Chapter 18: Global health and the changing contours of human life

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Abstract

The contours of human life – birth, childhood, maturity, reproduction, the experiences of health, illness, and disability, and death – have been and will remain nearly universal; but their duration and texture are undergoing great changes. In this chapter, we chart the transformations and make projections into the near future. Many of the trends are favorable: fewer children are dying, and many enjoy greater longevity. But these advances are not distributed uniformly among and within countries and regions. Furthermore, the value of longevity is compromised by an increasing number of people living with diminished health under inequitable systems of health and social care. A more just future can be achieved by a continuing emphasis on equity in global health systems even as human lives continue to be extended and enhanced.

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Introduction

For all of the great variations in history and culture among the world's peoples, and despite momentous changes in society, technology, and the environment over the past several hundred years, most human lives have had similar contours. We are conceived and born; if we avoid premature mortality, we go on to live as children, then as adolescents, then as adults; we form relationships based on kinship, love, and friendship; most have children of our own; we age; and we die. Each of us can respond with recognition and emotion to the stories and literatures of peoples remote from us in geography and time, for these universal contours of life constitute the human condition.

In the decades to come, these common patterns will continue to structure human lives, but their rhythms and textures will change greatly for many, reflecting personal and social consequences of economic growth, of scientific and technological advances, and the continuing evolution of political and moral aspirations and norms. In the main, these are welcome developments. Two centuries ago, even in the richest nations, parents could expect to see many of their children die. Not infrequently, their mothers died in childbirth. Though these tragedies still occur regularly in less affluent parts of the world, infant mortality rates are now below 1/100 in the vast majority of countries, and maternal death rates are in most countries well below 1/1000. Death rates have fallen across the lifespan, and people everywhere can expect to live longer and healthier lives. Raising children, which used to occupy a large part of people's adult lives, now occupies a third or a half. We can anticipate further improvement in the duration and quality of life, including the avoidance of illness and disability; and the prospect of both biological and technological enhancements of our capacities is now coming into view.

As impressive as these gains have been, however, their distribution across and within human societies has been staggeringly uneven. Identifying these inequalities serves both to identify important trends in these key concerns of each human's life and to contribute to a moral agenda dedicated to bringing these benefits to all (see Box 18.1 for a note on concepts and measures of inequality). In this chapter, we chart both these advances and their unequal achievement, and make projections into the near future.

Box 18.1. ***A note on concepts and measures of inequality***

Following the approach adopted in Chapter 3 on "Inequality and Social Progress", the conception of inequality used in this chapter is evidence-based (not merely perceived), static (not dynamic), and relative (not absolute). Note however that at different points, the present chapter uses different notions of equality and of distributive justice in health. Using either Chapter 3 or philosophical parlance (Cohen, 1989; Lippert-Rasmussen and Eyal, 2012), the differences pertain to how things are distributed (the distributive "pattern"), what is being distributed (the distributive "currency"), and to the area in which that assessment is made (the distributive "locus").

- *The distributive pattern:* Sometimes we focus on the gap or inequality in health as a morally significant fact in itself. At other times, we emphasize the avoidable health gaps exposed or caused by social and structural inequality, especially in the case of individuals or populations who are worse off. The concern with health gaps can reflect a straightforward utilitarian approach or a prioritarian approach. Prioritarianism puts greater weight on the health or well-being of those who are worse off rather than focusing specifically on the gap between them and those who are better off. At other points in this chapter, we emphasize the avoidable or even intentional wrongful human and structural barriers to better health which inequality

merely exposes. For example, inequalities in numbers of injuries may reflect officially-sanctioned violence against minorities. When we indicate inequalities in terms of various indices, that usually reflects pragmatic measurement needs rather than deeper thoughts on what fundamentally constitutes a health inequality, or the health inequality that matters.

- *The distributive currency:* The chapter focuses on inequalities in the availability of health services, but we also explore inequalities in other distributive "currencies", such as longevity or freedom from disability. Additionally, we discuss inequalities in probabilistic spaces like life expectancy and risk of disability. Our chapter lays emphasis on equality of true access to services. Cases in point would include ramps that equalize access to health facilities by wheelchair-reliant patients and language translators who equalize access across linguistic lines. An alternative emphasis is on equality in the resources being offered to all, for example, in whether all are allowed to use the staircase to the clinic. Related to the question of which currency is being used is the question of whether it is important to use multiple currencies. We sometimes focus on equality in a single component of health (e.g. in diabetes status, in ambulatory functioning), potentially suggesting that these may matter independently of one another. At other times, what we assess is equality in a summary measure of health (e.g. in overall disability status), or even in a related summary measure of utility or capability to which health is only one contributor (e.g. in welfare or in health-related quality of life). In current philosophical debates concerning equality, one also finds a very different notion of equality that focuses on equality of fundamental social status. Although distinct from a concern about distribution of fungible goods and services, fundamental equality in the relations among members of a population is rarely obtainable when inequalities in money, power, and, to some degree, health and health care, are large.

- *The distributive locus:* The present chapter is concerned both with inequalities within districts, countries, and regions of the world and with inequalities between them. Sometimes we discuss inequalities among individuals, as is common in economics (inter-individual inequality or, as per chapter 3, "vertical inequality"), but usually we focus on inequalities among social groups (inter-group inequality or "horizontal equality"). The groups whose health or access to health care we compare include different income quintiles, levels of education, racial and ethnic groups, age groups and genders. These groups are marked out either by their tendency to attract advantages and disadvantages across many - potentially reinforcing (Kabeer, 2010; Crenshaw, 1993) - distributive spheres, or by their social salience and relevance to personal identity. That said, often these two group definitions overlap (e.g. when a racial minority group is both socially salient and faces multiple disadvantages). Sometimes we focus on inequalities in contemporaneous health states but we do so largely for pragmatic or measurement reasons: what ultimately matters with respect to health (as opposed to access to health care) is inequality in lifetime health or inequalities within life stages. Sometimes we examine inequalities in the prevalence of certain health states (such as living with HIV). At other times we assess inequalities in the incidence of health states (such as when HIV infection took place).

1. Coming into being

For most of the history of our species, childhood was a grim fight for survival. At the dawn of the industrial age, one of five children would die before age 5 even in good times; in a

bad year, the early death was the rule rather than the exception. With the rise in living standards in much of the West and in Japan, mortality rates for children dropped steadily; but most children lived in low- and middle-income countries, where death in childhood remained stubbornly high. Indeed, the presence or absence of mortal threats to health during childhood represented one of the most tangible differences in the experience of growing up in a poor and rich countries, respectively.

These long-standing patterns changed markedly over the past three decades. Child mortality in low- and middle-income countries has plummeted. Moreover, because relatively few children in wealthy countries were dying, the huge improvement in child mortality lower-income countries effectively narrowed global health disparities. Having transitioned from universal high child mortality to sharply unequal child mortality, humankind is currently progressing rapidly in the direction of universal low child mortality. Happier stories than this are hard to come by.

Despite these very welcome advances, child mortality remains stubbornly high in some countries, particularly in sub-Saharan Africa; and significant disparities persist also within countries, both rich and poor. Moreover, there are grounds for concern that the resources and strategies that have secured the recent gains in child survival may be reaching their limit, requiring a more direct attack on sources of social inequality than may be possible with the means currently in use.

1.1 Infancy and child mortality

Two-thirds of the great reduction of global child mortality during the past half-century took place between 1970 and 2013 (Wang et al. 2016). The under-five mortality rate has almost halved since 1990, dropping from 90 to 46 deaths per 1000 live births between 1990 and 2014

(UNICEF 2014). With the notable exception of sub-Saharan Africa, the greatest absolute declines have generally been reported among the poorest households.

Yet despite these promising trends, there remains significant cause for concern. The absolute burden of under-five deaths is still very high: worldwide, 223 million died before the age of five between 1990 and 2013 (*ibid*). These premature deaths are overwhelmingly concentrated in sub-Saharan Africa and South Asia, which together account for 4 out of 5 under-five deaths worldwide. 1 in 11 children in sub-Saharan Africa dies before age 5, compared to 1 in 159 in high-income countries (*ibid*). The vast majority of these deaths are preventable. Proven interventions exist to avert the most common causes of unnecessary death among children and adolescents – from pneumonia, diarrhoea, malaria and HIV/AIDS to road injuries and drowning – pointing to continued failures of political will and global coordination.

Moreover, the global reduction in child deaths continues to elude the youngest of children. Neonatal deaths – that is deaths occurring in the first 28 days of life - make up almost half of all under-five deaths and are declining more slowly than other childhood deaths (UNICEF 2014). Preterm and labour-related complications account for almost 60% of neonatal deaths. These complications are correlated with the education level of the mother and are more common among low-income, rural households.

Large disparities in child survival exist also between countries. With 157 deaths out of 1,000 births, Angola is the country with the highest under-5 child mortality, while Finland, Iceland, Luxemburg, with 2 deaths per 1000 births, have the lowest mortality (UNICEF, 2015). "A child born in the highest under-five mortality country faces about 80 times the risk of dying before age 5 as her or his counterpart in the lowest mortality country" (*ibid*.: 27). Additional inequalities exist within regions and within countries. Within the European Union, for instance,

infant mortality is highest in Romania with 9.8 deaths per 1000 live births and the lowest in Finland with 2.3 (European Union, 2013). In 2010, Romanian children also experienced the poorest survival chances in the EU with 37 deaths per 100000 boys and 30 for girls. Child death rates have dropped to as low as 10 among 100000 Slovenian boys and seven among Danish girls (ibid:21).

Box 18.2. Infant/child deaths and the cultural construction of personhood

The continued high incidence of infant and child death in some countries plays a significant role in determining how personhood is bestowed over time, sometimes at a child's first or even fifth birthday, instead of at birth (Scheper-Hughes 1993; Conklin and Morgan 1996). In her study of early child deaths in Brazil, Scheper-Hughes (1993) shows how mothers learn to allow themselves to only bond with children who are likely to survive. At other times, naming ceremonies are postponed from the moment of birth to later in life. These practices of gradual personhood contrast sharply with the trend toward marking child, infant and even "prenatal" death much earlier in wealthier countries, through funerals, and other forms of memorialization, as infant and child death becomes comparatively rare (ibid).

The fourth of the Millennium Development Goals (MDGs) was to reduce child mortality (under five mortality) by two thirds between 1990 and 2015. Many countries, including Bangladesh and China, managed to reach this goal, while others, such as India, did not, and the world, taken as a whole, also failed (United Nations 2015). So while we can observe that on a global level overall child mortality has been decreasing significantly since the 1970s, a closer look at this trajectory reveals a more complicated spatial picture of ongoing progress in some countries and regions and pockets of remaining challenge in others. Nor has progress been

temporally continuous. The reduction in child mortality began to slow down in 1985 and reversed direction in 1994 (-1/2%) before resuming its former downward trend beginning in 1997 (*ibid.*). Uneven progress must be expected in an effort to mobilize the entire globe toward the goal of sharply reducing child mortality; nevertheless, the patterns that emerged during this period may be explained by attending to the socio-economic context in which the planning and execution of these programs was carried out.

1.2 Child mortality and the changing contours of global public health

The 1980s and 1990s were the period in which global financial institutions such as the World Bank and IMF used debt restructuring (known as Structural Adjustment Programs or SAPS) to force through draconian "reforms" of the public health sector in the global south. These reforms included mass privatizations, cutbacks in public spending, public sector employee redundancies, user-fee systems of health care access and a preferred model of public-private partnership in health care provision leading to the "NGOization" of the health care sector (Pfeiffer and Chapman 2010). The generalization of this regime had dramatic negative effects on public health, leading to a visible deterioration of public health indicators across Africa, the former Soviet Union and other countries in the throes of economic liberalization (Kim et al 2000).

This evisceration of the public health sector across the global south – combined with mass unemployment, growing inequalities, and the imposition of a new intellectual property rights regime at the hands of the World Trade Organization – could not have occurred at a less auspicious time. Many countries affected by World Bank and IMF debt restructuring in the late 1980s and 1990s were also facing a significant HIV/AIDS epidemic and found themselves

without the means (such as affordable medications) to implement any effective response. As a result, countries, especially in sub-Saharan Africa, saw horrific increases in child and adolescent mortality during this period (Farmer 2001; Poku 2006).

By the turn of the millennium, as the devastating impact of World Bank, IMF and WTO policies became difficult to ignore, this model came under increasing scrutiny. The adoption of the Millennium Development Goals (MDGs) by the United Nations in 2000 signalled a new resolve to develop a more progressive global health strategy at odds with the brutal fiscal conservatism of the global financial institutions. Under the strain of overwhelming criticism, the World Bank itself adopted a new focus on the social aspects of growth, initiating what some refer to as the post-Washington consensus era in global development policies (Bedford 2009). This turning point coincided with the arrival of a new set of institutional actors, including new private foundations such as the Gates Foundation, new national and global programs to combat specific infectious diseases (PEPFAR, the Global Fund), and new global alliances such as the Global Alliance for Vaccines and Immunization (GAVI), which have together profoundly transformed the landscape of global health interventions (McCoy and McGoey 2011; Gonzales-Block et al, 2012; Williams and Rushton 2011). This new global health complex has reinvested in health care at a time when states have retreated, and has generated a renewed focus on infectious disease research among pharmaceutical companies, who had neglected the area for many years. As a consequence of their interventions, we have seen remarkable progress in the treatment of HIV/AIDS, neglected tropical disease and other infectious diseases and faster than expected decreases in child and adolescent mortality. Mortality from infectious disease among children and adolescents remains high, but appears to be steadily declining (Kyu et al. 2015). Child deaths from HIV/AIDS peaked in 2005 and have

declined thereafter, no doubt as a consequence of greater access to anti-retroviral treatments (ibid.).

However, there are significant limitations in this new model of global public health. New institutional actors such as the Gates Foundation have no doubt made important contributions to the prevention and treatment of infectious disease and have had a marked positive impact on slowing the progression of HIV/AIDS in particular. At the same time, these actors have adapted to, rather than restructured, the public-private infrastructure of health care imposed by the first-generation Washington consensus, and they continue to rely on a mix of non-profit, philanthropic and private (pharmaceutical) entities to address public health challenges. The new global health actors work in close collaboration with big pharma and are to a large extent driven by the desire to generate a new drug innovation model and a new stream of revenue flows for the pharmaceutical industry, which has been faced with an innovation deficit and expiring patents for more than a decade now (Cooper 2013). In this way, "public health" is being resurrected as a profitable area of investment in ways that shape the kinds of health care interventions that are prioritized and foreclose the revival of a truly *public* health-care infrastructure (Clark, 2014). The result has been a pattern dominated by vertical funding schemes that focus on single diseases and a prioritization of distinct, commercializable medical interventions over environmental or infrastructural improvements in public health. While these schemes have contributed significantly to the decrease in child mortality overall, their vertical orientation has equally created a fragmented health care landscape, a new dominance of public-private initiatives and other parastate actors over national actors (Geissler, 2013; Rees, 2014), and a move towards 'projects' as units of action (Whyte *et al*, 2013; Krause, 2014), resulting in

an uneven geography of "the global health complex" (McGoey et al, 2011). To illustrate these shortcomings, we will now look at child and adolescent health and development in more detail.

1.3 Infancy health and development

Even as child mortality remains a priority at a global level, most children survive even in the poorest of countries, and there is an imperative to ensure that they thrive and remain healthy. In this respect, the new Sustainable Development Goals (SDGs) (United Nations 2016) offer a much more rounded perspective than the MDGs did, addressing issues relating to development over and above the reduction in mortality[4].

This emphasis on the interrelationship between development and child health followed on several decades' research on a hypothesis by the epidemiologist David Barker (1938-2013) that health over the life course was strongly influenced by foetal and infant development; indeed, that by the time children are born, events that have already occurred predict much of their future health, and even the health trajectories of their progeny. Barker hypothesized that environmental influences, such as nutrition, interact in utero with genetic factors to program development, a process then referred to as "biological programming." The theory was originally attacked by both geneticists and social epidemiologists, the latter arguing that Barker failed to account for social influences on development (Ben Shlomo and Smith 1991; Susser and Levin 1999). In fact, Barker was fully aware that biological programming was a process that was socially stratified and tied to family social circumstances. However, he overstated the reach of his hypothesis (Barker 1990) and claimed that health inequalities are already programmed in utero (Barker 1991), a claim which has been heavily criticized since (Vågerö and Illsley 1995).

[4] See SDG 3 and SDG 4

The vast amount of work that was triggered by the formulation of the foetal origin hypothesis has led to its reformulation in the form of a "developmental origins of adult disease hypothesis." According to the so-called DOHAD hypothesis, adult disease is heavily influenced by what happens during the first part of your life. This insight was first formulated in 1934 in an influential paper in the *Lancet* (Kermack et al 1934) which suggested that the first fifteen years of life shape survival chances in later life. The modern DOHAD hypothesis simply recognizes the fact that social and environmental factors influence child development in a broad way, and through this process also influence adult health, in particular circulatory disease and diabetes (Barker 2013). The biology of the process is better understood today with the rise of epigenetics, which explores the ways in which that the environment "talks to" the genome and influences gene expression (Carey 2011). Nutritional shock, trauma and infections are examples of external factors that may trigger epigenetic change in children and affect their long term development. Whether or not such epigenetic change can trigger a response in later generations remains controversial (Pembrey et al 2014; Davey Smith 2012).

If epigenetic processes can indeed exert such broad influence, programmes targeting children and overall economic development may have long-term consequences for adult health and survival. A focus on school is certainly necessary, but at the age when children normally start school the earliest environmental influences on children have already been at work. Attachment between child and parents (Roisman and Fraley 2012), children's language skills (Laplante et al, 2004), and non-cognitive social skills (Heckman et al, 2006) are all influenced by parents' experience, and affect children's development and long term health.

War, famines and trauma represent large scale social influences with the potential to influence public health broadly. Children who survived the famine during the siege of Leningrad,

1941-44, suffered "Leningrad siege hypertension" decades later. As adults, their mortality from circulatory disease was elevated (Vågerö et al, 2013). Children who survived the Ukrainian famine of 1932-33 were more likely to suffer diabetes as adults than children who were not exposed to the famine (Lumey et al, 2015). The "great leap forward" in China led to mass starvation in 1959-61; children born during those years were more likely than other children to develop schizophrenia as adults (Xu et al, 2009). Though the world is less convulsed by war and famine than in previous times (Pinker 2012), these have by no means been eliminated, and their consequences are likely to stretch long into the future. For example, the average duration in the instability of refugee camps is 17 years. Children who survive such calamities may nevertheless be scarred by their experience, suffering from impairments to health and wellbeing decades later.

1.4 Child health

Much of the recent success in reducing child mortality can be attributed to overall improvements in socio-economic status worldwide, to the improvement and wider availability of basic health care measures, and to the rapid scale up of WHO's Expanded Program on Immunization (EPI) since the 1970s. Furthermore, there has been significant success in the elimination of mother to child transmission of HIV (Mofenson and Cotton 2013; Chi et al, 2013; Wang et al. 2015). Early childhood education in this age group is critical to laying the foundations for cognitive development, but this is also closely associated with other factors that affect general health and well-being such as good nutrition, safe drinking water to protect again diarrhoeal diseases, sanitation and safety. A significant body of work identifies particular risks to the girl child through the workings of gender-based norms that may limit access to resources and education and provide preferential treatment to one gender over another. As girls grow older,

other structural factors impede access to education such as poor sanitation in schools which impact on menstrual hygiene (Kansai et al 2016;Phillips-Howard et al 2016).

Global health inequalities in child health remain pertinent: children from sub-Saharan Africa, South Asia, lower-income countries and fragile contexts still have the highest under-five mortality rates (UNICEF, 2015), as well as being disproportionally affected by disease, ill-health and unhealthy living environments. However, health inequalities within countries are wide-spread too, with the consequence that national and regional comparisons based on country league tables must be nuanced by attention to intraregional disparities.

Ghana is an instructive example. While economic growth has averaged 7% over the last decade, with the result that Ghana is now labelled as a low-middle income country, economic disparities are not only persistent but in some areas widening (UNICEF, 2014; Aryeetey and Kanbur, 2017). Poverty reduction has mainly succeeded in the country's more urbanised South, while in the agricultural North little progress has been reported. Yet the majority of the population continues to live in rural areas and depends on agriculture. In fact, poverty has increased substantially in the Upper West region, the poorest in Ghana, provoking the World Bank to declare that Ghana's success story in reducing poverty is confined to its southern and urban areas only (World Bank 2011, quoted in UNICEF, 2014: 2).

In addition, Ghana's 2010 Population Census found that "over 86% of Ghana's workforce are employed in the informal sector, making both job security and revenue generation a substantial challenge" (UNICEF 2014: 3). The economic gap between urban and rural, and formal and informal sector is starkly visible in health trends and outcomes in the country. A recent comprehensive survey of living conditions and health in Accra, the capital, calculated that

under-five mortality "ranges from 21 per 1,000 in some parts of the city to 78 per 1,000 in other areas within the city" (Weeks et al. 2013: 6).

Such large disparities in health services and outcomes are not confined to economically poor countries. In the United States of America, for instance, access to health services for children is highly unequal; minority children are much less likely to be insured. These racial inequalities are closely correlated with socioeconomic disparities: "Given these differences in income distributions, the shorter average life expectancy at age 25 for poor adults applies to more than 1 in 5 Black and Hispanic adults and fewer than 1 in 10 White adults" (Braveman et al. 2010: S192; see also NCHS(US) 2016).

In the European Union, where universal health insurance is the norm, stark inequalities in health outcomes mirror social and economic disparities both between and within countries Male life expectancy at birth, for example, varies by 11.8 years across the EU These 'intersecting inequalities' (Kabeer, 2010) in child mortality and health within regions and countries draw our attention to the fine-grained geographies of health care access and quality, as well as to how health prospects intersect with race, gender and economic status. They also point to the importance of going beyond country- and region-wide league tables in evaluating progress in child mortality and health.

1.5 Adolescent mortality and health

Mortality rates among adolescents are much lower than those of children and have shown a slight decline since the turn of the millennium. Recent data on the global burden of disease, collected for 2013, shows that more than 80% of overall deaths among those under nineteen occurred in younger children, while adolescents represented more than 60% of years lived with

disability (Kyu et al. 2016). The leading causes of death in this age group are road injury, HIV, suicide, lower respiratory infections and interpersonal violence (ibid.: 276). Lower respiratory infections rank among the top five causes of adolescent deaths in all regions except for high-income countries and the Western Pacific Region, with more deaths occurring among younger adolescents (under 14). Diarrhoeal diseases are also a significant cause of mortality, particularly in 10-14 year olds. Diarrhoeal diseases, lower respiratory infections and meningitis together account for about 20% of deaths in this age group in the African and South-East Asia regions (WHO 2014a; Kyu et al. 2016).

In other respects, however, mortality rates amongst adolescents evidence distinct singularities. One area of particular concern is the rise in HIV/AIDS mortality among adolescents, which has increased since 2000, bucking the overall trend towards improvement visible among all other age groups (Kyu et al. 2016). Most of these premature deaths are concentrated in the African region. It is possible that the increase reflects improvements in the treatment of paediatric HIV, as infected children survive into the second decade of life (WHO 2014a). Adolescents who were infected in childhood face particular challenges in adapting to the realities of chronic disease and in accessing successive antiretroviral drug regimens, particularly given the existence of extensive drug resistance in multi-drug-treated children. Adolescent HIV care must focus on morbidity related to long-term HIV care and treatment adherence (Mofenson and Cotton 2013).

We also see an increased vulnerability to *new* HIV infections between the ages of 10 and 19 and the emergence of a marked gender differentiation. Before adolescence, little difference is discernible between males and females, while after adolescence girls begin to contract new infections at a much greater rate. This trend is the same across countries but is starkest in sub-

Saharan Africa, where we find 85% of cases of adolescents living with HIV (Idele et al. 2014). In countries with generalized epidemics, more than 80% of new infections among adolescents were in girls (Idele et al, 2014). The overwhelming majority of these new infections are transmitted through sex; research indicates that adolescent girls in particular have very poor knowledge about HIV and very limited access to proven means of prevention such as condoms (Idele et al, 2014).

During adolescence, we see a distinct set of vulnerabilities emerge. The leading causes of disability-adjusted life years lost among this age group are depression (specifically unipolar depressive disorders), iron deficiency anaemia, asthma, alcohol and substance misuse; accidental and non-accidental injuries including road traffic accidents, violence and suicides, back and neck pain and HIV (WHO 2014b). Alcohol misuse was the highest risk factor for DALYs for young people aged 20–24 years, while unsafe sex as a risk factor increased from the 13th rank to the second for both sexes aged 15–19 years from 1990 to 2013 (Mokdad et al, 2016). Smoking, which remains the #1 risk factor for premature death worldwide, is a habit that typically begins during adolescence. Though its principal health effects are experienced later in the life course, its initiation reflects and is partly explained by the distinctive vulnerabilities of the adolescent phase.

During these years, gender, sexuality, sexual practice and sex/gender identity begin to play an important role in shaping experiences of health and exposure to health risk. Many young people have their first sexual experiences in adolescence, while many young girls get married or give birth during these years, in many instances, through coercion. Provision of comprehensive sexual health and sexuality education, as well as access to youth friendly health services is critical to mitigating these risks. It is also important to acknowledge the influence of family,

technology, social media and peers in the development of risky and health seeking practices in youth.

Other significant gender influences are evident in rates of injury and death from violence, with adolescent girls experiencing much higher rates of emotional and physical violence from intimate partners, while adolescent boys encounter increased risk from physical violence by other boys or men (see Chapter 10 for a more extensive discussion). The continued practice of female genital mutilation (FGM) is one example of gender-based violence that is still present in an estimated 28 countries, in Africa, the Middle East and South East Asia (Muthumbi et al, 2015). While the African Charter on Human and People's Rights on the Rights of Women in Africa recognises FGM as a violation of women's rights and a form of gender-based discrimination (ibid: 33), an estimated 125 million women and girls have undergone the procedure and many more are at risk (UNICEF, 2013).

It is clear from the preceding discussion that adolescent health presents unique challenges that would best be met by targeted, gender-sensitive interventions. However, the available data on adolescent health are extremely patchy when compared with data on children and adults, making it difficult to assess past successes or to plan future interventions (Idele et al. 2014). Thus, despite the relatively low level of mortality rates in this age group, adolescents are confronted with a unique set of vulnerabilities which until recently have been somewhat neglected by the leading global health actors. For example, adolescence is the time when many people experience significant mental health problems for the first time. Globally, depression, anxiety and disorders and schizophrenia are the top ten causes of disability among adolescents and young adults, and suicide was the second leading cause of death among 15-29 year olds in 2015 (GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, 2016). A recent

Lancet investigation into adolescent health and wellbeing concluded that increased attention to adolescent health is crucial for the world's future, as adolescence is "characterised by dynamic brain development in which the interaction with the social environment shapes the capabilities an individual takes forward into adult life", thus critical for achieving human potential (Paton et al, 2016). Initiatives to lobby for and promote adolescent health are important and welcome.

1.6 Conclusion

In most parts of the world, death rates among infants and young children have sharply decreased over the past four decades. These successes, which seem to be little noticed by the general public constitute a remarkable achievement. Nevertheless, they represent only partial fulfilment of the goal of ensuring a healthy childhood for each person. An infant's chances of surviving to adulthood are strongly linked to country of birth. Death rates in sub-Saharan Africa remain very high. The charted progress in reducing child mortality substantially achieves the objectives of a coordinated effort, targeted by the UN's Millennium Development Goals, and mobilized by both public agencies and philanthropists relying in large part on successful deployment of immunization and other technologies within single-disease interventions. However, the persistence of unmet need and avoidable suffering among millions of children, concentrated particularly in sub-Saharan Africa, illustrates some of the limitations of this approach. For instance, adolescents, whose numbers are at an all-time high, are vulnerable to infectious diseases affecting other children (and more vulnerable to HIV/AIDS) as well as harm from injury, violence, alcohol and drug abuse. The distinctive health needs of this age group, including those specific to gender, remain relatively less studied and less frequently targeted compared to those of other children. The Sustainable Development Goalss on health (SDG3),

education (SD4) and gender equity (SDG5) provide benchmarks for reducing child mortality and enhancing the wellbeing and development of children, adolescents and youth over the coming decades. But achieving a world in which each newborn, regardless of place and circumstances of birth, can be expected to proceed to a healthy and thriving childhood and adolescence will require that we go beyond the SDGs. Initiatives of the past three decades that have improved health for so many millions of children worldwide were the result of an alignment of public and private resources and initiatives whose impact may have reached its maximum. To continue to improve health systems in low-income countries will require a sustained and well-funded engagement with the underlying economic, structural, and social determinants of child and adolescent health throughout the world.

2. Longevity, life expectancy and inequalities in the risk of dying

2.1 Introduction: social progress in health and longevity

Compared to half a century ago, people all over the world now have a reasonable expectation not only of surviving childhood but of living longer and more healthy lives (Peto et al. 2014). Avoiding premature mortality is possible for a majority of the world population, even for the bottom billion , given the right circumstances and the right policies (CSDH 2008, , Norheim, Jha et al. 2015, UNPD 2012). This section looks at the vast improvements in global health, measured as rising life expectancy; but also at inequalities in life expectancy and longevity, conceived either as differences between individuals or between groups, within countries as well as globally.

As mentioned above, the general public may be unaware of the very welcome story that a review of global health trends tells. Globally, on average, we live longer and better lives, and even if many countries and groups lag behind and some may even reverse their previous progress, overall inequalities in average-age-at death between individuals are *decreasing*. This reflects a two centuries old process of reduction of infant, child and early mortality, discussed in section 1, which probably represents the single most important achievement of modern man (Smits and Monden 2009). This is a reason to celebrate.

➔ **Figure 18.1 Probability of dying before age 5, by World Bank income region, both sexes, 1970-2015 (*Source: UNPD 2015 revision*)**

Yet, in contrast to converging child mortality trends (Figure 18.1), adult mortality trends 1950-2015 appear *not* to be converging globally. The global picture is complex and mixed, showing both convergence and divergence. Despite the progress evident in much of the world, whole regions face long term stagnation or deterioration, such as in the former Soviet Union, 1970-2005, or in Sub-Saharan Africa in the 1990s.

Inequalities in mortality rates also persist within countries, mirroring differences in income, wealth, class and level of education. In many countries, these widening gaps are due to the success among the better off in forestalling death, leaving their less fortunate compatriots behind. Indeed, before the great rise in material wealth and in biomedical science brought on by industrialization, the lifespans of lord and commoner may have been fairly similar; when the means for living longer became available, the best-off were the first to benefit (Deaton 2013).

These inequalities proved to be transient, at least in part, where similar benefits eventually accrued to the less well-off. But this easing of inequality is not inevitable. Worse still, substantial inequalities persist and expand also when segments of the adult population in a country experience rising mortality trends, as has been the case in both USA and Russia recently. Much more can be done to accelerate social progress in health.

In this section we track the trends and patterns in longevity, life expectancy and inequalities in the risk of dying: our data and methods and terminology are briefly explained in Box 18.3 and Box 18.4.

Box 18.3: Data and methods on estimating inequality

To estimate inequality in life expectancy and longevity (age at death), we used UN Population Division (UNPD) historical life tables in its latest revision (Preston et al. 2001, United Nations Population Division 2012). These cover each five-year time period from 1950 to 2015, where the last five-year period is partly estimated. There are separate life tables for each country, World Bank income regions, and the world as a whole. Since age distributions differ between countries, and within countries over time, all life tables are age-adjusted. For every fifth year from 1970 to 2010, we estimated the death rates in it by averaging the age-specific risks in the five-year periods before and after it (so our 1970 rates describe 1965-75); this smooths out any sudden mortality changes. It should be noted that many countries lack vital registration, so UNPD mortality trend estimates are only approximate.

Inequality within each population is estimated by Le Grand's method: Gini applied to age at death (Le Grand 1987, Smits and Monden 2009, Norheim 2010). We shall hereafter use the

term longevity for age at death, and we are interested in whether inequality in longevity is increasing or decreasing. This terminology is important. Longevity is the actual age at death for each individual in a life table (and inequality in longevity can therefore be seen as an *ex post* measure), while life expectancy is an *ex ante* measure of average health for the whole population.

$Gini_h$ can be calculated in different ways and takes the values 0 for perfect equality and 1 for complete inequality (Asada, 2007). We use the formula:

$$Gini_h = \frac{1}{2} \sum_{i=1}^{n} \sum_{j=1}^{n} \frac{|y_i - y_j|}{n^2 m},$$

where y_i is the age at death for the *i*th person, n is the number of people in the population (100 000 in our life table model), and μ is average health (life expectancy at birth) in the population. We extracted the expected final distribution of people dying in different age groups from the ${}_nd_x$ column in the life table.

We only present results for both sexes combined. Gender inequality in mortality is an interesting field of inquiry in itself, but for ease of presentation, we do not present separate figures for females and males. Life tables by sex are available from UNPD.

Box 18.4. Terminology on mortality and associated concepts

Mortality refers generally to the process of dying and its intensity.

(Crude) death rate is the number of deaths that occur in a given year in a given population in relation to the population at risk mostly expressed as deaths/1.000 population.

Age-adjusted mortality (or age-standardized death rates) are used to compare population groups with different age distributions. They are calculated by applying age-specific mortality rates to a standard age distribution and hence allow a fair comparison between populations with different age structures.

Age-specific mortality rates refers to the number of deaths of a certain age divided by the population at risk of that age over a year, such as infant mortality (mortality before age 1); child mortality (usually mortality before age 5) or adult mortality, usually measured by 5-year age groups.

Life expectancy is calculated by using a life table in which empirically measured age-specific

2.2 Trends in life expectancy at birth

2.2.1 Life expectancy at birth in the 25 largest countries (1955-2015)

Figure 18.2 shows trends in life expectancy from 1955 to 2015 for the world (thick line) and for the 25 largest countries in the world. The average improvements for the world are immense: from 48 years in 1955 to above 71 years in 2015. This is an increase of 23 years over a time span of 60 years, or (put differently) more than additional 4 months per year.

→ Figure 18.2 Life expectancy at birth, 25 largest countries, both sexes, 1955-2015 (*Source: UNPD 2015 revision*)

2.**2**.2 Inequality in life expectancy between the 25 largest countries

Life expectancy differs between countries, and on first impression this graph seems to indicate that the dispersion is about the same in 1955 as in 2015 (about 35 years between the two countries with highest and lowest life expectancy). However, if we make pairwise comparisons

in life expectancy *between all* 25 countries and sum up the average relative difference, as the Gini measure does, we find that there has been substantial decrease in inequality between countries (Figure 18.3).

➔ **Figure 18.3 Inequality in life expectancy at birth, between largest 25 countries, both sexes, 1955-2015**

Figure 18.3 shows that in 1955, $Gini_h$ for inequality in life expectancy between these countries was about 0.13 and fell to about 0.06 in 2015 (a lower $Gini_h$ coefficient represents more equality than a higher coefficient). The lower line in Figure 18.3 shows inequality between countries when they are weighted by population size. This indicates even more inequality reduction by 2015 since large countries like China and India have had substantial mortality reductions at early ages and contribute more than small countries.[5]

2.2.3 Contrasting trends in life expectancy at birth in 36 developed countries.

In a recent paper, Timonin et al (2016) found that in 36 developed countries mortality trends are strongly patterned by global region, showing a widening east-west gap in mortality and life expectancy during the period 1970-2005. After 2005 it appears to narrow. This gap coincided with the East-West geopolitical division.

➔ **Figure 18.4 The East West gap in life expectancy trends 1970-2010. Based on 36 developed countries. Source Timonin et al, Population Health Metrics 2016.**

[5] The standard $Gini_h$ is population size invariant, and we have not adjusted for population size in the other results given below.

2.2.4 Trends in global life expectancy inequalities

Moser et al (2005) published a comparison of life expectancy trends for 1950-2000 in the 152 countries with more than one million inhabitants. The authors used population-weighted pairwise comparison of every country with every other country to calculated a global "dispersion measure of mortality" for both adults and infants and found that while differences infant mortality steadily narrowed, adult mortality trends after 1990 caused life expectancy to diverge. A similar finding was reported by Goesling and Firebaugh (2004) comparing 169 countries through 2000 also found that mortality convergence was replaced by mortality divergence in 1990 .

Figure 18.5 Worldwide convergence and divergence of life expectancy 1950-2000. Based on pairwise comparisons of 152 countries in the world. Source: Moser et al (2005)

2.3 Inequality in longevity

2.3.1 Inequality in longevity within World Bank income groups and the world

In the literature on measures and indices of inequality, there is an important distinction between inequality within populations and between populations (Tarlo, 2003). It arises also in understanding inequalities in health. When we compare life expectancy or longevity between countries we are comparing average values, by country. This ignores within-country inequality, and may lead to underestimation of total inequality.

Inequality remains high in each of the four World Bank income regions (low-income, lower-middle income, upper-middle income, and high-income), but the trend in age-at-death is

toward more equality. Here, we treat each group of countries (or the whole world) as one population and compare longevity for each individual within that population. Within-group inequality for the world was much higher in 1955 ($Gini_h = 0.36$) compared to between-country inequality ($Gini_h = 0.14$), although both within-group and between-group inequalities fell in the period (to 0.16 and 0.07 respectively in 2015). In our view, within-group and between-group inequalities are both relevant for monitoring trends.

2.3.2 Inequality in longevity within selected countries

Figures 18. 6 a-c show inequality in age-at-death within some of the 25 most populous countries in the world. Although the trend is towards more equality, some countries are still at high levels, and there are interesting inter-country variations in patterns.

➔ **Figure 18.6 a Inequality in longevity for four Sub-Saharan African countries**

Figure 18.6 a shows inequality trends in four Sub-Saharan African countries. Ethiopia's reduction of inequality has been more rapid in the last 25-30 years compared to that of Nigeria and the Democratic Republic of the Congo. South Africa stands out with a period from early 1990 to early 2000 where inequality *increased* due to very high age-specific mortality in children and young adults due to HIV/AIDS.

➔ **Figure 18.6 b Inequality in longevity for four large countries**

Figure 18.6 b shows time trends in India, Russia, Iran and China. Inequality in India is highest, but is steadily falling. Iran's reduction in inequality was interrupted by high adult male mortality between 1975 and 1985. China made a big improvement after around 1965, while Russia showed no narrowing of inequality during this period, and in some intervals inequalities worsened.

➔ **Figure 18.6 c Inequality in longevity for five high-income countries**

Figure 18.6 c shows trends for five high-income countries: USA, UK, France, Japan and Italy. Inequality in each of these countries is relatively low. Japan enjoyed high rates of decline in inequality early in the period while the US lagged somewhat behind after 1970, a trend that continues today.

Summing up, we find that inter-individual inequality in longevity (age-at-death) within countries are decreasing. Reduction of infant and child mortality is most important for this development. Some countries still experience high inequality and some countries even had periods with rising inequality in age at death (South Africa and Russia).

Overall, we find that there is, at the same time, overall convergence in age-at-death within and between countries, driven by falling early-life mortality, and increasing differences in life expectancy between some countries. The latter is driven by adult mortality trends, especially in Eastern Europe. The survival curve for the world is mostly moving in the direction of rectangularization, but this is not found everywhere and not in every segment of the population.

2.4 Global inequalities in age-specific mortality

When we look at age-specific mortality rates, the picture becomes both more complete and complex.

➔ **Figure 18.7 Relative difference in age-specific mortality rates, World, both sexes, 1990 and 2015 (Calculated from UNPD data, 2015 revision)**

Figure 18.7 shows that the *relative* difference (measured as Gini) in all *age-specific mortality rates* between all countries in the world *increased* in the period 1990 to 2015. This happens when the relative decrease in age-specific mortality for countries with lower mortality is faster than for countries with higher mortality, or when there is a rise in age-specific mortality in countries with high mortality (such as in Russia 1970-2005) and a fall among most other countries. This finding is the basis for the general observation that health inequalities within countries are increasing. (see also next section below).[6]

Increases in relative inequality are important for two reasons. First, even if inequality in age-at-death is decreasing (because of convergence in under-five mortality), the increase in relative difference in age-specific mortality rates shows that the speed of mortality improvement for high-mortality countries is slower than for lower-mortality countries (and especially so in adults). Thus the picture is not all positive. In particular, as can be seen from the graph, adult (ages 30+) mortality rates are more unequal in 2015 than in 1990. Second, we must keep in mind that data on child and maternal mortality alone – the only mortality trends taken into account by

[6] See for example Michael Marmot: "Health is improving globally. (...) Within many countries (…) inequalities in health are increasing – the health of the best off is increasing more rapidly than that of the worst off. The best and worst of times coexist." (Marmot, 2015)

the MDGs - do not tell us all that must be taken into account in assessing how people fare over their lifetimes. [7]

2.5 Social inequalities in mortality and life expectancy within countries

2.5.1 Mortality differentials by level of education

Education is one of the most important sources of observable social heterogeneity in all countries, and it is a very common social stratification variable in health studies as well. Its differential impact on health and mortality is strong. There is ample evidence (Baker et al 2011; Lutz and Skirbekk 2014) that education empowers people in various dimensions, and thus has a direct and causal effect on health related behavior, health, mortality and longevity. In all countries of the world, child mortality is significantly lower for children of more educated women even after adjusting for the effect of income and wealth (Pamuk et al 2011). Life expectancy of university-educated men and women exceeds that of those with basic education by as much as 12 years. In most developed countries the differentials have actually increased in recent years.

This phenomenon and the role played by the modern welfare state, have figured prominently in recent discussions of what is called the "welfare state paradox." Recent comparative studies of the size of health inequalities in a number of European countries tested the hypothesis was that comprehensive welfare states of the Nordic model should present the smallest inequalities. This might have been true in the 1980s, or earlier (Vågerö and Eriksson

[7] It is important to note that the choice of health measure may affect our results. Both types of measures are important, and analysts should always make clear what kind of health inequalities are reported.

1997), but later data suggest that this is no longer the case (Mackenbach et al, 2008). Most Western European states now offer a minimum of welfare provisions and social protection, but a divide has nevertheless become apparent between Eastern and Western Europe. Social inequalities in mortality are much more pronounced in the former communist countries of Easter Europe – both a legacy from the past and a response to the system collapse in the 1990s (Vågerö 2010).

2.5.2 Social inequalities in life expectancy and mortality within countries: The long view.

Social class differences in mortality have been tracked for over a century by the decennial supplements of occupational mortality published by the Office of Population Statistics (OPCS) in Britain. The reports, which compare the all-cause mortality of five occupationally-defined social classes, show the same gradient in mortality in every decade. Mortality in social class V (unskilled workers) is typically about twice as high as in class I (professionals) with classes II, III (consisting of non manual(IIINM) and manual (IIIM) and IV falling in between. The continuity in this pattern, decade after decade, in spite of a gradually changing disease panorama, impressive economic growth, modern medicine and welfare state provisions, is quite remarkable (OPCS 1995). It suggests that health differentiation is a fundamental social process, closely tied to the general stratification in society.

The "Black Report", presented by Sir Douglas Black to the British government in 1979, and immediately dismissed by the conservative government of that time, sought to understand these regularities and to suggest means of changing the situation. The Report's account of why social class differences in health reappear again and again in every new generation, which triggered academic and political controversy, focused on the contribution to health of poverty

and material circumstances in adult life. One critique of the report argued that issues of selection were not dealt with properly. Health and vitality in early life may to some extent determine social career and contribute to the social differentiation of health in adult life.

Such arguments about "selection" versus "causation" were once quite bitter. The introduction of a life course perspective has changed this. Today, this conflict has been resolved, at the theoretical level, by the insight (as discussed in Section 1.3) that health in early life is heavily influenced by the social circumstances of the previous generation (Vågerö and lllsley 1995, Kuh and Ben Shlomo 2004). Public health scientists today generally agree that life-long social circumstances have a dominant influence on people's health and survival and that health conditions may influence economic activity and social mobility, reinforcing the pattern of social inequalities in health (Greenhalgh, 2008).

The publication and controversy over the Black Report inspired a new generation of researchers who have produced a vast literature on health inequalities, now shown to exist in every country that has data to make a study possible. It is a general phenomenon, observable in rich and poor countries alike, on every continent and in every social system (CSDH 2008).

Social inequalities have typically been conceived as differences by occupational class, by education, sometimes by income or by residence in deprived versus affluent areas. In very general terms, patterns of inequality are similar across these social boundaries, but anomalies exist, often reflecting and looking at specific causes-of-death, or specific health conditions. Breast cancer among women, for instance, is generally higher among high-educated women than among those with low education.

Even if occupation, education and income are closely correlated in most societies, they cannot be interchanged for each other – though this is a common practice in social epidemiology.

Education, occupation and income tap into different etiologies and predict mortality and longevity independently of each other (Geyer et al 2006). Theoretical understanding of social inequalities in health, mortality and longevity in the adult population has to allow for several determinants and risk factors, distributed across the life span and within the previous generation. There is a complex and dynamic set of relations between those factors.

Access to health data is poorest in low- and middle-income countries. However, the Program for Demographic and Health Surveys, running since 1984, has been quite successful in providing data on child mortality by household economic level. Tanja Houweling, using World Bank country reports and DHS data for 43 low and middle income countries to compare the richest fifth of households with the poorest fifth in each country (Houweling 2007), found that child mortality in poor households was around double that of rich households in the same country. Wagstaff et al, using Living Standard Measurement Study data for nine countries, found very similar results (Wagstaff et al, 2000). Hosseinpoor et al (2005) using regionally representative DHS data for Iran in the year 2000, found a gradient in infant mortality from income quintile 1 to income quintile 5; infant mortality was more than twice as high among the poor compared to the rich. This is the typical pattern in any country, although the estimated size of mortality differentials is sensitive to the method of defining household income (income, assets, expenditure) (Houweeling et al, 2003) and varies between countries.

A scarcity of data prevents us from assessing how social inequalities in child mortality change over time within many countries (Victora et al, 2003). A study by Moser, Shkolnikov and Leon (2005) that uses country data to estimate global trends in infant mortality suggests that there may be a convergence in infant mortality worldwide. This is in contrast to global trends in adult mortality, which they suggest to be diverging after 1985 to 1990.

2.6 Four distinct patterns of health change within countries

Trends in social inequalities in mortality and longevity within developed countries and among adults are better studied and known. It appears that the dominant trend is one of increasing adult mortality differences.

We can distinguish four main patterns of how mortality in in general and also social inequalities in mortality have changed during the last few decades. The first three patterns describe growing mortality inequalities. We list them by the degree of moral concern they raise, with the most problematic pattern first.

- Pattern 1: Sharply fluctuating (falling, rising, falling) life expectancy trends nationally. Growing social inequalities in mortality and/or life expectancy, combined with falling life expectancy in large segments of the population.
- Pattern 2: Increasing life expectancy trends nationally. Growing social inequalities in mortality and/or life expectancy, combined with falling life expectancy in large segments of the population.
- Pattern 3: Increasing life expectancy trends nationally. Growing social inequalities in mortality and/or life expectancy, combined with increasing life expectancy in all segments of the population.
- Pattern 4: Increasing life expectancy trends nationally, combined with narrowing of the social gradient in mortality.

The first pattern can be illustrated by Russian mortality trends 1970-2005, where a long term trend of falling or sharply fluctuating life expectancy dominated from 1965 to 2005. It is combined with increasing mortality differentials by education, at least for the period 1980-2001,

during which period low-educated men and women experienced falling life expectancy (Murphy et al 2006). Similarly, Estonia demonstrate dramatically growing mortality inequalities both by education and by ethnicity during the 1990-2000 period, driven by rising mortality and falling life expectancy among the low-educated and in the Russian minority (Leinsalu et al 2003, 2004). South Africa probably fits this pattern too.

The second pattern can be illustrated by United States. Case and Deaton (2015) have recently noted that middle aged white Americans have experienced increasing mortality during the 1999-2013 period. However, this trend only applied to low-educated whites, not to those of middle or high education. Behind the phenomenon is a longer trend of generally widening mortality differences between educational groups, and not only in middle aged men and women, since at least 1990. The mortality of white men and women with less than twelve years schooling have been growing gradually worse over time (Olshansky et al 2012).

The third pattern is much more common than the first two. Countries that are doing quite well in general life expectancy trends often demonstrate increasing social inequality in mortality and ,life expectancy, such as many countries in Western Europe. Steingrímsdóttir and colleagues (2012) published annual life expectancy data for men and women in three educational groups in Norway from 1960- 2009. This series, perhaps the longest series of mortality differentials by education that we have, shows a continuously growing gap between all three educational groups over the fifty year period. The lowest-educated group is making progress, but at a slower pace than the other two groups. Shkolnikov et al (2012) demonstrated the same pattern in a comparison of Finland, Norway and Sweden for the 1970-2000 period. In all three countries, mortality is falling in all educational groups, but the rate of decrease has been greater with higher

educational attainment resulting in a growing life expectancy gap. Leinsalu et al (2009) demonstrated the same pattern for Poland and Hungary, for 1990-2000.

The choice of inequality measures makes a difference. The study of 6 western European countries by Mackenbach et al (2003) showed a widening mortality gap by education in all of them, when using a relative inequality measure. Differences in mortality were more stable when an absolute measure was used, except for Finland. Reducing absolute mortality differences should be easier than reducing relative ones when mortality rates are falling.

The long term increase in absolute mortality differences and in life expectancy between men and women of different educational backgrounds in Finland, Norway and Sweden is therefore quite remarkable. Much attention has been devoted by social epidemiologists to understanding this "welfare state paradox. The influence of global market forces and corporate actors over national income distributions, labour markets, consumption patterns, taxes and welfare policies in general may now be too powerful for national governments to balance.

The fourth pattern of mortality differentials and trends, outlined above, corresponds to what most governments aim for. The policy documents of WHO and of national governments, such as the Rio Political Declaration on Social Determinants of Health, October 2011, call for improved health in combination with smaller health inequalities. But this remains only an aspiration; in in reality, most governments will have to cope with the first three scenarios. The fourth pattern, of growing life expectancy and smaller health inequalities is not consistent with "business as usual", according to the influential report of the Commission on Social Determinants of Health (2008). Though this field remains an area of intense interest in policy making, he way forward is not very clear.

2.7 Conclusions

People are living longer. There is a tremendous increase in life expectancy and longevity throughout much of the world. Success in reducing infant and child mortality contributes greatly to increasing life expectancy and the convergence in age-at-death globally. Adult mortality trends and life expectancy demonstrate a long term convergence globally that was sustained until about 1990. The divergence after that point primarily reflects developments in two regions of the world, sub-Saharan Africa (where life expectancy is again improving after 2000) and former Soviet Union. Adult mortality is strongly socially differentiated in all countries, as is child mortality in low- and middle-income countries. Lower death rates have been achieved in many populations at each stage of life, with a small but growing number achieving active lives through eight and nine decades.

Nevertheless, others lag behind or even experience rising mortality. Within the richer countries, those with more education tend to live longer than those with less education; shorter lives are more common in many of the less-developed countries, often caused by high adult mortality rates; those burdened by the HIV/AIDS pandemic, and many in post-communist Eastern Europe. While overall gains in life expectancy and longevity are substantial and promising, national and global data indicate divergence as well as convergence. Achievement of better health and more equal life spans remains a priority in the global health and development agenda.

3. Diminished health: Morbidity, disability and chronic conditions

Diminished health compromises the value of longevity: the prospect of longer life spans has less appeal – or, in extreme cases, none at all – if those years are accompanied by poor health. Diminished health is also of concern independently for occasioning pain and discomfort, limitations or impediments to important activities, social isolation and stigma; and often for the need for seek and pay for care, which may be both urgent and financially catastrophic.

These are not merely biomedical considerations. Social acceptance can reduce or eliminate the stigma that many experience as a result of chronic or infectious diseases such as HIV/AIDS or cancer. Disabilities resulting in limitations on mobility, hearing and vision, and even cognitive function are much less burdensome in welcoming, tolerant social and physical environments. Serious illness does not lead to bankruptcy where there is social insurance.

A purely biomedical understanding of diminished health and disability would miss subtle but important dimensions of these issues (Hausman, 2015; Jones et al, 2012; Scully, 2004). Dyslexia (a learning disorder consisting in a difficulty reading) is problematic in some social and natural contexts and of no importance in others, while other health conditions, such as migraine headaches, cause hardships in every context. Some health problems, such as disfigurement, limit people's activities only because of social customs and the actions of others, while others would limit or harm people even given optimal social accommodations. Some health issues, such as the loss of an arm, provide no compensating benefits. Other problems, such as blindness, while limiting a crucial capacity, may sharpen the other senses and heighten the satisfactions individuals receive from them. There are many different ways in which humans may flourish, and health conditions that interfere with some of these ways need not prevent individuals from living well. When some activists in the Deaf community maintain that deafness is not a disability, they obviously do not mean that it does not limit a significant human capacity. They

envision an environment with access to facilities that enable an excellent quality of life. In lower income countries and communities where a significant proportion of people with hearing loss do not have access to hearing aids, their deafness limits the attainment of wellbeing (Lancet, 2016).

This chapter section is in four parts. In part one, we examine the different concepts of diminished health and make a case for choosing disability as our overarching conceptual framework. In part two, we present the current epidemiological and public health evidence on disability across the life course and in global context. In part three, we present the perspectives of affected communities, through fourcase studies of chronic illness and disability experiences. In part four we discuss potential responses to the challenges of disability particularly in poor countries with limited resources for health and social care.

3.1 Examining concepts of diminished health

The concept of "diminished health" is often used interchangeably with associated terms such as "morbidity," "disability," "impairment," "handicap," "injury," "disease," "pathology," and "illness" . Obviously, these are not the same, and picking any term as a catch-all risks serious confusion. If, for example, one regards any diminution of health as a loss in "health-related quality of life," as the most common generic health measurement schemes maintain, then one provokes the justified response of the Deaf community that although the lives of the deaf are *different* than those of people who can hear, they are not clearly of lesser quality. This is a significant debate that was raised in the conceptualization of disability weights, a quantitative and comparative scoring of disabilities that is used in descriptive epidemiology and in priority-setting (Saloman et al, 2010). Similarly the physiological state of infertility is voluntarily induced by millions of women, while the same physiological state is cause for medical

intervention in others, highlighting again the contextual nature of the interpretation of *illness* or *sickness*.

Instead of conceptualizing health decrements as involving lesser health-related quality of life, one prominent approach maintains that health limitations can all be conceived as limitations on activities and hence as "disabilities" of one sort of other. This language may be misleading as well inasmuch as it describes health problems as diminishing quality of life or overall ability. It is at the very least awkward to describe burns, rashes, and pains as disabilities. It would probably be least misleading to speak of "health decrements, limitations, or problems" but since "disability" is so widely used by demographers, epidemiologists and health economists, we shall often speak of all shortfalls of health as disabilities. Still, it is important to recognize that "disability" is herein a technical term for any sort of health issue, many of which would not in everyday language be called "disabilities." The remarkable improvements in longevity and life expectancy documented in Section 2 do not automatically imply any diminution in disability. To the contrary, if the extension of life leaves individuals with more mental and physical limitations, then people may end up trading longer life for more years with disability. But it is important not to be misled here. Along with the health problems that come with the additional years are all the good things that those years provide. Apart from the rare cases in which the additional lifespan consists in extreme suffering or humiliation, longer life is usually desirable.

One may question the conclusion, that longer life is usually a benefit, in two ways. First, an extended period of disability at the end of one's life changes its overall "narrative" (Griffin 1986, Velleman, 1991). Some would argue that a long period of substantially diminished physical, cognitive, or emotional capacities decreases how well that life as a whole would have gone, compared to the life of a vigorous, competent and authoritative person that ends with no

long period of dependency on others, mental confusion, or inability to contribute to the maintenance of a household. We do not take a stance on this controversial question. Second, even if a longer life is almost always a benefit to the individual, it may be costly to others. If individuals live into their nineties and retire in their sixties, then even if they do not require expensive care, they still require support from the working-age population. They may provide some compensation in the form of the wisdom and cultural continuity that they pass along, but providing for them can be a struggle especially in societies in which there have been recent decreases in fertility and hence relatively few working age adults to support them (Reidpath et al, 2015). The severity of this burden on younger individuals greatest in societies that lack social support systems for aging dependents (WHO, 2002a,b).

3.2 Global trends in disability

The World Report on Disability (WHO, 2011) and the systematic analysis of disability data by the GBD 2015 Disease and Injury Incidence and Prevalence Collaborators (2016) provide the most recent and comprehensive insights of global trends in disability. Both publications outline different types of disability including those affecting movement, vision, hearing, thinking and learning, and mental health. They highlight levels of severity encompassing very mild, mild, moderate, severe and profound.

Between 785 million (15.6% of the world population) and 975 million (19.4%) of people aged 15 years and older are estimated to live with some form of a disability. 110 million (between 11% and 14%) have significant difficulties in functioning: this refers to severe/profound disability for conditions such as quadriplegia, severe depression, and blindness. It is estimated that 95million children (5.1%) (aged 0-14 years) live with disability. Of these 13

million (0.7%) have 'severe disability'. The GBD analysis shows that over the last 25 years, the proportion of people of all ages living with disabilities (mild and or greater) has increased (although as mentioned above this partly reflects increased longevity). Their data suggests that as we move across the life course the causes of disability shift from common infectious diseases (diarrhoea, skin diseases) among children, to adult-onset chronic non-communicable diseases (diabetes, cancers) and mental health disorders (e.g depression, anxiety) (see Box 18.5). Furthermore, as the number of people living with co-morbid and multi-morbid conditions rise, the prevalence rates of associated physical disabilities and mental health disorders also rise (Barnett et al, 2012; Leone et al, 2012).

Box 18.5 Leading causes of disability across the life course

Age group	Leading causes of disability
Younger children (<5 years)	iron-deficiency anaemia, skin diseases, protein-energy malnutrition, diarrhea
Older children (5-14 years)	iron deficiency anaemia, skin diseases, asthma, mental health disorders including conduct disorders, autistic spectrum disorders, anxiety disorders
Adolescents and young adults (15-39)	iron defiency anaemia, skin diseases, depression, lowerback and neck pain, migraine, anxiety disorders and schizophrenia
Middle-aged adults (40-64years)	musculoskeletal disorders, mental health disorders in particular depression, diabetes and sense organ disorders
Older adults (>65years)	sense organ disorders, musculoskeletal disorders, chronic obstructive pulmonary disease
Oldest adults (>80 years)	ischaemic heart disease, Alzheimer's and other dementias

Source: GBD 2015 Disease and Injury Incidence and Prevalence Collaborators (2016)

The most vulnerable adult populations globally are: (1) people from the poorest wealth quintile; (2) women; (3) older people; and (4) people who are unemployed with low educational

qualifications. In child and adolescent populations, groups from poorer households and from ethnic minority groups have a significantly higher risk of disability (UNCF, 2008, see also sections 1 and 2 on the effects of child poverty on physical health and mortality). The intersections of these vulnerabilities complicate subjective experiences and the development of appropriate interventions.

Not all people with disabilities are equally disadvantaged. Women with disabilities arising from neglected tropical diseases (such as lymphatic filariasis or onchocerciasis), experience more pronounced gendered discrimination and stigma compared to men living with the same conditions (Allotey and Gyapong, 2005). Children with physical impairments fare better than children with intellectual or sensory impairments at school. Among the adult population, people with mental health and intellectual impairments are more likely to be excluded from the labour market. LMICs are disproportionately affected by chronic non-communicable diseases (NCDs) and the double burden of NCDs and infectious diseases. Within these LMICs the poorest citizens and increasingly those in productive years under age 40 experience the greatest burdens (Bukhman et al, 2015). These groups are more likely to bear a significant proportion of rising levels and cost of disabilities because weak health and social care systems undermine lived experiences and health/social outcomes.

3.3 Living with disabilities: case studies of four debilitating chronic conditions

There is a general lack of standardized culturally-sensitive data on disability. WHO (2011, p.20) observes that "methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally and applied consistently". The data that exist suggests that people with disabilities have poorer secondary health outcomes (e.g. greater vulnerability to

preventable secondary conditions, co-morbid chronic conditions and age-related conditions; higher risk of being exposed to violence), less economic participation, higher rates of poverty (frequently a vicious cycle), increased dependency and restricted participation in social life. Children with disabilities have lower educational achievements.

We present and discuss two case studies on the lived experiences of diabetes and dementia[8]. These case studies trace the complex trajectories of subjective and family experiences of serious chronic conditions, and highlight the ways these experiences are mediated by the physical and medical impact of the condition, as well as the social, cultural, economic and structural contexts of individual and family lives.

Some aspects of chronic illness experiences are shared across social and geographical categories. Most individuals (and their caregivers) make cognitive and psychological adjustments to a diagnosis of chronic illness or disability over time. They struggle to come to terms with their relationship with self and illness, and with self and society (see Box 18.5). As illness progresses, the subjective quest to regain one's lost self and former social roles cuts across illness experiences, regardless of condition or location (Bury, 1982; Reeve et al,2010).

The differences in illness outcomes and life trajectories arise when social, cultural, economic and structural factors are considered. Negative attitudes and stigma associated with impairments can be greater barriers to normal functioning than the impairments themselves . For example, in socio-cultural contexts where conditions like diabetes or dementia are poorly understood and are perceived through traditional lens of spiritual causes, there is a higher likelihood of stigma, with associated impediments to normal functioning by individuals living with such conditions.

[8] The longer online version of this chapter presents four case studies on diabetes, blindness, dementa and a rare condition, Harlequin Ichtyosis.

Severe chronic conditions have an economic impact for most sufferers: in addition to threatening one's livelihood, diet and other expensive lifestyle changes must be made, and medicines must be purchased . When one lives with a chronic condition like diabetes, in a rural or urban poor community in Africa, Asia or Latin America, structural and individual poverty permeates all aspects of the illness experience (see Case Study 1). As Capewell and Graham (2010) observe poor communities experience health disadvantage at multiple stages: from "the person's beliefs about health and disease, and actual behaviour, to presentation, screening, risk assessment, negotiation, participation, programme persistence and treatment adherence".

Culture shapes the illness experience in specific ways. Case Study 2 tells the story of a family's experience of dementia in the UK, a country with one of the most advanced systems of dementia care in the world. In the UK , dementia threatens 'valued elements of life' (Lawrence et al, 2011) for all sufferers, regardless of ethnic group, and people with dementia can live meaningful lives if their unique core values of self and social roles are understood, legitimized and supported. Yet in the UK cultural and structural factors can create barriers to comprehensive dementia care for black and ethnic minority groups. It is estimated that Black African and Caribbean elders have a higher prevalence and earlier onset of dementia compared with the White UK population (Berwald et al, 2016). Yet they present later to dementia specialist services, receive diagnoses when the disease is at advanced stage and experience poorer health outcomes. Studies focusing on how communities, caregivers and dementia sufferers from minority ethnic groups make sense of dementia highlight important ethnic and cultural differences in perceptions and responses (Lawrence et al, 2011; Berwald et al, 2016). African and Caribbean groups tend to perceive dementia as 'old white people's disease' or as 'memory problems' and are less likely to recognise the severity of dementia; they are more likely to see

psychiatric services as institutionally racist and care homes as undesirable and therefore present their problems late and rely exclusively on family support. Their experiences of poorer dementia health outcomes are partly attributed to these cultural factors.

Two further cross-cutting themes emerge in the case studies. First, it is clear that living with a debilitating or disabling condition affects the mental health of sufferers and their caregivers. Anxiety and frustrations arising from challenges or disagreements with everyday management are salient in the diabetes and dementia case studies. Individuals living with diabetes under conditions of poverty express despair (and suicidal ideation) about their difficult life circumstances. Stigma restricts the lives of sufferers and their significant others and deepens emotional conflicts and tensions within families. This shared experience underscores the importance of understanding the co-morbid relationships between common chronic physical conditions (diabetes, hypertension) and between chronic physical conditions and mental health disorders (diabetes and depression). Poor mental health has been strongly associated with poor self-care, poor self-efficacy and poor chronic illness management (Prince et al, 2007). Caregiver stress has been associated with poor physical and mental health outcomes (Schulz and Sherwood, 2008).

Finally, the case studies underscore the practice of health-seeking and healer-shopping across pluralistic medical systems. Individuals search for meaning and respite when they fall seriously sick and they experiment with available (recommended) health services as they seek solutions to their problems. In African and Asian contexts healer-shopping for a cure to chronic conditions is common (de-Graft Aikins et al, 2010; Yasin et al, 2012). As case study 1 shows, healer-shopping for herbal cures occurs for a range of reasons including the high cost of biomedical care, the perceived ineffectiveness of pharmaceutical medications and trust in the

recommendations of significant others. Similar dynamics are reported in the context of dementia care among UK black and ethnic minority groups, where individuals may seek diagnosis for early onset dementia symptoms in the 'black church' and try alternative therapies to stall the advancement of dementia (Berwald et al, 2016). These practices highlight the importance of traditional cultural beliefs about the aetiology of various health conditions, evolving explanatory models about the body and mind, and how medical pluralism is perceived, legitimated and used across contexts. Ethnographic and phenomenological studies on lived experiences of chronic conditions are rare, but they present important multifaceted insights. These insights underscore the importance of integrating medical and social models of disease and disability in research, practice and policy.

Case study 1: Diabetes experiences in rural Ghana

Ruth* (a middle-aged widow) lived with severe uncontrolled diabetes and chronic physical impairments: loss of appetite, severe weight loss, joint pains and body sores. This had a pervasive impact on her life. She was unable to carry out the simplest everyday chores and had had to abandon her previous job as a food hawker. In the early years, she had financial support from her extended (paternal) family—but she was on insulin, which was expensive, and gradually financial support had been withdrawn. Three caregivers were identified: an older daughter, Adjoa* (29), widowed, with three children, all of whom lived with Ruth; a son who lived locally, visited rarely, but made her yearly insurance contributions; and a niece, Cynthia* (40), a teacher, who helped financially when she could. Other forms of financial and social support came from sympathetic hospital staff and self-help group members. Ruth and her family attributed her diabetes to a mix of diet, lifestyle and spiritual causes.

Ruth's inability to treat her diabetes had led to acute weight loss. For a middle-aged woman who prior to getting diabetes and prior to abandoning regular treatment had had a healthy body image, the sudden change to her physical identity had caused some shock to her family and community. Shock turned to community speculation and gossip that Ruth may have contracted AIDS. Ruth experienced disruption to her social relationships: she was shunned by her friends, taunted in the streets by school children and lost customers.

When I sent food to the school to sell, the children wouldn't buy, because the teacher told them I have HIV/AIDS. [Ruth]

Her family became 'tainted' with this identity: they lived with 'courtesy stigma' (stigma by association) Adjoa's attempt to take over her mother's food hawking business failed, because people were unwilling to buy food from an individual living in close proximity with an alleged AIDS sufferer.

You see, at first, my mother was selling rice water ((rice pudding)). Due to her illness I had to

Case study 2: living with dementia in the UK

In 2016 the British Broadcasting Corporation (BBC) produced a rare multi-textured documentary filmed over two years on one family's experience with dementia: Chris Roberts, from north Wales, his wife Jayne and youngest daughter Kate. "From making the decision to choose his own care home to writing a living will, getting lost in his own house and not recognising his family, Chris chronicle[d] his changing life as his independence slip[pped] away. Once a businessman and a keen biker, he now struggle[d] to walk and talk - his life [wa]s beset by frustration, yet his remarkable insight allow[ed] us into his world."(http://www.bbc.co.uk/programmes/b07dxmyh). This is an edited version of a review of the documentary (Ross, 2016).

"At 55 years old, Chris Roberts often gets lost in his own home. At times he has to ask his wife, Jayne, how to get to the bathroom and regular household appliances, such as a kettle, can confuse him. Five years ago, the former property manager was diagnosed with both vascular dementia and early onset Alzheimer's disease after he started displaying behaviour that was out of character, such as unwarranted anger.

> *"The best thing you can do after your diagnosis is read up about it, find out all you can. It's the unknown that scares us*," Chris says in the programme. *"Some people try and hide from their dementia, hiding is easier than facing up to it sometimes. But you can only run for so long – dementia will catch you up. You will have to face it, you will have to live with it."*

The documentary follows their highs and lows, from bittersweet moments like Christmas day to a heartbreaking scene where Jayne struggles to comfort Chris as he screams in distress for no apparent reason.

> *"The person I miss most, is me,"* Chris says.

In one clip, Chris explains what it's like to wake up in the morning, confused about where he is and what's happening. He wanders around, shouts and searches for his wife, then says: "Trouble is, I don't know whether I'm dreaming or not. Can't find any notes..."It's really strange when you don't know what's real and what isn't."

The programme also reveals what it's like to be a family member of someone with dementia. Jayne opens up about her feelings of guilt as she drops her husband off to a daytime respite centre and Kate says having a dad with dementia "isn't all doom and gloom" as in many ways the illness has made them all closer.

> *"I need respite and I didn't think I'd ever say that*," Jayne says. *"He wants to go in and have respite overnight for himself. I'm not ready to let him do that. One of my biggest worries is that I won't want him to come home. I might like him being there."*

The family decided to take part in the one-off programme as they wanted to dispel myths about dementia and raise awareness of what living with Alzheimer's disease is really like.

> *"I really hope that the programme helps people and doesn't scare them. I haven't done this to scare anybody,"* Chris says. *"You've seen that I still live, I still have a life. Just a different quality."*

'Panorama - Living With Dementia: Chris's Story' on BBC One. Review Source: Ross (2016)

3.4 Addressing diminished health and disabilities

Resources required to support or enhance the quality of life differ significantly within and between countries. In low income countries it is estimated that less than 5% of those living with disabilities gain access to rehabilitative and associated services (DFID, 2010). The barriers to providing ideal disability care in these countries include inadequate policies and standards; negative social and professional attitudes; lack of provision of services; problems with service delivery; inadequate funding for disability services; lack of accessibility (environmental, social, institutional); lack of consultation, involvement, participation in the formulation and implementation of policies; lack of evidence and data (WHO, 2011; see case study on Ghana, Box 18.6)

Box 18.6. Politics of disability and mental health care in Ghana

In Ghana, the prevalence of physical disability is estimated at 7-10% and the prevalence of common mental health disorders is estimated at 10% (de-Graft Aikins and Koram, 2017). Adults and children living with disabilities lack access to appropriate health and social care and they experience stigma and associated socio-cultural responses that are life restricting. Epilepsy, a neurological condition, is typically treated as a mental health disorder with underlying supernatural causation. Adults and children from poor and rural communities are more likely to be hospitalized in psychiatric institutions or treated at traditional shrines and prayer camps, rather than receive neurological treatment (Read et al, 2009). The confluence of wrong medical and social diagnoses creates excluded communities of epilepsy sufferers and caregivers, who are served by under-resourced mental health NGOs (Cohen et al, 2012).

Ghana has a disability policy and a mental health policy. Both policies took over a decade to formulate and both are informed by contemporary global discourses and benchmarks on disability and mental health and focus on rights-based prevention and intervention. However, neither policy has been fully implemented as no funds have been allocated to support governing authorities and service delivery. Inequalities in care persist especially for children, rural communities and older adults (de-Graft Aikins and Koram, 2017). Similar gaps between policy rhetoric and action relating to disability and mental health are reported in other African countries (Akyeampong et al, 2015; Faydi et al, 2011) and in other regions (Saxena et al, 2011; Prince et al, 2007).

Paraplegia in a low income country setting, for instance, could still result in a reasonable quality of life with access to a wheel chair or crutches to be used in an urban environment built to support it. Similarly, with resources to ensure activities of daily living and access to physiotherapy, function and ability to engage within the community can be enhanced. Poorer families within the same lower income country may not have access to wheelchairs and even if they did, may not live in a built environment that would enable the adequate functioning of a wheel chair. Indeed there is evidence to suggest that life expectancy in such settings is significantly reduced from complications of the disability that would not arise in an environment where there was access to basic rehabilitation, nursing and social care (Allotey et al, 2003). In contrast, a similar injury that results in comparable reduction in physiological function in a high income country would lead to a different experience where social support and social protection, access to technology, high quality physiotherapy and rehabilitation and a disability friendly environment result in better health outcomes (Allotey et al, 2003). Participation in the Paralympics provides a stark indication of the inequalities in disability support across countries (Le Clair, 2012).

Continuing progress in addressing disability, however, should not be understood in purely biomedical terms. In addition to efforts to prevent disabling injury and morbidity, and to find and implement the means for restoring function, there remains a strong and complex social component. People living with disability should be able to expect extensive accommodations in their physical and cultural environment and access to technological aids that reduce or even eliminate the associated personal burden. These range from motorized wheel chairs and alternative means of communication to building designs, education of the non-disabled public to overcome prejudice and misunderstanding, and efforts to minimize social isolation. The goal of

supporting and enhancing the autonomy of those living with disabilities includes assistance in self-care, and support for affected communities and associations (Lancet, 2016).

With increasing life expectancy, there is a growing need to identify and provide support for ageing and chronic disease related poor health. In lower income countries, extended families are socially expected to provide that support. However with the dynamism of globalization and urbanization there are growing numbers of the elderly living alone (Wan Ibrahim et al, 2012).

3.5 Conclusion

The prospect of longer life spans will be attractive only if the added years are not seriously compromised by diminished health, disability, and chronic illness. The "squaring of the morbidity curve" (see section 2) remains a theoretical ideal whose prospects remain uncertain.

Disability has both biomedical and social components. What makes a condition disabling for an individual may depend on the physical environment and on social attitudes as much as, or even more than, compromised function. Support and respect for those living with disabilities requires affirmative efforts of accommodation, assistance, toleration, and respect for perspectives and priorities of "differently abled" communities.

4. Reproduction

Reproduction includes the biological processes and management of sexual practice, pregnancy, menstruation, abortion, birth, the treatment of infertility, reproductive technologies, birth control, adoption, conception, miscarriage, sterilization and menopause. The study of reproduction also includes the collection of vital statistics, the analysis of demographic trends,

population management, the codification of the categories of maternal and infant mortality, the management of family formation, parenthood (both same-sex and heterosexual) and child-rearing (see Box 18.7). More than in any other area of global health, reproduction engenders strong views that are based on demography, politics, social values, ideology, religion and morality. The extent to which people can enjoy their sexual and reproductive health is invariably intertwined with issues of disadvantage, inequity and rights violations: encompassing gender based violence; stigmatization on the basis of sexuality; and structural and system-wide barriers to accessing quality care. Who has sex, how and when they have it, whether, when and how often they reproduce, or have access to information and care for their sexual and reproductive health is in large part determined by, gender roles and power, societies, laws, politicians and increasingly, global funders (Allotey et al. 2011).

Box 18.7 State Power and Reproduction: Birth Registration in Malaysia

The demonstration of a state's power over reproduction is manifest in various ways.

Registration of births in Malaysia is mandatory in order for the child to gain access to services as a citizen. However this registration process is also used as a means to penalize individuals through a range of religion/societal imposed sanctions. The National Registration Department in Malaysia requires the presentation of the *surat nikah* (marriage certificate) in order to register the birth of a child. Children of unmarried couples are not allowed to have their fathers registered on their birth certificates. If the birth occurs less than 9 months after the date of the marriage, the child is considered conceived out of wedlock and is not allowed to have the name of the father recorded on the birth certificate, denying the child any corresponding future patrilineal rights.

Source: https://www.crin.org/en/library/news-archive/malaysia-birth-registration-

Given this chapter's focus on how inequality shapes the changing contours of human life, we deploy "stratified reproduction", a concept coined by the anthropologist Shellee Colen to

describe “the power relations by whom some categories of people are empowered to nurture and reproduce while others are disempowered”(Colen 1995,cited in Ginsburg and Rapp 1995, pg 3). The lens of reproductive stratification demonstrates how resources and class position shape reproductive phenomena. The concept can be used in analyzing the difference in reproductive horizons of West Indian nannies and the affluent families in New York City who they work for, how IMF mandated austerity measures and structural adjustment in the developing world have exacerbated differences in global rates of maternal mortality, and in how reproductive processes align with a distinction between communities that need “productive children” who contribute to household economies and communities that cultivate “priceless” children the joys of whose company are consumed for by their parents (Zelizer 1994). .

We also see stratification in forms of access to maternal health services and the quality of care received. Julio Frenk, former Minister of Health in Mexico, remarked in opening statements at the 2007 Women Deliver conference in London that maternal and child health are the best entry points to improve health-care system, and crucial to maternal and child health is the quality of birth attendance. Birth attendance is a frequently contested issue. With the exception of sub-Saharan Africa, rates of births assisted by a medically trained attendant have shown impressive increases over the past 15–20 years and today data indicate that 59% of LMIC births are assisted by a medically trained professional. The large majority of these births occur in a health facility.

4.1 Measuring reproduction

Understanding the measurement of reproduction is critical to the domains across which inequities can be assessed. Demography plays a key role where reproduction is discussed primarily in the context of its importance to ‘reproduction’ of the population and to the control of

the size of the population. From a gender and rights perspective, disaggregation of the data is critical to understanding who is reproducing, at what age, and how often. This also provides some measure of fertility control and choice, as a proxy indicator of inequities. In Box 18.8 we present notes on measuring reproduction. Demographers measure reproduction by a set of indicators which vary considerably in their meaning; the interpretation of time trends or differentials in reproduction require careful attention to these precise meanings (Lutz, 2013).

Box 18.8. Notes on measuring reproduction

Birth statistics usually start from the absolute counts of births that are registered in a given territory over a certain period, typically a calendar year. In countries that do not have complete vital registration systems this information is often estimated with surveys. To calculate the Crude Birth Rate (often called only the Birth rate), this absolute birth count is related to the mid-year resident population in the territory under consideration. The crude birth rate can be used to compare birth intensities of different populations across time and space, but does not consider the influence of age structure.

More sophisticated measures of reproduction differentiate birth by the age of mothers at the time of birth. The use of age-standardized fertility rates has become the norm for comparative analyses in reproduction. There are three dominant indicators : (1) Total Fertility Rate (TFR) is the sum of age-specific fertility rates (all children born to women of a certain age group divided by the number of women in this age group); (2) Gross Reproduction Rate (GRR) only considers female babies and thus gives the average number of daughters born to women over their lives; (3) Net Reproduction Rate (NRR) considers the survival of the child from birth to the mean age of childbearing and thus gives the extent to which one generation of mothers is replaced by

another one. A NRR of 1.0 means that the following generation of women reaching reproductive age will be exactly the same as the previous one; a NRR of 2.0 means that the population doubles each generation.

Another important distinction in the measurement of reproduction is that between a period and a cohort perspective. While period rates summarize the reproductive experience of different age groups of women in one period (typically a calendar year) cohort rates describe the experience of birth cohorts of women. During times of changes in reproductive behavior, such as postponement of childbearing (measured through an increase in the mean age of childbearing), the two kinds of rates can show very different pictures. Period TFRs can be artificially depressed (tempo effect).

Recently, methods have been developed to estimate tempo-adjusted period TFRs that can be interpreted as the "period quantum" of fertility or the mean number of children per woman as implied by reproductive behavior in recent periods. A naïve interpretation of the period TFRs as the mean number of children can lead to misleading conclusions.

4.2 Determinants of reproduction

The literature on the determinants of fertility distinguishes between proximate determinants and underlying determinants. The proximate determinants are the factors that are immediately causing pregnancy and birth in a biological sense. These determinants include the age of beginning of sexual activity and the frequency of intercourse, the prevalence and effectiveness of contraception, the prevalence of induced abortion (plus spontaneous intra-uterine mortality) and the duration of post-partum infecundity. Any change in observed fertility

levels occurs through changes in one or more of these proximate determinants which explain the mechanisms but not why women and couples are changing their behaviors.

When discussing the underlying social, economic and political determinants of fertility it is useful to distinguish between the secular decline in fertility levels which is part of the demographic transition from pre-modern high to modern low levels and the variations within low fertility societies. The global fertility transition began in France in the 19th century and by the beginning of the 20th century had started in most industrialized societies. It then spread globally during the second half of the last century. Except for a few pockets of still very high traditional fertility levels in Africa this secular fertility transition has been completed or is under way in virtually all parts of the world. The global TFR has declined from 5.0 in 1960-65 to 2.4 in 2010-15 (UNPD 2015). But even before the onset of the demographic transition, fertility levels varied among populations due to different marriage patterns and different lengths of post-partum infecundity, which are associated with different breast-feeding patterns. In Western Europe fertility levels in the 18th century were lower than in Eastern Europe and most of the rest of the world due to a distinct "European Marriage Pattern" (Hajnal 1965) which was characterized by a rather late age at marriage and high proportions of men and women remaining unmarried. On the other hand some traditional hunter and gatherer populations showed remarkably low fertility levels due to unusually long birth intervals that are associated with extended breast-feeding (Howell, 1979). But despite of these different levels of overall fertility, one finds no significant evidence of parity-specific fertility control in any of these traditional societies.

According to demographic transition theory, conscious family limitation has been a social innovation that was brought about by social and economic factors as well as cultural diffusion processes. While in traditional cultures there is evidence for some methods of avoiding

pregnancies as a consequence of non-marital sex, this seems to have been largely unthinkable within marriage. Based on an analysis of historical fertility transitions in Europe, Ansley Coale (1973) specified a set of three pre-conditions for a lasting fertility decline: (a) Fertility must be regarded as being within the realm of conscious choice. This factor seems to be closely associated with female basic education but cultural diffusion and mass media can also play a role. (b) There must be objective advantages to lower fertility. These can range from economic factors, to urbanization to health reasons. (c) Acceptable means of fertility control must be available. What is considered as acceptable is dependent on the specific cultural context, particularly with respect to abortion. In the context of the current fertility decline in low income countries, this factor also relates directly to the availability of modern reproductive health services.

How low fertility rates will fall in the later phases of demographic transition and what differentials within and between societies will prevail are topics of intense scientific discussions. Basten, Sobotka and Zeman (2014) provide the most comprehensive recent summary of fertility trends and differentials in low fertility countries as well as the different theories, approaches and arguments that can help to explain and forecast these differentials. Fuchs and Goujon (2014) provide a comparable assessment for countries whose fertility levels are still higher (with TFRs above 2.5). These assessments are based on the input of hundreds of internal population experts and cover all world regions. They discuss the drivers of fertility in four broad domains: (1) Reproductive Health: including availability of family planning, side effects of contraceptives, traditional methods, abortion, and religious attitudes to contraception,; (2) Economic costs and benefits: Child labor, cost of urban upbringing, old age security, and value of education; (3) Status of women: Arranged marriage, age at marriage, female educational status, autonomous

contraceptive choice, male support of contraception, and female labor force participation; (4) Cultural change: Ideal family size, son preference, politically promoted norms, attitude to childlessness, and educational differentials. For the case of low fertility countries there are much more detailed analyses regarding the nature of the partner relationship as well as different forms of combining employment and family care. Given this very broad range of relevant factors determining reproduction in different societies we can in the following sections discuss only highly selected aspects.

4.3 Population Growth, Fertility Control and reproduction governance

The development of the nation state produced a new focus on internal populations and vital statistics and the measurement of fertility. This focus codified sexuality and reproduction as processes that should be governed as a matter of great interest to the nation (Greenhalgh 2008; Morgan and Roberts, 2012). The development of the legal and medical management of reproduction sought to control reproductive behavior in both colonizing and colonized nations. Examples of these new regulatory forms included the late nineteenth century initiation of laws and morality campaigns directed towards making prostitution, abortion, and homosexuality illegal activities. Additionally, birth attendance (banning midwifery), fertility rates, infant feeding, and contraception were all newly regulated through legal, moral and medical means in the efforts to create strong working and fighting populations within nation states. Throughout the twentieth century and into the twenty-first, concerns about over and under population have been paramount in defining nations often through coercive means, such as eugenic programs or the inducement to reproduce.

With the exponential rise of world population new regulatory measures to curb population growth were instituted by nation states and international agencies, especially in LMICs. Fertility rates are highest in lower income countries in Africa and Asia. China and India now have the largest populations with the United States in third place. In LMICs, the management of reproduction during the Cold War and beyond took the form of internationally driven programs to limit and control specific populations. Deriving from early twentieth century nationalistic, eugenic policies, these programs sought to limit the population growth of developing nations to enrich their populations and make the world safe from communism. Conversely, wealthier nations in Western Europe and Japan have seen population decline often described as harbingers of national decline.

To combat this top down approach to population control, the Cairo International Conference on Population and Development in 1994 and the Fourth World Conference on Women in Beijing in 1995 developed programs of action through a human rights-based approach to reproductive health The approach advocated for individual rights, particularly women's rights over fertility choices, with the underlying assumption that given these forms of control, fertility would be curtailed. These efforts met with significant resistance, on religious and political grounds (Berer 2011). Countries like the United States placed limits on aid funding based on reproductive policies The Catholic Church also had significant influence over how reproductive rights played out in several countries. Despite these obstacles, international discussions of reproduction since Cairo have tended to be framed in terms of individual rights. Other countries developed controversial population level strategies to limit fertility, such as the one child policy in China and forced sterilizations in parts of the Americas.

30 years later, birth rates have dropped dramatically. However, the rights-based approach to reproduction also remains controversial. In emphasizing rights, this approach has made it natural to conceptualize some of the issues as a competition between the 'right-to-life' of the unborn and the 'reproductive rights' of women. Control of women's fertility has been exercised on other coercive forms in conflict situations through the use of 'breeding programs' (Hoile et al. 2002; Allotey and Reidpath 2015) and pressure, including through incentives, towards redistribution of resources across ethnic groups (Asiaweek, 1993)[9].

We can see the stratification at work in terms of the selective focus on population as over or under population. For instance much of the global anxiety about overpopulation is directed towards sub-Saharan Africa, which is also the site of the world's largest infertility belt due to the iatrogenic effects of poor health care infrastructure. Little attention is paid to this form of subfertility in aid programs.

4.4 Abortion and contraception

The control of fertility and birth through contraception and abortion has been the most controversial aspects of reproductive policy. One explanation is that these issues place women in control of the shape of their lives and sexuality, challenging traditional female roles. Sterilization is also controversial, in part for the same reason, but also because of the history of forced sterilization among devalued groups within many nation states. Modern contraceptive methods became widely available in the early part of twentieth century and have been partially responsible in lowering fertility rates worldwide. The use of contraception and abortion are

[9] Similar strategies are deployed in Singapore, Japan and Italy – although most tend to give some one time small incentives rather than make affordable child care more widely available so women can work.

highly stratified. Even where certain means of fertility control such as abortion are illegal, women with more resources have access. Women have access to contraception in most high income countries and in many LMICs that were considered overpopulated.

More coercive population control can be found in China, in its one child policy, in India that lowers fertility rates though giving ration cards in return for sterilization and in Tibet, Haiti, and Peru – often with groups considered unworthy of reproducing (Adams and Pigg 2005). Accepting the eugenic logic of the earlier twentieth century, governments have sought to limit the reproduction of minority groups, low castes, and indigenous communities. While development experts have understood lowered fertility rates to be key to economic development, many subaltern groups have framed population reduction policies and programs as forms of genocide (Ginsburg and Rapp 1995).

Abortion only became became illegal beginning in the late nineteenth century on, when states came to see robust and large populations as key to building strong nations. Illegality was framed around morality and the perceived risk of the procedure. The anthropological literature on personhood reveals North American debates about when life begins as local and specific. In different non-western contexts, personhood can commence at various times, often post birth; and the concept of individual life is not relevant to how children are made at all (Conklin and Morgan 1996; Kaufman and Morgan 2005). Even within the Catholic Church, currently one of the staunchest opponents of abortion, the definition of beginnings of life have changed over time (Noonan 1986).

The most recent estimates suggest 56 million abortions are performed each year, of which 88% occur in LMICs (Sedgh et al, 2016). Abortion conducted with trained practitioners and under sterile medical conditions can be safer than carrying a child to term. But in LMICs unsafe

abortions are common and almost 70,000 women die each year from complications due to unsafe abortion, a figure that constitutes 13% of maternal mortality rates. Illegality and censure do not prevent the practice of abortion. Despite the continued illegality of on-demand abortion in Latin America, except in Cuba and now Mexico City, the subcontinent now has some of the highest abortion rates in the world (Sedgh, et al. 2016). In Latin America women with means can access safe abortion, while women without means cannot.

Gender based mobilization for the right to abortion has been variable. In Latin America for instance, it has been hampered because unlike the right to vote – abortions illegality affects women differentially by class. Because clandestine abortion is easily available and relatively safe for women with means, there has been little impetus to work toward legalization (Htun 2003; See also Mooney 2009, 51). The current model for abortion decriminalization in developing countries makes the case for the right to public health, rather than the North American "right to choose" (Morgan and Roberts 2009, 2012).

Medical abortion (pharmaceutically induced) is changing the abortion landscape by providing women a safe and discrete means to abort outside of clinical settings. Reproductive stratification is also evident in access to medical abortion given that the ideal method involves a combination of mifepristone and misoprostol which achieves the highest efficacy with the fewest side effects. In many regions of the world, only mifepristone is available (Winikoff and Sheldon 2012).

4.5 Assisted reproductive technologies and selective reproductive technologies

The late twentieth century saw the rapid development of assisted reproductive technologies that facilitate fertility and selective reproductive technologies that facilitate and

prevent the births of children. As several social scientists and scholars of the social studies of science have argued, reproduction has always been assisted and children have always been selected through various kinds of social arrangements and practices, as well as familiar technologies of infant formula, paper work and forceps. The availability and reach of assistance and selection has, however, never been greater. This availability falls along stratified lines.

We can see stratification at work in the development and use of assisted reproductive technologies and selective reproductive technologies around the world. In the developed world, assisted reproductive technologies, such as in vitro fertilization, intracytoplasmic sperm injection (ICSI), egg donation and surrogate motherhood have produced anxieties about interference with nature. In LMICs assisted reproduction is now geared towards combating iatrogenic infertility – which perhaps involves ignoring larger structural causes for the high rates in these areas.

Rather than aiming to overcome infertility, selective reproductive technologies are used to determine which children are born. Two of the most common purposes are sex selection and preventing the birth of children with certain developmental conditions. In societies with extensive public pre-natal programs fewer and fewer children are born with conditions such as Down's syndrome. Disability rights advocates criticize this as an injustice, while defenders point to the difference between choosing not to bring someone with disabilities into existence and violating the rights of or showing disrespect to those who have disabilities (Gammeltoft and Wahlberg 2014).

In many LMICs the private use of selective technologies like amniocenteses and pre-implantation genetic diagnoses has resulted in a skewed sex ratio in favor of boys. This form of sex selection is partially explained by the fact that in the past, extended families have prospered through the propagation of boys. In fact in some places in sub-saharan Africa, women who only

have daughters are considered infertile because they have not produced what is necessary for family continuity (Inhorn and Balen 2002).

4.6 Developmental and Environmental Approaches to Reproduction

A developmental/environmental approach has started to shift the focus of reproductive policy, from an approach framed by genetic determinism, towards more general environmental factors. This environmental approach also allows social and biological scientists to shift the focus away from the individual reproductive body to larger global environmental conditions that shape reproduction in disparate and stratified ways. For example, declines in human male sperm production and the falling age of female menstruation worldwide have been linked to factors ranging from increased nutrition to synthetic chemical compounds like endocrine disruptors, BPA thaltes and antibiotics, and growth hormones (Steingraber, 2007).

One site where environment seems to be of particular importance is gestation. Epigenetic researchers examine environmentally triggered mechanisms (e.g. DNA methylation, histone modifications and DNA-binding proteins) that affect and regulate gene expression. Epigenetic researchers broadly define environment in terms of climate, stress and nutrition, emphasizing particular environmentally plastic reproductive moments such as embryogenesis, early gestation and the neonate period. Thus the bulk of epigenetic research focuses on the effects of the maternal body and maternal behavior on the "fetal programming" of offspring. Thus, as discussed in section 1, researchers have shown that children born to women stressed or starved during wartime have much higher levels of adulthood disease and lower educational attainment, characteristics that might be passed on to their children.

Epigenetics and studies of the social determinants of health have the potential to reshape social welfare policy towards more collective and distributed action, enlisting broader support for environmental regulation, public education and health care (CSDH, 2008). But within current neoliberal economic regimes in the United States and Western Europe, epigenetics researchers have focused on the implications of their findings for the behavior of pregnant women.

Similarly, governments and NGOs in LMICs find it more feasible to fund programs targeting pregnant women and infants than restructuring decayed public institutions such as schools and health care facilities. Pharmaceutical companies are attempting to produce drugs that will activate epigenetic mechanisms, including a drug that calms children who experienced "bad mothering" in the neonate period. Such a drug obviously does nothing to address the larger (and from the perspective of a pharmaceutical company, profitless) political and economic factors that produced "bad mothers" to begin with. The targets of these discussions and interventions are women of reproductive age who are made, yet again, to bear the bulk of responsibility for how their offspring fare. Epigenetics might reshape our understanding of socio-biological existences, or they might instead reinforce the policing of the behavior of pregnant women.

4.7 Conclusions

The historian of science Michelle Murphy argues that if we ask, "Where does biological reproduction reside?" the answer "the body" is simply not up to the task (Murphy 2011). Murphy advances a framework of "distributed reproduction" that allows us to examine "what counts as biological reproduction by tracking the dispersion of sexed living beings into their infrastructural and political economic milieu" (Murphy 2011, 22). The notion of the individual body is not up to the task, for instance, of understanding how only 35 boys are born for every 100 girls among the

First Nations Aamjiwnaang peoples in Eastern Canada, where, in the local waterways, the gonads and sex ratios of fish, fowl and reptiles have also been dramatically altered (Murphy 2013). To grasp the determinants of reproduction, Murphy argues that we need to move beyond individual bodies and sort through the specific tangles of diverse causal factors.

Murphy's insights are similar to a host of other scholars of reproduction, reviewed in this section, who caution against locating reproduction within individual women's bodies, and encourage a more expansive view of reproduction that examines reproductive phenomena as produced through larger structural factors such as inequality, gender roles, environmental health and family organization.

5. Enhancement: Better than well?

This section will explore the possible implications of human enhancement interventions, present and future, on the limits of health care and the fair distribution of medical resources. We shall suggest that many expectations and concerns regarding the biological transformation of humans by enhancement may be exaggerated. The important changes to the human condition that enhancement is likely to bring about will be social and cultural and mediated through the social effects, sometimes subtle, of the widespread adoption of such practices. Still, these changes will require regulation and rethinking of long-established principles in health policy.

5.1. What is enhancement?

Several practices that can be considered human enhancements are prevalent today. Examples are performance enhancing drugs in sports, off-label use of stimulants such as Ritalin

(methylphenidate), but also common products such as coffee. According to a standard definition among bioethicists, an intervention is an enhancement if and only if it improves a biological functioning beyond what restores or sustains health.[10] Such improvements can be physical (e.g, muscle strength), cognitive (e.g., attention span), and conative (e.g., mood). Enhancement is often contrasted with *treatment*, which is a biomedical intervention that restores or sustains health (Daniels 2000). The same medical procedure can sometimes be used both for treatment and for enhancement. For example, the drug Modafinil is used as a treatment for disorders such as narcolepsy and as such not considered an enhancement. However, it is also used by, e.g., the United States Air Force to enhance cognitive functioning in sleep deprived pilots during extended missions.[11]

We shall also distinguish between radical and non-radical enhancement. An intervention is a radical enhancement if and only if it improves a biological function such that it surpasses the current human range.[12] For example, a medical intervention that would extend a person's lifespan to 150 years would be a radical enhancement. By contrast, non-radical enhancement includes interventions that leave the improved abilities well within the human range. As most current and emerging human technologies belong to the latter group, our focus will be on non-radical enhancement (henceforth "enhancement").

What to count as an enhancement is not as straightforward as it might first seem, however. Firstly, according to the standard definition, human enhancement is distinct from interventions that impair or don't improve human biological functioning, such as tattoos,

[10] Cf., e.g., (Juengst and Moseley 2015). Our definition differs slightly from theirs. See also (Tännsjö 2009) for a different definition (more on this below).

[11] Air Force Special Operations Command Instruction 48–101 (sects. 1.7.4), U.S. Air Force Special Operations Command, November 30, 2012.

[12] Cf. (Tännsjö 2009) who distinguishes among "negative medical interventions (intended to cure disease), positive interventions (intended to improve, within the normal range, functioning) and enhancement (where a person is pushed beyond species normal functioning)". What Tännsjö calls "positive intervention" and "enhancement", we call "non-radical enhancement" and "radical enhancement" respectively.

piercing, genital cutting, cosmetic surgery, and other body modifications. We face here an interesting complication with the standard definition since some body modifications impair body functioning but confer a social advantage in some contexts. For example, skin bleaching harms the biological function of the skin (Olumide et al 2008; WHO, 2011). However, this practice would hardly be so popular if it didn't improve the social prospects of its practitioners. In several countries in Africa and Asia, lighter skin improves job prospects, wages and other social goods (Hunter 2007). Thus, how *improvement* should be characterized with regards to human enhancement is not straightforward and the distinction between health related and social improvements is sometimes difficult to maintain. This threatens to make the standard definition (where functioning does not include social functioning) too narrow.

Secondly, the standard definition depends crucially on what one means with "health". The meaning of this term varies across cultural and historical contexts, often depending on whether a condition is normal in the statistical sense.[13] For example, the diagnosis "idiopathic short stature" is defined as being of a height two standard deviations below the mean of a specific population (Rosenbloom 2009). This means that children of the same height can be diagnosed differently between countries with different average height. This in turn will determine, according to the standard definition, whether growth hormone therapy will be considered a treatment or an enhancement: For one child, it might just be treatment but for another child of the same height but in another country, it will be classified as an enhancement.

Moreover, claims about whether an intervention is an instance of enhancement or restores health may also be partly normative since health is commonly seen as a desirable good that ought to be promoted. If health is defined as the absence of disease, and associated with a "normal"

[13] Note that what is statistically normal is distinct from what is normal in the physiological sense, even though these states are often co-extensive. For example, statistical deviations from the norm in heart shape are often associated with abnormal heart function.

state, then interventions that restore human functioning to this normal state can be partly justified by virtue of promoting health. By contrast, if an intervention is defined as an enhancement, it will lack this justification. On this view, growth hormone therapy is, other thing being equal, more justified if it is a treatment rather than an enhancement. Thus, to state that an intervention is an instance of enhancement rather than a treatment may not merely be a descriptive claim but also a normative one.

Thirdly, whether an intervention is an enhancement also depends on what is perceived to be part of a person's abilities rather than something the person can do with help of technologies external to the person. Enhancement technologies are often seen as artefacts that are to a certain degree integrated with the body, for instance performance enhancing stimulants or implants. While rarely stated explicitly, this view is consistent with our folk-psychological notion of the boundaries of a human body. The account of enhancement technologies as necessarily attached or integrated with the body is complicated by the view of cognition as essentially embodied and extended (Menary 2010). On this view, cognitive processes are deeply embedded in artefacts and other objects in our environment. If a person's cognitive processes are regulated and (partially) executed by its environment, why should things such as calculators, maps, whiteboards, etc., not be considered enhancements? Arguably, some tools affect the human condition much more than some instances of bodily integrated enhancement. The view that a certain technology is an instance of enhancement only if it is inside the skin seems to be poorly justified.

These considerations show that what should be classified as an enhancement is not a straightforward matter and contested. This complicates the picture for those who ascribe special moral significance to the distinction between treatment and enhancement (e.g. Wasson 2011).

5.2. Enhancement and priority in health care

While most accept that human enhancement is in at least some instances permissible, there remains considerable controversy with regards to how such interventions should be prioritized when distributing limited health care resources. Modern medical practice and health care policy-making face an increasing number of conditions that could be addressed through medical interventions. A general principle that is often, implicitly or explicitly, used to guide deliberations in the face of this challenge is the principle that conditions that qualify as diseases (i.e. that impair health) yield a special normative claim to medical resources. Let's call this principle "Disease Priority". A strong version of this principle states that medical interventions that do not restore or sustain health are morally wrong.[14] A weaker version of Disease Priority states that all interventions that treat or prevent disease are to be prioritized before any other interventions. This weaker notion is part of standard approaches to prioritization in the health care system. For example, the National Board of Health and Welfare in Sweden explicitly states that medical services not associated with disease or harm have the lowest priority with respect to the distribution of medical resources (Larsson 2007).

According to Disease Priority, enhancement interventions, as we have characterised them above, would either be morally impermissible or in the lowest priority group. However, although Disease Priority may sound initially plausible, it conflicts with some instances of standard medical practice. Unwanted pregnancies, for instance, are generally considered to be a medical problem that ought to be addressed by the health care system, even though being pregnant or fertile is not a disease.

[14] Along this line, Sandel (2004) observes: "It is more plausible to view genetic engineering as the ultimate expression of our resolve to see ourselves astride the world, the masters of our nature. But that promise of mastery is flawed. It threatens to banish our appreciation of life as a gift, and to leave us with nothing to affirm or behold outside our own will".

An alternative and more pragmatic approach to the distribution of health care resources would avoid a strict reliance on the enhancement/treatment distinction but would instead base decisions about extending medical interventions to new areas on considerations such as cost-effectiveness and fairness. For example, it may now (or in the near future) be possible to partly address some social problems with modern medicine. According to a new study in the *New England Journal of Medicine*, the medication of prison inmates diagnosed with ADHD with the stimulant methylphenidate seems to lead to a reduction in reoffending (Lichtenstein et al. 2012). The same medication seems to improve math and reading skills among students with ADHD, according to a study in the *Journal of Pediatrics* (Scheffler et al. 2009). Though debate continues over whether ADHD is a genuine disease (Greenberg 2010), the pragmatic approach suggested here would not base a decision on the use of this drug for these students on the outcome of this debate. It would instead shift the focus to whether the symptoms typically associated with ADHD can be effectively addressed with medical interventions at a reasonable cost, and whether it would be desirable to do so. This approach could guide decisions on using medical interventions to ameliorate social problems in a wide variety of contexts, whether or not the results should properly be regarded as treatments of a disease or enhancements. What matters is the safety, fairness, cost and direct and indirect effects of the intervention.

5.3. The Limits of Human Enhancement

In general, existing enhancement interventions have limited medical benefits compared with many medical treatments. As we discussed above, sometimes enhancements are biologically harmful or neutral but may provide a social benefit. The pragmatic outlook proposed here suggests that not only medical benefits are worth taking into consideration when assessing

the relative importance of a specific intervention but also other benefits. For example, contraceptives have in most cases little or no medical net benefit but have quite substantial social benefits, such as reproductive autonomy and increased female workplace participation. Some of the effects of such interventions may not be very noticeable at the individual level at the same time as the group effect is significant, and this should also be taken into account. For example, we may hypothesize that if a large fraction of children would receive medication for certain behavioural traits, and this intervention was effective, then we should expect this to have significant consequences for youth culture and social norms. Bostrom and Roache have suggested that macroeconomic gains from increased cognitive function due to the removal of lead in gasoline have been considerable (Bostrom & Roache 2009). Similar gains could be the result of the proliferation of cognition-enhancing drugs, even when the effects of such drugs would be practically imperceptible at the individual level.

With respect to existing enhancement options, however, restoring human functions that have been impaired by disease is typically more effective than improving the functions of a healthy body. For example, fortifying food with essential micronutrients such as iodine to address iodine deficiency (not an enhancement, as defined here) is a much more effective way to improve intelligence (in those with said deficiency) than any existing cognitive enhancer. This does not imply, of course, that existing human enhancements have little or no effect, as is illustrated by the effects of anabolic steroids (and in elite sports, even small improvements can be decisive in determining who wins).

The apparent difficulty of enhancement interventions to radically enhance (in contrast to just enhance, see the definitions above) biological functions is in many cases explained by the fact that human bodies are complex systems where different subsystems coexist in an

equilibrium such that improving one function over a certain baseline often reduces some other functions. For example, while caffeine improves some cognitive functions, such as alertness and wakefulness, it has a detrimental effect on other functions, such as emotional stability (Vilarim et al 2011). Hence, unless an individual is prepared to accept considerable medical risks, radical enhancement is rarely possible, as illustrated by the many side-effects that athletes using performance-enhancing drugs have suffered. This may suggest that Disease Priority could still be used as a rule of thumb to assess the medical effectiveness of an intervention where enhancement and treatment compete for the same resources, although it is not an appropriate general principle for prioritizing between interventions.

In the discussion of how to allocate medical resources, it is useful to make a distinction between enhancements that confer a positional advantage and those that confer a non-positional advantage. For instance, the enhancement of executive functions (self-control, planning, concentration) is better for the enhanced individual because such functions are very helpful in avoiding costly mistakes. The same enhancement may also confer a positional advantage in that the person may benefit from being better off relative to others with respect to these abilities, but it would still be good for the individual even without such a positional advantage. Other enhancements, such as doping in elite sports and cosmetic surgery, typically confer only or mainly a positional advantage. Such enhancements are beneficial to the individual only if they improve a specific function in comparison to other people. Were everyone to use the same performance-enhancing drug in a contest, then it is possible that no one would be positionally better off as a result of taking the drug, and considering the side-effects, all would probably be worse off with respect to their well-being.

While individuals most often cannot be expected to adapt their behaviour in such problematic collective action situations, policy-makers should consider these problems when making decisions with regards to the allocation of medical resources. This is a typical collective action problem, where each individual stands to be better off by performing a certain act no matter what the others do, yet when everyone performs this act, each individual is worse off than she would have been had everyone not performed the act. Collective action problems of this kind are most often best solved by the intervention of an external actor (a regulatory body such as WADA, for example) which can impose costs, such as fines or banning athletes from future competitions, for such actions and thereby aligning the individual and the collective interest.

5.4. Enhancement and global inequality

The world's resources are dramatically unequally distributed, and this inequality has significant effects on human health, well-being and life prospects. Lack of access to clean water, vaccines and other crucial resources not only kill, they also stunt physical and cognitive development. For people that live under these conditions, non-enhancement interventions are likely to play a much larger role in improving their lives. Granting equal access to nutritious food, clean water, education, and other basic goods is both cheaper and more likely to have a greater positive impact than any enhancement technology.

Yet when it comes to biological functioning, humans are to a large extent born roughly equal when their most basic needs have been met. Some opponents of human enhancement fear that enhancement might change this. The worrying prospect is that human enhancement would create a cognitive elite who not only has superior material resources to perpetuate inequality but that also is genetically or otherwise biologically superior to the poor (Fukuyama 2002; Habermas

2003). While this scenario is indeed worrisome, it may be less plausible than is typically assumed.

Firstly, just as non-enhancement interventions that improve cognitive ability usually have declining marginal impact, so do known enhancements (Ileva et al 2015). In other words, enhancement interventions typically improve function most in individuals whose functions are on the lower end of what can be expected from healthy individuals. For example, methylphenidate, discussed above, seems to have a limited effect on "normal" people and the effect seems to be roughly proportional to the deficiency in attention and other related functions (Agay et al. 2014).

Genetic selection for increased cognitive ability is also likely to have a similar declining marginal impact. The number of genes associated with intelligence is large, and since each gene that can improve an average person's intelligence has only a very small effect, selecting for very intelligent offspring is rarely feasible (Bostrom & Shulman 2014). Yet, a few mutations are known to cause mental impairment and these have a comparatively large effect and could feasibly be selected against. Selecting against such mutations could not only be used to avoid cognitive impairment, but also to enhance intelligence among individuals with normal but below average intelligence. As such mutations are likely to be relatively rare among more intelligent individuals, this suggests that to the extent that social inequality is a result of a cognitive difference, enhancement could be a useful tool to reduce social inequality.

Secondly, detractors of enhancement typically assume that such interventions will be expensive. This largely depends on what kind of intervention one considers, however. A drug that improves cognition in the general population would have a very large pool of potential consumers, and could therefore be quite cheap (setting aside market failures such as

monopolies). If such drugs are effective and positive externalities are considerable, as suggested by Bostrom and Roache, it would be an appealing option for policy makers to subsidize them. Some other potential interventions are likely to be more expensive. On the other hand, transcranial direct current stimulation, a technique which might enhance learning, would be more expensive to administer on a large scale (Kadosh et al. 2012).

The prospect of enhancement reinforcing prevailing inequalities, while speculative, still raises concerns regarding unequal access to enhancement. For enhancement interventions that yield a considerable advantage, it is desirable that policy-makers ensure that access to such interventions is universal or at least that the use is regulated. The current situation in some countries in which off-label use of cognitive stimulants is widespread in academia might very well favour elites with easy access to medical technology and give them even further positional advantage (Arria et al. 2008). Yet, reforms to address these trends might be difficult to implement in an era where social and economic elites exert disproportionate political influence on government priorities (see, e.g., (Gilens 2014)). Moreover, as discussed above, it is important to consider the possible beneficial social effects on groups and population from enhancement, not the least from a global perspective. If some countries gain access to such enhancements before others, we might see increased inequalities between countries.

5.5 Conclusions

This section has discussed some important considerations regarding human enhancement for policy-makers with a focus on issues that we a likely to face in the close future rather than science-fiction inspired speculations of future radical enhancements. We have suggested that many expectations and concerns regarding enhancement may be exaggerated. The important

changes that enhancement is likely to bring about will be social and cultural and mediated through the social effects of the widespread adoption of such practices. Still, these changes raise some worrisome issues regarding inequality and collective action problems which will require regulation and rethinking of long-established principles in health policy. We pointed out a number of problems with the distinction between enhancement and treatment for policies regarding the distribution of health care resources. Instead, we suggested a pragmatic approach to the effect that decisions about extending medical interventions to new areas should be based on considerations of cost-effectiveness and fairness.

6. Death and dying

Death is the one certainty awaiting every human being. None of us can expect to avoid this calamity, but if we are fortunate death will come late in life and will be preceded by a minimum of suffering and indignity. The gains in longevity enjoyed in much of the world in recent decades, surveyed in sections 1 and 2 of this chapter, fulfill the first of these hopes for many; and palliative care at the end of life helps an increasing number to achieve the second. Extending these gains to all is a goal that heads the health agenda for the present century.

What constitutes a "good" death is understood differently by different peoples. In the Netherlands, what matters may be the manner of dying: "at home, without violence or pain, with the dying person being at peace with his (sic) environment and having at least some control over events" (Seale & Van der Geest 2004: 885). In Ghana, a good death is attained through "a well-organized and well-attended (public) funeral"-resources are expended in order to celebrate the life, maintain ongoing relationships and facilitate the passage to what lies beyond this life. Some

of these seemingly culture-bound variations may reflect underlying socioeconomic deprivation (see Box 18.9).

We focus on four key themes relating to the complexity of death and dying in the global context: (1) Dying unequally; (2) Palliative care; (3) Assisted dying; and (4) Changing conceptions of death.

Box 18.9. Cultural representations of death and dying

During the 2014/2015 Ebola outbreak mainstream press accounts focused on how African religious beliefs and customs, like touching the dead in order to become ancestors, or the female sharing of veils in Christian congregations served to spread Ebola in Liberia and Sierra Leone (Grundy 2014; Mark 2014). This narrative about cultural attitudes towards death obscured the fact that years of structural adjustment policies had stripped the region of the health infrastructural supports needed to establish and follow quarantine protocols and emergency public health services (Nyarko et al, 2015; Robinson and Pfeiffer 2015). According to politicians, doctors and clergy in Egypt in the early 2000's, low rates of organ donation were due to Egyptian's culturally backward, religious beliefs about death and the afterlife. Rates of organ donation picked up, though, through and after the Arab Spring stemming from a realigned relationship of trust between subjects and the state, after years of corruption and poor medical care. Low organ donation rates had little to do with cultural beliefs about death (Hamdy 2016). Death and dying as well as bio-medicine can be analyzed then, as phenomena shaped through history and political economic realities that often produce inequality (Lock and Gordon 1988; Singer and Baer 1995)

6.1 Dying unequally

The last century saw huge transformations in what people die of and how they die. In developed nations, people are living longer lives, with few mortalities resulting from communicable or infectious diseases (see section 2). With longevity, comes chronic conditions and complex diseases of aging that are costly to manage, e.g., more people living with heart disease, rather than dying of a heart attack. These transformations in cause of death will radically reshape how people die, where, with whom, and under what emotional and physical circumstances. Key to this transformation is the fact that in poor nations, non-communicable

causes of death are usually multi-factorial, stemming from multi-level, multi-faceted largely structural causes including poverty, lack of access to healthcare, weak health systems and policy (Bukhman et al, 2015; de-Graft Aikins and Agyemang, 2016).

The result of inequality is that too often, death and dying in poor nations does not approach the global health ideal of a "good death, ." with its connotations of a peaceful end at home in bed, perhaps surrounded by loved ones – an ending unobtainable when life ends as a result of violence, suicide, death from natural disaster and what we call "death by modernity".

6.1.1 Violent Death

While violent death does not make it on the top ten list of cause of death world wide it tends to be considered one of worst ways to die, and the most traumatizing for the bereaved. Violent death occurs disproportionally within poor and marginalized groups around the world and in countries experiencing complex humanitarian emergencies. Nations in Central America and South America – including El Salvador, Brazil, Venezuela, Honduras and Guatemala - have the highest country-wide rates of violent death in the world (Gagne 2017). In the United States homicide is the highest cause of death among black men 15-44, and African Americans are almost eight times as likely as white ones to be homicide victims; firearm injuries constitute the third leading cause of death and the second leading cause of injury-related death among US children aged 1-17 (Fowler et al, 2017). Boys, minorities and older children are disproportionately affected. In complex humanitarian emergencies in countries like Syria, violent deaths occur among internally displaced people and refugees (Heudtlass et al, 2016).

6.1.2 Suicide

Suicide rates have increased worldwide by 60 percent over the last 45 years, making it now the 15th leading cause of death. Among 15-29 year olds suicide is now the highest cause of death (WHO, 2014). Guyana has the highest rates of suicide, with 44.4 deaths per thousand with South Korea at second place with 28.9 per thousand. Eight Eastern European nations are represented in the top 25. lf we look at groups within nations however, the highest suicide rates in the world exist among first nations peoples in the Americas, where loss of life ways, and inter-generational continuity, poverty and violence and dispersed settlement patterns, contribute to high rates of suicide. In Nunavut, the mostly Inuit province of Canada, suicide is the cause of 27% of all deaths.

State and NGO interventions have been implemented at population, sub-population and individual levels to prevent suicide and suicide attempts among these groups. Much of this attention is medicalizing, geared toward improving mental health within individuals instead of focusing on larger structural issues that shape the, often, bleak collective life conditions for communities most affected by suicide (Stevenson 2014). The complex cultural representations of suicide are also ignored. While suicide can seem puzzling and pointless or even immoral from a modern global health perspective, it has been used and still is used to communicate sacrifice, honor or political resistance within collective life, which can then be celebrated and admired, especially when death is not experienced as completely disconnecting the dead from the living (Asad 2007; Staples and Widger 2012). A critical question for global health then is what suicide prevention is meant to do; save individual lives or create more equitable conditions that make life worth living?

6.1.3 Disaster

The term “disaster” connotes randomness, but social science research on tsunamis, earthquakes, floods, hurricanes heat waves, droughts and famines has amply demonstrated that human action, social organization and stratification determine whether a random natural event will produce a human disaster; likewise, they determine who is most likely to be harmed or killed. 56% of disasters happen in high income countries, while these same countries only experience 32% of the lives lost related to disaster, while low income nations experience 44% of the disasters but experienced 68% of the deaths from disaster (CRED, 2015). The psychic toll can be long term for disasters survivors when whole communities and life ways are obliterated in short order.

Heat waves are a representative example. With the increase in elderly people living alone, the degradation of shared urban space, and increased temperatures from global warming in the late 20th and early twenty first century, there has been a massive upswing in the rate of heat related death among the elderly. In 2003 over 11,000 people died in France during a heat wave, most of them elderly and low income and in Chicago in 1995 over 800 people died, mostly elderly poor residents living alone in dangerous urban neighborhoods, who could not afford air conditioning. They had no place to go for heat relief (Klinenberg 2002).

6.2 Quality of Death- Palliative Care and Hospice

“Quality of life” indices have paved the way for discussions around “quality of death”, which is measured in terms of access to palliative and hospice care. Palliative care is now considered part of the right to health, defined by WHO as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness,

through the prevention and relief of suffering ” (WHO 2017). Essential medicines for palliative care were included in the 18th WHO Essential Medicines List in 2013, and in May, 2014, the World Health Assembly (WHA) passed a landmark resolution urging member states to support access to essential medicines, and to strengthen palliative care as an integrated component of universal health coverage throughout the life course, stating that palliative care is an ethical responsibility of health systems (WHA, 2014).

Access to palliative care, however, is unequally distributed. It has been largely absent from the global health dialogue and consequently a low priority for donor investment (Powell et al, 2015). Hospice and palliative care is either non-existent or in its infancy in many parts of the world where an estimated 5bn people have insufficient or no access to medications to control severe or moderate pain (WHO 2017). Meanwhile, in high income countries, medical services have all too often focused on preventing death rather than helping people meet death without suffering pain, discomfort and stress (EIU, 2010).

A key assumption underlying “quality of death” is that cause of death will be a single, non-communicable disease, like cancer or heart disease hopefully at the end of life that can be palliated through the care of symptoms. Death from a single non-communicable disease occurs more frequently in high-income nations, where resources exist for both early disease diagnosis and the end of life palliation of pain. The situation is different for LMICs, where deaths arise from a burden of intertwined infectious and chronic non-communicable disease and a higher prevalence of co-morbidities and multi-morbidities. HIV/AIDS, diabetes, and neurodegenerative diseases present an enormous need for palliative care in low-income countries and populations, and cancer is a growing cause of death in low-income countries (de-Graft Aikins and Agyemang, 2016). In low-income countries, late diagnosis and lack of resources for palliative care make

death by non-communicable disease in these nations a traumatic experience for the dying and their families (Livingston 2012). Furthermore, pain control is essential but largely unavailable in low-income countries even in cases of severe injury, acute infections, and epidemics (eg, Ebola) and the fallout of natural disasters. Despite this widespread need, only 20 nations in total (8·5%) have integrated palliative care adequately into their health-care system (EIU, 2010).

Most studies associate palliative care with less health spending. Palliative care is perceived to reduce costs associated with hospital stays and emergency admissions, because the proportion of community and homecare is increased.

The costs associated with non-cancer palliative care are higher than for cancer-related care. And as the population ages, more end- of-life care will be needed overall. While the utilization of both hospital-based and in-home hospice and palliative care services significantly reduced the cost of care, while providing equal if not better quality care, studies to date are primarily from high income countries. Additionally, any measurement of the true cost of palliative care would need to take into account that most of the innovative palliative care programs in low income nations are resourced in through a patchwork of NGOs and volunteering groups, obscuring much of the labour costs involved in providing this kind of care, and making expenditures hard to measure..

The hospice movement, which advocates for end of life care at home or a home like setting, was developed in the UK. The UK now ranks first among nations in Quality of End-of-Life Care sub-category, based on indicators such as public awareness, training availability, access to pain killers and doctor- patient transparency. The failure of many wealthy nations to achieve similar results has been attributed to poor resource allocation and policy coordination, and a focus on hospital medical-care programs and reliance on oncologists and other medical

specialists rather than hospices (EIU 2010). In the US, for example, , hospice care is available, but it is only covered by health insurance if the patient is declared terminal. This narrows the scope of who it can serve and discourages its use. In the context of the US health system's focus on intensive care and heroic measures (Kaufman 2005), moving to hospice care can seem like "giving up".

Though this fear of "giving up" might appear to be a as a cultural belief that could be alleviated through the right education, it is better explained by the pattern of rewards and incentives. Medical providers are paid for procedures rather than outcomes, while hospices are paid on a daily basis, usually regardless of length of care. As more and more people spend longer living with chronic illness, the challenge will be to come up with payment models that allow for hospice care at an earlier stage, which could reduce the inevitability of heroic measures, and the unwarranted assumption that hospice represents not a choice among alternatives but rather resignation when no alternatives remain. One barrier to palliative care around the world is unequal access to opioids for pain relief either through lack of resources or through strict narcotics control which contributes to acute suffering in the dying (Stonington 2015). In India, one of the largest producers of opium and morphine, access by the poor to end of life pain relief is minimal because of complicated regulations put in place by the British in the 19th century to control their opiate supply for export (Jacob and Mathew 2017). Kerala, a state with a long history of community organizing and high literacy rates, has bucked this trend through the development of comprehensive palliative care centers where pain relief is available, and a network of volunteer health aids who provide home health care. Recently this program has inspired some change in opioid regulation at the national level (EIU 2010).

Another pharmaceutical trend in palliative care in many high income nations is that

increasingly the dying are medicated for anxiety as well as pain, in order to make the experience less stressful for the family who are not accustomed to seeing the agitation that imminent death can bring among the dying.

Palliative care is also shaped by disclosure practices, which vary widely. In much of the world it is common practice for family to keep information about negative prognosis from the dying because this knowledge will dampen their health and spirit (Gordon and Paci 1997). Nondisclosure can seem problematically paternalistic and highly antithetical to notions of autonomy and consent so valued in many high-income nations. However, if we understood nondisclosure as part of the ecology of family care necessary in many low-income nations we can see how this ethic serves to maintain the emotional well being of families. In some cases palliative care has in fact been structured around non-disclosure. For instance, in Thailand hospice care is provided without the explicit disclosure of imminent death to the patient (Stonington 2013).

6.3 Assisted dying

While death is governed less than reproduction, euthanasia (pharmaceutical death administered by physicians) and assisted suicide (pharmaceutical death carried out by and within the family of the dying) provoke reaction, controversy and legal regulation, even though they affect only a tiny proportion of the terminally ill, and account for only a tiny fraction of all suicides. Nonetheless, pressure brought on policymakers over these issues can be a catalyst for the improvement of palliative care services—as in Australia, where the federal overturning of a Northern Territory euthanasia law in 1996 may have had the effect of increasing national funding for end-of-life (EIU 2010).

There is some momentum globally to legalize and regulate both euthanasia, and assisted suicide under the umbrella term assisted dying, although in some locales where assisted dying has been legal, such as Switzerland, stricter controls are under consideration (EIU 2010). At this time however there are only eight nations where forms of assisted dying are permitted: Columbia, Switzerland, Canada, Albania, The Netherlands, Belgium, Luxembourg, and in the US, where in some cases state laws, rather than federal laws, permit these practices.

The premise of these laws is that for some individuals, a *chosen* death – i.e., a death that occurs at a time and in a manner under the control of the individual – is closer to a "good death" than that which would otherwise occur. For example, the individual might prefer to avoid prolonged decline in an unfamiliar hospital setting. Where patients fear becoming dependent on machines whose use is determined largely through the impersonal imperatives of hospital organization within a nexus of ventilators, insurance reimbursement codes, state legislation, and pain relief (Kaufman 2005) – as is the case too often in the United States – "patients' rights" are asserted not in the sense of entitlement to treatment, but rather of liberty to decline it (Roberts 2009). In less resourced contexts, there tend to be fewer concerns about the artificiality of these technologies, with more focus on how these technologies can strengthen family relationships through intensive care for the dying (Stonington 2013). [15]

6.4 Changing conceptions of death

Beginning in the 1960s, legislation in some Western countries broadened the legal

[15] This is not the case however, in Northern Thailand where relatives insist on keeping their dying relatives hooked to machines to pay off their "debt of life" and at the last possible second bring them home, where they can die surrounded by loved ones and their possessions. In these cases, machines like mechanical ventilators are not experienced as new problematic impositions but as a means to expend resources to pay off family debts (Stonington 2013).

definition of death so that it applied to certain comatose patients who, thanks to mechanical ventilators and other intensive care, continued to breathe, circulate blood, and even continue gestation. Whether this constituted an historic change in our conception of death remains a matter of debate. For some, the acceptance of the new definition by some countries is evidence that death has become less a sharp boundary of the end of life than an ill-defined nether region presided over by those who control machines according to their own purposes (such as maintaining organs slated for eventual transplantation). In an alternative perspective, the change in the legal definition of death signaled no new understanding of what death is, but was rather a stratagem to ensure that those who removed vital organs for transplantation (with the permission of the patient or next-of-kin) would not be held legally responsible for the patient's death (Wikler 1993).

The most radical reconception of human death would be its abolition; indeed, the hope for immortality is both eternal and doomed. The closest approximation that might be achieved would be an open-ended lifespan. Though the percentage of the "oldest old" (age 85+) in the wealthiest countries has been increasing rapidly, hardly any human beings live past age 110. Scientific opinion is divided over whether there is an immutable upper limit, but funding for research seeking a route to indefinite life extension has been abundant, in part from donations by aging billionaires.

6.5 Conclusions

As with many of the "contours of human life" examined in this chapter, death and dying constitute an intimate and complex admixture of biomedical, social, cultural and personal elements that are in a dynamic process of change and transformation. As in other domains,

wealth and poverty – at personal, social and national levels - are factors determining not only when and from what cause death will occur but also the experience of dying. For the under-resourced there is a notable deficit in palliation. Abundance of resources, however, also has its drawbacks, in the form of over-reliance on institutional care and life-extending efforts that go past the point of diminishing returns. The advent of technologies that sustain life processes after permanent loss of consciousness, and are used to facilitate successful organ transplantation, creates new existential categories whose contours remain contested across cultural contexts.

Chapter Conclusion

The "contours of human life", include childhood and adolescence, reproduction, the experience of disability and chronic conditions, and death. These stages and aspects of life are universal. They will remain so, but scientific, social, and environmental changes are transforming their timing, texture, and patterns.

There is much to celebrate in the trends we have examined. Most populations are living longer. Child mortality has decreased enormously in recent decades, even in many of the poorest countries. Where overpopulation was only recently among humankind's greatest concerns, birth rates have fallen. Science offers the prospect of welcome enhancements in coming decades. For many, more extensive use of palliation has eased the agony of dying.

These advances, however, are not universally shared. Serious inequalities persist in longevity, morbidity and disability, control over reproduction and sexuality, and in care at the end of life, and some of these disparities are widening, and the availability of enhancements could exacerbate these injustices. Vigilant monitoring of these inequalities, combined with forceful engagement with their economic and social determinants, are needed to ensure that the

favorable trends in the contours of human life become each person's birthright.

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