in the Philippines one person in 10 suffers from malaria each year, while one person in 15 suffers each year from tuberculosis. The economic losses due to these two diseases alone are estimated at \$33 a year for every person in the population. A major part of this heavy *burden of disease* can - as you and I well know - be readily lifted from the shoulders of the human race; and we have no lack of factual experience at our disposal to prove what can be accomplished to demonstrate its economic value. (1952, p. 192, our emphasis).

Winslow's calculations were broad in scope, as he argued that "[i]n addition to the loss of life-capital through premature death, preventable disease imposes a heavy burden in the loss of productive power, due to non-fatal but disabling illness, and in increased needs for the medical and institutional care of those afflicted" (1951, p. 13). Such calculations would during the course of the 1950s give form to the discipline of health economics which Muskin famously defined as being "concerned with the optimum use of scarce economic resources for the care of the sick and the promotion of health, taking into account competing uses of these resources" (Muskin 1958, p. 792). With the development of national and private healthcare systems came the responsibility of ensuring that what was being paid for did, in fact, improve 'health', i.e. secured a health-yield. As such, health economists called for a more rational approach to prioritisation as well as to the measurement of health gains at the level of the population. Such a measurement imperative translated into increasing efforts to gauge the impact of disease on the one hand (as Dempsey, Karnofsky and Steinbrocker were proposing) and the "impacts and effects of health programs" (Muskin, 1958, p. 790) on the other. This distinction between prioritising according to the extent of burden a disease is seen to exact and measuring health gains, as we will see, remains central to this day. We will return to the notion of burden in the following; for now, let us look at the important question of how to measure the aggregated health of a population within this incipient style of epidemiological thought.

In a 1966 *Vital and Health Statistics* report entitled 'Conceptual problems in developing an index of health', Daniel Sullivan argued that there is "a difficulty inherent in the use of mortality statistics as measures of health status. They tell little about *the living*, while the health of the living has become a very important aspect of health status" (1966, p.1, our emphasis). Indeed, by 1970, upon calling for the construction of a Health Status Index (HSI), Fanshel and Bush complained that "more is known about the consumption of macaroni and corsets than the health status of the population" (1970, p. 1022). Even if plenty was known about the birth, death and morbidity rates of national populations around the world, these rates did not reveal the *health* status of these populations since there was more to health than bodily pathology and associated mortality. It is no coincidence that these doctors, health economists and epidemiologists were writing at the very same time as the birth of the notion of 'quality of life', not as a term, but rather as something that can and ought to be measured, calculated

and monitored (see Armstrong & Caldwell, 2006; Wahlberg, 2007; Kearns & Reid-Henry 2009). Indeed, the closing decades of the 20<sup>th</sup> century have been characterised by a palpable influx of rating scales, scoring systems and indices for assessing the quality of life, wellbeing or happiness of an individual, community or population each of which tell us something about ‘the living’.

Now, while the exact definition of and means of measuring ‘quality of life’ have been and remain highly contested, what is less contested was the need for a form of assessment that measured disease impact on daily life. Moreover, with the help of standardised scales and indices, this impact could then be aggregated to a population level as proposed by Kaplan and colleagues, who made a case for taking into account not just the loss of aggregated potential years, but also of aggregated healthy years or ‘well-years’:

The difference between 58.6 well-years and 71.9 expected years represents an average of 13.3 years of life of diminished quality for each resident of San Diego County. It is to this gap – to the quality of life – that health planning, improvements in health care delivery, medical research, preventive medicine, and programs to produce changes in lifestyle should be addressed, perhaps as much as to extensions of the life expectancy itself. (Kaplan et al. 1976, p. 505)

The shift in focus from mortality and years of potential life lost is conspicuous. The “13.3 years of life of diminished quality” are ‘live’ years and what is lost to disease is not life itself (at least not initially) but rather the ability or capacity to carry out activities of daily living. When healthy life is lost, it is morbid living that takes its place, a kind of living that is seen as of diminished quality (cf. Wahlberg 2009). In 1986, the following summary of what was, by then, a common critique was put forward in the *Morbidity and Mortality Weekly Report*: “Mortality statistics are frequently used to quantitate the extent of public health problems... [and] although [death] rates are important measures of the nation’s health status, they often fail to tell the entire story” (Centers of Disease Control 1986, p. 1S). Let us now look at how this shortcoming came to be addressed in the closing decades of the 20<sup>th</sup> century as health economists and epidemiologists proposed a profound rethinking of how to measure the health of the world’s populations.

### **Aggregating the impact of disease**

In the early 1980s, a project team consisting of health planners, doctors and epidemiologists working in Ghana set out to tackle a puzzle: in spite of a threefold increase in health expenditure over a 20-year period “vital statistics have changed little” (GHAPT, 1981, p. 73). As a result, the team wanted to find a

better way to detect the effects of public health interventions by “develop[ing] a method whereby the health impact of different disease problems may be estimated quantitatively” (ibid.). They argued:

The 3 most important effects that a disease may have in a community are as causes of illness, disability and death. With some exceptions, other social and economic effects of a disease are directly related to its *severity* as measured by these 3 factors. We have quantified each of these factors in terms of the number of days of healthy life which are lost due to a disease, and we use the total days lost in the community as a measure of the health impact of the disease. (GHAPT, 1981, p. 74, our emphasis)

Building on the critiques of classic vital statistics and life tables seen above, the Ghana Health Assessment Project Team’s methodology would end up catalysing a series of methodological innovations that culminated in the publication of the World Bank’s report *Investing in Health* in 1993. This report marked the decisive moment when, during the 1990s, the World Bank, in the words of Abassi (1999, p. 865) changed image “from uncaring bully to compassionate stakeholder focusing on health” displacing the WHO in many respects, and reshaping its ways of thinking in economic directions. Taking its cue from the Ghana project team, the World Bank’s report proved to be pivotal in transforming the way in which a national population’s health status could be calculated and compared globally in terms of the impact that different diseases were having on the lives of an individual, community or population. This was the so-called “global burden of disease” methodology. And of course, that calculability, framed in terms of ‘the burden’ of disease, forges an intrinsic link between the pain, suffering and frustrated life chances of individuals, families and communities, and the costs to society, not just in terms of the direct costs of health care and the indirect costs of lost productivity, but also in terms of a diminution of the human capital that was now seen as so vital to national competitive success.

The World Bank once again pointed to the shortcomings of classic epidemiological health calculations:

Any discussion of health policy must start with a sense of the scale of health problems. These problems are often assessed in terms of mortality, but that indicator fails to account for the losses that occur this side of death because of handicap, pain, or other disability. (World Bank, 1993, p. 25).

And crucially, they adopted a measure initially developed by Murray and Lopez, in a background study conducted in collaboration with the WHO – the DALY:

A background study for this Report, undertaken jointly with the World Health Organization, measures the global burden of disease (GBD) by combining (a) losses from premature death, which

is defined as the difference between actual age at death and life expectancy at that age in a low-mortality population, and (b) loss of healthy life resulting from disability. The GBD is measured in units of disability-adjusted life years (DALYs). (Ibid., 25)

The World Bank agreed with the likes of Kaplan, Sullivan, Karnofsky and Steinbrocker that loss of (potential) biological life because of morbidity (i.e. mortality) was only one part of the story when it came to gauging the scale of a nation's health problems; equally important was "loss of healthy life resulting from disability". Put in another way, disease was not just something that occurred in certain patterns (prevalence and incidence) and resulted in premature deaths in a given population, it was also something that impacted on the lived *lives* of this population's individuals and communities. In this new epidemiological style of thought, disease was not only something one had and/or died from, it was equally importantly something that many people *lived with* for months, years if not decades. As a result, new forms of epidemiological calculation were called for, giving rise to new requirements of data collection and collation:

Most assessments of the relative importance of different diseases are based on how many deaths they cause. This convention has certain merits: death is an unambiguous event, and the statistical systems of many countries routinely produce the data required. There are, however, many diseases or conditions that are not fatal but that are responsible for great loss of healthy life... These conditions are common, can last a long time, and frequently lead to significant demands on health systems. (World Bank, 1993, p. 26)

In 2000, the World Health Organization followed suit, transforming their global life expectancy tables into healthy life expectancy rankings by publishing Disability Adjusted Life Expectancy estimates for the world's nations (see Wahlberg, 2008). As argued by Alan Lopez of the WHO's Epidemiology and Burden of Disease Team:

[I]n the old system, we measured a total life expectancy based on the average numbers of years males and females could expect to live in each country. However, people don't live all those years in perfect health. At some point in your life, you will have some level of disability... The WHO decided to measure healthy life expectancy for all member countries using DALE for the first time, to give a truer picture of where good health reigns, and where it doesn't. (WHO, 2000)

We can see then how a new epidemiological style of thought emerged in the closing decades of the 20<sup>th</sup> century: the aggregated number of potential years of life lost to a disease has been supplemented by calculation of the number of 'well-years' lost to that same disease; epidemiological profiles of a population's morbidity and mortality rates have been broadened through burden of disease profiles; life expectancy estimates have been tweaked into healthy life expectancy estimates. In this relatively recent style of thought, the gauging of disease impact as a matter of severity takes precedence over the

tabulation of disease incidence, prevalence and mortality. As a result, overall objectives of healthcare interventions have expanded. Not only should mortality and morbidity rates be reduced, also “a given community should allocate to health care so as to maximize the returns to the community in terms of net increase of what I may call disability-free, productive life” (Sanders, 1964, p. 1069).

### **Living with disease – gauging severity**

Of the numerous methodologies, indices and scales that have been developed over the past few decades to measure the aggregated health level or status of a given population, two instruments stand out: the QALY and the DALY. The Quality Adjusted Life Year (QALY) was originally developed by health economists in the late 1970s to assist in evaluating the cost-effectiveness of particular health interventions (see Fanshel and Bush 1970), while, as we have seen, the Disability Adjusted Life Year (DALY) was developed by epidemiologists in the 1990s to calculate the burden of disease in a given population as a way to assist governments in the setting of health priorities (see Murray and Lopez 1996). Put in another way, QALYs help health administrators ask the question of “how much health do I get in return for a given intervention or treatment?” while DALYs help those same administrators ask the question of “which disease should we be focusing on as a matter of priority?”

Since their introductions, QALYs and DALYs (not to mention most other scales and indices) have been subject to considerable critique concerning the assumptions about health and valuing of life which underpin them (for an overview see Gold et al., 2002). For the purposes of this paper, however, we will turn our attention towards what QALYs and DALYs *do* – that is to say, what the construction of QALYs and DALYs as methodologies for gauging health levels or status can tell us about the ways in which knowledge about *living* has come to be governmentalized: rendered into thought not merely as a body of knowledge which can underpin a form of expertise, but also enabling the formulation of a set of programmes and strategies for intervention (Rose and Miller, 1992). Although the two methodologies in some senses do the same thing – i.e. allow for the measurement of the impact of disease on the lives of individuals or populations – they are nevertheless based on two very different forms of calculation. Whereas QALYs rely on the answers of patients with a particular disease to questions on a standard scale (e.g. the EQ-5D questionnaire or the Standard Gamble test), DALYs rely on an expert committee’s ranking of diseases according to the impact they are perceived to have on the lives of individuals. And, whereas QALYs ‘positively’ measure the level of quality of remaining life-years, DALYs ‘negatively’ measure the severity of disability caused by a particular disease multiplied by the expected duration of the condition (to remission or to death).



[Table 2 here]

As such, what the two methodologies have in common is their focus on ‘the living’, i.e. those individuals currently *living with* a particular disease or condition. One can say that morbid death is no longer the paramount epidemiological problem, rather it is morbid living. Hence, it is knowledge and data about the personal and social experience of living with a disease that needs to be collected, collated and tabulated through what Sanders had called “a modified life table method of analysis” (1964, p. 1067). Thus the sense of necessity that surrounded the development of QALYs and DALYs – as we have seen, they were specific responses to perceived failures of past forms of vital calculation – cannot be detached from wider social scientific and medical interest in what Arney and Bergen (1982) have called “medicine’s subjective object” and Armstrong (1984) “the patient’s view”. While some bemoan the lack of impact of social science in the ‘real world’, in this area of health and medicine, as in so many others, social scientific research has played a crucial role in generating knowledge about ‘living with a disease’ in terms of coping strategies, therapeutic itineraries, existential quests for meaning frameworks, etc (see Wahlberg, 2008; Whyte, 2012; Osborne & Rose 1999). While much of this research has relied on in depth, qualitative methods for eliciting patient narratives, biographies and accounts, QALYs, DALYs, HALYs and other similar rating scales can be seen as efforts to quantify the ‘patient perspective’ in order to enable aggregation and comparison across different diseases and populations.

Both QALYs and DALYs rely on a quantitative valuation of ‘health states’ which represent “societal assessments of levels of health in different states” (Mathers et al. 2001, p. 24). With DALYs these valuations range from 0 (which represents a state of ideal health) to 1 (which represents a state equivalent to being dead), while with QALYs 1 represents perfect health and 0 represents death and there are even negative values for health states of ‘extreme pain or discomfort’. As noted earlier we can broadly distinguish between valuations carried out by consensus through instances such as the WHO’s Committee of Experts on Measurement and Classification for Health, and those aggregated from individuals’ responses to certain questions/questionnaires such as the EQ-5D about their state of health.

As can be seen from the disability weighting table used for calculating DALYs and the EQ-5D health valuation table (see Table 2), it is the impact of a particular disease on “daily living” that is at stake. Professor of Health Services Research Ann Bowling has argued that, whatever their shortcomings, the very “idea of using a QoL score is to broaden the measurement of health beyond more conventional

yardsticks such as biochemical measurements, and into territory more directly relevant to patients themselves: their well-being, comfort and satisfaction” (NICE, 2008, p. 6). To calculate QALYs and DALYs, various domains or dimensions of health (or health-related quality of life), such as mobility, self-care, daily activities, pain and discomfort and affect (anxiety/depression) are identified such that diseases can be scored according to whether an individual with a particular disease has “problems walking about”, “moderate pain or discomfort”, “some problems washing or dressing”, or “needs assistance with toilet use”. The resulting scores can then be used to classify and rank diseases according to severity and/or health states according to utility (i.e. something desired). In both cases, health is a continuum that spans ‘perfect’ or ‘good health’ to death or ‘worst possible health’.

Now, while, as already noted, such efforts to standardise disease experience have been subject to substantial critique (not least about the ironies of quantifying the qualitative), our concern is with what they make possible. Indices, rating scales and scoring systems which seek to tabulate and make comparable the impact of a disease on the daily life of an individual allow for aggregations. And so, just as the compilation and tabulation of vital statistics – death rates, birth rates, morbidity rates, life expectancies, etc. – contributed to the birth of the ‘population’ in the 18<sup>th</sup> and 19<sup>th</sup> centuries, we see something novel emerging from the middle of the 20<sup>th</sup> century as ‘modified life tables’ made up of disability weightings, health state valuations, quality of life scores, etc. have come to be compiled and calculated. Paraphrasing Foucault, we might speak of a ‘species soul’ (cf. Rose 1999): the aggregated vital body that is the population is now equipped with a mental life, a ‘soul’ that is constituted by the experiences of living, coping and caring, not just as personal, but also as social phenomena. Disease burden calibrates the affliction of this species soul, and its variations in time and space, as it is subject to fluctuation, reduction, intensification, etc. in a given community or population. The problem is no longer merely one of finitude, of the extinction of life by death: the problem space now concerns the loss of the mode of life proper to vitality consequent on the impact of disease on the individual and collective. Accordingly, to assess the health of a population it is not sufficient to count the dead and record what they died from: we must study the ‘costs’ of disease for ‘the living’ – for each and for all – and how they individually and collectively suffer from, and cope with, the diseases with which they live. Let us now turn our attention to the ways in which this novel form of aggregation has come to generate new forms of visibility for a specific group of diseases by the turn of the century.

### **‘The Burden of Brain Disorders’**

When the European Brain Council (EBC) took its report on the “Cost of Disorders of the Brain in Europe 2010” to the European Parliament on the 4<sup>th</sup> of October 2011, estimating that the total cost of such disorders to Europe in 2010 was €798 billion (Gustavsson et al., 2011), one of the co-authors succinctly summarised the report’s main argument: “People don’t die from them, rather they live in a disabled state for most of their lives. That’s why disorders of the brain are so costly” (Jes Olesen cited in Andersen, 2011). For many years it was routine for those working in psychiatry to complain about the relative lack of investment in research into mental disorder compared with other conditions such as cancer. But, we suggest, problems of mental health and neurological disease have gained a newfound prominence in global efforts to set health priorities, at least in part as a result of the shift from calculating the cost of *dying* from disease to calculating the cost of *living* with it. Central to this shift in priorities has been the consolidation of *psychiatric epidemiology* as a sub-field of epidemiology, and its shift of focus, in step with the rest of epidemiology, from the mapping of incidence and prevalence to the calculation of disease burden.

Some historical reflection might lead us to pause before giving an unreserved welcome to this contemporary focus on calculating burden. Concern with the ‘burden’ of mental disorders has taken different forms over the course of the 20<sup>th</sup> and into the 21<sup>st</sup> centuries. For something similar was also at the heart of the strategies of eugenics. Is this contemporary language of burden, then, merely a continuation of the earlier conception of burden within eugenics? Or is it linked to different socio-political problematisations? In short, how has ‘the burden of mental disorder’ come to be perceived today as a governmental problem? And with what consequences?

As we have seen, populations can be problematized by those who govern them in many different ways in relation to different objectives, and in the context of different strategic objectives – size, quality, density, fitness, composition in terms of race, the balance of the sexes, disease patterns, or age profiles and so forth. But it was in the late nineteenth century, with the birth of the idea of degeneracy and a geopolitical conception of a struggle between nations where success depended on the fitness of the national population, that one can see the idea of ‘burden’ taking shape around matters of the mind, thought at that time as an expression of a defective physico-moral constitution (Pick, 1989). Burden, here, as we know from many excellent historical studies, was thought of partly as a matter of cost, and partly as a matter of fitness. On the one hand, supporting all those defectives, lunatics, alcoholics, and others with a weakened and degenerate constitution imposed a financial cost on the healthy – and one that, in the case of the Nazi’s, was carefully calculated in Reichsmarks (Burleigh, 1994; Proctor, 1988).<sup>3</sup> On the other, a population burdened with an increasing number of degenerates would lose out in the

imperialist struggle between nations, and this made it imperative to identify those, such as the feeble minded, whose often invisible presence was so damaging to military and industrial fitness. This style of thought took a lethal turn in Nazi Germany, but it also infused the policies of identification, segregation and sterilization in many other nations from Mexico to Japan, and continued in attenuated form in the Nordic countries until the mid-1970s and in China until the end of the twentieth century (Broberg & Roll-Hansen, 1996; Dikötter, 1998; Dowbiggin, 1997; Stepan, 1991).

But it would be misleading to regard the contemporary discourse of the burden of mental disorders and brain diseases as merely a continuation of this eugenic discourse, even if the question of the economic cost remains central. In the decades following the end of the second world war there were innumerable studies of the 'prevalence' of 'mental illness', 'mental distress', 'mental morbidity' and the like – in short, of what was to become called psychiatric epidemiology. Perhaps surprisingly, since eugenic thought was still active in the late 1940s and early 1950s, eugenic arguments played no part in these studies. In his review of psychiatric epidemiology published in 1964, Michael Shepherd attributes this new post-war concern not to eugenics, but to “the unprecedented interest taken in the mental health of both the military and civil populations during the conflict” and to “the post-war renewal of interest in the psychosocial components of morbidity and the emergence as a separate discipline of social, or ‘comprehensive medicine’” (Shepherd and Cooper, 1964).

Morton Wagenfeld, in a paper published in 1983, reviews these studies and their implications. There was “the 1954 survey of the entire non-institutionalized Baltimore population, in which it was that in any given point in the year, 10% of the total population (all ages) had a mental disorder classifiable by the ICDA”; there was the Midtown Manhattan Study of 1954 which found that “23% of the adult population (age, 20 to 59 years) were affected by serious psychiatric impairments at any point in time”; and there was the 1967 study in New Haven, Connecticut, which “found a point prevalence mental disorder rate of about 16% in the adult population (age, 20+)” (Regier, Goldberg et al., 1978, p. 687). These studies were heavily criticised because of the vagueness of their object – they used different definitions and categories, raising the question of “Just what was being measured?” (Wagenfeld, 1983, p. 171). Nonetheless by the early 1980s, it was widely believed that some 15% of the adult non- institutionalised population suffered from mental disorder, much of which was unrecognized and ‘unserved’ by mental health services (Regier, Goldberg et al. 1978), and some were contending that the US was facing a pandemic of mental disorder (Kramer, 1982).

From around the early 1980s, we can see the beginnings of a profound transformation in the ways in which this prevalence is conceptualised; a transformation from distribution to impact. From then onwards, we see increasing attempts to quantify the experience of living with mental disease, to estimate the costs – to individuals, families and society – of mental disorders and in particular of depression. By the mid-1980s, this was being articulated in the language of burden, understood not as genetic load on a population as with eugenics, but as costs borne by health care systems. Alan Stoudemire and his colleagues were among the first to frame a paper in these terms, in a 1986 paper titled “The economic burden of depression” (Stoudemire, Frank et al. 1986). “Despite the ubiquity of depression as a clinical entity,” they write, “few systematic attempts have been made to approximate the economic burden that this form of mental illness places on American society” (Stoudemire, Frank et al. 1986, p. 387). In estimating burden, it appears, one needs to take account not only of the direct treatment costs, such as doctor and hospital costs, pharmaceuticals and so forth, but also to include the indirect costs arising from time lost from productive work due to the illness “and the relative dollar value of that lost time” (ibid.) which of course includes estimates of time lost in respect of those individuals with the condition who are not in receipt of treatment. The authors conclude (Stoudemire et al., 1986, p. 393):

These economic figures, along with emerging epidemiologic data, demonstrate the magnitude of depression as a public health and socioeconomic problem of major proportions for our society. These data further emphasize that timely recognition and administration of currently available treatments for depression may result not only in decreased human suffering and reduced morbidity, but also potentially diminish the drain on our overall socioeconomic resources caused by this illness. The figures also provide a basis for calculating the potential cost savings to society by decreasing the morbidity and mortality of the illness by assuring rapid and effective treatment for affected individuals.

And while the authors remark that “the full economic burden of depression would include not only the costs calculated here but also would take into account pain and suffering experienced by the individual involved and/or his family and friends” (Stoudemire et al., 1986, p. 388), it would not be until the early 1990s that brain disorders would enter new epidemiological forms of calculation where non-fatal outcomes such as decreased quality of life and loss of healthy life years are used to assess the health status of populations. When they did so, what was most evident was the power of the single figures that were used to encapsulate burden.

From the 1990s forward, surveys in the US (Kessler et al., 1994; Kessler et al., 2005) and in Europe (Wittchen et al., 1994; Wittchen and Jacobi, 2005) were regularly estimating that 25% of the adult population not receiving psychiatric attention could be diagnosed with a mental disorder in any one

year, and 50% in a lifetime. And it was soon argued that this was not merely a 'Western' problem or a problem of developed economies or societies. Partly framed in terms of estimates from the WHO of the contribution of different disorders to the burden of disease, a growing movement took shape to address "the grand challenge in global mental health" (Nature 2011) focused specifically on what were now termed the MNS disorders (mental, neurological and substance-use) which were said to constitute around 13% of the total global burden of disease.

In its current form, we can probably date this transnational concern to the first global burden of disease study which, as noted earlier, was initiated by the World Bank in 1990. Reflecting on that report in 1993, its authors note that:

The results of the 1990 GBD study confirmed what many health workers had suspected for some time, namely, that noncommunicable diseases and injuries were a significant cause of health burden in all regions... Many diseases, for example, neuropsychiatric diseases and hearing loss, and injuries may cause considerable ill health but no or few direct deaths... Neuropsychiatric disorders and injuries in particular were major causes of lost years of healthy life as measured by DALYs, and were vastly underappreciated when measured by mortality alone. (World Bank, 1993)

While in earlier global estimates, psychiatric disorders were in the background, in this study, depression figures in the very first paragraph of the Summary (Murray et al., 1996, p. 1).

The next two decades will see dramatic changes in the health needs of the world's populations. In the developing regions where four-fifths of the planet's people live, noncommunicable diseases such as depression and heart disease are fast replacing the traditional enemies, such as infectious diseases and malnutrition, as the leading causes of disability and premature death.

This new prominence was, at least in part, a consequence of the new method of calculation. As we have seen, this study, which tellingly was conducted for the World Bank *and* the World Health Organization, used a new measure of burden, the DALY, to make its estimates – where the single figure of the DALY expresses years of life lost to premature death and years lived with a disability of specified severity and duration; one DALY is thus one lost year of healthy life. They concluded that, in both developed and developing countries, depression in the middle years of life was the single most burdensome illness, accounting for at least twice the burden imposed by any other disease. They argued that traditional approaches to measuring the economic costs of disorders had seriously underestimated the burdens of mental illnesses, such as depression, alcohol dependence and schizophrenia, because they took account of deaths, but not of disabilities – and while psychiatric conditions are responsible for

little more than one per cent of deaths, they account for almost 11 per cent of disease burden worldwide.

In 2003, when Wang, Simon and Kessler reviewed the literature on the economic burden of depression and the cost-effectiveness of treatment (Wang et al., 2003), they assigned discussion of the “personal costs that depression exacts from afflicted individuals, families and communities” to “earlier research”, and focussed on economic calculations of burden, pointing out that “In the past decade, research on the social consequences of depression has begun to focus on the economic costs” (ibid., p. 22). They attributed this change of focus to the growing recognition of the “sheer magnitude” of this economic burden, and to the social policy debate, especially in the US, about the extent of health insurance coverage for mental disorders in the light of necessary decisions about the allocation of scarce resources. And indeed it is in cost-benefit terms that they cast their argument – concluding that current inadequate and insufficient treatment practices compound the economic burden of depression, but that aggressive outreach and improved quality of treatments, which are currently resisted by primary care physicians, healthcare systems and purchasers of care, are, in fact, cost effective.

Their paper was published just after what was to become the foundational documents of the new approach – the WHO’s 2001 paper *Mental Health: New Understanding, New Hope* (WHO, 2001):

Today, some 450 million people suffer from a mental or behavioural disorder, yet only a small minority of them receive even the most basic treatment. In developing countries, most individuals with severe mental disorders are left to cope as best they can with their private burdens such as depression, dementia, schizophrenia, and substance dependence.... Already, mental disorders represent four of the 10 leading causes of disability worldwide. This growing burden amounts to a huge cost in terms of human misery, disability and economic loss. Mental and behavioural disorders are estimated to account for 12% of the global burden of disease, yet the mental health budgets of the majority of countries constitute less than 1% of their total health expenditures. The relationship between disease burden and disease spending is clearly disproportionate. More than 40% of countries have no mental health policy and over 30% have no mental health programme. Over 90% of countries have no mental health policy that includes children and adolescents.

These figures, so stark and compelling, seem to speak for themselves of the need for political action. Indeed the following words of the WHO report became iconic: “By the year 2020, if current trends for demographic and epidemiological transition continue, the burden of depression will increase to 5.7% of the total burden of disease, becoming the second leading cause of DALYs lost. Worldwide it will be second only to ischaemic heart disease for DALYs lost for both sexes. In the developed regions, depression will then be the highest ranking cause of burden of disease” (2001, p. 30). Soon after, in

their 2005 report, the European Brain Council stressed the huge cost of these disorders to national economies:

There are an estimated 127 million Europeans currently living with a brain disorder out of a population of 466 million. The total annual cost of brain disorders in Europe was estimated to €386 billion in 2004. Direct medical expenditures alone totalled €135 billion, comprising inpatient stays (€78 billion), outpatient visits (€45 billion) and drug costs (€13 billion). Attributable indirect costs resulting from lost workdays and productivity loss because of permanent disability caused by brain disorders and mortality were €179 billion, of which the mental disorders are the most prevalent. Direct non-medical costs (social services, informal care and other direct costs) totalled €72 billion. (European Brain Council, 2005, p.x)

And as we have already mentioned, by 2011, Hans-Ulrich Wittchen and his colleagues, upgraded these figures, estimating that “each year 38.2% of the EU population suffers from a mental disorder... this corresponds to 164.8 million persons affected....” a total cost of “disorders of the brain in Europe” that they put at 798 billion euros in 2010. Their recommendations followed as night follows day (Gustavsson et al., 2011, p. 720):

Political action is required in light of the present high cost of disorders of the brain. Funding of brain research must be increased; care for patients with brain disorders as well as teaching at medical schools and other health related educations must be quantitatively and qualitatively improved, including psychological treatments. The current move of the pharmaceutical industry away from brain related indications must be halted and reversed. Continued research into the cost of the many disorders not included in the present study is warranted. It is essential that not only the EU but also the national governments forcefully support these initiatives.

But it is not merely that the quantification of the burden of ‘living with disease’ generated new grids of epidemiological visibility through which these ‘brain disorders’ gained a new found prominence in developed countries, underpinning demands for increased political action and funding for research; estimates of the burden in low and middle income countries, as for example in the regular WHO reports, formed a crucial rhetorical underpinning for those seeking to promote intervention on mental disorders in those regions (see Table 3):

Depression is the leading cause of disability as measured by Years Lived with Disability (YLDs) and the 4th leading contributor to the global burden of disease (DALYs) in 2000. By the year 2020, depression is projected to reach 2nd place of the ranking of DALYs calculated for all ages, both sexes. Today, depression is already the 2nd cause of DALYs in the age category 15-44 years for both sexes combined (WHO cited in Reddy 2010)



As a result, from virtual absence in global health priority setting agendas, Patel and Prince described a “recent rapid increase in the visibility of the [global mental health] field”:

About 14% of the global burden of disease has been attributed to neuropsychiatric disorders, mostly due to the chronically disabling nature of depression and other common mental disorders, alcohol-use and substance-use disorders, and psychoses. Such estimates have drawn attention to the importance of mental disorders for public health... [Still] the burden of mental disorders is likely to have been underestimated because of inadequate appreciation of the connectedness between mental illness and other health conditions. (Prince et al., 2007, p. 859)

As we have already said, these arguments led to the development of a powerful movement to address “the grand challenge in global mental health” (Nature, 2011) focused on schizophrenia, depression, epilepsy, dementia, alcohol dependence and other mental, neurological and substance-use disorders which are now thought to constitute 13% of the total global burden of disease. This ‘grand challenge’ sets out 25 constituent challenges ranging from those concerned with identifying the biological basis of disorder to those of redesigning health systems to give adequate attention to mental disorders.

Predictably, this approach has been widely criticized by those who contest these estimates of burden, arguing that the diagnoses, classifications and treatments within this movement are based upon a culturally specific Euro-American model of mental health problems generalizing ‘Western’ definitions of illness and practices of intervention to non-Western culture. However we have argued in this paper that, while many seek to turn these estimates of burden to their own account, their form must be understood in terms of a more complex genealogy of the processes by which the costs and impact of living with disease, the burdens that stunted vitality places on the species soul, became a calculable problem calling for professional and political action.

## **Conclusions**

Alongside the birth of medicine’s subjective object as an object of knowledge and health intervention somewhere around the middle of the 20<sup>th</sup> century, we have seen how a novel epidemiological gaze has crystallized. This gaze shifted focus from biological processes and events of life (disease and death) to social processes and events of living (disability and health); from morbid death to morbid living. The bio-political figure of the population remains, as it has for so long, the privileged object, problem and target of knowledge and of management, yet it is transformed once more, now in terms of the amount of healthy life years lost, levels of health (understood as nonfatal health experience) and levels of quality of life. QALYs, DALYs, DALEs, HALEs and the like represent an aggregation of this notion of

health as lived experience. One of the consequences of this novel epidemiological gaze has been the construction of a new understanding of disease as a burden on populations because of the impact that disease has on the daily living of individuals as well as on national health care systems. In the process, the previously invisible demands that afflictions of the mind place upon the vitality of a population became all too evident, as most vividly seen in the consolidation of a global mental health movement.

We have shown how the social activity of living with a disease has been broken down into different domains or dimensions, which in turn have been mapped out and tabulated through questionnaires and expert committee valuation exercises. In this way, in a transformation of quality to quantity, the existential condition of living with disease is rendered calculable, subjected to expertise, and thereby amenable to novel forms of health intervention. The societal costs of living with disease have become a problem that our authorities are obliged to address. It is not that conceptualising what a good life is and how to live in the face of illness and suffering is novel to those who seek to conduct our conduct – such conceptualising can be traced to Antiquity and beyond. But in governmentalizing the human costs of disease to those who experience it, in transforming the demands of this experience into numerical indicators such as DALYs and QALYs, politicians, policymakers and healthcare officials have been enabled to know their populations in a novel way, in a form of knowledge that can be translated into political programmes for intervention, into strategies for prioritisation and evaluation. As a result, novel health priorities, objectives and strategies have emerged. Global health is not only about reducing mortality and morbidity rates (however important this task remains) but also about reducing the total number of Disability Adjusted Life Years, increasing the number of Quality Adjusted Life Years and raising the level of health and the quality of life of a population. As human technologies, aggregations of health levels and quality of life in the form of DALYs and QALYs take into account collective levels of disease severity, suffering, well-being, comfort and ability to function.

Although health interventions today continue to target the biological body – pharmaceutically, genetically, preventively, regeneratively or surgically – therapeutic objectives increasingly involve not just saving life but also improving the daily living, quality of life or health experience of individuals and populations. Yet it is paradoxical that these human costs of disease – the pains of suffering, the limitations illness imposes on vitality, the demands and obligations of care – should achieve political recognition only by their transformation into the language of numbers and their implications for economic productivity. Nonetheless, we suggest, this practice of counting and calculating has not just forced illness, in a new way, into economic calculations; it has also provided powerful resources for those biosocial movements campaigning for political attention to ‘their’ disorders. In a socio-political

This paper has been accepted for publication in *Economy and Society*, and the final (edited, revised and typeset) version of this paper will be published in *Economy & Society*, Volume 43, by Taylor & Francis, All rights reserved. © Taylor & Francis Group

context where almost everything is to be monetised, where value and cost are so often merged, what is counted can be made to count in many different strategies and in many different forums. In multiple ways, then, we suggest that the new forms of calculation we have traced in this paper are playing a vital role in the governmentalization of living.

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## Footnotes

<sup>1</sup> Such efforts would, of course, build upon the collection of records and statistics that churches and later state institutions had carried out in the preceding centuries in the form of parish registers for baptisms, marriages and burials, bills of mortality, cemetery registers and civil registration (see Emery, 1993).

<sup>2</sup> Movement here refers to change rather than migration, i.e. changes in population growth, birth and death rates.

<sup>3</sup> A famous illustration in *Volk und Rasse*, published in 1935, shows a healthy Aryan labourer carrying a beam on his shoulders with a caricatured mentally defective individual sitting at each end: the text reads "You are sharing the load. A genetically ill individual costs approximately 50,000 Reichsmarks by the age of sixty". From W. Gross, 1935, *Drei Jahre rassenpolitische Aufklärungsarbeit*, *Volk und Rasse*, 10: 335, reprinted in Proctor, 1988, p.182.

## Acknowledgments

We would like to thank participants at the Government of Life symposium held at the University of Copenhagen in April 2013 as well as anonymous reviewers for comments which have helped improve the paper. Ayo would like to acknowledge and thank the Danish Council for Independent Research (grant no. 10-094343) for funding which made research for this article possible.

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## Tables

**Table 1: Ranking national populations**

TABLE V  
NUMBERS AND PERCENTAGE OF THE POPULATION OF  
THE WORLD IN CERTAIN GROUPS (IN  
MILLIONS) ABOUT 1920

	Number	Per Cent
The world.....	1,730	100
Group A.....	320	18.5
Group B.....	157	9.0
Group C.....	1,253	72.5

Briefly stated, the characteristics of these groups from the standpoint of their vital statistics are: Group A: Very rapidly declining birth-rate and death-rate with the former declining more rapidly than the latter so that the rate of natural increase is also declining. Group B: Evidence that decline in both birth-rates and death-rates is under way in certain classes, but that the death-rate is declining as rapidly or even more rapidly than the birth-rate with the result that the rate of natural increase will probably for some time remain as great as now, or even become larger in the near future. Group C: Both birth-rates and death-rates are less controlled than in either A or B. But in some of these countries, e.g., Japan, there is some indication that death-rates are coming under control faster than birth-rates. In such of these lands as are developing modern industry and sanitation, there is likely to be a very rapid increase in numbers during the next few decades. In many of these lands, however, both birth-rates and death-rates are quite uncontrolled and we may expect either a rapid increase or almost a stationary population dependent upon the harshness of the "positive" checks to population growth, viz., disease, hunger, war, etc.

1. *The Age of Pestilence and Famine* when mortality is high and fluctuating, thus precluding sustained population growth. In this stage the average life expectancy at birth is low and variable, vacillating between 20 and 40 years.
2. *The Age of Receding Pandemics* when mortality declines progressively; and the rate of decline accelerates as epidemic peaks become less frequent or disappear. The average life expectancy at birth increases steadily from about 30 to about 50 years. Population growth is sustained and begins to describe an exponential curve.
3. *The Age of Degenerative and Man-Made Diseases* when mortality continues to decline and eventually approaches stability at a relatively low level. The average life expectancy at birth rises gradually until it exceeds 50 years. It is during this stage that fertility becomes the crucial factor in population growth.

**THE FIVE STAGES-OF-GROWTH—A SUMMARY**

The traditional society. The preconditions for take-off. The take-off. The drive to maturity. The age of high mass-consumption. Beyond consumption. A dynamic theory of production

	<i>Developed areas</i>	<i>Intermediate areas</i>	<i>Underdeveloped areas</i>
Proportion of world population . . . . .	One-fifth	less than one-sixth	two-thirds
Annual per capita income, in US dollars . . . . .	461	154	41
Food supply, calories per day . . . . .	3,040	2,760	2,150
Physicians per 100,000 population . . . . .	106	78	17
Life-expectancy at birth, in years . . . . .	63	52	30

Global hierachizations of national populations as proposed by Thompson (1929), Winslow (1951), Rostow (1966) and Omran (1971)

**Table 2: Ranking daily living**

	Description	Weight
Class 1	Limited ability to perform at least one activity in one of the following areas: recreation, education, procreation or occupation.	0.096
Class 2	Limited ability to perform most activities in one of the following areas: recreation, education, procreation or occupation.	0.220
Class 3	Limited ability to perform activities in two or more of the following areas: recreation, education, procreation or occupation	0.400
Class 4	Limited ability to perform most activities in all of the following areas: recreation, education, procreation or occupation	0.600
Class 5	Needs assistance with instrumental activities of daily living such as meal preparation, shopping or housework.	0.810
Class 6	Needs assistance with activities of daily living such as eating, personal hygiene or toilet use.	0.920

Health state	Description	Valuation
11111	No problems	1.000
11221	No problems walking about; no problems with self-care; some problems with performing usual activities; some pain or discomfort; not anxious or depressed	0.760
22222	Some problems walking about; some problems washing or dressing self; some problems with performing usual activities; moderate pain or discomfort; moderately anxious or depressed	0.516
12321	No problems walking about; some problems washing or dressing self; unable to perform usual activities; some pain or discomfort; not anxious or depressed	0.329
21123	Some problems walking about; no problems with self-care; no problems with performing usual activities; moderate pain or discomfort; extremely anxious or depressed	0.222
23322	Some problems walking about; unable to wash or dress self; unable to perform usual activities; moderate pain or discomfort; moderately anxious or depressed	0.079
33332	Confined to bed; unable to wash or dress self; unable to perform usual activities; extreme pain or discomfort; moderately anxious or depressed	-0.429

Disability weightings used in DALY calculations and health valuations used in QALY calculations

**Table 3: Ranking disease burden**

Table 13: Leading causes of burden of disease (DALYs), countries grouped by income, 2004

Disease or injury		DALYs (millions)	Per cent of total DALYs	Disease or injury		DALYs (millions)	Per cent of total DALYs
<i>World</i>				<i>Low-income countries<sup>a</sup></i>			
1	Lower respiratory infections	94.5	6.2	1	Lower respiratory infections	76.9	9.3
2	Diarrhoeal diseases	72.8	4.8	2	Diarrhoeal diseases	59.2	7.2
3	Unipolar depressive disorders	65.5	4.3	3	HIV/AIDS	42.9	5.2
4	Ischaemic heart disease	62.6	4.1	4	Malaria	32.8	4.0
5	HIV/AIDS	58.5	3.8	5	Prematurity and low birth weight	32.1	3.9
6	Cerebrovascular disease	46.6	3.1	6	Neonatal infections and other <sup>b</sup>	31.4	3.8
7	Prematurity and low birth weight	44.3	2.9	7	Birth asphyxia and birth trauma	29.8	3.6
8	Birth asphyxia and birth trauma	41.7	2.7	8	Unipolar depressive disorders	26.5	3.2
9	Road traffic accidents	41.2	2.7	9	Ischaemic heart disease	26.0	3.1
10	Neonatal infections and other <sup>b</sup>	40.4	2.7	10	Tuberculosis	22.4	2.7
<i>Middle-income countries</i>				<i>High-income countries</i>			
1	Unipolar depressive disorders	29.0	5.1	1	Unipolar depressive disorders	10.0	8.2
2	Ischaemic heart disease	28.9	5.0	2	Ischaemic heart disease	7.7	6.3
3	Cerebrovascular disease	27.5	4.8	3	Cerebrovascular disease	4.8	3.9
4	Road traffic accidents	21.4	3.7	4	Alzheimer and other dementias	4.4	3.6
5	Lower respiratory infections	16.3	2.8	5	Alcohol use disorders	4.2	3.4
6	COPD	16.1	2.8	6	Hearing loss, adult onset	4.2	3.4
7	HIV/AIDS	15.0	2.6	7	COPD	3.7	3.0
8	Alcohol use disorders	14.9	2.6	8	Diabetes mellitus	3.6	3.0
9	Refractive errors	13.7	2.4	9	Trachea, bronchus, lung cancers	3.6	3.0
10	Diarrhoeal diseases	13.1	2.3	10	Road traffic accidents	3.1	2.6