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Public Health – ethical issues





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Sirpa Soini (Editor)

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Foreword

During the last decade, Public Health Ethics has started to emerge as own discipline.¹ Public Health Ethics has been defined as being “concerned with the ethical issues that arise from all aspects of public health theory and practise” (Dawson 2006, p. 64). Pandemics (SARS, Swine Flu) explain part of the need for such a discipline, but also rapidly expanding non-communicable diseases (NCDs) mostly due to unhealthy life-style choices also generate ethical debate around policies and responsibilities surrounding health. Further, increasing health inequalities raise concern.

Issues relating to health promotion and disease prevention in the population have not been on the agenda of traditional bioethics that has concentrated mostly on issues relating to modern biotechnology and its their applications. Autonomy has been the key concept, but which as a sole value does not fit very well to the public health approach. Also medical ethics is mostly interested in the doctor-patient relationship in the clinical setting.

Classic text from 1920 defines public health as:

“the science and art of preventing disease, prolonging life, and promoting physical health and efficiency through the organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organization of medical and nursing service for the early diagnosis and preventive treatment of the disease, and the development of social machinery which will ensure to every individual in the community a standard of living adequate for maintenance of health” (Winslow 1920, p. 30).

Contemporary public health discourse is interested in equity and justice in health. UNESCO introduced the principle of social responsibility and health in Article 14 of the Universal Declaration of Bioethics and Human

¹ For instance, WHO dedicated its Bulletin in August 2008 for ethics and public health. The same year the first volume of a peer-reviewed international journal “Public Health Ethics” was issued by Oxford Journals.

Rights in 2005 (UNESCO 2005). With this article, UNESCO extended the scope of bioethics by a social dimension. Indeed, many policy fields are relevant to public health; trade and economics, environment, agriculture, social politics, security, just to name some. A few years ago an initiative “Health in all policies” was introduced during the Finnish EU-presidency (Ståhl et al., 2006). A couple of years later the WHO Commission on Social Determinants of Health issued its final report (CSDH 2008). As a matter of fact, also a concept of “Population Health” (Young 2005) has been suggested to provide a more interdisciplinary academic approach to the health of population: in addition to epidemiology and its quantitative tools, “Population Health” exploits qualitative methods of social sciences and humanities, demography, anthropology, history and ethics to understand the health of populations and to develop policies. Still, the terminology around different concepts is far from clear.

The Nordic Committee on Bioethics organised a conference in Reykjavik in August 2010 to hear expert views and discuss ethical issues relating to public health. The programme was divided into three sessions: 1) Individual Freedom and Public Health, 2) Health Responsibility and Life Style, and 3) Social Equality and Justice. The speakers offered a wide multidisciplinary perspective on these topics. I feel privileged to be the editor of this book to which most of the speakers sent their valuable contributions. The structure of the book follows the programme of the conference.

The first session of the conference framed the theme, and provided insights. *Haraldur Briem* raises the ethical question as how to protect people from dangerous communicable diseases while at the same time taking into account individual rights and freedom of movement. *Kalle Grill* defends the thesis that liberty is an important value, but with no claim to priority. *Helena Kääriäinen* discusses population screenings using neonatal screening of genetic diseases as an example. The major problem in the programmes relates to their quality. Thus, she stresses that population screenings require careful planning, and appropriate pre-test information. *Stefán Hjörleifsson*, on his part, considers pros and cons of screening programmes. In his opinion, benefits do not usually outweigh the harms and the costs.

The second session focused on health responsibility and life style. Many of today’s burdening health problems are related to life style, and unfortunately often correlate with lower socioeconomic status. But who is respon-

sible for individuals' health in the end? To what extent can the state use paternalistic measures to guide people to the right course? *Ole Faergeman* thinks that too little attention is given to the impact of climate change on health. He sees policy-makers have failed to react to climate change partly due to corporate structures in the state. *Bjørn Hofmann* examines the question "do people have a right to live an unhealthy life?" Even though many theories might justify public health intervention to induce people to live healthy lives, the answer does not seem simple; not least due to a difficulty to define key concepts. *Ástríður Stefánsdóttir* suggests in her contribution that a major epidemic of our times, obesity, should first and foremost be seen as a social problem because an increasing number of children and adults are living in an environment that makes it more and more difficult for them to lead healthy lives. *Tinna Laufey Ásgeirsdóttir* argues that efficiency is one of multiple possible ethical barometers that we can use for individual and societal guidance. In her view, ethical and economic analyses are two ways of describing or weighing the various possible means to optimal decision making, one being a subset of the other. *Pekka Louhiala* contemplates in his text whether it is necessary for a good life to be healthy. He concludes that happiness cannot be measured by scientific terms, but require evaluations that are formed in a social settings.

In the third session of the conference, Social equality and justice, poverty was identified as one of the key causes underlying poor health and increasing health inequalities. The overall challenge concern policy-making in all fields; daily living conditions, environment, equal distribution of resources, market responsibility. Moreover, these policies should have a life-course perspective. Particular focus should be targeted on marginalised or vulnerable populations. But above all, it was claimed, effective health improvement policies and practices should be purely evidence-driven and evidence-based. In the third part of this book these ideas are developed further. *Geir Gunnlaugsson* highlights the importance of the early years for the development of the child, and later health in adulthood. He also notes that low social position is in fact an important determinant *per se*; possibly through stress and the consequences it has on the human body. *Janne Nikkinen* argues that Nordic welfare state has not been able to manage socio-economic factors affecting childhood adequately: health inequalities exist and are rising in the Nordic countries. Finally, *Ketil Lenert Hansen* discusses how the Sami living

in the Nordic countries experience prejudices and discrimination both as individuals and as a group.

The texts in this book plunge into the core of today's public health challenges. Interestingly, several texts claim that current politics fail to see the upstream causes in deeper political structures that result in major public health problems. It is evident that more discussion and more evidence are needed in the society to improve public health, and to maintain confidence in the just and fair Nordic welfare state.

Sirpa Soini²

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Individual Freedom and public Health

1. The Ethics of Infection Control

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1.1 Introduction

Infection control measures inevitably affect the freedom and self-determination of individuals and groups of people. Such measures are justified because of their benefit to public health, not necessarily for the benefit of individual patients. The ethics of infection control therefore emphasises justice with special focus on community values and the common good, whereas clinical ethics underscores patient autonomy (Bryan et al., 2007). Bioethics includes clinical ethics (euthanasia, genetics, stem-cell research etc.). Although infectious disease should be recognised as a topic of primary importance for bioethics, the general topic of infectious disease has received relatively little attention from the discipline of bioethics (Selgelid 2005).

1.2 History of epidemics and infectious disease control

History is marked by the devastating consequences of epidemics caused by infectious diseases (McNeill 1976). The Black Death eliminated one third of the European population during the 14th century; the 1918 flu killed between 20 and 100 million people. Smallpox was perhaps the most devastating infectious disease ever. Even before the cause of infectious diseases was understood infectious disease measures were applied. In Venice and Milan, during the Black Death in 1370–1374 infected people were denied access to the cities and in Ragusa (Dubrovnik) 30 days of

isolation were applied (tertiana) before access was permitted, which later was changed to 40 days of isolation (quartana) by legislation in 1465. The term quarantine is derived from this measure. The modern definitions of quarantine and isolation can be found in the International Health Regulation (“IHR”) of WHO (2005). “Quarantine” means the restriction of activities and/or separation from others of suspect persons who are not ill or of suspect baggage, containers, conveyances or goods in such a manner as to prevent the possible spread of infection or contamination; “Isolation” means separation of ill or contaminated persons or affected baggage, containers, conveyances, goods or postal parcels from others in such a manner as to prevent the spread of infection or contamination.

The cholera epidemics that hit Europe in 1830 and the following years made apparent the need for international cooperation in public health. The European Health Council was consequently established in Constantinople in 1839 – at the time the threat was considered coming from the Middle East. The first International Sanitary Regulations were adapted at the International Sanitary Conference in Paris in 1851 (Stern and Markel 2004).

1.3 Ethical issues regarding infection control measures

Measures against infectious diseases raise difficult ethical questions. While infected individuals can threaten the health of other individuals and society as a whole, for example, public health measures such as surveillance, isolation and quarantine can require the violation of widely accepted basic human rights and liberties.

Unfortunately the practice and politics of quarantine lacked uniformity and most often reflected issues other than protection against infectious diseases. Social injustice was often blatant as for instance when only third-class passengers emigrating from Europe to USA were detained in quarantine at Ellis Island. Another kind of social injustice was linked to ethnic groups, e.g. when San Francisco was hit by a plague epidemic in 1900 President McKinley ordered a quarantine of all Chinese and Japanese persons in the city (Edelson 2003). Quarantine has also been closely connected with the restriction, protection and control of trade. A classical example is the dispute between Britain and France in 1885 over a proposal relating

to the inspection and quarantine of vessels from India scheduled to traverse the Suez Canal (Maglen 2003).

1.4 Recent revision of international health regulations

The risk perception of health events of international concern has been gaining momentum in recent decades. Concerns regarding HIV/AIDS, SARS, pandemic influenza and the threat of bioterrorism have been increasing, especially after the attack on the Twin Towers in the USA on the 11 September 2001 and the anthrax events in the aftermath which led to the adoption by the World Health Assembly of new and revised International Health Regulations (“IHR”) in 2005 (WHO 2005). Previous versions of the regulations were considered to have limitations due to the narrow scope of notifiable diseases (cholera, yellow fever and plague), as well as dependency on official country notifications and lack of formal internationally coordinated mechanisms to prevent the international spread of disease.

The new IHR refers to all public health threats of international concern instead of only that of three diseases. The new regulations provide for adapted response, border measures and containment at source instead of preset measures. In essence, the aim of the new regulations is “to prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks, and which avoid unnecessary interference with international traffic and trade”. Obviously the international community is trying to take human rights into account. The ethical question is how to protect people from dangerous communicable diseases while at the same time taking into account individual rights and freedom of movement.

1.5 Ethical challenges for clinicians and public health servants

Clinicians dealing with infectious diseases are often confronted with ethical dilemmas. In times of epidemic, are those caring for patients suffering from a naturally occurring disease outbreak or an intentional attack with an infectious agent fulfilling an inherent obligation of the healing professions? Or are their actions, in the face of significant personal risk, heroic, altruistic and beyond the call of duty? Review of ethical codes and existing law offers no definitive answer to these questions and indicates the need to carefully consider the proportional value of the healer's professional role as compared with his or her acceptance of a personal sacrifice in performing the duty to treat. Today's public health threats, like past epidemics, call for a coherent professional ethic setting forth the parameters of a duty to treat. Occupational risk is an accepted, inherent part of the health-care professional's calling. Ethical guidance should be established as to how much risk physicians, public health and other health-care workers should be expected to accept (Olick 2004). Clinicians are often faced with choices of ethical nature in their practice. How should the prescription of antibiotics be balanced between intention to treat and the risk of developing antimicrobial resistance? Should a patient with a serious infection due to multi-resistant bacteria be treated in a different way than other patients?

The pandemic of HIV/AIDS has raised many ethical dilemmas for health-care workers, public-health officials and health authorities. One aspect was the need to know the extent of the problem and the epidemiology of HIV infection in the community. Early in the epidemic, when there was no effective treatment while diagnostic methods became available, privacy issues were much debated. Data from diagnostic testing, or obtained after explicit consent to unlinked testing, inevitably produced biased estimates of the prevalence of HIV. Therefore, unbiased results were needed. This posed an ethical dilemma. Is it possible to obtain a result from a blood test without informed consent? Internationally, most countries have followed the United Nations Programme on AIDS and the World Health Organization's recommendation to use the technique of unlinked anonymous testing as a legal and ethical concept (Nicol 2000). Before testing, every specimen is irreversibly unlinked from information that would identify the source individu-

al and infection status can never be traced back to a person. Essentially, the results represent groups in the community and not individuals.

1.6 Ethical challenges of public health measures against severe pandemics

Facing severe pandemics health authorities and governments may have to consider draconian measures to respond to the health threat to the people and the national security. WHO has recommended that nations should prepare at all levels (local, national, regional and global) for response to the pandemic influenza (WHO 2009). One measure often considered is border closure but such a measure is unlikely to delay the spread of influenza by more than 2–3 weeks unless closure is more than 99% effective. School closure during the peak of a pandemic can reduce peak attack rates by up to 40% but has little impact on overall attack rates, whereas case isolation or household quarantine could have a significant impact, if feasible (Ferguson et al., 2006). The ethics of school closure have been questioned since evidence of the efficacy of this intervention has not yet been firmly established which calls into question whether the measures will be useful against the threat itself. In addition, school closures have the potential to create serious adverse consequences, which will disproportionately affect vulnerable populations (Berkman 2008). However, the success of isolation and quarantine depends on the degree to which individuals and the public understand the necessity for the restrictions. The dilemma is to convince the public of the necessity of such involuntary measures when people of modern times have not experienced the devastating consequences of past pandemics. Isolation is probably an acceptable and desirable public health measure but quarantine is more controversial. There are ethical dilemmas due to the fact that quarantine might lead to spreading an infection among susceptible individuals from an infected individual without symptoms when quarantined (Day et al., 2006).

The use of vaccines for preventing infection during pandemics has mainly focused on the allocation of scarce vaccines. Who should decide the priorities? Who should be prioritised, the health-care workers taking care of patients, the vulnerable patients or the people essential for the national security? On the other hand what should one do if health-care

workers or people essential for the national security refuse to be vaccinated? Should vaccination be mandatory? Many factors must be considered in determining the ethical justification for mandatory vaccination programmes such as effectiveness, beneficence, and necessity. To satisfy the ethical principle of effectiveness, each vaccine and the programme as a whole must be both effective and safe (Steckel 2007).

Conclusion

Legislation on infection control measures must be in place, readily understood and widely accepted. In a public health crisis, actions must be swift and there will be no time for reflection on widely accepted basic human rights and liberties. In time of peace, on the other hand, there is time to discuss and to examine the legal and ethical aspects of infection control measures. Then there is also the time to apply the best scientific evidence to creating sensible preparedness and response plans for serious threats to humans.

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2. Individual liberty in public health – no trumping value

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2.1 Introduction

Public health policy often limits people's liberty for their own good. The very point of many types of public health measures is to restrict people's options in order to stop them from doing unhealthy things, for example use harmful recreational drugs or drive without a seatbelt. While such restrictive public health policies enjoy widespread support, so does the traditional liberal idea that liberty (or autonomy) is a higher value, to be given priority in most, if not all, circumstances. In this text, I will defend the thesis that liberty is an important value, but with no claim to priority.

Public health ethics is very much concerned with finding the appropriate approach to liberty. There is some consensus that the main goal of public health is to promote other values than liberty, typically population health (Holland 2007, p. 10–11). Some authors argue that this rather consequentialist goal must be controlled by a strong commitment to individual liberty, so that interference with liberty is justified only under certain conditions, if at all (I will provide some examples below). Other authors find this traditional liberal perspective ill fitted for the evaluation of public health policy, with its essentially non-individualist aims. This latter position may lead to attempts to develop a more community-oriented interpretation of central liberal values (Jennings 2009), or to a more radical rejection of the privileged status of liberty (Dawson 2009). To this debate, I will contribute three arguments against treating liberty as a trumping value, preceded by an argument to the effect that even moderate liberal positions are committed to treating liberty as a trump in many cases. Two of the arguments against

trumping resemble arguments presented elsewhere (Grill 2010), but are here set in the context of public health more specifically.

Public health policy crucially targets populations or groups. This means that individual liberty typically cannot be protected through respectful personal interactions the way it can in clinical settings. Prohibitions and requirements are blunt tools. The population perspective also raises important and difficult questions concerning how to balance one person's liberty against another person's health, as well as some people's liberty interest in having a rich variety of options against other people's liberty interests in structuring their lives by making their environment safer and more conducive to health. I have discussed these questions elsewhere (Grill 2009) and will here disregard interpersonal balancing problems in order to focus on the simple case where all are equally affected by a policy – having their liberty limited but some other value, typically their health, promoted or protected.

My arguments are directed at the liberal who shares my conviction that liberty is valuable, whether or not this value is reducible to some higher value in the final analysis. I will therefore take the value of liberty for granted. I will assume, furthermore, that any government must take a stand on public health issues, either by making policy or by abstaining, and then this decision must be justified in terms of how it affects relevant values. In other words, I will not discuss the legitimacy of government authority in general.

2.2 Trumping

When two values are in conflict in the sense that both of them cannot be fully realized, a straightforward approach is to balance these conflicting values according to their relative importance or weight. Such a balancing approach may be consequentialist in a broad sense, incorporating such liberal values as respect for individual choice. However, a balancing approach may also be based on *prima facie* duties and so be an instance of deontology. For the sake of simplicity, I will speak no more of duties, but only of values, with the understanding that value can refer either to consequentialist outcomes, or to the fulfilment of *prima facie* duties.

Trumping occurs when, instead of balancing, one value automatically overrides one or more other values, with no consideration of the extent to which each is affected. From the perspective of balancing, trumping appears to amount to the attribution of indefinitely greater importance to some values, or to the lexical ordering of some values before others. However, friends of trumping typically do not think in terms of indefinite importance or lexical priority, but rather have a more loose idea of what makes one value trump others.

When it comes to limitation of liberty, the most explicit account of trumping is arguable that of Joel Feinberg (1986):

“The most promising strategy for the anti-paternalist is to construct a convincing conception of personal autonomy that can explain how that notion is a moral trump card, not to be merely balanced with considerations of harm diminution in cases of conflict, but always and necessarily taking moral precedence over those considerations” (1986, p. 26).

Anti-paternalism is the doctrine that paternalism is morally wrong or unacceptable. On most accounts of paternalism, a policy can be paternalistic even it does no good, as long as the motivation or rationale for the policy is to do good. Such policies are of course pointless. If we restrict our attention, therefore, to public health policies that do in fact promote population health, the connection between anti-paternalism and trumping is very close. That such paternalism is wrong means that the value of unrestricted liberty always defeats the value of promotion or protection of population health. To take this position quite generally, without consideration of the details of any particular case, is in all essence to hold that the value of liberty trumps the value of population health.

True to his own recommendation, Feinberg attempts to construct an account of personal autonomy as a moral trump, in large part by appealing to the readers intuitive response to imagining being forced to do things and be in ways that others deem best, with no consideration of one’s own will. Such intuitions are powerful, and may explain why so many authors, albeit realising that some instances of paternalism must be acceptable, presume that paternalism is normally unacceptable, even if it promotes or protects people’s health and other fundamental interests.

In the general philosophical literature on paternalism, it is common to accept anti-paternalism as a rule, while arguing that paternalism is ac-

ceptable in some cases. The proposed conditions for justified paternalism include that the aim be preservation of autonomy (Dworkin 1972; Kleinig 1984), that the benefits be much larger than the costs (Groarke 2002), and that the person would consent to limitation under certain hypothetical circumstances (Van De Veer 1986). Explicitly or implicitly, these accounts entail that when the appropriate condition is not met, then paternalism is unjustified. It is unjustified in these remaining cases not because the value of liberty is weighed against the value of health and other interests a person may have and found greater in all cases. These authors make no such comparisons. Unless special conditions are met, paternalism is unjustified, it seems, because liberty simply trumps other values for a person, such as the value of health.

In the literature on liberty-limiting public health policy specifically, it has become common practice to list a number of conditions for when paternalism is justified, with the assumption that it is unjustified in all other cases. In a much cited article (Childress et al., 2002), ten authorities on medical ethics state that public health measures must meet five “justificatory conditions” which “determine whether promoting public health warrants overriding such values as individual liberty”. The conditions are effectiveness, proportionality, necessity, least infringement, and public justification. A policy that does not meet these conditions, for example because another policy would have been less intrusive (though perhaps more likely to be effective) is supposedly not justified. The policy may still have great positive effects on public health, and the infringement may be small. It seems highly unlikely, therefore, that the value of liberty is greater than the value of health in all cases not covered by the conditions. In those cases, therefore, liberty must simply trump population health.¹ Even authors who are in favour of far-reaching and invasive measures to protect population health tend to believe that there must be more to the justification of such measures than mere balancing (e.g. Bayer and Fairchild 2004, pointing to the need for “a set of principles that would preserve a commitment to the realm of free choice”).

¹ Childress has reaffirmed his position in a more recent co-authored article (Childress & Bernheim 2008). Other influential lists of conditions for justified limitation of liberty in public health include Kass 2001 and Upshur 2002.

While few authors are as uncompromising as Feinberg, the most common positions on liberty in public health are clearly anti-paternalist, though with exceptions. In other words, these positions treat liberty as a trumping value in many but not all cases. Trumping, however, has several undesirable consequences. If there are exceptions to the trumping, these consequences do not follow from the exceptions. They do, however, follow from those cases that are not exceptions. In this and the following three sections, I will briefly describe three undesirable consequences of trumping. In brief, the first problem is that the friend of trumping must either accept a narrow conception of liberty, which disregards many instances of apparent liberty limitation, or accept clearly counter-intuitive results in some cases. The second problem is that trumping leads to peculiar jumps in justifiability when comparing very similar policies. The third is an unwarranted disregard for the liberty of less able decision-makers.

2.3 First problem with trumping – wrong answers or narrow liberty

Some public health policies apparently have great positive consequences and lead to rather trivial limitations of liberty. The prohibition of heroin might be a real world example. Assume for arguments sake that this prohibition is enforced not by harsh punishment of users and small-scale dealers, but by effective prevention of production and importation. Assume also that there are plenty of other hallucinogenic drugs available (such as cannabis and perhaps LSD), which are weaker, and thus less addictive. In these circumstances, the prohibition of heroin might have very positive effects, preventing people from becoming addicted to heroin, and hence losing interest in their lives, mismanaging their jobs and neglecting their children. In such circumstances, furthermore, an effective prohibition would not seriously limit anyone's liberty. Still, liberty is limited, and if liberty is a trump in this case, the prohibition is unjustified.

Now add the assumption that the people who would start to use heroin were it available are not reckless teenagers or people in desperate circumstances, but adult people with comfortable lives who would simply be attracted by the fast route to ecstasy. Notice also that the policy targets first use; it is not a policy directed at people who are slaves under their

addiction. This all means that the policy cannot be defended by claiming it protects people who are incapable to direct their lives. If the prohibition of heroin seems exceedingly illiberal even in this hypothetical example, consider the case of a hypothetical drug that is more addictive than heroin, has less pleasant effects and is much more hazardous, but which is in strong demand due to some quirk of popular culture (cf. Arneson 2005, pp. 272–3, for similar examples).

There are plenty of other examples of very reasonable public health policies, including seat belt laws, water fluoridation, and product safety regulation banning everything from exploding TVs to poisonous food (even when clearly indicated on the packaging). Strict anti-paternalists would seem to be opposed to these kinds of public health policies (unless, perhaps, they are implemented for the sake of a willing majority aiming to restrict their own options, or if the harms to non-consenting others are substantial). Moderate anti-paternalists, who believe in trumping with exceptions, will be opposed to these kinds of public health policies unless they met certain conditions. The policies may very well not meet such conditions (if for example some less restrictive policy would be possible).

Confronted with examples like these, the friend of trumping can of course bite the bullet and reject the policies as unjustified, but this is counter-intuitive and in some cases amounts to liberty fetishism (critics will construct ever more devastating hypothetical scenarios where very trivial limitations of liberty yield enormous benefits). In fact, friends of trumping that see this problem with their position tend not to bite the bullet, but rather argue that for any reasonable apparently liberty-limiting principle, liberty is not actually limited. Common explanations for this is that people do not really or truly want to make the unhealthy choices prevented by the policy (Dworkin 1972), that the policy has long term effects which yield a net increase in liberty (Sneddon 2001), or simply that the limitation in question is so trivial. These strategies, however, belittle liberty, or at least imply too narrow a conception of liberty.

That people of normal capacity are prevented from doing what they want to do is a limitation of their liberty, even if they would not want these things after an advanced course in nutrition or ten sessions of psychotherapy. Wants that are easily changed by improved information or insight may possibly warrant less respect than more sturdy wants, but they certainly warrant some respect as long as they remain. Similarly, that

someone is restricted at present is a limitation of her liberty even if this restriction means that she will be more autonomous or have more options five years from now. And, lastly, even very trivial limitations, such as banning some types of candy or some rather obscure and dangerous sport, are nonetheless limitations.

The various “not really liberty” strategies have in common a focus on something more important or long term or both, a sort of liberty that is more worthwhile than the relatively trivial or temporary or superficial instances. This focus is admirable, but the mistake is to refuse to recognize the lower forms of liberty as liberty at all. This mistake becomes clearer when we aggregate a lot of such small liberties. It also becomes clearer when we realize that liberty may be only one among several values threatened by the same policy.

It may be tempting to claim, in the face of a trivial limitation of liberty with great benefits, that this limitation doesn't really limit liberty, or doesn't limit real liberty. For example, a ban on a certain new and hazardous recreational drug, enforced by policing and moderate punishments, may seem not to limit liberty in any interesting sense. Consider, however, a case where the banned drug is popular among the minority, and where a similar new drug, popular among the majority, and even more hazardous, is not banned. Assume that this asymmetry makes the policy unfair or discriminative. Assume also that although unfair, the policy is still beneficial for the minority and that this benefit just barely outweighs the unfairness so that the policy is justified, having considered only fairness and health effects. Now, if the policy would be in any way liberty-limiting, this would make the policy less justified and so tip the balance, making it all things considered unjustified. In such a case, one sees more clearly the price of a narrow conception of liberty – on such a conception the fact that the policy is restrictive or intrusive will not even weigh in on the matter.

In actual policy-making, that some people's liberty is limited and that this has some benefits for the same people are typically only two considerations among several. Our position on liberty-limiting policy should cover such common cases (if not all cases). Given this general ambition, liberty cannot be reduced to a core of the most important liberties, but must include both our most central life choices and our everyday, mundane choices. With this inclusive, wide understanding of liberty, however, it is quite unreasonable to insist that liberty trumps other values. Quite to

the contrary, liberty should sometimes be limited just because the benefits in terms of population health are greater than the liberty cost to that same population.

2.4 Second problem with trumping – jumps in justifiability

What does it mean more precisely that liberty trumps other values for a person or group? It might mean only that no limitation of the liberty of a certain group should be accepted whatever the benefit to that group. If so, however, we must ask how to evaluate cases where a limitation of liberty can produce both benefits to the group, for example in the form of improved health, and other desirable consequences, such as increased fairness, or benefits to third parties. For example, banning some dangerous motor sport may both protect people who would otherwise practice that sport from harm, and protect the local and global environment (to the benefit of other people). Assume that the environmental benefit of banning the sport is just about outweighed by the liberty cost, making the ban unjustified considering only environmental and liberty effects. Now, the suggested definition of trumping does not preclude the direct harm prevention from counting in favour of the policy, making it all things considered justified. However, this seems contrary to the intentions of the friends of trumping. It also seems peculiar, or even slightly incoherent, to hold that liberty trumps harm prevention when these are the only two concerns, but can be outweighed by harm prevention as soon as there is some relevant third concern. We should, therefore, take trumping to mean that benefits to people, which are caused by limiting their liberty, can never even contribute to the justification of such liberty-limitation.

This understanding of trumping, reasonable as it is compared to the alternatives, leads to peculiar jumps in justifiability. This is partly because factors determining whether or not some behaviour is an expression of liberty come in degrees. For example, our liberty is limited only if the limitation targets a choice or an action that is to some extent voluntary. Preventing people from giving up their money under gun threat, or from sleepwalking into empty elevator shafts, is not to limit their liberty (unless, perhaps, they have declined intervention in an earlier, more volun-

tary state). How much and what kind of voluntariness is required for an intervention to amount to a limitation of liberty is a central issue for anti-paternalism, and Feinberg consequently dealt extensively with voluntariness. Voluntariness minimally involves being informed and being able to process information into decisions. Such ability and informedness come in degrees – tiny bits of information and tiny improvements in decision-making ability make decisions more voluntary. There must be some point where there is sufficient voluntariness for trumping to set in.

The benefits of public health policy may be great. They may, like seat belt laws, save thousands of lives annually in a medium size state. Since I have disregarded interpersonal balancing problems at the outset, assume that all drivers are equally informed and able when it comes to the decision whether or not to use a seatbelt. Assume further that, as in the actual history of most countries, most people will not use seatbelts unless required by law to do so. Now consider the public health policy of making seat belts mandatory. Does this policy limit people's liberty? Different opinions have been offered, some of them involving one of the "not really liberty" strategies criticised above. Our concern now is not whether liberty is limited, however. Our concern is this consequence of trumping: If people are so badly informed and so incompetent as decision-makers when it comes to seatbelt use that forcing them to wear belts does not limit their liberty, then the great health benefits are a very strong consideration in favour of this policy. If, on the other hand, people are somewhat more informed and able, so that forcing them to wear seat belts does limit their liberty, then the great health benefits are trumped and so do not contribute to the justification of the policy. As a result, at the threshold between insufficient and sufficient voluntariness, the justifiability of the policy takes a "jump".

If, as in the case of seat belt laws, the health benefits are great, then the jump in justifiability is very long. One policy can be overwhelmingly justified, while a very similar policy can be overwhelmingly unjustified. This is unreasonable. The problem here is not the standard problem of arbitrary line drawing. It is uncontroversial that some policies are justified and some are not, and that very small differences may make the difference between this moral status of policy. We must distinguish between the binary status of being either justified or unjustified, and the quality of being more or less justified in the sense of being supported by a larger or

smaller excess of *pro* reasons over *con* reasons. This latter quality has practical impact for example in that more justified policies should take priority over less justified ones. Now the problem with trumping is that it entails that very minor empirical differences potentially give rise to huge gaps in justifiability. This is both conceptually peculiar and practically difficult. It is conceptually peculiar because it is very hard to accept that very minor differences can change the moral status of a policy from overwhelmingly justified to overwhelmingly unjustified. It is practically difficult because it is hard to conduct sound public policy if priorities change dramatically with very small developments in for example public risk awareness.²

2.5 Third problem with trumping – no liberty for the less able

There are not only, as noted above, small liberties for informed and able decision-makers; there are also liberties, small and large, for less informed and less able decision-makers. I propose that liberty is important not only for the most able, but also for minors, for the ignorant, and for people who are confused, intoxicated or affected by strong emotions (these being factors which are generally considered to decrease voluntariness). It is not as if the value of having some control over one's own life kicks in only at a certain degree of voluntariness. Perhaps there is some level under which people cannot choose for themselves or cannot appreciate self-determination. Liberty, however, has value for people that are well above this level but that we should nonetheless obviously coerce in their own interest, for example 15-year olds. With this, every liberal should agree. However, this presents the friend of trumping with a hard choice.

² It may be suggested that there is no sharp line but rather a grey area. If this area is grey only in the sense that it is hard to know when a policy amounts to limitation of liberty, this does not affect the argument, which is focused on the peculiarity of there being a jump, regardless of our ability to pinpoint it. If the area is grey in the sense that it is genuinely indeterminate whether some levels of voluntariness are sufficient, then there is no sudden jump but rather a twilight zone of indeterminacy. Jumps are avoided at the price of giving up comprehensiveness. This is no improvement.

Three positions are possible for the friend of trumping: First, she can insist that the liberty of young teens is of another type than the liberty of (allegedly) informed and rational adults and so does not activate the trumping quality of liberty. This distinction, however, is mysterious. One might say that the important value is not liberty but autonomy, and that young teens are not fully autonomous. This does not help, however, as there is no difference in kind between almost full autonomy and full autonomy, whatever full autonomy is exactly. Full autonomy is presumably partly determined by decision-making ability, which comes in degrees.

Second, the friend of trumping can claim that the liberty of young teens does trump other concerns. However, we have seen the problems such a view entails even for very able decision-makers. Even those who bite the bullet and reject as unjustified seemingly reasonable public health policies targeting adults cannot reasonably accept such passivity in relation to young teens.

Third, the friend of trumping can say that for young teens, the value of liberty is appropriately reflected in its relative importance, with no need for trumping. For example, the liberty cost of increasing the minimum moped driving age from 15 to 16 in some state may be too great relative to the small expected decrease in road accidents. This third position is the most plausible. But if this is one's position on young teens, it is entirely unclear why things should be any different for competent adults. Interference with more able decision-makers generally yields smaller rewards, since there is less room for improvement. It may also be that interference with more able decision-makers has a greater cost in terms of liberty, because more liberty (or autonomy) is sacrificed in some sense. However, none of this indicates that the benefits of liberty-limiting policy cannot contribute to the justification of policy, or that these benefits may not outweigh the costs.

It may be suggested that the above argument disregards the important distinction between the competent and the incompetent, or between the healthy and the (mentally) ill, or between adults and children. These categories, however, depend on underlying physical properties, which vary by degree. Once bestowed, legal status may admittedly make a normative difference. It is perhaps worse to limit the liberty of an adult, because this frustrates legitimate expectations induced by the legal system. However, such legal circumstances can only reinforce an underlying normative real-

ity, which must be spelled out in terms of non-legal, concrete physical or psychological properties of persons. It would be hopelessly vacuous to argue that the people we must protect from intrusions are those that have been granted a legal right to be so protected. On the contrary, when deciding the proper age of majority and the conditions for legal competence, an important factor is the extent to which it is justified to limit people's liberty for their own good.

In conclusion, a trumping approach fails to address the issue of whether or not to interfere with less than sufficiently voluntary choices made by rather autonomous people such as young teens. It makes no sense that the liberty of people who barely reach the threshold of sufficient voluntariness should trump other concerns, while the liberty of people who make somewhat less voluntary choices is simply one value among others.

Conclusion

While there are many positions on the justification of liberty-limiting public health policy, most positions share a commitment to the idea that liberty trumps other concerns in all or some cases. Such trumping has very undesirable consequences: It forces us to choose between a very narrow conception of liberty and morally very counter-intuitive conclusions, it leads to peculiar jumps in justifiability, and it leaves out less able decision-makers, such as young teens. We should therefore reject trumping in favour of a balancing approach, according to which liberty is one value among many and decisions to limit liberty can and must be justified by showing how such limitation will yield benefits that outweigh the disvalue of the loss of liberty.

A balancing approach avoids the objections to trumping. Furthermore, reasoning in terms of the balancing of various values has strong methodological and democratic advantages. An official statement that a policy is justified because it does not conflict with a trumping principle (with or without exceptions) says nothing about how policy-makers weigh different values. The public may possibly infer that policy-makers will abide by the principle in the future as well, but we will know nothing about how policy-makers will treat matters not covered by the principle. In contrast, relative value estimates are more transparent. A judgment that some public health measure leads to more good than bad is straightforward and can

be fruitfully questioned and discussed. Public health officials can explain what exactly they expect to gain (so many saved lives, so many prevented illnesses) and what they are prepared to pay (so many people being detained, so many jobs not being done etc.), and why they find the gains more important than the losses.

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3. Population screening: neonatal screening of genetic diseases as an example

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3.1 Introduction

The aim of population screening is to detect some individuals in a pre-symptomatic stage of a disease in order to offer them diagnostics and treatment, and thus improve the prognosis of their disease. Those with normal results in the screening programme are expected to feel relieved when they were not found to have the condition. False positive results along with inconvenience and worry created by the screening programme are often mentioned as negative side effects.

The principles of population screening defined in 1968 by Wilson and Jungner are still often cited as a basis for population screening programmes. These principles emphasise the importance of a given condition to public health, the availability of an effective screening test, the availability of treatment to prevent disease during a latent period, and cost considerations (Wilson and Jungner, 1968). At that time, detecting diseases in a pre-clinical stage was not very common, but today a growing number of diseases can be easily detected very early, even in the pre-pathological stage, often using molecular genetic diagnostic techniques. Because of this and the fact that medicine in general and the consumer-view in it have considerably changed since 1968, the principles were recently revisited (Andermann et al, 2007). In this paper, the acceptable starting point for population screening is no longer “important public health problem” but instead, the screening programmes should “respond to a recognized

need". In this paper, neonatal screening is discussed as an example of population screening programmes. The special problem of detecting carriers in these programmes is discussed as an example of complicated concomitant consequences of screening programmes.

3.2 Aims of neonatal screening

The usual aim of neonatal screening is to detect infants with a severe but treatable disease early enough to prevent serious outcome such as irreversible organ changes, mental handicap or death. Exceptionally, neonatal screening programmes (usually pilot programmes) have been instituted with the aim to diagnose a severe, hereditary condition in the family early enough to give the parents time to adapt to the situation and, also, for family planning (Parsons et al, 2002).

In case of neonatal screening of metabolic disorders with an effective treatment, the aim is clearly to prevent morbidity due to the disease. If the aim were to find carriers and thus prevent affected cases from being born, a more efficient way of screening would be carrier screening of young adults before their first pregnancy. The different options for screening or diagnosing such diseases are schematically depicted in Figure 1.

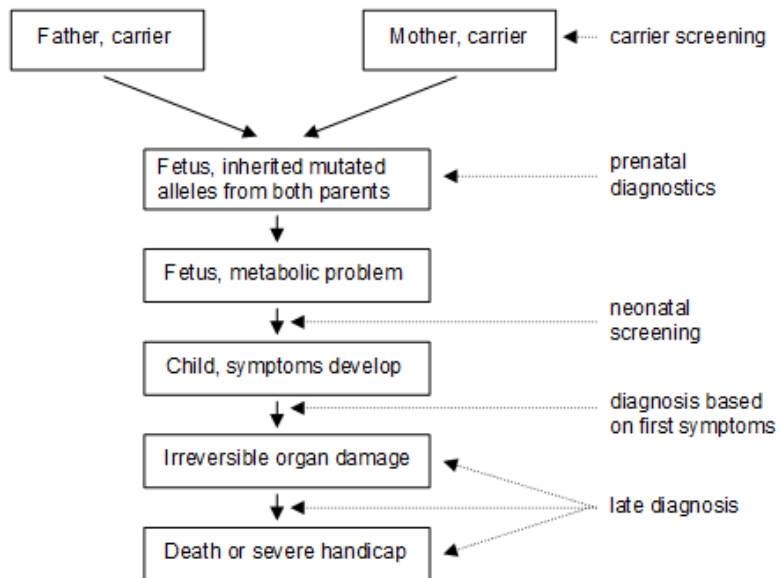


Figure 1. In case of autosomal recessive metabolic diseases, both parents are asymptomatic carriers and their offspring have a 25% probability of inheriting the mutated gene from both parents and developing a symptomatic disease. Carrier screening and prenatal diagnosis would offer a possibility to prevent the affected children from being born. Neonatal screening and early treatment, when available, prevent the severe consequences of the disease. Some of the metabolic diseases can still be treated successfully when diagnosis is made soon after the first symptoms. In some other diseases, irreversible damage has already occurred at that time and severe handicap or death will follow because the possible treatments have been started too late.

The aim of neonatal screening of treatable metabolic diseases is thus ethically straightforward and it is generally well accepted by both parents and health care personnel. For health care providers the question may be more complicated, because many of the diseases are extremely rare and, sometimes, the treatment only slightly improves the long term prognosis. This means that the costs per QALY gained (quality adjusted life year) may become very high. Yet the positive aim of detecting newborns needing treatment often outweighs the problem of high cost in political discussion. The difficult ethical questions related to carrier screening programmes (with the aim to offer the option of terminating pregnancy) are

not directly raised in neonatal screening programmes. However, many of the families want to choose prenatal diagnostics in future pregnancies.

In spite of this acceptable goal, neonatal screening programmes create also serious problems. One is of course the paradox of costs: even though preventing morbidity (or death) saves some costs in the long run, the testing procedure with training of personnel, information and counselling of the couples, optimal logistics, best possible treatment of the conditions etc generates costs. On the whole, the cost-benefit calculations are complicated by many diverse benefits and harms which are hard to measure or compare with one another (Kerruish and Robertson, 2005). In addition, offering a screening programme to detect serious diseases in neonatal period will inevitably cause some worry and anxiety, the long term consequences of which are impossible to predict or measure. Finally, in addition to real false positives, healthy carrier siblings may be inadvertently detected. This problem of detecting carrier newborns who will never get symptoms will be discussed in more detail below.

3.3 Neonatal screening in Finland

In Finland, currently the only disease that is being screened for in newborns is hypothyreosis; this screening is performed from naval cord blood. Most Western countries offer much wider screening programmes to the newborns. Especially, phenylketonuria (PKU) is screened in neonatal period in practically all Western countries.

In Finland, PKU is known to be rare. Cases have been systematically searched for by screening mentally retarded individuals in institutions and healthy newborns. These studies, performed some 30 years ago, resulted in an approximation of the incidence of PKU to be 1/100 000 – 200 000 newborns. Because of the rarity of PKU, it is not screened for in newborns in Finland (Palo 1967, Visakorpi et al 1971, Simell 1974).

In other countries, the extended screening programmes are built on the existing PKU-screening. PKU-screening has traditionally been considered very efficient in preventing mental handicap in the affected children and thus regarded as cost-efficient in countries, where the incidence of PKU is relatively high (Blau et al, 2010). As the samples are taken and sent to a screening laboratory anyway, adding other diseases with less well

proven beneficial effects of early diagnosis does not add to the costs very much. Thus, in many countries where PKU-screening is offered, screening for other (metabolic) diseases has been added to the programme.

Recently, due to increased immigration to Finland from various countries, a newborn screening for PKU is being offered for non-Finnish couples. On the other hand, the new possibilities to screen for several metabolic diseases simultaneously using tandem mass spectrometry prompted a health technology assessment project on the effect and costs of expanded newborn screening (Autti-Rämö et al, 2005). The evaluation found out that, with a selection of diseases consisting of PKU, MCAD, LCHAD, glutaricaciduria, and congenital adrenal hyperplasia, the costs per quality-adjusted life year (QALY) gained would be a maximum of 25.500 euros and, after discussion, a decision was made not to start expanded neonatal screening at that time. The discussion is, however, still ongoing.

In addition to real monetary costs, also untoward side-effects of the possible screening programme were evaluated. One of those was that there might be a very young sibling in the family and finding a disease in the newborn might create acute worry about possible risk of disease in the elder sibling. Another untoward side-effect was detecting inadvertently carrier newborns.

3.4 Carriers of autosomal recessive diseases in neonatal screening

In case of autosomal recessive inheritance, a child will be affected only if he or she gets a mutated gene from both parents. Such a carrier couple has each time a bigger chance (50%) to get a carrier and a smaller chance (25%) to get an affected baby (Figure 2).

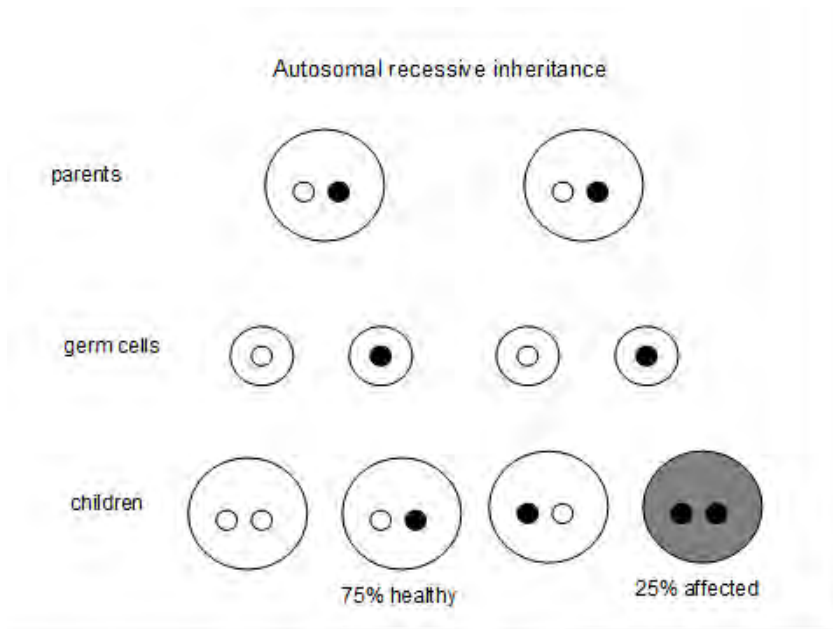


Figure 2. Carrier parents have one normal allele (white dot) and one mutated allele (black dot). In autosomal recessive inheritance, one mutated allele does not lead to any symptoms but to being a carrier. If the child happens to inherit a mutated allele from both parents he or she will be affected.

Most carriers never marry another carrier, and thus are never at risk of having affected children. Instead, half of their children are carriers. For instance, if the incidence of carriers in a population is 1/10 (a very high incidence), then only 1/100 of couples are carrier couples and, in their each pregnancy, the likelihood of an affected child is 25%. This high number of asymptomatic carriers in the population of all recessive diseases, in relation to the number of affected, leads to the fact, that newborn screening programmes will find much more carriers than affected individuals if the screening method is such that also carriers will be detected.

By definition, autosomal recessive inheritance means that the heterozygote carrier's phenotype cannot be differentiated from that in the normal homozygote. Often, however, some special methods reveal slight abnormality, like half amount of the protein concerned in the carrier's blood sample when compared to the normal individual. Sometimes mild phenotypic manifestations have also been detected (Arvio et al, 2004). If carriers

have real symptoms of disease, the philosophical question arises whether the mode of inheritance can be called autosomal recessive any more.

On the contrary, there are several examples of situations where heterozygous carriers have a “heterozygote advantage” which is considered to be the most common explanation for the fact that some recessive mutations have become so prevalent in the population. The best known example is the protective effect of being a β -thalassemia carrier against malaria (Flint et al, 1993).

Recently, at least one example has shown that being a carrier for a rare autosomal recessive disease may be a risk factor for another disease. This is the case in Fanconi anemia, where one of the genes, FANCD1, is identical to BRCA2 and thus being a heterozygous carrier of FANCD1 mutations means clearly elevated risk to breast and some other cancers (Papadopoulos and Moustacchi, 2005). This implies that, in the future, some other situations of being “symptomless carriers” may turn out to be associated with serious health consequences for the individual.

3.5 Positive and negative consequences of finding a carrier in newborn screening

Finding a newborn to be a carrier may have both positive and negative consequences. The shock to be told that something “not normal” was found in the screening may as such create anxiety among the parents since they can be exceptionally sensitive and vulnerable in the newborn period (Oliver et al, 2004). This anxiety should usually alleviate with prompt and comprehensive counselling while some parents may remain anxious even after the best possible information and counselling. In addition, there could be situations where it is difficult to tell whether the child is “only” a carrier or really affected. This could be the case when neonatal screening is based on mutation testing. Finding only one mutation most probably means that the newborn is a carrier but there could be another mutation that was not detected. Thus it is not always possible to assure the parents that the child will definitely not be affected.

Save for the immediate anxiety, it could be argued, that parents and the family benefit from the detection of carrier status in their child. This information tells immediately that at least one of the parents must be a car-

rier as well and they may even be a carrier couple. In the latter case, there could be an earlier child in the family who might benefit from diagnosis of the disease concerned. For instance, LCHAD could be still asymptomatic in a previous sibling. Also, the parents could choose to terminate a future pregnancy. Detecting carriership in a parent may also lead to cascade screening of more distant relatives if the family so wishes.

It has also been claimed that finding carriers is also a useful thing for the newborn because when growing up he or she will know the situation and will be able to request the partner to be mutation screened as well. Thus carrier couples could be detected in good time and birth of affected children could be prevented.

It has, however, been shown that finding mutation carriers in childhood does not necessarily lead to correct information for the child at an optimal time as a young adult, or to a correct understanding of the information (Mitchell et al, 1993; Jolly et al, 1996; Järvinen et al 1999; Järvinen et al, 2000). The parents may misunderstand the situation and convey the message incorrectly, choose not to tell about the carriership at all, or simply forget the whole issue. In cases where the parents have told about the carriership to the child, many of them have felt this task very difficult and demanding.

Detecting carriership in a newborn takes away definitely the child's right not to know, and also his or her right to privacy: as a young adult the child might have chosen not to disclose the result of a carrier test to the parents, for instance, to safeguard the privacy of making decisions of possible prenatal testing in future pregnancies (Borry et al, 2009).

The fact that one knows about carriership for a recessive disease in young age may, as an extreme, cause feelings of stigmatization, disturb one's self-esteem and form an obstacle in starting relationships and committing to them (Jolly et al, 1996).

3.6 Should extensive newborn screening be promoted?

When screening programmes are offered to the general public, it usually means that most individuals get a normal result. Looking at the situation retrospectively, those individuals never benefited from the screening programme. The ones who were found to have the conditions screened for are the ones who get the benefit. Those who got results that are difficult to interpret or that give some information that was initially not the goal of the programme (like finding carriers in neonatal screening) are the ones that actually get no benefit but instead some harm.

This happens to some extent in most screening programmes. In a way, the wellbeing of these individuals is partially sacrificed in order to get the important benefit to the others. As stated by the Tavistock group, the complexity and cost of healthcare delivery system may set up tension between what is good for the society as a whole and what is best for the individual (Tavistock group 1999).

The four ethical principles of the healthcare, beneficence, non maleficence, respect for autonomy and justice, are all important, but the hierarchy between them is not self evident and may be different in different situation in the healthcare.

When looking at the neonatal screening programmes, the possible options would be:

- No screening is performed and the affected newborns are likely to be diagnosed too late for optimal treatment. Some well informed couples may purchase the test from private sector, which may lead to injustice. Most newborns are non-affected and no harm is caused to them
- Screening is performed, affected children are diagnosed early, but also some concomitant consequences of screening will occur, including possible anxiety in the target population. The most complicated of the consequences is that carriers are detected. This leads to the positive result of detecting a carrier/a carrier family and being able to get genetic counselling as well as the negative consequences of carrier testing in childhood, including testing before being able to give consent to it

3.7 How to maximise benefits and minimise harm?

Many of the problems discussed in this paper are related to the quality of the screening programme. The author's opinion is that screening programmes should never be initiated without careful planning and the aim should always be to create a programme of as high quality as possible. If the resources do not allow for a high quality programme, then it might be wiser not to proceed. The planning, performing and evaluating of (newborn) screening programmes should give special emphasis to the availability of comprehensive pre-test information to those who want it and ample resources for immediate support and (genetic) counselling in case of results suggesting the individual to be affected.

Also the problem of detecting carriers in newborn screening programmes is, in the end, a problem of pre-test and post-test information and genetic counselling. Optimally, the possibility of detecting carriers should be discussed with the couples before the screening test as it might affect their willingness to consent. In reality, however, comprehensive pre-test information is often not given in population screening programmes and false positive result or detecting carriers may come as an unexpected surprise to the parents.

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4. Challenging population screening

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“Hey Mr. Olafsson, you want me to find out if you’ve got prostate cancer? Even if you don’t have any symptoms you still might have prostate cancer. If you let me do the PSA-test on you Mr. Olafsson, it could save your life.” Surely this sounds like a good offer for a 60 years old man who has seen his friend die within two years after getting prostate cancer. At first sight, screening men at the age of 60 with the PSA (prostate-specific antigen)-test to find and save those with early or “presymptomatic” cancer looks like a splendid case of preventive medicine. But unfortunately there are serious drawbacks. Mr. Olafsson will probably hesitate once he learns that for every man whose life is saved as a result of currently available screening procedures, 47 men are over-diagnosed and treated for prostate cancer for which they do not need treatment (Schröder et al., 2009). Some of those 47 men suffer side effects of the treatment, such as urinary incontinence and loss of erection. If Mr. Olafsson is screened, the chances are great that he will get a negative answer. But if he gets the answer that he has prostate cancer and then receives treatment based on that answer, it is most likely (47/1) that he will receive treatment that he does not need. Sadly, this means that population screening with PSA-testing is a poor way of preventing prostate cancer, and therefore such screening is not recommended in most countries.

4.1 Screening for common and complex diseases

In this paper I discuss population screening to identify people at risk or suffering from early stages of disease, with a focus on arguments disfavouring population screening. I limit my case to screening for the so-called common and complex diseases, focusing on some of the “big killers” in privileged parts of the world. In addition to prostate cancer, which I have already mentioned, I will take breast cancer and cardiovascular disease as my examples. These are certainly common diseases, being leading causes of death in most countries where people don’t die at early age from malnutrition or infections, or from war or natural catastrophes. And they are complex in the sense that the reasons why people get these diseases are multiple, and most cases appear to be caused by a combination of inheritance, behaviour and environmental influence. I will not deal with screening rare diseases caused by so-called monogenic inheritance, which run in particular families. Screening for these diseases within afflicted families is often useful, and I will not challenge it in this paper. Neither will I discuss screening for diseases caused by a single infectious agent or other distinct causes. The common and complex diseases, however, don’t run in a few families, and there is no single genetic or non-genetic cause that determines whether or not someone has e.g. 0%, 50% or 100% chances of getting such diseases. Nevertheless, genetic tests are currently being developed with the aim of providing a certain amount of information about the risk of developing one among a score of common and complex diseases. As it has been proposed that such tests provide a way of amending some of the limitations of currently used methods for population screening, I will also discuss this.

4.2 Preventive medicine – from the group approach of sanitization to the individual approach of screening

Preventive medicine has greatly improved public health, increased life expectancy and contributed to welfare in modern times. Most of these achievements have been accomplished by comparatively simple methods of immunization and sanitization that are applied to entire populations or their surroundings, i.e. increasing people’s resilience against infectious

agents or preventing the spreading of such agents. In recent decades however, preventive medicine has increasingly oriented itself towards the individual, applying new and advanced technologies for investigations and preventive treatment at the individual level. This individually oriented form of preventive medicine seeks to identify individuals affected by early stages of disease or with increased risk of being affected by disease, so they can receive preventive measures. This is what population screening is about, i.e. subjecting an entire population to a test or investigation to find those individuals having presymptomatic disease or increased risk of disease. These individuals are then offered preventive or early treatment, whereas for the rest of the population it is concluded that they do not need treatment to prevent that particular disease – at least until the next round of screening.

The screening situation raises different challenges than both the sanitization approach in preventive medicine and the conventional medical situation where a patient seeks the help of a doctor. With screening, in order to save one person you need to bother many others and even endanger their health. Traditionally, the role of the doctor has been to provide help to a person in distress. The doctor-patient relationship therefore comprises a person experiencing a problem who seeks the help of an expert who is supposed to be able to solve the problem or at least provide some relief. However, when doctors seek to identify people at risk by screening entire populations, the relationship between the expert and the one receiving help has changed. Mr. Olafsson is not in distress – he is not experiencing any problem. Therefore he has not seen any reason to seek help. On the contrary, it is the expert who seeks Mr. Olafsson and tells him that even if he is not in distress, he might nevertheless be in need of help.

Different authorities such as the World Health Organization (Wilson and Jungner, 1968), the United Kingdom National Screening Committee and the Danish National Board of Health have published criteria and guidelines for appraising the viability, effectiveness and appropriateness of screening programmes.¹ Some of the main principles found in these documents include the requirement that before making any decision on

¹ In addition to original WHO-criteria, see the webpages of the United Kingdom National Screening Committee (www.screening.nhs.uk) and the Danish National Board of Health (www.sst.dk) for their respective policy-documents.

the initiation of a screening activity, the following must be evaluated: The validity of the testing system, predictive values of test results, the ethical and psychological consequences for the examinees, stigmatization, the consequences of “false positive” and “false negative” test results. Furthermore, adequate plans must be made for informing the target group about the screening programme and for disseminating the test results. An economic evaluation must also be made.

Some screening programmes that are technically feasible and have been proposed due to their apparent benefits have nevertheless not been implemented because when scrutinized by criteria such as those listed above it turns out that the benefits will not outweigh the harms and the costs. Screening for prostate cancer is an obvious example, as the number of false positive answers would be high and many men would receive treatment they do not benefit from. Other screening programmes that have already been implemented in many countries are subject to criticism on similar grounds. Mammography screening for breast cancer is a pertinent example. In mammography screening the number of false positives is also high, and unfortunately the target group has received very limited information about this.

4.3 Preventing breast cancer and cardiovascular disease

In many countries, women above a certain age are recommended to have x-ray pictures taken of their breast at regular intervals to search for early stages of breast cancer. The aim is to prevent death from breast cancer by detecting and treating the disease at an earlier stage than would have been possible without the screening procedure. However, for every death from breast cancer prevented by early detection in the so-called mammography programmes, a number of women receive false positive results. These women receive the information that according to the x-ray pictures they may have breast cancer and that they therefore must undergo further investigations and even treatment. In reality these women do not have breast cancer. But how many women receive such “false positive” results? First, according to a recent estimate by the Nordic Cochrane Centre (Gøtzsche and Nielsen, 2006), to save one woman from dying from breast

cancer 2.000 women will have to be screened every second year for 10 years (10.000 mammographies). Furthermore, for each woman who is saved 10 women will be overdiagnosed and undergo treatment for cancer without any benefit, and 200 women will undergo further investigations including needle biopsy due to false positive results from mammography. Advocates of mammography screening argue that the Nordic Cochrane Centre overestimates the proportion of women who receive a false positive result. However, a study from the Norwegian Cancer Registry published in 2010 (Kalager et al., 2010) indicates that the cost-benefit ratio of population screening for breast cancer with mammography is even higher than estimated by the Nordic Cochrane Centre. According to the study from the Norwegian Cancer Registry 12.500 and not 2.000 women will have to be screened for 10 years to save one woman from dying. The proportion of false positive answers leading to distress and unnecessary treatment will of course be correspondingly higher. As in all research, the analysis by the researchers at the Nordic Cochrane Centre and the Norwegian Cancer Registry are subject to uncertainty and controversy. But it is alarming that in most countries the target group of mammography screening has received very limited information about false positive answers and the resulting distress and non-beneficial cancer treatment. As long as this is so, the women in the target group cannot make sufficiently enlightened decisions about whether to participate or not.

Cardiovascular disease is another common cause of disability and death, mainly in the form of stroke and disease of the coronary arteries of the heart. Hypertension and high cholesterol levels are among the risk factors for cardiovascular disease. As hypertension and high cholesterol levels can be treated, identifying individuals with those risk factors and treating them appears to be a promising way to prevent cardiovascular disease. Although nationwide population screening programs have not been implemented, in many countries widespread screening activities are pursued to find individuals with elevated risk of cardiovascular disease. But what are the consequences of such screening? One highly relevant way of answering this question is to calculate how great a proportion of the population will be defined as being at risk and in need of preventive treatment according to the criteria used in the screening procedure. Unfortunately, when the current European guidelines for preventing cardiovascular disease were issued in 2003 and updated in 2007, their authors

did not include an estimate of their impact. Recently however, another group of researchers has performed a modelling study to calculate the impact of applying these guidelines to the adult population in the county of North-Trøndelag in Norway (Getz et al., 2005; Peturson et al., 2009). The results of this modelling study show that according to the European guidelines for the management of hypertension, nine out of ten women above the age of 40 and all men above the same age should be classified at medium or high risk for cardiovascular disease. Furthermore, three quarters of all adults in Nord-Trøndelag need medical treatment to prevent cardiovascular disease. And if this were to be achieved, it would be a full-time task for about 100 general practitioners per 100.000 inhabitants in a county currently employing about 90 general practitioners per 100.000 inhabitants. In other words, the impact of screening the adult population in a community currently enjoying greater longevity and a more extensive healthcare service than most other communities in the world would be staggering: Almost all persons from the age 40 and upwards would receive the stigma of being at increased risk of cardiovascular disease, and the costs of healthcare would escalate as three quarters of all adults would be in need of preventive treatment and the number of general practitioners would have to be doubled to provide this treatment.

4.4 The risk epidemic and the overwhelming task of keeping risk at bay

The understanding that every individual is at risk of developing disease and should take specific preventive measures has only recently come to the foreground of medical research and healthcare. Social psychologist John-Arne Skolbekken (1995) has demonstrated what he calls a “risk epidemic” in medical research. While in 1967-1971 the word “risk” occurred in the title or abstract of 0,1% of medical research papers indexed in MEDLINE, in 1987-1991 the same word occurred in 4,5% of all papers. For the leading generalist journal *New England Journal of Medicine* the corresponding figure rose from 0,2% to 10,3%. Thus, the concept of risk has come to play a central role in medical thinking. Epidemiological studies provide statistical evidence of an ever-increasing number of risks to health, and preventive

healthcare expands by incorporating many of these risks into its field of vision, seeking to identify risk in individuals and eliminating it.

As shown above with the examples of breast cancer and cardiovascular disease, the full implementation of screening programmes requires a tremendous mobilization among the population and in the healthcare services. Actually, so many screening procedures and preventive programmes are available and so many individuals are eligible for preventive treatment that prevention threatens to outrun available healthcare resources. Thus in 2003, it was estimated that to comply with the recommendations of the US Prevention Services Task Force, general practitioners in the US should spend 7,4 hours each day managing risk (Yarnall et al., 2003). In other words, the most enthusiastic approaches to screening and individually oriented prevention are not sustainable.

As mentioned earlier, the study from the Norwegian Cancer Registry indicates that preventing the untimely death of one woman from breast cancer with mammography screening requires that 62.500 mammographies are performed: 12.500 women must have their breasts x-rayed every second year for ten years. The benefit for the one woman is therefore based on an involvement of a very large number of women who do not get any benefit for themselves. According to Rose, one of the leading epidemiologists in the era of risk epidemic, this is the “prevention paradox”. In order to prevent a limited number of cases of disease or death, many more individuals must be involved than those who actually receive the benefit of not developing a disease from which they would otherwise have suffered. The prevention paradox points at serious challenges for population screening programmes. Because each individual is unlikely to benefit from screening and preventive treatment, it can be hard for doctors as well as individuals among the target population to find motivation to participate. Second, as the benefit for each individual is uncertain and the number of individuals receiving treatment is high, any considerable side effects can turn the balance of benefit and harm. Third, even if motivational problems can be surmounted and side effects are acceptable, the cost-benefit ratio of the population screening tends to be high.

A conceivable way of circumventing the prevention paradox might be to develop methods to increase the chances that each person will benefit from the screening procedure. This might for example be achieved if screening methods were available that would inform each person about

their increased or decreased risk for a wide range of serious diseases. Everyone would then receive preventive treatment that was “individualized” or “tailored” to his or her “risk profile”. If risk estimates can be differentiated more precisely and more specific preventive measures can be prescribed, motivational problems will be overcome and a greater proportion of individuals will actually benefit from prevention, or so the argument goes. Enter human genetics.

4.5 Genetic risk profiles

In recent years great expectations have been mobilized that human genetics will provide preventive medicine with new and powerful tools. While these expectations received maximum publicity at the time of the Human Genome Project at the turn of the century, policymakers and healthcare authorities still seem to hold strong hopes that research in human genetics will translate into improved preventive healthcare. The idea of individualizing prevention based on genetic information is central to these expectations, as is seen in this quote from the White paper on genetics published by the Government of the United Kingdom in 2003, with the title *Our Inheritance, Our Future – Realizing the potential of genetics in the NHS*: “Above all, genetics holds out the promise of more personalized healthcare with prevention and treatment tailored according to a person’s individual genetic profile” (Department of Health 2003).

Francis Collins, the influential leader of the National Human Genome Research Institute in the United States of America, has described instructively how prevention is expected to be “tailored according to a person’s individual genetic profile” (Collins 1999). In his vision of the *medical and societal consequences of the Human Genome Project* published in 1999, Collins makes it clear that he believes that soon genetics can be used to screen people for increased risk of many different diseases. In this paper Collins describes a hypothetical case situated in year 2010, in which a 23 years old man named John undergoes screening as part of a medical examination required for employment. John’s future health is then secured through different preventive measures based on the results of 15 predictive genetic tests for common and complex diseases. The account of this case is thoroughly optimistic:

“Confronted with the reality of his own genetic data, [John] arrives at that crucial “teachable moment” when a lifelong change in health-related behavior, focused on reducing specific risks, is possible. And there is much to offer. By 2010, the field of pharmacogenomics has blossomed, and a prophylactic drug regimen based on the knowledge of John’s personal genetic data can be precisely prescribed to reduce his cholesterol level and the risk of coronary artery disease to normal levels. His risk of colon cancer can be addressed by beginning a program of annual colonoscopy at the age of 45, which in his situation is a very cost-effective way to avoid colon cancer. His substantial risk of contracting lung cancer provides the key motivation for him to join a support group of persons at genetically high risk for serious complications of smoking, and he successfully kicks the habit” (Collins 1999, p. 36).

The predictive genetic profiling described by Collins and others is not yet to be found in population screening programmes in any country, and the technologies needed for its implementation have not been developed as fast as Collins suggested in 1999. Nevertheless, rough versions are already available from private companies.² The customer pays for the service and sends sample of saliva and mucus from the inside of her cheek to the company. A few weeks later she will be informed about her allegedly increased or decreased risk of developing any of up to 97 different conditions including Alzheimer disease, breast cancer, heart attack, lung cancer, and multiple sclerosis. She may for example learn that if she is a smoker, her genotype is associated with a relative risk of 1,07 of developing lung cancer. This means that her lifetime risk of developing lung cancer 7% higher than for smokers in general. According to the company providing this genetic analysis, it is known that 17 of every 100 smokers develop lung cancer, and it is estimated that for every 100 smokers who have got the same genotype as she has, about 18 will develop lung cancer. Similarly for many other diseases, the customer will be informed about being at a slightly increased or decreased risk due to his or her genetic makeup.

But how useful is currently available genetic risk information about common and complex diseases? The answer to that question is depressing. Firstly,

² Three of the most well known of these, named deCODEme, 23andME and Navigenics, appeared on the internet in 2007. Today, individuals must visit their doctor if they want to order the services of Navigenics, whereas the services of deCODEme and 23andME can be ordered directly by the consumer on internet.

by well-established scientific standards that are used for evaluating ordinary healthcare services, the clinical validity of this information is totally in the blue. Secondly, its clinical utility or usefulness for the purpose of improving the health of the public is probably non-existent. Based on the example above, this should not come as a surprise. The information that one has a relative risk of 1,07 for developing lung cancer is not useful – not any more than the information about a relative risk of 0,97 for developing lung cancer would be. To this date, no research by the companies providing this information or other scientists has demonstrated that genetic risk profiles are useful for improving health. On the contrary, available studies conclude that using currently known genetic markers of risk for common and complex diseases add nothing to conventional clinical methods. Furthermore, it is very unlikely that genetics will provide significantly better methods for screening for common and complex diseases in the near future.³

4.6 Catalogue of established and potential harms of screening

As explained above, the benefits of screening come at the cost of producing false positive results. But it should be noted that in addition to positive results that are later found to be falsely positive with definite testing, screening also leads to overdiagnosis, i.e. the diagnosis of “disease” that would otherwise not go on to cause symptoms or death. According to a recent article in the Journal of the National Cancer Institute summarizing current evidence about overdiagnosis in cancer screening programmes, the magnitude of overdiagnosis is “about 25% of mammographically detected breast cancers, 50% of chest x-ray and/or sputum-detected lung cancers, and 60% of prostate-specific antigen-detected prostate cancers” (Welch and Black, 2010).

³ For an overview see for example the report issued by the leading UK centre for public health genomics: PGH Foundation 2010. For studies about genetic markers for two different clinical conditions see Blinkenberg et al., 2010 and Paynter et al., 2010.

But when balancing the pros and cons of screening, it must also be taken into consideration that increased awareness of risk through screening can have adverse effects for individuals not experiencing symptoms of disease. There is ample evidence that this is the case (Stewart-Brown and Farmer, 1997), but unfortunately the extent of such adverse effects is not sufficiently well known. Several studies have shown that people found to be at risk suffer psychological stress and perceive themselves as weak and vulnerable. For example, women receiving false positive results from mammography screening suffer high levels of anxiety, which do not resolve immediately when definite testing (biopsy) shows absence of disease (Advisory Committee on Breast Cancer Screening 2006). Similarly, a recent study from Denmark showed that women who learn from bone scans that they are at risk of developing osteoporosis tend to draw the conclusion that their entire bodies are weakened, and become uncertain and restricted rather than empowered (Reventlow et al., 2006). On the other hand, anxiety resulting from information about risk tends to decline with time, and it is not known to what extent anxiety or perceived vulnerability are harmful to those who are told that they are at risk. The gratitude frequently expressed by participants in screening programmes is taken by some as an indication that these disadvantages may be acceptable.

One line of argument that adds weight to the concern that risk information can be harmful comes from a body of evidence demonstrating that people's perceptions of their health predict how their health will develop by objective measures. Several studies have shown that self-perceived health is an independent and reliable predictor of future health. For example, even when account has been taken of cholesterol level, smoking status and other cardiovascular risk factors, people who perceive themselves to be in poor health are more likely to develop and die from cardiovascular disease than are those reporting that their health is good (Heistaro et al., 2001; Moller et al., 1996). This does not in itself prove that information that makes people reconsider their beliefs about their own health actually has a causal effect on health by objective measures. Nevertheless, the evidence cited above suggests one potential negative effect of risk awareness on health.

Finally, when looking for side effects of screening programmes and risk the risk epidemic, a societal level of analysis is relevant. I will only briefly indicate one problem at this level, namely the danger that screening and individually oriented preventive treatment are used unsuccessfully

ly to manage challenges that require ring social or political approaches. This is the danger originally described in 1975 by Ivan Illich in his book about medicalization or iatrogenesis (Illich 1995). An unwarranted focus on screening and individual prevention may actually result in the depoliticization of such challenges and erosion of the cultural resources required for managing them. I will take a contemporary example to briefly illustrate this. In Norway, healthcare and teaching personnel working with children at pre-school and school age are currently receiving instructions to screen all children for obesity and psychological disturbances. However, the fundamental problems those need to be addressed to end the obesity epidemic lie at a political and societal level, having to do with structures of consumption and transportation among other things. While it is possible that some children benefit from being identified at an early age as obese, screening programmes for the detection of obesity are part of a “downstream” approach that may inadvertently take focus away the “upstream” causes of this serious problem. Similarly, observing and evaluating children for psychological disturbances, and then referring many of them to professional treatment are highly questionable. The quickly rising proportion of minors labelled as having psychological problems indicates that the criteria used to distinguish between normality and deviance are inappropriate. The professional management of light psychological disturbances can take focus away from the societal and cultural causes of such disturbances, and undermine the resources within families and local communities to prevent and manage these disturbances. In addition it may result in reducing the amount of professional resources available for those with serious psychiatric diseases.

4.7 Better safe than sorry and individual empowerment – *Mundus vult decipi*

Although any healthcare intervention has its price, screening programmes are sometimes presented as if they were good beyond question. The rhetoric used frequently combines the “better safe than sorry” and “individual empowerment” – appealing to the responsibility of the citizenry to do everything within their power to avoid disease. And our common fear of deviance, suffering and death provides a strong motivation to believe in

screening. This is the “power of goodness”: When offered reassurance invested with the cloak of science, we are strongly inclined and swayed by psychological forces to perceive the offer as trustworthy and beneficial. Unfortunately, many current and proposed population-screening programmes do not meet those criteria.

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Health Responsibility and Life Style

5. Public health, climate change and ethics

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5.1 Introduction

Climate change is our most important public health issue. Margaret Chan, the current Director-General of the WHO, has put it well: “Every century has its own public health challenges; climate change is our century’s challenge” (WHO 2010).

5.2 Public health and climate change

Human disease and climate change are related in ways that bear directly on adaptation to and mitigation of climate change (Faergeman 2007). There are diseases that are caused by or worsened by climate change, and there are diseases that share causes with climate change.

The first group includes heat stroke, vector-borne infectious diseases, allergic diseases, trauma, malnutrition, and psychiatric diseases. Health systems of the world must adapt themselves to these consequences of global warming.

The second group includes cardiovascular diseases and respiratory diseases as well as certain cancers, because they are due, in part, to the same activities that emit a lot of greenhouse gases. Eating large amounts of meat, for example, raises the risk of cardiovascular disease and cancer (Sinha et al., 2009), and production of livestock is an important contributor to global warming (Steinfeld et al., 2006). Similarly, burning fossil fuels and biofuels produces not only CO₂ but also air-borne particulate matter

that contributes to cardiovascular and respiratory disease (Pope et al., 2002). Climate change can therefore be mitigated by measures that also reduce risk of this second group of diseases.

These relationships have been extensively reviewed by others (McMichael et al., 2007; Costello et al., 2009), and public health professionals as well as clinicians have good reason to be interested in our century's public health challenge. In this paper, however, I want to argue that we must also be interested in our apparent inability to mitigate climate change and thus the health consequences of disastrous climate change. After two years of work, the Intergovernmental Panel on Climate Change published its first report in 1990, and the problem has only been getting worse and more intractable since then.

There are two kinds of reasons for this paralysis as far as I can see: first, the way we think about looming calamities such as climate change, and, second, the way we have organized ourselves in complex, corporate societies. The two are obviously related, and public health and public health ethics are important parts of these larger issues.

5.3 Thinking about climate change

We seem to entertain three main lines of thought. According to the first line, climate change is either not happening, or it is happening as a natural phenomenon that we can observe but not affect. Many US Congressmen subscribe to this school of thought (Oreskes and Conway, 2010; Nature, 2011). According to the second school, climate change is happening, it is due mainly to human activity, and we can prevent climate disaster by a host of new techniques and measures that stop short of austerity. This is the position taken by governments and industry that say they trust the optimistic of the various scenarios for climate change delineated by the Intergovernmental Panel on Climate Change (IPCC) (Pachauri and Reisinger, 2007). Finally, according to the third school of thought, climate change is happening and climate disaster looms unless we do far more than envisaged by government and industrial planners. This is the thinking of most climatologists, not least James E. Hansen (Hansen et al., 2008), and it is the point of view argued by journalists like George Monbiot

(2007). It is also central to activist movements such as 350.org, founded by Bill McKibben (www.350.org).

Some of us are firmly rooted in one of these thought lines, but others jump from one to another, and a few, nimble-minded and three-legged, have one foot in each camp. As we know from psychology and indeed psychiatry, our wonderful illogical brains can entertain countless ways of thinking that are mutually exclusive. According to a well-known anecdote, Niels Bohr had a horseshoe above the door in his summer cottage, where Max Delbrück came to visit. On seeing it Delbrück exclaimed, "Why Professor Bohr, I had no idea that you are superstitious! You actually believe that horseshoes bring luck!" Bohr replied that he was not in the least bit superstitious, but that he had been told that horseshoes bring luck even if you don't believe in them (Favrholdt 2009).

Such is also the nature of the roles we play within our social and political institutions. In a report to Agence France Presse on August 25, 2009, Marlowe Hood asked Rajendra Pachauri whether he supported calls to keep atmospheric carbon dioxide concentrations below 350 parts per million (ppm). "As chairman of the IPCC," he said, "I cannot take a position because we do not make recommendations, but as a human being I am fully supportive of that goal. What is happening, and what is likely to happen, convinces me that the world must be really ambitious and very determined at moving toward a 350 target" (Hood 2009).

So what is happening, and what is likely to happen? A non-expert reading of the literature tells us that global mean temperature has probably increased by about 0.8°C over the past 100 years, and that warming continues, largely due to emission of greenhouse gases from human activity. The most important greenhouse gas that we emit is CO₂, which now contributes about 390 ppm (parts per million) to the composition of the earth's atmosphere. That concentration is rising at more than 2 ppm per year. The European Union and other political bodies have decided that disaster can be avoided if mean global warming is limited to 2°C above preindustrial temperatures (Commission of the European Union 2007). Even that degree of warming is likely to precipitate irreversible climate change, however, and the way things are going, a decade into the 21st century, we can expect 3°C to 4°C of warming. That will require what scientists now call "transformative adaptations" on our part (New et al., 2011).

Warming of the planet has numerous consequences for marine and terrestrial life, almost all of them undesirable from the point of view of humans and many other species. The calamities already happening, with more in store, include draughts, floods, storms, heat waves and rising sea levels. We must anticipate scarcity of food and water as well as new ways of life for insects and microorganisms that cause diseases of animals and humans, mass migrations of countless species of plants and animals including humans, and collapse of the many complex ecosystems on which our civilisation depends. A few generations down the road, our descendants might have to live in a world quite unlike the one we know.

Informed guesses about that future world can be made in part from paleoclimatological data. In its latest report, the IPCC wrote that the mid-Pliocene epoch (about 3.3 to 3.0 million years ago) is the most recent time in Earth's history when atmospheric CO₂ concentrations were between 360 and 400 ppm and mean global temperatures were substantially warmer for a sustained period (2°C to 3°C above pre-industrial temperatures). At that time sea levels were at least 15 to 25 meters above modern levels (Jansen et al., 2007).

Of the many consequences of global warming, rising sea levels are interesting for inhabitants of low-lying countries like my own, Denmark, and the water is rising slightly faster now than it did a few decades ago. Over the past 50 years or so, the rates of rise have increased from 1.8 to 3.1 mm/year or more, as the effect of melting glaciers and ice sheets has been added to that of the thermal expansion of water (Copenhagen diagnosis 2009; Nicholls et al., 2011). A possibility of particular concern is rapid disintegration of the ice sheets covering Greenland and West Antarctica, a non-linear process that could cause sea levels to rise at still higher rates, for example 50 mm/year ~ 5 meters/century. A phenomenon of this kind, known as a melt water pulse, probably occurred about 14,000 years ago (MWP-1A), at the end of the last ice age. In geology, a "pulse" can last a few hundred years – good to know for people in public health and medicine.

In contemplating the data and the many non-linearities or "tipping points" that could be involved in climate change, scientists realize that the goal of limiting global warming to < 2°C above preindustrial temperatures is not enough. Even a < 1.5°C goal, mentioned in the Copenhagen Accord of 2009, would not necessarily be enough to avoid irreversible climate change. Drawing on climate modelling, direct observations and, in particu-

lar, the paleoclimatological data, James E. Hansen has argued, convincingly in my non-expert view, that we must adopt a goal of reducing atmospheric CO₂ to less than 350 ppm if our descendents are to have a chance of living on a planet with the kind of climate in which human civilisation has evolved (Hansen et al., 2008). Hansen has proposed that, of all the things we could do, the most important would be to levy taxes on carbon at the source, high enough to make wind and solar energy profitable. We could then leave most of the remaining fossil fuel carbon in the ground, and with afforestation (creating new forest) and other measures we might be able to stabilize and then slowly lower CO₂ to less than 350 ppm.

And what if we don't? A series of recently published papers looks at a world that by 2100, or even by mid-century, could be 3°C to 4°C warmer than ours (New et al., 2011). In one paper, Anderson and Bows observe that "there is now little to no chance of maintaining the rise in global mean surface temperature at below 2°C, despite repeated high-level statements to the contrary. Moreover, the impacts associated with 2°C have been revised upwards, sufficiently so that 2°C now more appropriately represents the threshold between dangerous and extremely dangerous climate change" (Anderson and Bows, 2011).

Non-linearities and unpredictable amplifications of effects increase with further warming. The exercise of looking at a much warmer world is therefore inherently difficult, but, couched in careful language, the descriptions of our prospects imply such problems for public health that the idea of public health could lose its meaning.

If this third line of thinking is the right one, as I think it is, why do we not act on it? In a well reasoned analysis, William E. Rees (2009) argues that mainstream economic thinking compounds a fundamental biological characteristic. All species, including humans, expand to occupy all accessible habitats and to use all available resources unless or until constrained by negative feedback. In the competition for habitat and resources, evolution favours individuals who are most adept at satisfying short-term needs even when negative consequences down the road are obvious. In other words, a tendency to discount the future has evolved by natural selection. Rees argues that the consequences of that biological trait are then worsened by the idea of continuous economic growth, an idea that became important to economic thinking only in the middle of the past century.

Any high school student, not to speak of any physician or public health expert, can appreciate that annual percentage growth in the exploitation of physical resources is incompatible with finite physical resources. Yet the concept of exponential economic growth, even that based on exploitation of physical resources, is not questioned by mainstream economists or political leaders. Why not?

5.4 Complex corporate societies

The COP 15 in Copenhagen in 2009 (15th Conference of the Parties initiated by the 1992 United Nations Framework Convention on Climate Change) was a failure. The Copenhagen Accord, an agreement engineered by the United States, reversed the United Nations approach of seeking unanimous agreement between countries. Instead it asked each country to make a pledge to cut its greenhouse gas emissions, and a majority of countries have now done so. The current pledges mean that there is a greater than 50% chance that global warming will exceed 3°C by 2100 (Rogelj et al., 2010). The COP16 in Mexico in 2010, less obviously a failure, nevertheless produced no substantial improvements, and for the time being national governments and the UN have been unable to provide leadership.

I am neither political scientist nor economist, but even a simple physician can observe some of the mechanisms of institutional paralysis. For what it's worth, here's what I have observed. In my country, Denmark, agriculture, livestock production in particular, accounts for an important part of the country's emissions of greenhouse gases. The Danish government's Ministry of Food, Agriculture and Fisheries therefore commissioned a university report on agriculture and climate change, but it required that recommendations were not to include changes in the organization of Danish agriculture or in the production of food, most of which is exported. The university report therefore explicitly excluded a reduction in livestock production from its recommendations (Olesen et al., 2008).

The three institutional players here – government, university, and industry – are closely related. The current Minister, for example, with responsibility for regulating agriculture and the food industry, was until 2007 vice-chairman of the organization that represents agricultural and industrial interests (the Danish Agriculture & Food Council). The ministry

is also an important source of funding for the departments at the University of Copenhagen and the University of Aarhus that produced the report on climate change and agriculture. So, at least in Denmark, close relationships between government, industry and university ruled out the most obvious way to reduce emissions of greenhouse gases from agriculture: producing fewer cows and pigs. Relationships of this sort characterize the corporate state. That's not always bad, but in this and many other cases, the resultant of the forces involved has been paralysis of a process that, by any measure, could have been good governance.

I have tried to make two arguments in this paper, and they come together here. The second line of thinking, namely that we can deal with anthropogenic climate change with new industrial methods ("new technology") and a modicum of support for poor countries, is almost certainly wrong. Since it is logically compatible with the equally dubious idea of perpetual economic growth, however, it is the idea adopted by the corporate state, in which industry, agriculture, university and state form an organic whole.

The question for public health is how to serve the real and long-term interests of the public within the corporate state. In my view, the answer must be to accept a responsibility to study and understand these issues and to influence government policies for adaptation to and mitigation of climate change. Public health authorities have avenues to do that, and public health experts without such avenues have a responsibility to take part in professional and public debate about climate change and policy as well as they possibly can.

5.5 Ethics

Corporatism implies interesting ethical problems. Whoever or whatever made us, he, she or it seems to have locked ability to be compassionate into our genes, and we are most often fairly kind to family and all who resemble us. For those who don't, things are a little different of course, hence the parable of the good Samaritan. And for huge chunks of people such as the people of cities and countries and continents and corporations, we come up with more sophisticated ethical systems. Hence the volumes and volumes of the philosophy of ethics. There are consequentialist ethics

and deontological ethics, there are ethics for medicine and for the military, ethics for farming and for industry, and ethics of all kinds for just about any institution you can think of. Within the corporate state, the government civil servant or the politician, familiar perhaps with the ethics of good governance, is chummy with the industrialist who might know his ethics of corporate social responsibility or, more probably the ethics of his responsibilities to shareholders.

Ethics quickly become complicated, we can be stopped in our tracks if we think and talk about them, and simplification is clearly needed when things get serious. Climate change, like nuclear war, threatens human civilisation. One difference between the two is that the latter won't happen unless we do something stupid, whereas the former will happen unless we do something smart. Another is that nuclear war will kill us who live now, whereas disastrous climate change will make life unpleasant or impossible for our descendents. James E. Hansen (2009) has written about that moral twist, the intergenerational injustice of condemning our children's grandchildren, perhaps our own grandchildren, to such difficulties.

The 1955 Russell-Einstein Manifesto puts it well (Born et al., 1955). In contemplating the dangers of nuclear war, Bertrand Russell and Albert Einstein and nine other scientists signed the document that had a simple message: "remember your humanity, and forget the rest." That simplification of ethical philosophy also covers our choices, including our choices of public health policies, in times of climate change.

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6. Obesity: a personal illness or a public problem?¹

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6.1 Introduction

Those who pay attention to the public debate on obesity soon notice that it is shaped in a certain way. Obesity is commonly described as one of the most serious health problems of the present day. Phrasing the problem in this manner suggests that obesity is a situation that leads to a disease, diminishing the quality of life for the person involved, or quite simply it defines obesity as a disease in and of itself. Those who are obese are therefore conceived as imminent or current patients, in need of assistance from health professionals. This view would suggest that the fight against obesity is primarily the task of the health system.

We see this view on obesity clearly in theoretical and scientific debate. Most of what is written on obesity is in the field of public health and medicine. An interesting example that describes both the epidemiology of obesity and possible treatment is the article from Wechsler and Leopold from 2003 called "Medical management of obesity," published in *Langenbeck's Archives of Surgery*. The article is in many ways typical for articles within medicine addressing the subject. The authors commence by looking at epidemiological facts on obesity where they claim that the prevalence is

¹ This is based on a public lecture given in Reykjavík 4th. Dec. 2008: "Ofitta – sjúkdómur einstaklings eða vandi samfélags?"

highest in countries like the US, UK and Germany, where more than half the population is overweight or obese (Wechsler and Leopold, 2003).

The article goes on to describe the dangers of obesity; obesity leads to diseases that diminish quality of life and can further lead to an early death. The main focus of the article from Wechsler and Leopold centres on possible treatment for obesity. The authors view the task from a German perspective and suggest solutions, which they think, should be adopted in Germany. They conclude by saying that to succeed in treating obese individuals it is necessary to structure a team to treat each individual patient. The team should have a doctor, a psychiatrist, a physiotherapist, and a nutritionist. The treatment should preferably take place in special institutions and it is important for long term success that the treatment is over a long period of time. They conclude by saying:

“The treatment period should be at least 6 months or, better, 12 months. Weight-loss drugs should be used for a limited period (6–12month) and in a weight-loss program including diet and physical activity. Patients with severe and therapy-refractory obesity should have a surgical intervention according to the guidelines published by the World health Organization... Specialized hospitals and treatment centres for outpatients should take care of the 60% of the population suffering from overweight and obesity.”

This paragraph, especially the final sentence, is worthy of some consideration. It raises serious questions about the medical view on obesity. I do not doubt the gravity of the fact that a large portion of the population of many nations is overweight or obese, nor do I doubt the causal link between obesity and many diseases. On the other hand ideas such as these raise some serious questions. Is it useful and is it right to regard obesity as a disease that leads us to define up to 60% of the nation as patients? To answer this question I approach the subject both from the view of medicine and from the view of ethics, focusing on the autonomy of the individual and the good life. The key to dealing with any problem in a sensible way is to describe it correctly. Without a correct description and a sound understanding of an issue the proposed “solutions” will at best be of little use and will at worst increase the difficulties. I will try to show that the tendency to regard obesity as a health problem, thus making it primarily the task of medical professionals, will lead us on the wrong track and make it more difficult for us to find realistic and sensible solutions. This

does not necessarily mean that health science and medicine do not have a role in the fight against obesity. It simply means that obesity is not the kind of problem that is only for specialists to solve. On the contrary it is a problem that should be addressed both by the individual and the society as a whole.

6.2 The medical approach

What sort of a problem is obesity? Let's view how modern medicine defines it. Overweight is defined as BMI (Body Mass Index; $\text{mass}(\text{kg}) / \text{height}(\text{m})^2$) in the range of 25–30. Obesity is when BMI is above 30. Both overweight and obesity are the consequence of more energy intake than energy need. The overweight and obese individuals fail to expend more calories than they consume. There are certainly those who maintain that the problem is more complex than this (see e.g., Thomas 2008; Vasilakopoulou and Roux, 2007), but for the sake of this argument I will treat the aforementioned as an undisputed fact. The question I will rather focus on is how are we to interpret this fact? The medical view on being overweight and obese is based on the fact that this imbalance is situated first and foremost within *the individual* and therefore it is crucial to treat the individual to gain the right balance. This way of viewing the problem has deep roots within medicine. The medical doctor is trained to focus primarily on the patient. The patient is defined as a person that cannot deal with his problems on his own. He seeks help from the doctor by placing the problem in his hands. The idea of *the Patient* is closely related to the idea of the one who is *passive* and *patient* and bears his *sufferings* in silence.² The role of the doctor is to use methods that he masters to treat or change the one who suffers and is ill, e.g. by using drugs or surgery. When the doctor focuses on obesity he behaves accordingly. In his view obesity is located in the individual that suffers from obesity. The individual is not normal. The problem is solved by changing this particular

² Britannica World Language Dictionary: "patient: ...1.A person undergoing treatment for disease or injury. 2. Anything passively affected; the object of external impressions or actions: opposed to *agent*...[<OF *pacient* <L *patiens*-*entis*, ppr. of *patiri* suffer]

individual, by making him undergo the right treatment. Based on these premises the conclusions of Wechsler and Leopold, as discussed earlier, are quite logical. They conclude that 60% of the German population are patients that are in need of long-term treatment in specialized clinics. This view is a logical consequence of the assumption that everyone who weighs too much is a patient in need of personal treatment. From this perspective the medical doctors of Germany face an enormous problem: to treat 60% of the population with medicine, surgery or some kind of behavioural modification.

The medical approach puts a huge cost and strain on the health system by defining all who are overweight and obese as patients and attempting to treat them as such. Not only is this way of dealing with the problem difficult, but also it has not proven to be fruitful. Medical treatment for obesity has not been successful and on some occasions it has even been harmful. Treatment plans that consist solely of giving people advice on how to change their diet and exercise more are not working (Abramson, 2005). If nothing else is done during treatment it can be assumed that 90–95% of those who lose weight on a regular diet will be back to their original weight within a matter of years (Wooley and Garner, 1994). Even worse, there are some findings that indicate harm being done by trying to lose weight and failing. This can result in the individual's loss of self-confidence and self-esteem. It has also been noted that although the patient seeks advice from the doctor, entrusting him with the problem, there is a tendency to blame failure on the patient. Wooley and Garner (1994) describe medical treatment for obesity in the following way:

“...Prejudice is revived daily in the routine interactions of doctor and patient in which patients are offered dietary treatments and fail to benefit from them. This ongoing failure demands a culprit: either treatment is flawed or the patient is flawed, failing to comply with the appropriate remedy. As the more credible medical profession is refusing to blame its prescriptions patients are left to absorb the stigma failure. We should stop offering ineffective treatments aimed at weight loss. Researchers who think they have invented a better mousetrap should test it in controlled research before setting out their bait for the entire population. Only by admitting that our treatments do not work-and showing that we mean it by refraining from offering them-can we begin to undo a century of recruiting fat people for failure.”

The authors of this article are blistering in their description, but with reason. 15 years have passed since this was written and yet we have not

come any closer to solving this problem with medicinal methods. By viewing epidemiological figures the obesity problem on a global scale has never been more serious than at present. Still, we are faced with offering treatments that do not show good results, and still the responsibility is placed on those that are obese. We need to face the fact that doctors have, over the last few decades, failed to cure the obese patient and they have failed to lower the prevalence of obesity in the society. It is urgent to re-think this matter and seek new methods and solutions.

6.3 The “obesogenic environment”³

One way out of this dead end of medicine is to take a broader view, look outside the individual and simply ask: Why do most people consume more than they need? This question directs our attention to the context that we live in. We live in a society where individuals do not need much energy and have easy access to high energy food. Can we change this context? Instead of constantly focusing on how to change the appetite of the individual with medicine, surgery or behavioural modification we can ask: “What is it in our surroundings that changes the energy balance of the body in a healthy individual?” To take a better look at this view it is necessary to highlight what we know about the influence of our surroundings on obesity.

In an overview article on obesity in children and adolescents it is stated that time used for motion in schools has dramatically decreased in the US over the past 15 years (Spear et al., 2007). According to the article, the recommended amount of moderate to intense physical activity for children and adolescents is at least 60 minutes daily. The same article states:

“Safety concerns, such as heavy traffic and high crime rate, lack of equipment, lack of space, and urban development that favours vehicular transportation are barriers to activity outside school. The World health Organization has identified transport-related physical activity as an important intervention with which to address the global obesity epidemic, as well as environmental issues such as traffic congestion and its associated pollu-

³ This term is taken from Greener et al., 2010.

tants. In the United States, a decrease in transport activity parallels the increase in paediatric obesity. Walking or biking to and from school can help students meet their physical activity needs. However, heavy traffic, lack of bicycle lanes, unmarked intersections, and other obstacles have reduced the number of children who transport themselves to school today, compared with previous generations.”

In an environment where children’s safety is of concern, e.g. in areas affected by poverty and high crime rates, it is more common that children spend more than two hours a day sitting in front of the television.

Studies from the US also show that there is a clear connection between the opportunities a person has to exercise in daily life and the prevalence of obesity. Those who live in surroundings where the possibilities for motion and outdoor activities are not available tend to be heavier than those who live in neighbourhoods where this is possible (Spear et al., 2007).

In some societies it appears more difficult to stay in normal weight, as compared to other societies. In the UK and in the US the problem of obesity has increased faster in recent years than in other countries. Now about two-thirds of adults in these countries are overweight or obese (66,90%, 66,30%) (WHO). A counterexample would be Norway where the problem seems to be a little better controlled where “only” about a third of the population is overweight or obese (33,40%). The main explanation for the difference between these nations seems to lie in different social structures and thereby different environments. In an editorial in the *British Medical Journal* 2002, David Crawford (2002) writes about means to prevent obesity. He refers to research that state that the environment we live in influences, and at present directly increases, the obesity problem (Hill and Peters, 1998; Jeffry 2001; WHO 1998).

It must be noted that my understanding of the concept “environment” is very broad. By environment I mean those things in your life that you, as a person do not control, as they are controlled by outside factors. They can be the results of political decisions or decisions by public institutions or private companies. In short, I am referring to construction and design of public places, means of transportation, access to healthy food at work and in schools, and even the acceptance of the attitude that exercise and motion are a normal part of everyday life in the structure of the school day and the arrangement of our work facilities.

The reports and articles that I refer to above all point to the conclusion that by changing our environment we can control the prevalence of obesity in the community. Now it may well be the case that some of you are getting tired of listening to this view, that we humans are beings without any free will. It has been stated that by changing the environment we can control the consumption and behaviour of every human being. Are we then controlled by our environment? I do not think I am contradicting myself when I say that nothing is farther from my belief. I believe we can as persons take control ourselves and rise above that. By highlighting these facts I am simply saying that one consequence of viewing obesity as a personal disease is that it makes the problem of the environment invisible. Another consequence of looking at the problem as a personal disease is that it changes the obese person into a patient. The responsibility and capabilities required of the person to tackle his or her problem is therefore grossly undermined because the doctor is supposed to cure the patient, patients are not supposed to cure themselves. The solutions offered by medicine do not attack the real root of the problem, as they are solely aimed at the symptom, which in this case is the fat individual. This is one of the two reasons it is wrong to look at obesity as a disease. Let us now turn to the other reason; how medical treatment for obesity can harm the individual.

6.4 How can medical treatment for obesity be harmful?

As mentioned above the way we lead our daily lives has changed tremendously in the last decades. There are a multitude of factors that seem to encourage us to increase consumption, to take in more food, and thus energy, while at the same time our possibilities for motion and exercise in daily life have diminished. How can we as individuals gain better control over our lives and prevent this imbalance from damaging our health and quality of life?

My thesis, and the core of my argument, is that although the root of the actual problem we are facing is in our environment, the solution to which is primarily changing the environment and making it a better place to live in, we should be careful not to undermine the possibilities that individuals have to change their lives and the situation in which they live. We are all

capable of remaking ourselves, of expanding our possibilities and changing our lives for the better. To do that we need self-confidence and faith in the possibilities of life. No theory aimed at understanding our lives should cast any doubt on our ability to know our own way to happiness. Everyone, especially those who are struggling with their weight, have to believe in themselves and have faith in the belief that they can shape their lives. This inner strength is necessary so they can fight the influence that the environment has on their health. It is exactly here that the medical view on obesity can be harmful. By viewing obesity as a disease that can be cured we strengthen the impression of overweight or obese people that they cannot, of their own volition, gain control of their lives and live them in normal weight. These people are led to believe that they need professional supervision, medicine, surgery, or behavioural treatment, in order to gain control of their lives. This “medicalization” of obesity is closely related to the paternalism so often connected with medicine. Medical solutions, in the case of obesity, are too often characterized by giving people advice that they have no means to follow, and by doing so the supposed treatment does nothing but undermine their self-confidence and self-control, increasing the sense of helplessness. The fat individual as a patient can therefore end up in a much worse situation than the fat individual as just a person. As a patient the fat individual bears the shame of bad results, making it even more difficult to face the problem.

6.5 If obesity is not a disease, what is it then?

Throughout this talk my underlying question has been: “*Is obesity a disease?*” I have outlined the two main reasons why we should not view obesity as a disease. The first is that this view makes the real problem invisible, and second, it can be harmful to the fat individual. Let’s look at the question in more detail. The definition of a disease has been much debated over the last decades. Disease tends to be defined by the relation to the sick individual, not to some situation in the society as a whole. Historically disease is related to individual sufferings and we show compassion with those who are ill. The role of the doctor is to cure and to care. He takes on this role by reacting to the sufferings of his fellow man (Jonsen,1990) By relating the obesity problem to a disease and to the patient we personalize the problem.

Thus obesity becomes primarily the problem of those who suffer, and of those who are in need of our compassion, that is, it becomes the problem of the obese individual. We are diverted from looking at obesity as a problem of society as a whole, which would allow us to see it as a problem for everyone, regardless of weight. Specialist knowledge on the “disease” of obesity resides among health professionals. The solution to the problem becomes the subject of health professionals but the responsibility for the problem has a tendency to lie primarily with those who are too fat.

In this article I am attempting to show that the medical view of obesity is a shallow way of facing the problem. It has much deeper roots and we will not be able to solve it if we only look at it as a health problem and a personal problem of those who suffer from obesity. This narrow way of defining the problem hinders us from finding solutions. To solve it we must regard increased obesity as a signal, indicating that there is something wrong in our way of life. Instead of saying that obesity is a disease, we could just as well say that at present being fat in fact signals a healthy response from the body in Western societies. The body reacts to its environment in exactly the way nature expects it to in the given situation.

When asked if obesity is a disease my answer is, quite simply, no, obesity is not a disease, at least not a disease of individuals. It is on the other hand an indication of a deep-rooted problem in society, and could even be described as a disease of society (Hjörleifsson, 2004).

Increased incidence of obesity is in no way some private matter of those who are too fat. It is of concern to all of us. Those who are fat show us the problem. They themselves are not the problem, but they do make it visible. We could say that obesity is much rather a sign of an ethical problem, than a personal disease. It is an ethical problem because in its worst form it prevents us from living the good life. Furthermore, we can say that the problem is not only the problem of the present but it also points to the future. Children today are living in environments that lead to obesity. Children are those who are most sensitive to changes in the environment.⁴

⁴ “Time to supersize control efforts for obesity” (editorial), *The Lancet*, 370(2007):1521. In this editorial the author claims that in the last ten years the prevalence of obesity in Britain has increased 30% among women, 40% among men and 50% among children. (taken from Lancet’s webpage, 28th. April. 2011: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(07\)61639-0/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)61639-0/fulltext)).

It is not a coincidence that the incidence of obesity is increasing faster among children than in other age groups, faster than we have ever seen before. Their position is much worse than the position of the adults. They neither have the necessary control over their own lives to avoid becoming overweight or obese, nor do they have the knowledge or inner strength necessary to avoid becoming too fat in the environment they are placed in. Those who shape this environment are responsible for changing it. This change needs to be made on a societal basis and is therefore outside the sphere and the reach of the health care professional and the family. We have to take increased obesity among children as a serious signal of something inherently wrong in our society. It is ethically wrong to raise children in such an environment that sentences an increasing proportion of them to an overweight and obese life. It cannot be emphasized too much that the responsibility for this is not on the children that do not exercise enough and eat too much. The responsibility is on the family. It is in the hands of those who structure our neighbourhoods, organize our transportation, and run our school system. It is the responsibility of the food industry and it is in the hands of the politicians. In fact all adults, parents and non-parents alike, share in this responsibility. We need to shape our society in such a way that it is possible for us all to lead a healthy life. The point I am making in this article is not original in any way; there exists much knowledge on this subject already. If the words “overweight and environment” are entered on Google the result was at least 3 million hits in January 2011. A lot we can also derive from our common sense. The biggest step is to admit the real root of the problem and go from there in our search for solutions.

What then is the conclusion of these writings? The first conclusion is that to be able to make any progress against the problem of obesity it is necessary to approach the problem differently. We must not emphasize the traditional approach of medicine and we must phrase it in a different way. We need to see it primarily as a societal problem and not as a problem of the fat individual. We need to view obesity as a signal, indicating an environment where it is not possible for the majority of those living there to lead healthy lives. We need to make the responsibility for that political. Those who are responsible are those who structured this environment, not the children and the adults that grew fat in it.

Two things flow from this way of thinking. First, the view discussed here is a necessary foundation for the social solutions that need to be created; solutions that make it easier for people to live a healthy life. In other words fewer individuals will lose control over their weight. Second, this view will take the responsibility of the problem from those who are fat and free them from the shame they live with in today's society. The personal influence of that sort of freedom will empower them to gain better control over their personal life and might even make it possible for them to change their weight.

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7. Fair versus Efficient: Debunking a False Dichotomy

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7.1 Introduction

In August of 2010 the Nordic Committee on Bioethics held a conference, in Reykjavik, on ethical issues in public health. Life style, as well as common diseases and other health issues, was on the agenda. In the conference program the following question was posed: „What are the most efficient and fair ways to deal with these problems?” The fact that this question seems anodyne to the average reader betrays the fact that not only the general public, but health professionals and other scholars as well presume that efficiency and fairness – stand-ins for economics and ethics – are, as the question implies, separate phenomena, or perhaps even opposites.

I hope by the end of this chapter to have persuaded you that this widespread view, based on some understandable misconceptions, primarily about the nature of economics, is misguided: that efficiency is one of multiple possible ethical barometers that we can use for individual and societal guidance; that the field of economics is, in effect, only one of many fields encompassed by a unifying ethical paradigm.

Fragmentation is a tool often used to model and understand complex phenomena. As far back as Aristotle, theories about the relation of parts to the whole have been an integral aspect of scientific research and experimentation. When it comes to scholarly work, it is vital that one understands the logic of, and thus be able to recognize and identify fallacies about, the relation of parts to the whole. This is such a fundamental ele-

ment of human perception that we manage to express it verbally, and to avoid making nonsensical associations of the two: for instance, most of us would almost instinctively balk at the phrase “dogs and animals” or “tables and furniture”. As people are obviously competent in recognizing the predicament in such presentations, I assume that a similar listing of a set and a subset – the pairing of ethics and economics or efficiency and fairness – is based in something besides the language comprehension. Thus it seems to me that the reason as to why dichotomization of ethics and economics or efficiency and fairness does not strike the average person as equally odd stems from a fundamental misunderstanding of the nature of each element and therefore of their relationship as well. In these next few pages I hope to shed some light on this relationship, with special regard to issues in public health.

7.2 What is the proper placement?

The concept of ethics has generated many schools of thought. Virtue ethics, associated with Aristotle, emphasizes the character of the moral agent, whereas John Locke rooted them in natural rights, and Immanuel Kant, only a century later, in duty. Some have argued the case for consequentialism: that is, that the consequences, good or bad, of a given action are the only valid basis for judging that action: in other words, the end justifies the means. Consequentialism is usually distinguished from deontological ethics, in that the latter determines whether a given deed is morally right or wrong on the basis of its nature – its adherence to a given rule or set of rules – rather than on its consequences. For example, the non-aggression principle is deontological, in that it states that the initiation of force is illicit because contrary to natural law; the consequences of pre-emption, versus passiveness, are not taken into consideration. In contrast is the system of majority rule, in which an action is judged according to its consequences (for the majority). If one substituted, say, “disadvantaged” for “majority,” the rule would still be based on a consequential ethical system, although the consequences are differently defined. What all consequentialist systems share is their valuing of good consequences above all other considerations; where, however, they differ is in how they define those

consequences: in how they select, out of countless, those by which they will judge the deed in question.

There are several types of utilitarianism besides the classical, hedonistic, type, but all of them are based on the belief that the best choice is the one that generates the most net utility for those concerned: that moral worth is a function of utility. With classical hedonism as its guiding principle, a given institution, private or public, would thus aim to institute and execute policies that would serve to maximize the well-being of a maximum of those under its sway.

Thus utilitarians represent a variety of consequentialists, in that they gauge the moral worth of an action in terms of its outcome: the good that it generates minus the bad that it generates. The fact that Jeremy Bentham (1748–1832), John Stuart Mill (1806–1873), and Adam Smith (1723–1790) could all be considered both utilitarian philosophers and economists is due to the fact that all three evaluated the moral value of policies affecting well-being in terms of their utility. Of course, economics is not a philosophy but an intellectual structure that permits various forms of robust analysis. The methods provide a positive descriptive detection, that – despite its positive nature – can include the semi-normative phenomena; and while normative analysis is an infrequent guest in the realm of academic economics, when called upon it often proves to be quite useful in helping its hosts to determine whether, in a given situation, one is getting more for less or less for more.

While that last sentence apparently describes a thoroughly pragmatic-consequentialist viewpoint, it is not consequentialist in the strict sense of the term, since it allows for the possibility that the approach (the means) might diminish the value of the achievement (the end), hence the use of the term semi-normative. For instance, if one lies in order to achieve a beneficial end, the benefit of that end is diminished accordingly.

If a consequentialist contends that lying is wrong, he/she does so on the basis of the undesirable consequences thereof; he/she can therefore also conceive of situations in which lying would be morally acceptable; since his/her exclusive concern is with consequences, the value of honesty per se is not elemental and immutable but rather a function of its application to particular situations. For example, not long ago the Western medical establishment considered it morally acceptable to withhold from mortally ill patients information about their life expectancy. Whether or not

this policy was misguided is a secondary issue; the point that I am trying to make is that this policy was probably utilitarian in its intention – to maximize the quality of the patient’s remaining days by minimizing his or her anxiety, and agony. While economics seems, on first consideration, a rather narrow basis on which to establish a policy, on reflection one will appreciate the fact that it is, in fact, quite broad – broader than pleasure and certainly much broader than financial achievement – in that it embraces a variety of values. Pleasure may be beyond the reach of a mortally ill patient, but a policy that eases his or her pain, mental as well as physical, is far more pertinent than one based on a concept whose value is nothing but hypothetical, as far as the patient is concerned.

Let us now consider a somewhat more complex medical-ethical dilemma. John, a sterling citizen who has never violated a single traffic regulation, is en route home from the office one evening when a drunk driver runs a stop sign just as John enters the intersection, totalling John’s car and leaving John seriously brain-damaged and quadriplegic. However, his biological state is just short of vegetative; medical machinery and therapy could make a difference, if only a marginal one, to the, admittedly vastly diminished, quality of his life. The hitch is that the cost simply of keeping him alive, not to mention making him feel, if only intermittently, that he is better off in this state than dead, is astronomical. Further complicating the issue is the fact that these costly resources are limited, and providing them to John means that they will not be available to several other patients who might benefit from them to a significantly greater degree: a group of children whose legs got blown off by a land mine, say, but who could go on to lead fulfilling lives if they were provided with prostheses (which would have to be modified as they grew) as well as long-term physical therapy; or several flat-chested women to whom silicone breast implants promise a happy ending to each one’s search for a mate and greatly increase their (and their mates) utility. If the decision as to how best to distribute the limited resources is a utility-based one, its outcome will be a function of how utility is defined, which in turn is a function of how the society at large defines complex notions such as and happiness. On the other hand, if the decision is based on a broader utilitarian approach, it may take into consideration a certain notion of right and wrong, then John might have an edge over the alternative. After all, justice may well be worth something.

I deliberately made John's need for limited resources one that is not just a matter of life or death but also due to pure accident; the children's need one that arouses our sympathies, and for which an excellent case could be easily made, since they are young, their loss almost reversible, and the potential benefits of the investment, when measured in years as well as quality of life, incalculably great; and the women's need relatively superficial, and nearly totally selfish ("nearly" because the implants might bring pleasure to several others, chiefly their mates). In fact, I could have gone further, and constructed a scenario in which the women are John's sisters and they execute the "accident" in order to inherit the family property for their above-mentioned goal. In such a case I am sure that justice would start weighing quite heavily in the utility calculation. It is difficult to imagine a society in which pure pleasure-pain utilitarianism was the unique value system and the women's collective benefit from John's incapacitation was deemed more valuable than the benefit, albeit minimal, that he could garner from further medical therapy. Under normal circumstances, however, the dilemma is far more complex than that. Whatever one's end judgments might be, most persons would derive disutility from morally inadequate method of resolving resource scarcity problem described above.

It is for this reason that economists have defined various sorts of utilitarianism, the most popular of which may be the preference-satisfaction one. Since preference is subjective, this sort of utilitarianism is extremely open-minded, taking into consideration the fact that good and bad are concepts that vary not just among cultures but also among individuals, and thus are a function of where the individual in question is located, in both space and time. Preference-satisfaction utilitarianism therefore acknowledges that every person's experience or satisfaction will be unique, and it gives great respect and power to the complexity and diversity of human fulfilment.

Other forms of utilitarianism used in public-health economics sway away from such an individualistic approach. In cost-effectiveness analysis it is for example traditionally assumed that a life year in full health that is gained is as important for all individuals, although empirical observations show that people are quite different in the sacrifices that they are willing to make in order to preserve their life. This approach thus refuses to distinguish between the values of life across individuals.

In other words, there are multiple varieties of utilitarianism. For somebody who has concluded that well-being is all-important and therefore is the only end worth living for, and therefore is an end that justifies any and all means, utilitarianism of some form is an adequate ethical system. To those whose instincts are more nuanced, and are ready to make intermediary sacrifices, utilitarianism helps them to weigh the costs versus the benefits of a given decision, and even to justify one that is, on the surface, counter-intuitive: one that fails to meet the definition of “general efficiency” rule, which states that the utility of a given set of limited resources is being maximized. Those who labour in the field of economics have developed analytical tools that permit such determination of what the tradeoff would involve.

7.3 Further relevance to health

Throughout today’s world there is widespread debate about whether certain of the elements that compose a people’s well-being, most notably health care, should be distributed by non-profit, public-sector institutions or should instead be subject to market forces, ruled by the profit motive, and distributed by private enterprises. A hard-core utilitarian would argue, of course, that one should choose the distribution system of greatest overall utility, but this answer begs the question. How, in fact, does one gauge the value of health care relative to other elements that contribute to the well-being of an individual or to that of the general public?

It is now time to consider money: something all too often mistaken for an end, if not the only end worth many means to reach; but in fact it is the means to many ends: a measure of exchanges – of tradeoffs. Money, or currency, is a secondary, symbolic measure of value, recognized and respected by buyer and seller, even if of scarcely any intrinsic value (for instance, a hundred-dollar bill) that stands in for non-symbolic materials of intrinsic value; but in some cultures the valuable materials themselves are exchanged, and thus function as money: so many cattle, say, or bolts of cloth, buy a house. Of course, it is somewhat easier to exchange currency in the form of beads or bills or coins than that of the often more cumbersome objects whose value they represent (hence their invention). But in either case money represents a sacrifice of sorts: the decision to forego

one opportunity (in some cases represented, in turn, by an object: a pair of new shoes that would help one get one's foot in a job-interview door; a car that would permit one to commute to that job; a silk tie that would help one to get promoted to a better-paying one), in exchange for another.

The same theory that underlies an individual's analysis of the benefits of a given cost is in operation on a national scale in the public sector. A government's list of annual expenditures: each item that the government has deemed worthy of acquisition or investment is defined in terms of a certain sum of money – which is an implicit judgment on the value of that acquisition or investment relative to those for which money will not be exchanged. While converting this sum from one currency to another rarely arouses an emotional response (unless the conversion rate itself is a surprise), converting government tender into life years (or lives, or any other such health-related unit) saved is another matter entirely. How many life years, say, does a year's worth of funding of a national theatre's performances, or the public-school system's Christmas decorations – or physical therapy for a single brain-damaged paraplegic car-accident victim – cost?

When it comes to public funding of the health-care sector, the key utilitarian question is: How should we maximize the potential health benefits of this resource allocation? How much do we decide to allocate to each of several health-related problems. Are we willing to sacrifice five units of health-*improving* therapy, say, for one unit of relatively costly unit of life-*saving* surgery? Should we be willing to save one life if this means diminishing the quality of five others? A utilitarian would reply: Yes, but only if you have a good reason for thinking that you should not, instead, do the opposite. Whether or not this reply inspires you to join the utilitarian ranks, you must concede that it does not reduce the dilemma to a question of efficiency versus fairness, that is, of economics versus ethics.

Conclusion

When it comes to multi-level dilemmas in the health-care sector, is the economic analysis simply at loggerheads with the ethical angle? Of course, when it comes to two individuals' different needs, comparability can be virtually impossible, but this does not diminish the importance of trying, at least, to determine whether a sacrifice is worthwhile or not. In fact, the very difficulty signals that there is an urgent need to pursue this line of

investigation, in the hope of improving our good-choice score. But first we must acknowledge that “What is fair?” and “What is efficient?” are simply two ways of posing a question on ethical choice; that ethical and economic analyses are, in fact, two ways of describing or weighing the various possible means to optimal decision making, one being a subset of the other.

8. Is There a Right to Live an Unhealthy Life?

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Abstract

Is there a right to live an unhealthy life? This core question is addressed through a series of controversial questions: If there is a right to live an unhealthy life, what kind of right is this? Can an autonomous person choose to live an unhealthy life? Is a choice to live an unhealthy life an autonomous choice? Do we have a duty or a responsibility to live healthy life? Does health neglect or own responsibility for poor health have consequences for access to health care and health care prioritization? How to justify public health interventions in order to make people live healthier lives? What is “health” and “unhealthy” in a right to lead an unhealthy life? By addressing these questions I will highlight that they have many answers, resulting in different responses to the question of whether there is a right to lead an unhealthy life. Which of the answers one prefers, strongly depends on perspectives and theoretical viewpoints, which are discussed in the paper. Acknowledging the strengths and weaknesses in the answers and their justifications is important for framing and implementing policies in public health.

8.1 Introduction

Unhealthy life-style contributes most to the burden of disease (WHO 2002). Smoking, alcohol consumption, drug use, unhealthy food, and passive life style are only some of the factors in focus (Easthope 2006; NCHC 2007; CDC 2011). Obesity may serve as one example: it is associated with a higher risk of diabetes type 2 (18 fold risk), hypertension (7 fold risk), as

well as obstructive sleep apnea, many cancers, dyslipidemia, cardiovascular disease, and stress urinary incontinence (Hensrud 2006; Medical Advisory Secretariat 2005). Persons with extreme obesity have a twofold all-cause mortality risk, and they have a shortened life expectancy of 7–20 years (Hensrud 2006). Hence, obesity has become a significant health problem, which causes a dramatic increase in health care expenditures (Sturm 2002; Finkelstein et al., 2003; Finkelstein et al., 2005a; Arterburn et al., 2005; Livingston 2005; CDC 2011). It is said to represent a medical crisis (Hensrud 2006), and has called for concern from patient organizations, health care personnel, health insurers, and health policy makers.

At the same time as the concerns for life-style associated diseases increase, individual freedom to choose and lead your life according to your own plan has become ever more valued and emphasized in the north-western part of the world. Correspondingly, as our knowledge about health effects and our possibilities to influence our own health (e.g. in nearby health studios) has increased significantly, the criteria for a healthy life become ever more ideal and distant. This raises the question of whether there is a right to live an unhealthy life and whether we have a responsibility for our life style choices with respect to health care services (Knowles 1978; Minkler 2000; Callahan 2000; Wikler 2002; Resnik 2007; Reid 2010).

Whether we have a right to live an unhealthy life hosts a series of questions, which will be discussed in this paper:

- If there is a right to live an unhealthy life, what kind of right is this?
- Can an autonomous person choose to live an unhealthy life?
- Is a choice to live an unhealthy life an autonomous choice?
- Do we have a duty or a responsibility to live healthy life?
- Does health neglect or own responsibility for poor health have consequences for access to health care and health care prioritization?
- How to justify public health interventions in order to make people live healthier lives?
- What is “health” and “unhealthy” in a right to lead an unhealthy life?

Hence, in order to address whether there is a right to live an unhealthy life, we need to address these questions.

8.2 Infringement of personal liberties

The question of whether we have a right to neglect our health hinges on issues of basic liberties. It is far from clear that there is a *positive right* to live an unhealthy life, for instance, a right to assistance to smoke or to eat large amounts of unhealthy food. However, there may be a *negative right* to non-interference with regard to unhealthy behaviour. A person may well have the freedom to exercise the right to make independent choices about diet, fitness activities, the consumption of nicotine or alcohol, or professional and recreational activities.

Hence from a libertarian perspective it is quite clear that people have a basic (negative) right to lead an unhealthy life, as long as this does not interfere with other's rights. Some people have great pleasure in and are happy with living in ways others consider to be unhealthy, and as long as this does not infringe the liberties of others, this is quite well.

However, the question is whether, when, and how people's choice of life style affects others, for instance in increased morbidity and escalating health care expenditures. Furthermore, there are several areas where we tend to accept infringement of personal liberties in the interest of public health, such as newborn screening, vaccination, infection control, interfamilial marriages, and compulsory protection, such as motorcycle helmets. In other cases we accept personal liberty even if it may be detrimental to our health, inter alia, in case of obesity, tooth decay, piercing, and drug abuse.

From socially oriented perspectives that see the individual as defined and shaped in social relationships, it can be argued that everybody has a duty to preserve himself, that is to produce oneself in a manner that facilitates non-violative relationships to other people (Cornell 1992). Hence, in communitarian and phenomenological perspectives, as well from various conceptions of solidarity, it can be argued that there is no such thing as an individual right to lead an unhealthy life. Emphasizing positive rights, e.g. health care and education, socially oriented perspectives are endangered of violating negative rights, and there appears to be no easy alternatives to reconcile these perspectives.

Hence, socially oriented perspectives will emphasize that there is no right to live unhealthy, as we are defined by and shaped by relationships with other persons constituted by ties and duties also embracing our-

selves. Individually oriented perspectives tend to argue that there is a right to lead unhealthy lives justified by basic negative rights.

8.3 Can an autonomous person choose to live an unhealthy life?

The question whether you can be an autonomous person if you prefer to live an unhealthy life appears pertinent. A strong version of the argument would be that you cannot be autonomous if you choose to live an unhealthy life. This is obviously not sound, as it would make people's autonomy depend on the content of their choices: if you have certain preferences, hold certain views or make particular choices, you are not autonomous.

A weaker version of the argument is that reducing a person's health could reduce the person's autonomy, and hence should be avoided in order to preserve the person's autonomy. The challenge with this interpretation is that it tends to confuse autonomy and liberty. It may be that reduced health restricts a person's liberty; in other words, being very heavy may reduce one's ability to run fast, but it does not imply that the person's autonomy is diminished. Furthermore, it presupposes to know the preconditions for the autonomy of an individual. Objective knowledge of individuals' values in general, and their valuation of autonomy in particular, is controversial. Moreover, it is not obvious that health hampers autonomy before the health condition becomes extremely poor (and when health interventions would be warranted for other reasons).

Hence, according to the principle of self-determination respect must be given to the wishes of the person, so that, if a competent person wishes to live in a manner that endangers or reduces his health, this must be given effect even if we do not consider it to be in his best interests to do so.

On the other hand, socially oriented perspectives highlight that a person with well established social relationships and with socially well-attuned preferences, would not want to live an unhealthy life. Hence, a socially well-integrated person would not want to live an unhealthy life.

8.4 Can living an unhealthy life be an autonomous choice?

Is the choice to live an unhealthy life an autonomous choice? It can be argued that drinking and excessive eating is due to addiction, and that “drinkers” and “eaters” lack voluntariness, and hence are not autonomous persons (Mackenzie 2010). However, basing autonomy on the conception of authenticity (Frankfurt 1999; Dworkin 1988) would bypass this argument. A person who has a second order preference to lead a certain kind of life, which may be considered to be unhealthy and where the person is well informed about the potential consequences, would be considered to be autonomous.

8.5 Do we have an obligation, a duty or a responsibility to lead healthy life?

A personal duty may be argued for from various perspectives. First, we can argue from *fairness*, that those who need more health care due to certain unhealthy behaviour (e.g. smoking) should contribute more to health care costs. It seems unfair to burden those who make healthy choices with paying the costs of care in higher insurance premiums or taxes for those who make imprudent choices (Buchanan 2008). Second, the duty to live a healthy life can be argued for from a *utilitarian* perspective. Making people responsible for their health conditions could change their behaviour in a way that promotes health and wellbeing and reduces total health hazards and costs. Third, personal duty can be argued for because it expresses and promotes self-respect. A fourth argument for a personal duty to lead a healthy life may be because health promotes autonomy. Being autonomous to a large extent presupposes health, and increasing health may increase a person’s autonomy. Correspondingly, one may argue that health promotes and increases human flourishing (Wikler 2002; Schmidt 2009).

Justice theories may be used to justify personal responsibility. In a *luck-egalitarian perspective* one can argue that we are responsible for inequalities in health that reflect personal choice (“option luck”), while we are not responsible for health conditions deriving from features of our circumstances which are not chosen, i.e., “brute luck”. (Daniels 1985). A

libertarian perspective would highlight the personal responsibility for own health. Beyond a minimal level of basic care, everybody is left to himself or herself. In a *communitarian perspective* the health of the community is the primary goal, and the common good justifies that the state or community require individuals to contribute to this common good by showing responsible health behaviours. What is good for the whole group is good for the individual (Faden 2010). A public system that exerts pressure and withholds resources in cases where individuals do not comply can thus be justified (Buyx 2008; Schmidt 2009). A *liberal-egalitarian perspective* highlights both the individual choice and justifies health care institutions to promote equal opportunities, and an added *solidarity principle* may set limits to individual demands (Buyx 2008). Hence, there are many theoretical perspectives that justify personal responsibility for own health.

8.6 Does health neglect or own responsibility for poor health have consequences for access to health care and health care prioritization?

If people have a personal responsibility for their own health, then it can be argued that this has implications for the allocation and prioritization of health care services. However, personal responsibility for health is seldom used as an explicit prioritization criterion. This may be because the causality of bad health is complex and ambiguous, and difficult to assign to individuals. Nevertheless, there are several suggestions how personal responsibility for own health may be justified in priority setting (Buyx 2008). One way to justify it is to make people responsible for their choices and not the consequences of their choices, e.g. by putting taxes on unhealthy products (Cappelen 2005). Another one is to argue that unhealthy lifestyle may be considered a co-responsibility (Schmidt 2009): “Health responsibilities concern one’s reasonable prospective and retrospective obligations as a healthy person, patient or convalescent, to lead a healthy life, to respect the health of others, and to contribute to an efficient healthcare system, insofar as available choices and external factors permit this.” (Schmidt 2009). To attribute co-responsibility requires passing certain tests. First, there has to be *evidence* that personal behaviour (such as smoking) generate more health care costs. Second, one has to choose the

least intrusive and the most effective measure. Third, relating attribution of responsibility to level of choice. Fourth, there has to be coherence between cases of responsibility attribution, and last, consequences on (doctor-patient) relationships have to be assessed.

Yet another approach to address personal responsibility in practice is in terms of adding personal responsibility as a distributive criterion in priority setting process or by introducing bonus and/or malus systems (Buyx 2008). Analogous to the Rawlsian account that people with “expensive tastes” should have to compensate for these compared to people with moderate tastes (Rawls 1982), Norman Daniels argues that individuals can be held “responsible for living with the requirements of justice” (Daniels 2009a; Daniels 2009b). For instance, they can be made responsible for the costs of some of their choices in terms of special insurance policies and higher deductibles.

Hence, there are several theoretical justifications of personal responsibility for personal health decisions and some suggestions for practical approaches in priority setting exist. Common for most of them are that they are prospective and that they address an overall level of allocation, and not the individual behaviour.

8.7 How to justify public health interventions in order to make people live healthier lives?

There seem to be many arguments for interventions promoting people to live healthy lives. Some of these are based on theories of justice (as briefly described above), and some have other sources and justifications. The most obvious is the argument from overall benefit. If the overall benefit from the intervention is high, it is acceptable and praiseworthy. According to this argument, public health decisions made on the basis of overall evidence is ultimately better for each one of us, even if particular interventions may not directly benefit some of us (Faden 2010). However, this argument does not hold against some claims of individual liberty (see above).

Another argument for public health intervention is the collective efficiency. For many public health interventions most people have to participate in order to obtain a certain outcome. Herd immunity in vaccination is but one example. Accordingly, one could argue that people have to be

brought to lead healthy lives in order to obtain a good public health. Many people have to live healthy lives in order to give weight to the health norms. Nevertheless, it is not obvious that his argument holds with regards to personal health as there are no significant (biological) “herd effects” of public health interventions towards individual healthy lives, and in times of individualism the strength of the social “herd effects” is doubtful.

The communitarian argument has been presented above, where what is good for the whole group is good for the individual. However, this appears to be a *petitio principii*: When the good for the individual is defined by the welfare of the group (which is defined by the community of individuals), the argument tends to become circular. Correspondingly, the argument for fairness in the distribution of burdens, where the burdens have to be roughly equivalent for everyone, are acceptable in an egalitarian context, but may be dismissed in a libertarian framework.

The harm principle is widely considered to be a valid justification for interfering with the liberty of an individual (Mill 1869), and can be used to argue for general intervention in people’s life style choices. However, what kind of harm are we discussing? There is no direct physical, mental or economic harm to others. The harm may however be indirect. Some people’s unhealthy life may have consequences for the access to and quality of health care of others due to scarce or limited resources, warranting interventions. The problem may be to demonstrate the relationship between self-inflicted life-style related health costs and reduced access and quality of health care. The opportunity in the “opportunity cost” may be difficult to identify.

Yet another argument for public health intervention follows the line of The Nuffield Council’s “Intervention ladder” (2007). The level of intrusion has to be adjusted to the health needs. Informing and educating the public as well as enabling individuals to change their behaviours represent a low level of intrusion that may be justified with respect to people’s life-style. Correspondingly, to guide choice through changing default policy or through incentives or directives, as well as restricting choices would require significantly better arguments. To quote Sen: “The good life is a life of genuine choice, and not one in which the person is forced into a particular life” (1999).

Paternalism is also one traditional way that could justify health interventions towards people's choice to live unhealthy lives. The table below lists various variants of paternalism.

Table 1: Various forms of paternalism. Based on (Feinberg 1986; Dworkin 2005; Faden 2010)

Anti-paternalism	Soft Paternalism	Hard Paternalism	
		Weak Paternalism	Strong Paternalism
No restrictions of an agent's actions except actions that harm others	Social control where a caring action does not violate the recipient's autonomy	Intervening in conditions that compromise a persons' ability to act autonomously	To protect or benefit a person by limiting the person's autonomy even if the person's contrary choices are autonomous.

Interventions to influence people's choice of living healthy lives appear to be in the realm of soft paternalism.

Any public health intervention towards people's life-style will have to face criticism of medicalisation and "healthism". The traditional goals of public health interventions have been heavily contested. Especially that the task of the medical profession "is to bring about a change in day-to-day behaviour, to create a new style of life, and almost, if we dared a new morality, a true psychological change." (Szasz 2004). The lesson learnt from the German program of "Gesundheitspflicht" (duty to be healthy) in 1939, the same year that Hitler began the Euthanasia program, should still be kept in mind.

8.8 What is "unhealthy"? What is "health"?

The question of whether there is a right to live an unhealthy life also harbours the issue of what is unhealthy. If health refers to WHO's definition of health as complete physical, mental and social well-being, it is quite obvious that there is a right to live an unhealthy life, as most people do not and cannot obtain complete physical, mental and social well-being. *Ought* implies *can*, and if people cannot, there cannot be an imperative. Correspondingly, health can be conceived of as the ability to realize goal (Pörn 1984), but many persons would not be able to realize their goals, even if the goals were within reach.

Other conceptions of health are more open for discussions of whether there is a right to lead an unhealthy life. Health can be conceived of as a person's ability to act and respond to a wide variety of situations and to contribute to obtaining one's goal (Whitbeck 1981) or as an ability to realize vital goals (i.e., minimal happiness) (Nordenfelt 1987). Accordingly, living an unhealthy life would reduce our ability to respond to a variety of situations and be contrary to our (vital) goals. The question of whether there is a right to live an unhealthy life becomes vacuous, because health is a human goal. One could of course object that above a certain minimum of health (ability to realize vital goals) we are free to live unhealthy lives.

However, the question of whether we have a right to live and unhealthy life also challenges these very same conceptions of health. What if I have as my goal to live in a way that is physically or mentally detrimental to me, but that this still is my sincere goal? Does this make my goal contradictory or impossible, or does it make health into "unhealthy" in a way that challenges (action theoretic and) goal-oriented conceptions of health? This is not the proper place to discuss theories of health. Here it is sufficient to point out that the question of whether there is a right to live an unhealthy life hinges on our conceptions of health at the same time as it challenges these conceptions.

However, a final note on terminology may be appropriate. The discussion on whether there is a right to live an unhealthy life uses terms, which are value-laden. For instance, the term *self neglect* is described as the "inability of a person to understand the consequences of his or her actions or inaction when the inability leads to or may lead to harm". Both the term and its definition oppose a right to lead an unhealthy life. The same goes for alternative definition of self-neglect, such as "the failure to provide for oneself the basic needs to avoid physical harm or suffering" and "the inability to understand the consequences of that failure". Self-neglect is furthermore conceived of as a "lack of wilful intent" and conceived of as an "act of omission." Furthermore the right to lead an unhealthy life can also be discussed in terms of *self-preservation*, gaining negative connotation through the want of something essential: *lack of self-preservation*.

Hence, prevailing conceptions of health question the right to live an unhealthy life, as health is defined as the ability to realize (vital) goals. At the same time the issue of whether there is a right to live an unhealthy life challenges these same conceptions of health.

Summary

The issue of whether we have a right to live an unhealthy life hosts a series of controversial questions, which have been discussed in this paper:

- If there is a right to live an unhealthy life, what kind of right is this?
- Can an autonomous person choose to live an unhealthy life?
- Is a choice to live an unhealthy life an autonomous choice?
- Do we have a duty or a responsibility to live healthy life?
- Does health neglect or own responsibility for poor health have consequences for access to health care and health care prioritization?
- How to justify public health interventions in order to make people live healthier lives?
- What is “health” and “unhealthy” in a right to lead an unhealthy life?

What then are the answers to these questions and to the overall question of a right to lead an unhealthy life? I have not given an explicit answer to this, as it will depend strongly on context and perspective; if one is involved in practical public health work, in policy making or in civil rights movements, and on theoretical perspective (libertarianism, communitarianism, liberalism, luck-egalitarian etc). Each answer and each justifying argument appears to have its strengths and weaknesses. Acknowledging this is important in framing and implementing policies in public health. In particular in minimizing their negative side effects.

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9. Health and good life

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“Unless it is about issues that are real to you, or could become so; about problems you actually have, or could have; about ways of thinking that really are yours, or are real options for you; then philosophy is existentially empty” (Magee 2000, p. 397)

“Life is not long or short; it is long or short relative to what we want to do” (Carel 2008, p. 122).

9.1 Introduction

Are you happy? If you answered “yes”, would you also say that you are leading a good life? Or that the quality of your life is good? Do you think that other people would agree with you on your quality of life? Whatever your answer was, what was your time-perspective? Did you think about your happiness *right now* or *these days* or perhaps *these times*? Or did you refer to your *past*, recent or remote? Or even the *whole life* you have lived so far? Or did you think about the future you are expecting?

Whatever your answer was, did you consider health as a significant contributor to your happiness or unhappiness? If you did, what did you mean by health? The absence of disease or illness? Life without disability? Something else?

Philosophers have written millions of pages about good life – much (or most?) of the history of philosophy is, in fact, history of various aspects of good life and how to get one. Many of those pages have also touched issues of health – understood in a number of different ways. The major part of what follows will not refer to this rich philosophical tradition. Instead, I will first reflect upon cases from my own experience and other sources. Second, I will discuss shortly two definitions of health. Third, the relationship be-

tween health and quality of life is explored. Finally, the possibility of *health within illness* is discussed in the light of a recent book by Havi Carel.

9.2 A few life stories

Case 1. A couple of years ago I was working at a paediatric out-patient clinic and studied the medical history of the next patient *A*. He was a 5-year-old boy who had been born prematurely at 28 weeks. *A* had spent 3 weeks in the neonatal intensive care unit, suffering from, inter alia, respiratory distress syndrome. On follow-up a diagnosis of cerebral palsy was set at the age of 2 years. When I opened my office door and called his name, a happy and smiling boy came running to me. What was left of his early difficulties was a hardly recognisable position of his feet, typical of mild cerebral palsy.

Case 2. *B* is a girl who was born with hydrocephalus and open high meningomyelocele. These were unexpected but on the other hand, her mother had missed the second-trimester ultrasound screening. There are two treatment options for *B*: 1) active surgery within 24 hours to correct both conditions and 2) comfort care, that is, feeding, holding and pain medication. If the second alternative is chosen, *B* will die within days or weeks. If the first alternative is chosen, she may survive but in spite of the surgery she will never be able to walk. It is also probable that complications will occur and *B* may need more operations and extensive periods of intensive care in the future. The doctors ponder over the options and the role of the parents in the decision making.

Case 3. *C* is a professor of mathematics who completed a living will several years ago. In the will he stated that in case he would lose his ability to enjoy intellectual challenges he would not want active medical treatment, for example intensive care or resuscitation, even if these were indicated in normal circumstances. In his fifties *C* had a severe car accident but survived with brain damage and ended up in a nursing home. His former intellectual life was history but he spent his days watching cartoons on TV and seemingly enjoyed them very much.

Case 4. A newborn baby *D* (later to be known as Baby Doe) is noted to have Down syndrome and oesophageal atresia, a condition requiring urgent surgical intervention to enable feeding. An obstetrician notes the

baby's condition and consults a paediatrician. The latter again consults another paediatrician. The doctors disagree about appropriate care. The obstetrician recommends that the baby stay at the hospital and be kept comfortable and free of pain. The paediatricians suggest transfer to another hospital, where surgical repair of the atresia would be possible. Mr Doe had sometimes worked closely with Down syndrome children and is of the opinion that such children never have a minimally acceptable quality of life. His wife agrees, and they decide to follow the suggestion of the obstetrician. Baby Jane Doe has comfort care and dies of hunger one week later (Kuhse and Singer 1985).

These life stories demonstrate some varieties of the relationship between health and good life. They certainly are connected, but that connection is not simple. *A* had a very difficult beginning but quite obviously was leading a normal boy's life at the age of five. *B*'s life so far has lasted only a few hours and her doctors and parents have extremely difficult decisions to make. If an active treatment policy is opted, and if *B* is very lucky, after 10 years she will be a schoolgirl with normal intellectual function. Due to the high meningomyelocele, however, she will never walk. If she is not lucky, she will suffer immensely from various treatments and treatment complications. If the comfort care policy is chosen, her life will be very short, but she will not have to face the risks of the operations. *C* seems to lead a happy life, although very different from the former life of *Professor C*. In a way the current *C* is, and in a way he is not the same person as the former *C*. If he falls severely ill, the practical question is whether the living will should be respected or not. *D*'s case was famous and widely discussed in the 1980's, leading even to protective legislation in the US. In the light of scientific evidence that was available already at that time, *D*'s father was simply wrong when he stated that "such children never have a minimally acceptable quality of life."

9.3 What is health?

The relationship between health and a good life is, of course, dependent on how we understand these two terms. In this paragraph I will examine briefly two definitions of health, one by the World Health Organisation,

and one by Professor Lennart Nordenfelt. Both definitions look far beyond the biological and the bodily.

According to the famous WHO definition from the 1948, "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." It is far too easy to ridicule this definition and I have to admit that I have made myself guilty of that, too. It should not be seen as an attempt for a scientific definition that would define who is healthy and who is not. Instead, it could be seen as a programme declaration that shifts our thinking from merely biological understanding of health and well-being. It is certainly utopian, but again, what is wrong with being utopian, sometimes? (I wish to thank Dr. Ossi Rahkonen for pointing out these issues).

Lennart Nordenfelt, a Swedish philosopher of medicine, has divided theories of health into two categories, which he names *analytic* and *holistic*. He criticises the former and especially Christopher Boorse's biostatistical theory, according to which the definition of health can be done without value judgments.

Nordenfelt himself promotes a holistic perspective, which he calls the *welfare theory* of health. Like Boorse, he aims to cover both somatic and mental health. Nordenfelt's focus is on a person as a whole and on the question whether this whole person is healthy or not. In his book *On the Nature of Health* (1987) he performs a thorough analysis of several basic concepts and finally defines:

"A is healthy if, and only if, A is able, given standard circumstances in his environment, to fulfil those goals which are necessary and jointly sufficient for his minimal happiness." (ibid., p.79).

Alike the WHO definition, this is not meant to be used in the sense that people could be classified as healthy or not healthy. Instead, it points out the interrelatedness of health, happiness and the environment. Questions about the nature or degree of happiness are not scientific questions but evaluative ones in the welfare theory. These evaluations are formed in social settings.

One further point should be made about the nature of health. It is worth noting that *subjective* and *objective* health may be quite different things. It is, in fact, quite common that a person does not feel healthy but her physicians cannot find any objective signs of disease. It happens too

often that the physician feels lost and the patient abandoned in such cases. The opposite situation is also quite common: a person may feel healthy but, according to her physician, has a disease. During recent years many risks have become diseases, or at least the difference between these two concepts have not been made clear to the general public. A person with high blood pressure and high cholesterol is healthy although in many cases it is good to treat those conditions.

Amartya Sen, a Nobel laureate in economics, has pointed out that “public health decisions are quite often inadequately responsive to the patient’s own understanding of suffering and healing” (Sen 2002). He has, however, also addressed the limitations of the subjective perspective: statistics based on self reported morbidity may mislead public policy on health care and medical strategy. Especially from the global point of view it is important to notice that the patient’s subjective assessment may be seriously limited by his or her social experience. For example, somebody brought up in a community with many diseases and few medical facilities may be inclined to take certain symptoms as “normal” when they are clinically preventable (Sen 2002).

9.4 Quality of life

“Good life” is nowadays measured in terms of *quality of life*. We are so used to the concept that we often forget how recent it is. “Quality of life” was brought into the discussion in the 1950s to criticise policies aiming at unlimited economic growth (Musschenga 1997). Social scientists use also “well-being”, but in medicine and health care “quality of life” is the term of choice. By the 1960s it had become obvious that quantitative measures were not enough to describe health-related well-being.

The term “quality of life” may be rather recent, but the issue as such is not. The concept of happiness is not equal to quality of life, but the present discourse on the latter has its roots in the earlier discourse on the former. Classical utilitarianism was interested in the maximisation of happiness, roughly the same as subjective quality of life. For the early utilitarianism it was irrelevant, how happiness was distributed in society (Louhiala 2004).

The nature of quality of life as an *entity* has also been questioned. Schalock (1996) has suggested that it should be seen more as a process or

flow or an organising concept. Others have pointed out that the concept was formulated to encapsulate the well-being of populations rather than that of individuals. Some writers have even cautioned against the use of the quality of life term altogether (Hatton 1998).

Empirical research often aims at using *objective* indicators in measuring quality of life. Examples of such indicators are nutrition, air quality, incidence of disease, crime rates, health care, educational services and divorce rates. For an individual person, however, quality of life means perceived satisfaction. It may or may not be something that people *think* about, and generally thoughts are devoted to quality of life mostly during “the highs and lows of life” (Taylor and Bogdan 1996).

The distinction between “objective” and “subjective” resembles the philosophical distinction between “needs” and “wants”, which is far from a settled issue (Allardt 1993). In empirical social science the distinction is a concrete dilemma. When, for example, housing standards are measured, one could rely on objective measures like the space available or one could ask the respondents whether they are satisfied with their housing conditions (ibid.).

A strictly utilitarian perspective to quality of life may, however, be quite narrow. Amartya Sen has suggested the “capability approach”, which is concerned with people’s actual abilities to achieve various valuable functionings as a part of living (Sen 1993). “Functionings” represent parts of the state of a person – in particular the various things that he or she manages to do or be in leading a life.

Sen’s approach has much in common with the empirical work done on the quality of life in social sciences. The Finnish sociologist Erik Allardt has developed a *basic needs approach* that combines both subjective and objective aspects of well-being, and is categorised by the catchwords Having, Loving and Being:

“*Having* refers to the material conditions necessary for survival and for avoiding misery. It covers such needs as nutrition, air, water, protection against diseases, and the like. Empirically, it is measured by indicators denoting economic resources, housing and working conditions, health and education. *Loving* stands for the need to relate to other people and to form social identities. The level of need satisfaction in this area is assessed by measures denoting attachments to family and the local community, relationships with workmates, active patterns of friendship and the like. *Being* stands for the need to integrate into society and to live in harmony with nature. Personal growth and alienation represent the positive and negative aspects of Being,

respectively. Empirical indicators measure, for example, the extent a person can participate in decisions and activities influencing his or her life, opportunities for leisure-time activities, meaningful work and so forth. (Louhiala 2004, summarising Allardt 1993)”

The relationship between quality of life is demonstrated below in five figures, which are, of course, simplifications, but show how this relationship is far from linear. Figure 1 represent a simple case in which a person falls ill, is treated successfully and returns to life that is similar to the life before falling ill. In figure 2 the disease and the treatment are more complicated and the latter as such worsens the quality of life of the patient for a while. Many surgical operations are examples of this. In figure 3 the case is otherwise similar but the quality of life will never return to the level it was before.

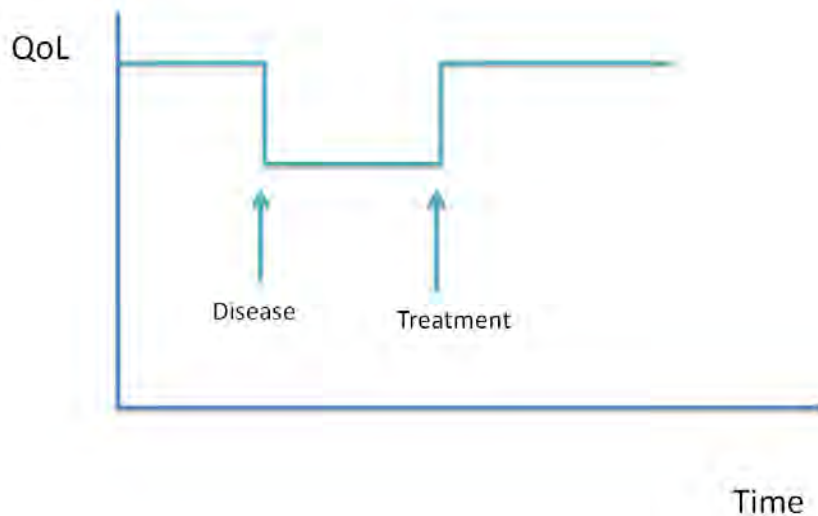


Figure 1.

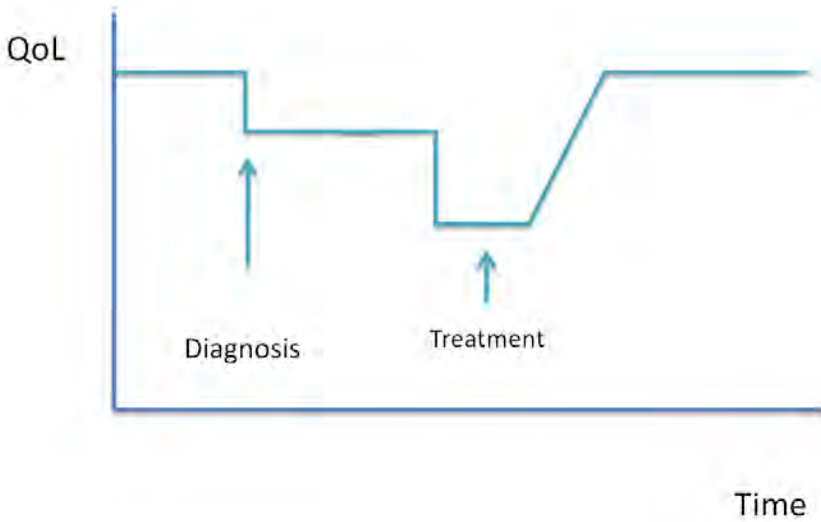


Figure 2.

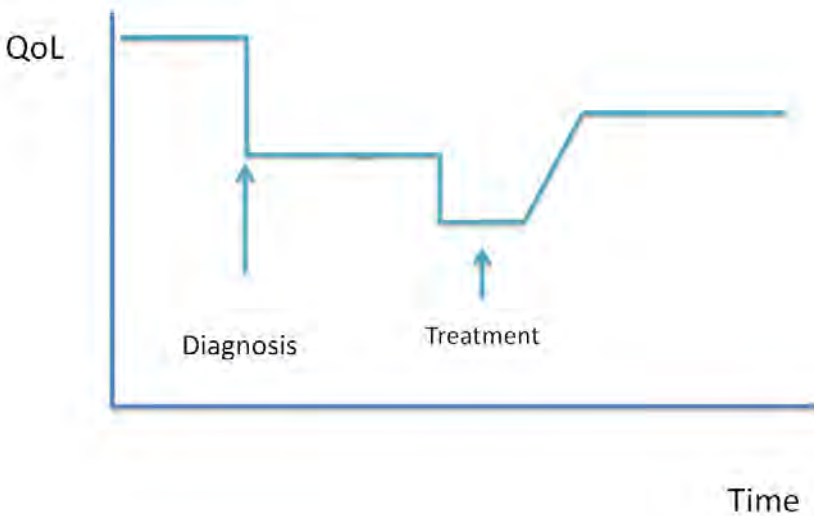


Figure 3.

Sometimes treatment fails and figure 4 represents the worst possible scenario, treatment leading to death. Medical practice is certainly more efficient and safer than it was, for example, 50 years ago, but treatment-related death are possible and not extremely uncommon.

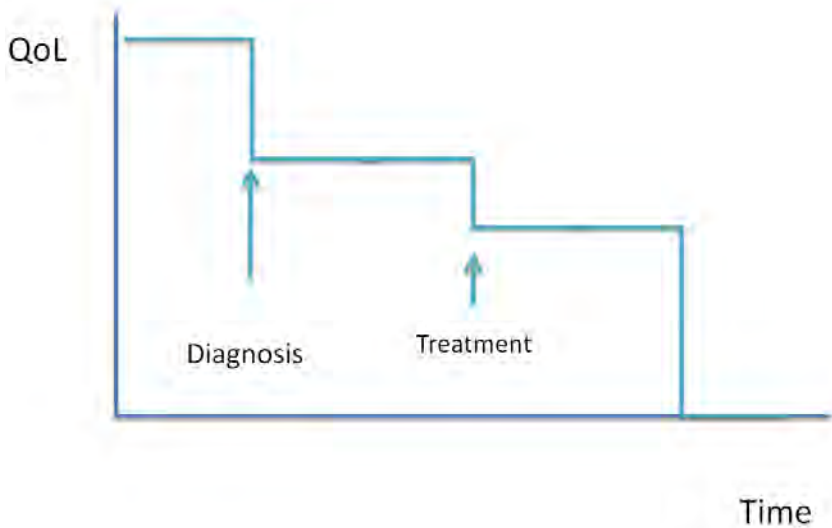


Figure 4.

In figure 5 the situation is the most interesting one: can quality of life *after* a disease (or even *with* a disease) ever be better than it was *before* the disease? The whole idea may sound counter-intuitive at first, and individual life-stories may not convince one. There are, however, some interesting studies that show light to this question.

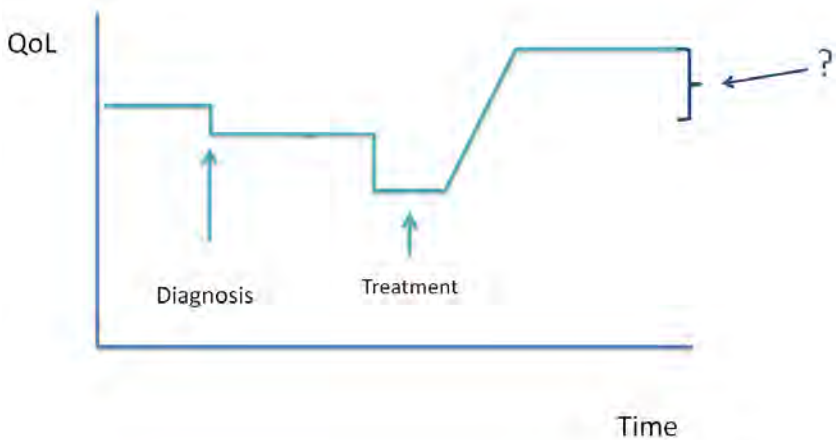


Figure 5.

In a study in Sweden, 61 adolescents who had had cancer were followed up for several years. The reference group consisted of 300 randomly drawn persons of same age. Not unexpectedly, the cancer group reported lower levels of mental health and vitality and higher level of depression up to 6 months after diagnosis. A reversion occurred, however, at 18 months after diagnosis and it seemed to persist since still at 48 months after diagnosis the cancer group reported higher level of vitality and lower levels of anxiety and depression than the reference group (Larsson et al. 2010).

9.5 Health within illness

Havi Carel, a young British philosopher, fell gradually ill in her early thirties. On April 10, 2006, after 16 months of uncertainty and weakening lung function, she finally received a diagnosis. It was lymphangioleiomyomatosis, a degenerative and potentially fatal lung disease, for which there is no treatment. Carel's book *Illness* is a philosophical journey, a moving and personal account of what it is to live with a progressing illness (Carel 2008). She concentrates on a question so much overlooked in the vast philosophical literature on happiness: "what happens to the good life or to happiness when health is permanently absent?" (p. 71)

Carel's major point is that health and illness are not dichotomous or separate kingdoms. We should not see them as mutually exclusive opposites but as a continuum or blend:

"In the same way that episodes of illness can occur within health, an experience of health within illness is a possible, if often overlooked, phenomenon." (p. 77)

She also notes the lack of correlation between objective health (the biological body) and subjective health (lived experience) (p.78). When people are asked about illness, their responses focus on illness. But if they are asked about *health within illness*, more positive dimensions of illness emerge:

"I was surprised at this, as this ability to be ill and happy, to be gravely ill and yet feel so normal, was not something I expected. I don't know what caused this response but I thought about it like this: I have no control over this illness but I have full control over my emotions and my inner state." (p. 64)

The lesson the author learned through her illness was an eternal theme found in various thought traditions, *carpe diem*:

"And so I continue to ride my electric bike to work, go to yoga class and see friends and family. I continue to walk my dog, listen to music, write. I continue to live. Sometimes my illness makes life hard. It often takes up more time and space than I would like it to. But it has also given me an ability to be truly happy in the present, in being *here* and *now*." (p.135)

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Social Equality and Justice

10. Social determinants and the health of populations

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10.1 Introduction

It is in a socio-economic context that a child is born. At conception, the so-called structural genome of the growing foetus is the result of contributions from the mother and father, and the final composition influences the future health of the child (National Scientific Council on the Developing Child, 2010). In addition, despite living in the sterile environment of the womb, all through the pregnancy the foetus is exposed to diverse influences that may impact on its growth and later adult health. Such influences may include but are not limited to prenatal infections (e.g., malaria, rubella and cytomegalovirus), environmental toxic exposures (e.g., mercury, lead, and organophosphate insecticides), drugs, alcohol, and domestic violence (National Scientific Council on the Developing Child, 2007). The earlier the impact of noxious stimuli, the greater is the potential damage on the growing brain, and later adult health. For example, babies with low birth weight as a result of a range of negative influences during pregnancy have an increased lifetime risk for cardiovascular disease, diabetes, and learning difficulties (Shonkoff, Boyce and McEwen, 2009).

10.2 Infant mortality in Iceland

Globally the infant mortality rate (<1 years of age) – IMR – and the under-five mortality rate – (U5MR) – are taken as sensitive outcome measures for the performance of health systems. Thus, these indicators are frequently used to monitor human development of countries and continents, e.g., in the Human Development Report (UNDP, 2010), and global progress to achieve Millennium Development Goal 4 (MDG4) (WHO and Unicef, 2010). Actually, it is worrying that compared to the other MDGs, the one on child survival (MDG4) shows least progress.

A historical analysis of the IMR in Iceland serves well to illustrate the importance of socioeconomic context on life and wellbeing of children. Earliest data on infant mortality in Iceland are available from the time when Laki volcano fissure erupted in 1783. It lasted for eight months with devastating effects on the life of people, spreading a massive haze that covered most of Europe and parts of North America. This cloud was even reported to have extended into Asia and North Africa, and some claim it contributed to the French Revolution in 1789. After the eruptions, hard times followed with famine, a period called *Móðuharðindin*. At this time it is estimated that about 2/3 of all the children born died within the first year of life (Figure 1). The recent eruption of Eyjafjallajökull in 2010 reminds us, once again, what an impact a volcanic eruption can have on the livelihood of children and families living in its vicinity as well as on global air traffic.

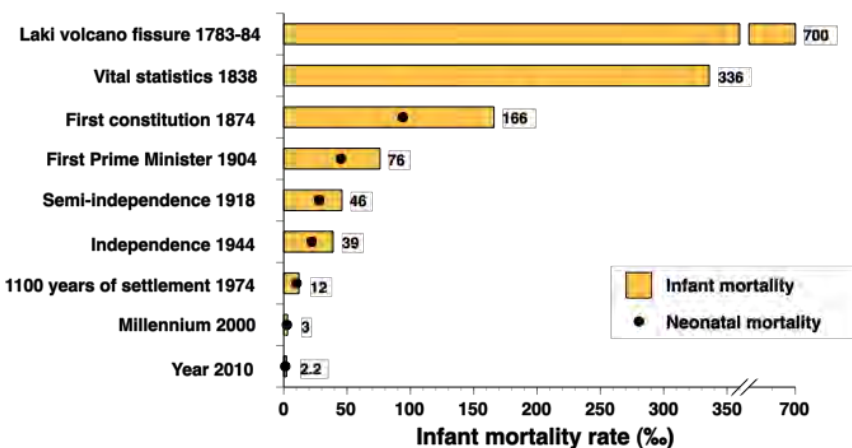


Figure 1. Development of infant mortality rates in Iceland by historical milestones.

After the catastrophic effects of the Laki volcanic eruption, the IMR has gradually declined to become the lowest in the world. Interestingly, the decline began long before antibiotics were available, or access to sophisticated diagnostic equipment and medical treatment. Improved breastfeeding practices in the 19th century have been proposed as one important contributing factor to this positive development (Garðarsdóttir, 2002). This was further facilitated by better hygiene and improved services to pregnant and delivering mothers, in addition to gradually improved socio-economic development. Evidently, not so long ago it was not favourable to be born in Iceland compared to other neighbouring countries.

Today, the Nordic countries rank globally as those with the best IMR, claimed to illustrate their good socio-economic development. Nevertheless, when the rates are compared between the very same countries considerable variation in IMRs emerges (Figure 2). Thus, the rate in Denmark is about twice that for Iceland in 2008 (Nomesco, 2010). Yet, despite all the Nordic countries have low IMRs in a global comparison, it would cause an outcry in Iceland if the rate would increase to the level of Denmark, e.g. in the wake of the current economic recession and financial constraints.

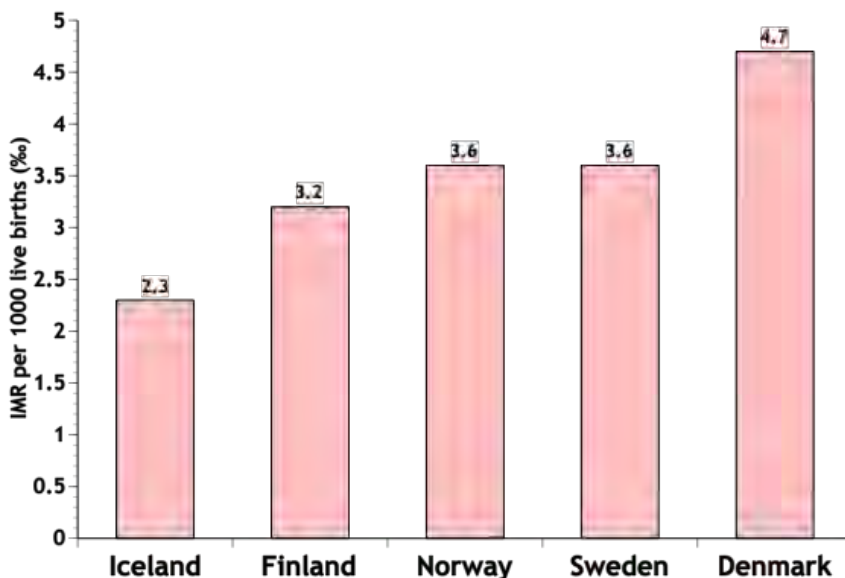


Figure 2. Infant mortality rates in the Nordic countries in 2008 (Nomesco, 2010)

10.3 Socioeconomic determinants and health

An interesting aspect of the child mortality rate is that it is only partially dependent on the Gross Domestic Income (GDI). Rather, it is how governments address issues such as health services and education with the aim to reach all to reduce socioeconomic inequality within countries. Thus, countries need to look for the underlying factors behind the causes of child mortality (Save the Children, 2009). The direct causes may be pneumonia and diarrhoea, and intermediate causes mental health, health services, etc. while the underlying causes for mortality are often socio-economically driven combined with inequity. For example, data from many countries show that children to mothers with no education fare worse than children to mothers with secondary or higher education (WHO 2008). There are several contributing factors, e.g., better understanding of the needs of children, improved health care seeking behaviour, and better attention to adequate food and nutrition.

Three case histories serve the purpose to illustrate how social determinants can shape the health of populations. The first case to study is Iceland. As evidenced above, it has experienced extraordinary decline in IMR in the last 150 years and currently the rate is the lowest in the world. The very low rates are the result of a combination of factors, such as good socio-economic development supported by well-organized preventive health care services for pregnant women and newborn children as well as high quality medical support in case of need. In the most recent Human Development Index (HDI) list, Iceland ranks 17 out of 169 countries included (UNDP, 2010), a significantly less spectacular place compared to the first place attained in the 2008 report.

A second case to study is Guinea-Bissau, a small country on the west coast of Africa on 12°N. It became an independent republic in 1974 after 11 years of war with the colonial power Portugal. The country is now classified as a fragile state and ranks 164 on the HDI list (UNDP, 2010). Despite some improvement, the rate of IMR is now stagnating around 115 per 1000 live births from 142 in the year 2000, and U5MR is estimated to be 193 (Unicef, 2010). Guinea-Bissau is among countries that are not expected to reach the MDG4 regarding child mortality (WHO and Unicef, 2010). This outcome is to some degree the result of poor institutional

infrastructure, bad governance, lack of education, poorly equipped health services, as well as poverty.

Portugal serves well as the third case to study. From early 1960s to mid 1970s, Portugal was engaged in wars in their sub-Saharan African colonies, i.e., in Guinea-Bissau, Angola and Mozambique. Under the authoritarian dictatorship of Salazar engaged in wars in far away countries, civil resistance in Portugal gradually increased. This resulted in the so-called Carnation Revolution, lead by militaries such as António de Spínola who himself had served for several years as Military Governor in Guinea-Bissau. Since becoming a democratic country in 1974 and later member of the European Union, Portugal has enjoyed rapid socio-economic development in the last three decades. IMR has declined rapidly from a level of 45 per 1000 live births in 1974 to about 3 per 1000 live births in 2009 (Unicef, 2010). On the HDI 2010 list, Portugal ranks 40 out of 169 countries (UNDP, 2010). Through, e.g., primary health care reforms, better attention to socio-economic situation of the population and universal access to services the success of post-colonial Portugal, not at war, is evident.

10.4 Life expectancy

As evidenced above, the socio-economic situation shapes the health of the young and gives indication for the health of the population. The Preston curve is illustrative (Preston 1975). At very low levels of Gross Domestic Product (GDP), the slope of increase in life-expectancy at birth is steep as per capita income gradually increases in low-income countries. Yet, at an income level higher than about 5000 international dollars (PPP \$ – purchasing power parity) the relationship becomes non-linear, as life-expectancy in richer countries is not as sensitive to variations in GDP despite slight increase with higher GDP.

Analysis of the Preston curve is interesting from another perspective, i.e., an analysis of the situation of outliers. Countries with similar income show greatly different outcomes in what regards life-expectancy of their citizens. To take an example, in 2009 the GDP/capita of Equatorial Guinea and Chile was roughly equal (15.342 PPP\$ inflation adjusted and 13.087 PPP\$, respectively). Nevertheless, life-expectancy in Equatorial Guinea is only about 51 years compared to 79 years in Chile (gapminder.org). Evi-

dently such a difference in outcome is most likely the result of governmental policies, e.g., how social determinants of health are being addressed. For comparison, in 2009 the life-expectancy was 82 years in Iceland that enjoyed GDP of 34.990 PPP\$ *per capita* (gapminder.org).

The Preston curve is a powerful illustration of how socioeconomic situation can shape the life and death of people. Different lifestyles and social contexts significantly contribute to many of the differences observed. Yet, people can live long lives without being healthy. Thus, an important task in the case of Iceland, and as well in the other Nordic countries, is to add life to years rather than years to life. To take an example, in the period 2010-2050 the increase in life-expectancy for a 65 year old Swede is estimated to be 2.6 years (Regeringskansliet 2010). The challenge for the government is thus to compress morbidity in this final stage of life. As foundations for good health at older age are laid in early childhood, it is important for policy makers to pay due attention to preventive actions for the young and their families (National Scientific Council on the Developing Child, 2007; Halfon, Larson and Russ, 2010).

10.5 Mortality and social class

Social position is a powerful determinant for the health of the population, and an individual's placement in the hierarchy influences the outcome. This indicates how psychosocial wellbeing can influence health outcome. Does bad social position result in bad health or does bad health result in low social position? Much research has come to the conclusion that low social position is in fact an important determinant *per se*; possibly through stress and the consequences it has on the human body (Marmot and Wilkinson, 2006). This indicates that organization of the workplace, social exclusion and a feeling of empowerment may influence the health of individuals. How do social determinants of health get "under the skin" to influence the health of individuals?

A conceptual framework proposed by Turrel, Oldenburg, McGuffog, and Dent (1999: 284) is helpful when we analyze the socio-economic determinants and their impact on health. In this framework, the determinants are divided into upstream (macro-level) factors, midstream (mid-level) factors and downstream (micro-level) factors. Interestingly, people and govern-

ments alike often tend to give more attention to downstream events, such as mortality and morbidity, and there is popular pressure to offer treatment options for diseases. However, mortality is the result of past experiences of risk factors while morbidity is the result of on-going influences. As important as mortality and morbidity are for all those affected, to restrict actions to down-stream factors does not address the socio-economically driven determinants of health that are found more up-stream.

To identify what preventive actions to take we need to look for up-stream determinants for health, i.e., risk factors found in the social, physical and economic environment in which we are born, live and work. Here governmental policy plays a key role, and is in turn influenced by still more up-stream determinants of global forces. Factors that modify the outcome are the indirect influences of midstream factors such as psychosocial processes and health behaviour of the individual. Direct influences can e.g. include accidents, violence, and injuries. At this level the influence of the health system is debated but many argue it plays only a modest and moderating role for morbidity and mortality, in particular with regard to socio-economically disadvantaged groups. Yet, without a well-functioning health system the levels of morbidity and mortality are in fact high, as evidenced by the case of Guinea-Bissau.

Up-stream approach regarding health and disease aims to offer people support and interventions so as to enable them to live a healthy and productive life in their communities (Eriksson and Lindström, 2008). The interventions should be both population-directed (protective) and individual-based (preventive). Protective, appropriate population-based interventions limit the risk of disease and ill health while prevention is achieved by active interventions to reduce the negative effects and risks of disease. Thus, during the life-course people are constantly under the influence of factors that influence their life, either positively or negatively. In the absence of risk reduction and health promotion, people may not reach their developmental potential and their quality of life becomes sub-optimal. This is clearly visualized by the developmental trajectories of people living for example in Guinea-Bissau compared to those who live in Iceland and Portugal.

10.6 Economic recession

Iceland is currently under-going a profound economic recession that begs the question: how will it impact on the life and health of its people? So far there are no signs that the health of the population has greatly suffered, at least in the short term. The IMR is still improving (was 2.2 per 1000 live births in the year 2010), and life-expectancy is increasing (Hagstofa Íslands, 2011); in 2010, life-expectancy for males was 79,4 years and 83,1 years for females. The suicidal rate is on level with previous years, or even less. Particular attention has been given to the mental health of children and young people, but still there are no signs of a rapidly deteriorating situation. For example, adolescents report more time with parents in 2009 compared to the year 2006, and the prevalence of the use of tobacco and alcohol continues to decrease (Guðmundsdóttir, Kristjánsson, Sigfúsdóttir and Sigfússon, 2009). Yet, compared to surveys before the economic collapse in 2008 the happiness score has slightly declined. Thus, in the Health and Wellbeing Study conducted by the National Public Health Institute, the score was 7.9 in the year 2007 compared to 7.8 in 2009, a statistically significant decline (Dóra Guðrún Guðmundsdóttir, personal communication).

There is no doubt that Icelandic families with young children are under the strain of heavy debts (Vignisdóttir and Ólafsson, 2010), and unemployment rates are historically on a high level (Vinnumálastofnun, 2011). This may have a negative impact on the family dynamics with intra-familial conflicts and abuse as a consequence. Such experiences may have impact on the later health of the young. For example, a study conducted among Icelandic adolescents who were 14–15 years old shows that lifetime experience of intra-familial conflicts may increase the risk for depression, anxiety, anger and self-esteem (Gunnlaugsson, Kristjánsson, Einarsdóttir and Sigfúsdóttir, 2011). Thus, in light of the current crisis it is important to monitor closely the future development of the health situation of children and keep a close eye on known risk factors that may negatively impact on later adult health of the young. Governmental policy responses are crucial for how the economic recession will affect household functioning, and children's experiences of poverty. The burden can be alleviated through, e.g., fiscal stimulus, social protection and policies that address the labour market and support to families (Harper, Jones, McKay, and Espey, 2009).

10.7 Determinants during the life course

As highlighted earlier in this paper, the early years are crucial for the later development of the child. During this time period, the foundations of good physical and mental wellbeing are being laid (Halfon et al, 2010). Consequently, it is important to nurture positive life-experiences from birth – and even earlier during pregnancy (Marmot, Allen, Goldblatt, et al., 2010). Due attention should be given to inequality and its negative impact on the long-term health of children. Unequal access to education influences negatively their physical and mental health, and their possibilities for higher income and good employment at an older age. Appropriate employment is a positive and protective factor for good health while unemployment is known for its adverse impact on the wellbeing of people. In the workplace, individuals should be given opportunities for continuous education, flexible working hours and a balance between work and family. The families should also be given opportunities to live in an environment conducive for good health. This should include, but not be limited to, proper attention to the quality of the neighbourhood, transport, access to services, etc. Sustainable communities and places lay the foundation for equal opportunities for all to develop and prosper according to their potential.

10.8 Reorganization of the Directorate of Health

In the year 2010, the Directorate of Health in Iceland celebrated its 250 years of existence. Since it was established, the health of the population has experienced remarkable improvement, and some of the successes have been highlighted in this paper. Historically, such improvement has partly been the result of rapid social development as well as improved health and educational services that reach all of the population. The National Public Health Institute was established in 2003, and took over some of the public health tasks of the Directorate of Health at the time. In addition, during its existence the Institute has developed and strengthened public health work and research in Iceland.

In the wake of the economic crisis, the government decided to merge the activities of the National Public Health Institute with the Directorate of Health. A reorganized Directorate of Health, in effect from May 1, 2011, is

built upon four main pillars: (1) *Determinants of Health* with focus on non-communicable diseases; (2) *Health Security and Communicable Disease Control* with focus on communicable diseases and acute health threats; (3) *Health Quality Assurance* for patient safety, quality of health services and inspection; and (4) Health Information. The four pillars are supported by crosscutting activities of *Administration*, e.g. for finances, human resources, the website and publications. According to the newly passed law, the General Director is required to have a medical diploma with specialization in any field of medicine and management experience while experience and/or training in public health is an advantage. The over-all foundation of the reorganized Directorate is focus on the life-course and the social determinants that shape the health and wellbeing of the population, and the systems that are set up to deal with illness.

Conclusion

In this paper I have paid attention to some key determinants of health and how they impact on the life and health of populations. As shown, the Icelandic population has experienced dramatic improvement in several key health indicators, such as the IMR and life-expectancy. Governmental policies shape and determine the context in which we are born, live and die. During the life-course, people are constantly exposed to both positive and negative factors that influence their life. By giving due attention to the needs of the young and their families, in particular with regard to socioeconomic risk factors, foundations are laid for the general well-being of the whole population from birth to older age.

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11. Vulnerable population groups and priority setting

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11.1 Introduction

During the last few decades, there has been a great deal of discussion in academia about finding efficient ways to ration public health care services. In the rationing debate it is often taken for granted that there is a permanent imbalance between supply and demand and that the public health services are always unable to cope with the acceleration in the cost of medical care or with (allegedly) rising public expectations (Nikkinen 2007). The current economic slowdown will only increase the demands for rationing care provided by public funding, with possible consequences for those population groups who have only limited opportunities for trusteeship on their own. Increasingly, the idea of rationing is being replaced by the notion of priority setting: setting priorities is seen as something that is inherently part of a health care system, because rationing is imposed from the outside (by politicians). However, the change in wording should not prevent us from asking the reasons for the increased demands for rationing or for determining whether there are population groups that are more vulnerable to a policy of rationing than others.

11.2 Understanding the issue of rationing: some conceptual remarks

First, it should be noted that in any public health care system, there are always two directions in which to channel resources: one direction is to the health care providers and the other is to the health service users. In the Nordic countries, there are great differences between the salaries of doctors by comparison with other workers in the public health care sector. At least in the Finnish discussion, it has been observed that Finnish physicians tend to underestimate the effect of their own salaries on health care costs (Martikainen and Valtonen 2004, p. 23). Second, if rationing is applied to patients by limiting access to specific health care services, then the question of constantly rising costs is left unanswered. Rising health care costs result from human actions, not deterministic developments. For example, the impact of technological innovation on the cost of medical care in the future is something that cannot be evaluated with certainty. In other fields, technological development usually leads to cheaper products and services. The information available from the 1970s does not support the claim that new technologies always increase costs. In many cases, new applications are cheaper than old alternatives, pharmaceuticals being a remarkable exception. Yet it should be noted that the pricing of drugs is a complicated process in which technology plays only a minor role. For example, in India the cost of statin (a drug used to lower cholesterol levels) is one-seventh of that in the United Kingdom, although all statins are manufactured for the same purpose, having quite similar active components with each other (Frankel et al. 2000, p. 42).

While it may be true that prices in some countries have risen faster than prices in general, this phenomenon is by no means applicable only to the health care sector. Similar developments have occurred in all those professions in which the human contribution is an important factor (such as the automobile repair industry) and in which pricing is subject to negotiation and the capacity of the provider side to charge more for the services given. When health care service is free (or almost free) at the point a patient enters a treatment facility, as is the case in the Nordic countries, this often leads to an increase in provider charges, as the customers have no incentive to demand cheaper pricing. To some extent it may be said that health care in the Nordic countries still comes fairly cheap; the share

of GDP devoted to health care in the Nordic countries was consistently close to the OECD average in the decade 1990–2000 (Pedersen 2005, p. 165, Table 9.1.) and has not risen remarkably since.

Third, it might be suggested that health care has been under-resourced rather than over-resourced in the Nordic countries. This is because the health care industry is not only a cost factor, but also an important employer, offering valuable services to the people it serves. It is therefore more a question of a society's values as to whether more is allocated to the health care system than to other societal undertakings. There is no right or appropriate GDP-level of health care spending. Comparisons of health care expenditures between countries are particularly difficult, given that there are great differences even between Nordic countries with homogeneous populations having similar GDPs and similar social systems. These problems result primarily from heterogeneous definitions and difficulties in conversion to common prices, as was noted by Nordic researchers already in the 1990s (Gerdtham and Jonsson 1994). Thus, it is difficult to compare the share of GDP devoted to health and the results that good health care achieves. The United States is the country that devotes the greatest share of its GDP to health care, but the U.S. also carries out a lot of expensive medical research that is not conducted elsewhere, and in most cases the results are made available in medical journals and other publications. Health care litigation is also an important factor in rising health care costs in the U.S. However, litigation is not something that can be affected through health care rationing, because it relates to a factor external to health care, namely, the judicial system.

Finally, it is sometimes a matter of perspective whether rationing or priority setting is to take place. If a medical treatment that a patient does not need is withheld, then it is more a question of patient protection than of rationing. It should also be noted that rationing has not saved any resources in large-scale public rationing experiments, such as in the American state of Oregon and in New Zealand. The assumption that money saved in one part of a health care system will be available in another part does not work if the savings efforts are directed against the users, without limiting the options for cost increases in the supply and provider side. As Princeton economist Uwe Reinhardt has pointed out, an increase in health care spending may result in more available resources for patients or have an effect on the income of the providers (Anderson et al. 2003, p. 100).

In line with Reinhardt, the question of rationing is thus more about whether the flow of health care resources is directed to providers or to patients. The solution, however, is not to single out one group of health care professionals (such as doctors) as being responsible for exhausting the health care resources, because their working hours are often more than the average person's work week. There are several places, however, where a public health care system is vulnerable to unnecessary increase in costs. For example, in Finland, the health care system currently has around 4,000 versions of data systems, a situation which has created opportunities for consultants and IT-companies to make a large number of sales.

11.3 Vulnerable population groups and equity issues

A common qualification in discussing vulnerable population groups is to include "...those at risk at any particular point in time for unequal opportunity to achieve maximum possible health and quality of life because of differences in intrinsic and extrinsic resources that are associated with good health" (Danis and Patrick 2002, p. 312). Thus, it is possible to refer to numerous groups in this sense, including people with low educational status, immigrants, derelicts, abusers of alcohol and other substances, and so on. The Nordic welfare state is characterized by its strong reliance on universal social programs, and through the state, there is a large distribution of resources that serves to level inequalities in health and welfare (Ervasti et al. 2008, p. 5).

There are conflicting views as to whether this approach has been as successful as is sometimes suggested. Kjell Arne Brekke and Snorre Kverndokk have observed that several empirical studies seem to indicate that health inequalities are actually worse in the Nordic countries than in other parts of Europe (Brekke and Kverndokk refer to Doorslaer and Koolman 2004, for example, and to Mackenbach et al. 2008, among others). In one OECD study published in 2004 in which eighteen countries were compared, Finland ranked along with Portugal and the U.S. as the three most unequal distributors of health care (Doorslaer et al., 2004). In part this may be because only occupational health care provides fast and free access to care, whereas municipal health care centres and private health care providers charge for health care services. The charges are not

necessarily high, but they affect mostly the poor, the unemployed, and low-income groups. As a result, there may be a delay in seeking care, which then leads to a worsening health situation (OECD 2005).

In their contribution, Brekke and Kverndokk suggest that inequalities may be partly explained by poor methods of measurement. Still, those with low incomes are also the worst-off in terms of health. Even though comparisons between countries are difficult to make, they nevertheless suggest that the issue of income-related health inequality should be taken “very seriously” in the Nordic countries. In their evaluation of Nordic social attitudes vis-à-vis those in other parts of Europe, Heikki Ervasti et al. note that “it may...be that the Nordic way of producing and delivering health care is not as efficiently transformed into good health as it usually is supposed...” (Ervasti et al. 2008, p. 43).

Where health care inequality is concerned, one possible point of comparison where the measurements are similar among the Nordic countries is the mortality level among men who are blue-collar workers and white-collar workers. For example, the mortality risk for a Swedish blue-collar worker in the 30–59 year-old-age group is almost the same as the mortality risk of white-collar worker in the same age group in Denmark. In this sense the poorest Nordic country with the greatest inequality (irrespective of measurement) is Finland, which has 690 blue-collar worker deaths per 100,000 person years; in Sweden the level is only 410 deaths per 100,000 person years (Vallgård and Lehto 2009, p. 262, Table 12.2, which makes reference to Boström and Rosen 2003). In evaluating the “white papers” issued by Nordic governments, Signid Vållgård and Juhani Lehto write that, although they do not know whether politicians and civil servants recognize these figures, the numbers clearly indicate that health inequalities are on the rise (Vållgård and Lehto 2009, 262–263).

Although it is possible to state that health inequalities exist and are on the increase in the Nordic countries, it is more difficult to discover the reasons and to determine whether the increase is being affected by the available means in the health care system. According to Kjell Moller Pedersen (Pedersen 2005), certain Nordic studies have addressed this issue. In Finland, Ilmo Keskimäki and his colleagues have researched the subject of whether private surgical services in the 1980s had an influence on socioeconomic differences (Keskimäki et al., 1996). Another study authored by Keskimäki (Keskimäki 2003) focused on the Finnish econom-

ic recession in the early 1990s. In a Swedish investigation Bo Burström addressed the issue of the growing inequalities in health care utilization across various income groups in the 1990s (Burström 2002). All the aforementioned studies, however, have considerable difficulties in data collection and data interpretation, as Pedersen observed.

In connection with a study dealing with the impact of private surgical procedures and their contribution to health care inequality conducted by Keskimäki and his colleagues, Pedersen writes that, although the authors claim that rates for hysterectomies, prostatectomies, and cataract operations in the private sector contribute to socioeconomic differences, a "...critical reading of the article and evidence presented, i.e., graphical displays, leads to questioning this conclusion" (Pedersen 2005, p. 181). When evaluating Keskimäki's study of the recession in Finland in the 1990s and the impact of its changes on the Finnish health care provision, Pedersen notes that only a slight shift toward a pro-rich distribution can be observed (primarily owing to an increase in surgical care in high-income groups); other conclusions are somewhat difficult to draw, because a substantial number of surgical operations are paid for by the public sector in Finland (and thus cannot distort equity). In evaluating a third study from Sweden (Burström 2002) regarding the increasing inequalities across income groups, Pedersen states that "[a]s is the case of Finland [i.e., in the studies presented above], the question of changes due to various reforms is not an integrated part of data analysis, and must fairly be categorized as "speculations", usually based on popular beliefs about the direction of change in equity, not a scientifically rigorous discussion" (Pedersen 2005, p. 181).

There are other texts dealing with the issue of equity in health care in the Nordic countries, but similar limitations also apply to them. For our purposes here, it is meaningful to evaluate the challenges faced by vulnerable population groups in the Nordic welfare states only in a highly generalized way. A report prepared for the Nordic Social-Statistical Committee by Tor Morten Norman and his colleagues (2009) gives certain useful indications of the current challenges. For this report, data available from European Union statistics on income and living conditions (EU-SILC) were used from the year 2006. Even in that survey, there are reservations and questions related to the adequacy of the results obtained from sample surveys. Nevertheless, the report does give an indication of certain marginalized, excluded, and disabled people in the Nordic countries. In this marginaliza-

tion Finland has the highest share of the population, especially when young people are taken into account. In other Nordic countries marginalization from work is not a major issue, but it is in Finland by comparison with Eastern European countries such as Poland and Hungary. Again, in evaluating three health-related variables (self-evaluated health, chronic illness, and limitations in activities), Finland stands out vis-à-vis other Nordic countries. Not only does Finland show the poorest state of health overall among the Nordic countries, but also its health situation is one of the worst in the whole of Europe. This is especially the case with chronic illness, in which Finland differs from all other European nations, including those in southern and eastern Europe (Normann et al., 2009, p. 157, Fig. 8.3.3.).

Yet even though Finland seems to have the most critical situation at the moment, it is worth paying attention to these issues in all the Nordic countries. Below I present three health interventions that address issues connected to rationing, ethics, and vulnerability. I will focus less on individual groups and more on the contexts in which the health care service is provided. I thus use vulnerability as a more general term, a state in which someone may be only temporarily, for example, as is the case with women during the time of pregnancy.

11.4 Public health care provision and vulnerability

An exploration of the situation of vulnerable populations in the Nordic countries in relation to priority setting and rationing requires much more detail than is possible to present here. I will only point out three contexts that address issues related to equal treatment and ethics, namely, mental health care, prenatal screening for disabilities, and the role of IVF in the treatment of infertility. There is a clear basis for using mental health patients as a primary example, because the burden of mental illness on society is already high and on the increase. For example, globally speaking, schizophrenia and bipolar disorder are among the top ten causes of years of life lost to disability (OECD 2009, p. 126). Prenatal screening and IVF are mentioned specifically in reference to the bioethical discussion, since their roles illuminate the problematic relationship between policy interventions, ethics, and the issue of rationing.

According to Nordic public health researchers, there is a significant gap in the life expectancy of mental health patients in the Nordic countries. Women with severe mental health problems have a life expectancy that is 15 years shorter than average, while the life expectancy of males with severe mental health problems can be as much as 20 years shorter than average (excluding Iceland, where disparities in this regard are less dramatic). This is the group that not only has a higher risk of death by suicide, violence, or accident, but also a greater need for health care since their physical diseases are often left untreated owing to their psychological symptoms. Moreover, lifestyle diseases are prevalent in this group, including smoking, lack of exercise, and excessive use of alcohol, all of which are related to mental health problems (Bengtson 2010). In a Finnish study that investigated the impact of 29 chronic conditions on health-related quality of life using the well-being scales of 15D and EQ-5D, it was observed that mental disorders were associated with the largest annual loss of quality-adjusted life-years. The study concluded that mental health disorders remain “undiagnosed and untreated” in the Finnish primary health care system (Saarni et al., 2006).

It is therefore convenient to suggest that, because mental health patients have great health care needs, any rationing or priority setting affects them the most or in a shorter period of time than it affects others. For example, in Finland, child and adolescent psychiatric services and beds are prioritized, while adult mental health services rely heavily on medication and outpatient treatment. In the public discussion, Pekka Sauri, the Chairman of the Finnish Central Association for Mental Health, has pointed out that detailed care plans seldom get done in adult mental health care. Thus, patients are not registered as being in need of care, patients are not put on a waiting list, time frames for treatments are accordingly not established, additional resources are not requested for services, and options for outsourcing are underused, even when these are available (Sandström 2006). In addition, unplanned hospital re-admission rates are commonly used to evaluate whether there is a lack of coordination of care when a patient is released after an inpatient stay due to a mental health disorder. Compared to other OECD countries, all the Nordic countries with the exception of Iceland are above average in re-admission rates of schizophrenia and well above average in re-admission rates for bipolar disorders. The OECD evaluation study noted that supply factors

alone (i.e., the availability of psychiatric hospital beds or the exact profile of an in-patient facility, whether psychiatric or general care) do not explain the variation of these re-admission rates. Instead, it may be that differences in crisis management explain the variation, at least in part. In Finland and Denmark, interval care protocols are used to place unstable patients in hospital care, while in the U.K., Spain, and Italy, community-based care is used instead (OECD 2009, 126).

Taking into account this information in the overall discussion of rationing and priority setting, it is questionable whether a change in supply would influence the overall functionality of mental health care (if supply factors do not play a role at all, as is suggested in the OECD report, although it was based on somewhat anecdotal evidence). In any event, mental health care would be a very difficult area for setting priorities, if cost-inefficient and medically ungrounded treatments are to be rationed. Many psychiatric treatments may not be particularly cost-effective unless they lead to a worsening health situation (for example, mild depression, which is mostly hidden, may develop into a major depressive disorder).

In somatic health care, rationing on the supply side on the basis of medical benefits or efficacy alone would have to start with those services that are provided for social reasons. For example, the abortion of a healthy fetus usually has no medical benefit; in this context, rationing would of necessity apply to most procedures. Risto Pelkonen, the Archiatre of Finland, has stated in public discussion that, in principle, abortion is “contrary to a doctor’s ethics,” and fetal screening leading to selective abortion is problematic, especially from the perspective of the disabled, because their lives are evaluated as being less worthwhile (Pelkonen’s comments are quoted in Härkönen 2010; for extensive research into ethical problems in Finnish fetal screening practices, see Pruuki 2007 and Meskus 2009).

Although medical care is justified based on the costs to societies and families of raising a disabled child, this view presupposes that a disabling condition precludes having a satisfying life and that social endorsement of prenatal screening will expand women’s choices. This approach has been questioned since the 1990s. Adrienne Asch, for example, showed that several problems associated with disability in fact result from inadequate social arrangements, an issue to which public health professionals should pay more attention (Asch 1999; see also Saxton 2000, Chipman 2006 and Skotko 2009). In news items published during a medical convention in

eastern Finland, it was reported that in case-selective screening of 1,000 women, ages 36 and 37 age, Down syndrome will be detected in five of them. Yet the risk of miscarriage arising from the screening procedure means that ten healthy fetuses will be aborted in the process of making this determination (Jormanainen 2010). People with a low level of education and a difficult life situation may find it particularly difficult to evaluate the risks related to prenatal screening and base their decisions on misconceptions of what is achievable through this procedure. There should be more discussion about the true benefits of prenatal screening and the societal goals that are advanced by its use. When ten healthy fetuses are lost for every five who have Down syndrome, the loss of productivity is remarkable when compared to possible benefits of prenatal screening. It should be noted that most adults diagnosed with Down syndrome can live a quite healthy life, and many of them are also capable of pursuing vocational goals.

In the Finnish discussion Markku Äärimaa, the former head of the Finnish Medical Association, has also questioned whether in-vitro fertilization (IVF) should be provided for healthy individuals through public health care unless infertility is the result of a disease (Äärimaa 2006). In the British National Health Service (NHS), the rationing of IVF has been implemented in many counties, and further reductions may be ahead (Donnelly 2010, Vickers 2010). Given the similarities of the British NHS to the Nordic public health systems, it is reasonable to expect that the cost-cutting measures in public health care being adopted by NHS might be emulated elsewhere. Since IVF is provided by both public and private health care systems, it is possible to reduce treatment cycles by referring patients to private care. Furthermore, the need for IVF is partly a result of such lifestyle options as smoking, drinking, being overweight, and a general desire to have a child at a later stage in life than is optimal. Those who are poor, unemployed, or have unhealthy lifestyles may be more likely to find themselves in situations in which IVF is the only remaining option (Horsey 2008). With the reduction of inequalities within a society, the need for IVF could be reduced if public health actions and social policy measures are invested in such a way as to enhance healthy living and encourage natural conception at a younger age, not at a time when fertility is reduced.

Conclusion

The concept of rationing is a difficult one, as it invokes two notions that are related, but distinct, to borrow Carl Cohen's distinction (Cohen 1985). The first notion is that we tend to assume that there are equitable restrictions at the micro-level, so that a person does not get too much more than his (fixed) share. There is also a macro-level view that assumes there is intelligent deployment taking place, so that greater societal goals are advanced. In this regard the general understanding is that finite resources, such as in health care, must be rationed (the basic meaning of rationing is to withhold some beneficial good or service because of its limited supply). However, based on Cohen, one cannot fully understand the issue of rationing without invoking the idea of reasonableness in the sense of using *ratio* in its Latin meaning of "to reason," i.e., to plan ahead coherently and with forethought.

In practice this means that since good health is not apportioned equally among all citizens, it is not necessary to deliver health care in the same manner, in the same fixed quantity for all. It would be more important to find those patients and groups able to benefit from treatment. In most cases the need for health care is finite within a society, just as the population is finite. Thus, a certain portion of the population that can benefit from treatment should be identified. For example, it is possible to determine who needs cataract surgery or hip replacement operations by using epidemiological studies and to allocate resources that specifically target those groups.

In addition, the available resources for health care are neither finite nor infinite, but rather undefined, in the sense that health care budgets may be constantly re-shaped, based on a society's values and perceptions of how much its citizens are willing to invest in health care. In many cases debates about rationing are triggered, not by conventional health care procedures, but by controversial medical applications. It should be remembered that in the U.K., the introduction of Viagra played a key role in establishing the National Centre for Clinical Excellence (NICE), which now has an important function in setting priorities for the British NHS and in quality-of-life calculations (Phillips 2005, p. 32).

Of course, it is important to influence pricing and reduce costs wherever possible. Price controls have been shown to be effective in limiting the increase in the cost of drugs to the public health care system in Finland, and detailed data make it possible to make comparisons between the Nordic countries (Aalto-Setälä 2007). Before adopting all the available cost-

containment measures, the need for more efficient health care rationing remains unclear, as rationing has thus far not provided any savings in any public rationing experiments (meaning chiefly the state of Oregon in the U.S. and New Zealand). At least more attention should be paid to existing inequalities in health care provision before implementing any rationing models that may have unforeseen effects on vulnerable populations or those populations in vulnerable health care situations, including mental health patients, and pregnant or infertile women as addressed in this writing.

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12. Ethnic discrimination and health in Sami settlement areas in Norway – The SAMINOR study

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12.1 Introduction

To our knowledge, this is the first Norwegian study into ethnic discrimination, bullying and health outcomes in indigenous Sami and non-Sami adults using a large, population-based sample (Hansen 2011; Lund et al., 2007). Research into discrimination and health is growing rapidly and progressing (Williams and Mohammed, 2009). The findings in our study indicate that a large proportion of Sami individuals experience discrimination based on their background (Hansen et al., 2008), affirming findings from studies into the Sami youth population (Bals et al., 2010). Furthermore, our results demonstrate that ethnic discrimination is associated with inferior self-perceived health (Hansen et al., 2010) and psychological distress (Hansen and Sørli, 2011), which is supported by several other studies across multiple population groups in a wide range of cultural and national contexts (Williams and Mohammed, 2009) including indigenous communities in the circumpolar north (Young and Bjerregaard, 2008). These findings suggest that perceived discrimination is an important emerging risk factor to negative health outcomes.

12.2 The Sami population

The Sami are the natives of Scandinavia and they live in the northern regions of Fennoscandia in what today comprises the northern areas of Norway, Sweden, Finland and Russia's Kola Peninsula (Figure 1). The Norwegian government has ratified the Sami as the indigenous people in Norway (ILO-convention no 169, 1990). The Sami include several sub-groups stratified by different geographical areas and dialects (Jernsletten 1993). The size of the Sami population has been reckoned to approximately 70,000–100,000, but estimates vary accordance with criteria used like genetic heritage, mother tongue and the personal sense of ethnicity. The largest proportion of Sami is believed to reside in Norway (60,000), followed by Sweden (36,000) and Finland (10,000), with the lowest proportion residing on the Russian Kola Peninsula (2,000) (Statistics Norway, 2010). Moreover, it is difficult to operate with some minimum- or maximum numbers due to the fact that there are no current demographic numbers to indicate the size of the Sami population, due to a lack of information on ethnicity in public registers (Pettersen 2006). In Norway, about one-third of the Sami live in Finnmark county (Spein 2007). Current figures from 2010 found that 13,890 Sami were recorded in the Norwegian Sami electoral register (Statistics Norway, 2010).



Figure 1. Sápmi, home of the Sami, stretches over four countries – Norway, Sweden, Finland and Russia.

Source: Nordic Sami Institute

Sami are engaged in a variety of livelihoods, including farming, fishing, trapping, sheep and reindeer breeding and herding. Although considered as “traditional” and a cultural marker of the Sami, reindeer herding was of relatively recent vintage, developing during the sixteenth century. In Norway and Sweden, but not in Finland; semi-nomadic reindeer herding is, by law, an occupation strictly reserved for Sami (Young and Bjerregaard, 2008). Data from 2009 found that only a minority (3,010 individuals) of the Sami in Norway is occupied in reindeer herding with slightly more men than women (Statistics Norway, 2010). And today, many Sami live in the large cities, especially Alta, Tromsø and Oslo, and are involved in all the modern professions, occupations, and trades (Young and Bjerregaard, 2008).

Today the challenge faced by the Sami population consists of conserving traditional knowledge, values and culture traits while both the local

community and the world continues to change (Flemmen and Kramvig, 2008) Many Sami people find themselves in a transitional state where it is important to adapt to a new world without losing sight of the values of the traditional world (Young and Bjerregaard, 2008).

12.3 Background

Scientific knowledge about the health and living conditions of the Sami people in Norway has increased in recent years, notably after the establishment of the Centre for Sami Health Research in 2001. Prior to the initiation of activities at the Centre, various public documents constitute the primary source of information. In 1995 the *NOU 1995:6 Plan for health- and social services to the Sami population in Norway* (in Norwegian, *Plan for helse- og sosialtjenester for den samiske befolkningen i Norge*) was published. This document was the first public document to address the need to establish health- and social services for the Sami population. The plan focused on the demand for additional knowledge about the health and living conditions of the Sami, and suggestions were made that a research-based effort should be launched in the field. Scientific knowledge regarding Sami health and living conditions in Norway (as well as in Sweden, Finland and Russia) was seen as limited in comparison to the wealth of detailed demographic information on the health and socio-economic conditions of indigenous peoples in, for instance, North America, Australia and Greenland.

An extensive and representative health survey was determined to be a precondition for research into health and living conditions in the Sami areas. Such a survey was conducted in 2003–2004 in partnership with the National Health Screening Service (SHUS) (since renamed the Norwegian Institute of Public Health (NIPH)). The health survey in areas containing mixed Sami and Ethnic Norwegian settlements is known as SAMINOR; the study has been the Centre for Sami Health Research's main priority. Invitations were sent to approximately 28,000 between 30 and 36–79 years of age. In total, nearly 17,000 people participated in the survey (61 percent). Geographically, the survey comprised 24 municipalities (see figure 2) in which at least 5 percent of the residents reported in the Census of 1970 to have one or more Sami-speaking grandparents (a clear indicator of Sami ethnicity). In addition to information gained from questionnaires some

physical measurements and blood samples were obtained; this material is currently stored in a purpose-built biobank.

Making statements about the Sami population is conditional on the ability to distinguish between Sami and non-Sami individuals. Operationalising ethnicity has been of great importance to our analysis, as ethnicity is not recorded in Norwegian public registries. The SAMINOR study has been of significance in the effort to clarify different definitions of Sami ethnicity and affiliation. By creating several categories of Sami ethnicity we have revealed that the differences within the Sami population become more apparent in regards to ethnic discrimination and health.

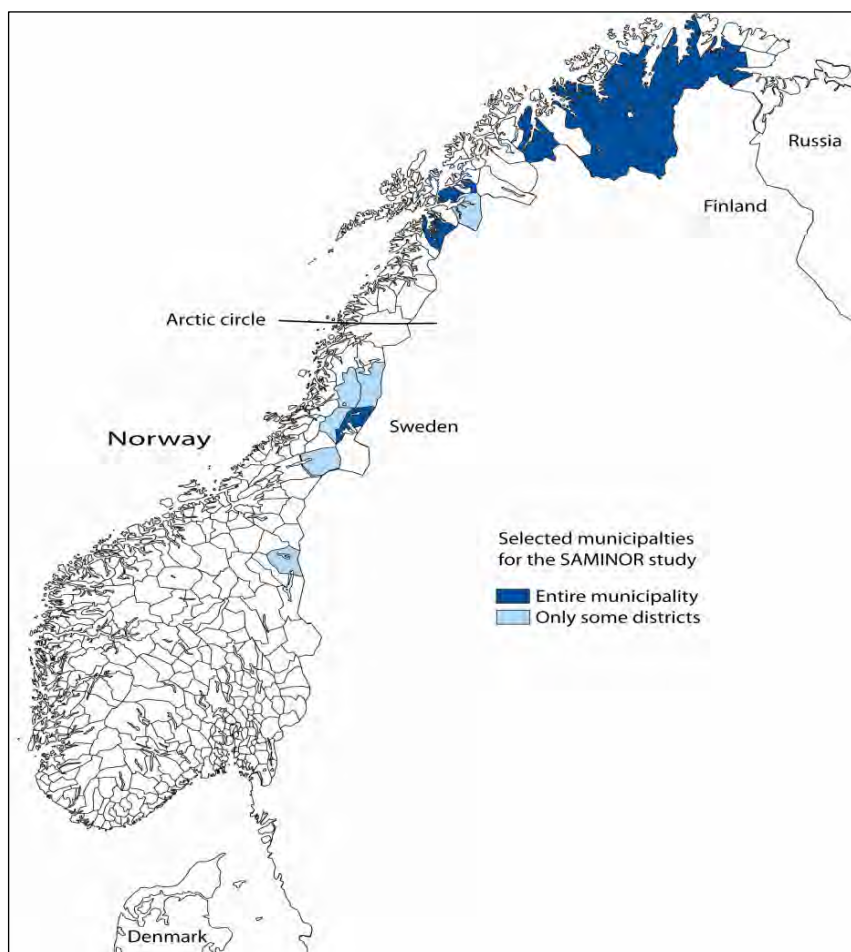


Figure 2. Study areas of the SAMINOR study

12.4 Racism against the Sami

Ethnic minorities and native peoples have been exposed to assimilation, racism, segregation, ethnic discrimination and oppression in many Western societies. For numerous indigenous populations the encounter with Western nations has included tremendous consequences in terms of health. In Norwegian Sami communities the *Norwegianisation process*, by which the Sami were subject to state-sanctioned assimilation policies, has been described as dramatically impacting the Sami culture; large parts of the Sami population lost their Sami language and identity.

Norwegian racism extends far back into history. Svein Lund (Lund 2008) notes that while the slave trade was going on in Africa, northern Scandinavia was also colonised. The Sami were seen as subservient; they were wild hedens; and their land was rich in resources. The colonisation took many forms, such as taxation, trade, christening, acquisition of land for agriculture and, as mentioned, Norwegianisation. The practicalities of colonisation and racist ideologies “walked hand in hand”, figuratively speaking. In 1776 the *Governor of the North (Amtmannen of Nordland)* said:

“These pointless and harmfully running-around Sami are just that which one wishes to have cleared from the country ... This chasing away cannot be done in any more convenient way than have their turf huts and sod houses torn down and burned.”

Even in Europe the myth of the wild nature of the Sami was widespread. In his dissertation on how the Sami were portrayed in French novels and scientific literature in the eighteenth century, Martin Wåhlberg (Wåhlberg 2009) focused particularly on the depiction of Sami sexuality. In a novel by Marquis de Sade, the following statement was highlighted: “It is an honour, amongst the Sami, to prostitute their wives to strangers”. These declarations were repeated by authors Voltaire and Regnard. The source of this myth was traced to the professor Johannes Scheffer at the University of Uppsala, whom wrote the first dissertation on the Sami: *Laponia*. In his work Scheffer wrote that there *might have been cases in history* in which the Sami offered their spouses to others. The myth regarding Sami sexual morals was then connected to the race theories of the eighteenth century. Amongst others, Georges-Louis Leclerc, the Count of Buffon, wrote in his *Historie naturelle, générale et particulière* that the

“despicable sexual morals” of the Sami separated them from other races, and he thus placed them lowest of all human races (Wählberg 2008).

12.5 Measurements of Sami skulls

In the mid-1850s a novel branch of science – physical anthropology – reached Scandinavia. Through the identification of “typical” Sami and Nordic racial traits, primarily the shape of the skull, it would be possible to empirically determine and trace which race first inhabited Europe’s far north. A number of physical characteristics were associated with the measurement of skulls. The partitioning doubled as an “evolutionary scale” and the theories predicted the blonde “long-skulls” (the Nordic race) to be the superior product of evolution both in the bodily and spiritual sense. The Sami, on the other hand, belonged to the “short-skulls” and were described by the researcher Halvdan Bryn as being of a lesser and lower race that did not have a future. He writes: “despite having lived in the immediate vicinity of more highly cultured races, they [the Sami] never arrived at any form of higher culture” (Bryn, 1925). Some of the information was collected from living individuals; other measurements were conducted on skeletons from Christian and pre-Christian burial sites. Often, such excavations were performed in a manner which the Sami considered highly offensive and degrading (Schanche 2000).

The cause of scientific interest in crania, and, in particular, those of Sami and other indigenous peoples, was closely connected to colonialism, nationalism, and the need for legitimisation of new forms of power exertion through a new world order.

12.6 Results

The findings in our study indicate that a large proportion of Sami individuals experience discrimination based on their Sami background; roughly four in 10 men and one in three women of Sami speaking participants reported have experienced being discriminated against “often” or “sometimes” – compared to just 3.5% among the ethnic Norwegians. Also, in the more mixed Sami groups the reporting of discrimination was high; for

subjects with at least two Sami-speaking grandparents the reporting was 19%. All together, 1,269 respondents reported having been discriminated against based on ethnicity. This was 10.3 per cent of the respondents in the total sample. Moreover, Sami individuals living outside the defined Sami areas report the highest levels of discrimination. Among them almost 1 in 2 reported being discriminated against (Hansen et al., 2008).

For bullying in general 403 respondents reported being bullied last year and 2150 respondents previously. Overall, Sami respondents reported bullying twice more often than the ethnic Norwegians. For those who reported bullying in the past year, the most common locations were at work and in the local community. The Sami respondents, furthermore, report more often (than ethnic Norwegians) that discriminatory remarks were the most common forms of bullying (Hansen et al., 2008).

Respondents who reported discrimination as happening “often” were more likely to report adverse self-reported health status than those who did not report ethnic discrimination at all. And the most unsatisfactory conditions were reported by Sami females living outside the defined Sami area (with greater integration and assimilation). Those findings suggest that self-reported ethnic discrimination contribute to inequalities in self-reported health when Sami and Norwegian majority population are compared (Hansen et al., 2010).

The prevalence of psychological distress and the association between ethnic discrimination and distress was also examined among Sami and non-Sami responders. We found that Sami males reported greater levels of stress than Ethnic Norwegians. Ethnic discrimination was strongly associated with elevated levels of psychological distress (Hansen and Sørli, 2011).

12.7 Ethnic discrimination and the Sami

Although this research study the situation regarding the Norwegian Sami, it is likely that the issue of discrimination is similar and relevant to circumstances in other Nordic countries as well. The Sami population inhabiting Russia’s Kola Peninsula, however, find themselves in a somewhat different situation. Unfortunately, there is less information regarding racism and ethnic discrimination on the Russian part of traditional Sami ter-

ritory. Consequently, this chapter is limited to Nordic Sami, with particular focus on Norwegian Sami.

The Nordic countries have enacted relatively comprehensive legislation designed to combat ethnic discrimination (Åhren 2001). Nonetheless the Sami living in the Nordic countries experience prejudices and discrimination both as individuals and as a group. In Sweden the Sami report discrimination in all aspects of society according to the Ombudsman on Ethnic Discrimination (*Diskrimineringsombudsmannen (DO)*) in a report published in July 2008 (Pikkarainen and Brodin, 2008). Meanwhile, few Sami individuals report such discrimination to the police. The Ombudsman on Ethnic Discrimination Katri Linna states that whilst the Sami have a high level of tolerance for insults and experienced discrimination she encourages the discrimination to be brought to the attention of law enforcement (Labba 2008). In Finland the Ombudsman for Minorities and the Sami Parliament have repeatedly emphasised the fact that the Sami have the right to maintain and develop their own language and culture. However, several municipalities fail to implement the right to Sami-language day care as required by the Children's Day Care Act and the Non-Discrimination Act, and not all relevant municipalities provide social welfare and healthcare services in Sami. Problems occur especially outside the Sami homeland (UN Committee on the Elimination of Racial Discrimination (CERD), 2007).

In Norway the Centre Against Ethnic Discrimination (*Senter mot etnisk diskriminering*, or *SMED*) was established in 1998, and in 2006 the country passed a law dedicated to combat discrimination (Ministry of Children, Equality and Social Inclusion, 2005). The purpose of the law was to "promote equality; ensure equal opportunities and rights; and to prevent discrimination based on ethnicity, national origin, descent, skin colour, language, religion and/or worldview". The SMED was abolished in 2005 and its duties transferred on 1 January 2006 to the then recently established Equality and Anti-Discrimination Ombud (*Likestillings- og diskrimineringsombudet, LDO*). Later, in 2009, the Norwegian Government presented a new plan of action to promote equality and prevent ethnic discrimination for the 2009–2012 period (Barne- og likestillingsdepartementet, 2009) as a continuation of the efforts detailed in the former plan against racism and discrimination (2002–2006). The new plan focuses on strengthening the effort against discrimination of the Sami as well as discrimination within the Sami community. As an element of the execution of *Report No. 20 to the Storting*

(2007–2008): *Sami policy* the Government was to take the initiative to invite the Sami Parliament and the Equality and Anti-Discrimination Ombud to a cooperative endeavour against discrimination in the Sami society. The Report refers to attitudes from the *Norwegianisation Policy* lingering in people's minds despite the reversal of policy. Thus, it concludes, it is important to maintain focus on questions associated with personal and structural discrimination of the Sami people: "The Government, therefore, will continue to have a strong focus on the discrimination of the Sami (...) Meanwhile, the discrimination and harassment of Sami individuals in the workplace and workforce is a challenge in terms of industrial relations. Continued research into the discrimination of the Sami is important, and to this effect the Centre for Sami Health Research could play an important role" (Report No. 20 to the Storting (2007–2008), Section 4.1.1).

In its report on Norway (2009) the European Commission against Racism and Intolerance (ECRI) advises Norwegian authorities to intensify efforts in several areas. Among other things, it recommends a substantial increase in the availability and application of professional interpreters in the justice and health systems, and that the implementation of such an increase be prioritised over the two years subsequent to the recommendation. ECRI also advocates incisive research to map out institutionalised ethnic discrimination in the health sector. Finally, the Commission recommends improvements to the monitoring and investigation of racist incidents in general, with a specific awareness of discrimination against the Sami population (European Commission against Racism and Intolerance, ECRI, 2009: Fourth report on Norway)(Hollo 2009).

On this point, the Government's plan to promote equality and prevent ethnic discrimination (2009–2012) states the following: "It is difficult to determine the population at risk of ethnic discrimination as there are no available data on the numbers of Sami individuals in Norway. For historical reasons there is also significant scepticism among the Sami towards such registration. Hence it is necessary to utilise new methods of illuminating the nature and scope of discrimination. Presently, the collections of such data are distributed across departments, research institutions, volunteer organisations and the Equality and Anti-Discrimination Ombud. There exists a need for a more holistic and systematic collection and synthesis of knowledge ranging from the nature and scope of discrimination

in different areas of society to the causes of such discrimination.” (*Barne- og likestillingsdepartementet*, 2009).

12.8 Sami children and adolescents growing conditions

In the Nordic countries today, Sami youth come of age in a society in which their culture and language have a completely different status compared to the conditions under which their parents were raised. Young people who are proficient in the Sami language and culture enjoy a more liberated and less politicised definition of “Saminess” than did the preceding generation. Many adolescent Samis express a complex identity including both Norwegian and Sami culture and language; some identify themselves with Swedish or Finnish society as well. Among the youngest Sami generation, which families have been exposed to force assimilation. This has cause lots of discussion between the Sami generations, particular when individuals of similar background choose different solutions in order to form their identity. A recent report published by the Nordic Ombudsmen for Children (In Norwegian, *Barneombudene i Norden*, 2008) shows that Sami children are still bullied due to their ethnicity. However, most of them are proud of their Sami identity even though it may be difficult for some Sami children and adolescents to be honest about their Sami background. Some children are subjected to prejudices within the Sami community, as they sometimes are not accepted as “real Samis” by other Samis.

12.9 Health in the Sami population

Overall, previous research on the Sami population presents a uniquely positive situation regarding health compared to indigenous peoples of the Arctic regions of the United States, northern Canada, Greenland, and Arctic Russia. This can largely be attributed to living conditions being largely comparable to those of the non-indigenous populations sharing the same regions (Symon and Wilson, 2009; Young and Bjerregaard, 2008). A possible interpretation of the Sami health situation could be that Sami and the majority populations in northern Norway have lived side by side in rural

multiethnic communities with an almost equally high standard of living (Nystad 2010), similarities in culture, and equal access to health care services. Indeed, “health status linked to acculturation experiences in a culturally pluralistic society is expected to be better than in culturally monistic one” (Hassler et al., 2008). Also, the “north-south” disparity in Scandinavia is much less marked than that of North America and Russia (Young and Bjerregaard, 2008). This may be due to the social democratic hegemony of the Nordic countries.

Meanwhile findings of this study show that Sami participants report somewhat poorer self-reported health than the Norwegian majority population, and the most unsatisfactory conditions were reported by Sami females living outside the defined Sami areas (Hansen et al., 2010). In terms of mental health the findings reveal Sami males to have higher levels of psychological stress than ethnic Norwegians, confirming similar findings from the reindeer-herding Sami males of Sweden (Kaiser et al., 2010). Furthermore this study reveals that social factors such as ethnic discrimination may contribute to ethnic inequality in matters of health. Respondents whom reported discrimination were more likely to report adverse self-reported health status and more psychological distress.

Summary and implications for future research

Overall, our findings suggest that increased levels of perceived discrimination are associated with increased psychological distress and poorer self-reported health status even when income, education, marital status and age are controlled for. These results are consistent with previous research showing that perceived discrimination is associated with a variety of negative physical and mental health consequences (Williams and Mohammed, 2009). However, studies into mental health continue to dominate the discrimination and health literature, and it was precisely between discrimination and psychological distress we found the strongest association. Ethnic discrimination is progressively receiving empirical attention as a class of stressors that may have consequences for health and for understanding disparities in health between minority and majority groups. This is according to the interest in the role of stress as a determinant of social health disparities (Pearlin et al., 2005). Psychological stress is associated to and possibly accelerates cellular ageing (Epel 2009) and “the chronic

stressors triggered by multiple environmental assaults can lead to wear and tear on the body that can dysregulate multiple biological systems and lead to premature illness and mortality” (Seeman et al., 2004).

The proper understanding of the relationship between perceived discrimination and health requires a focus on situating discrimination within the context of other health-related aspects of racism; measuring it comprehensively and accurately; assessing its stressful dimensions; and identifying the mechanisms that link discrimination to health (Williams and Mohammed, 2009). However, researchers still disagree on how to conceptualise and measure exposure to ethnicity-related (and socio-economic status-related) stressors (e.g. discrimination and bullying) in accounting for ethnic health disparities over the life course (Myers 2009). Ethnicity-determined differences in the burden of cumulative vulnerabilities are hypothesised to contribute to differential health status over time. Suggestions are made on the role likely played by ethnicity- and socio-economic-related processes as contributors to persistent ethnic health disparities (Myers 2009). Research into indigenous peoples worldwide has showed a persistent disparity in health status among many ethnically native groups compared to the respective majority populations (Paradies 2006). Health outcomes are the by-products of the complex interaction of many factors over time (Myers 2009). In epidemiological research consensus remains, however, on the major factors that contribute to disease risk although little is known about the complex synergy between the biological, psychosocial, cultural and behavioural explanations which may account for ethnic disparities in health between, for example, indigenous and non-indigenous populations. “Thus a major public health challenge is to identify the complex set of biopsychosocial factors that contribute to or maintain these persistent health disparities and to design innovative interventions to close the health gaps” (Myers 2009).

Bjerregaard and colleagues indicate that discrimination and being disrespected could possibly be causally related to high suicide rates and alcohol and drug abuse in many circumpolar communities (Young and Bjerregaard, 2008). Despite the large number of studies investigating the association between discrimination and health, a great number of questions remain unanswered (Pascoe and Smart, 2009). Thus, additional research is required into useful intervention techniques (on the organisational and individual levels) to identify determinants and reduce the impact and frequency

of interpersonal and institutional discrimination and to ensure equalities in health status between Sami and Norwegian majority populations.

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Sammanfatning

Under det senaste decenniet har *folkhälsoetik* utvecklats som egen disciplin¹². Denna har definierats som "etiska frågor som förekommer inom alla aspekter av folkhälsa både i teorin och i praktiken" (Dawson 2006, s 64). Pandemier (SARS, svinfluensa) förklarar en del av behovet, men även snabbt ökande icke smittsamma sjukdomar som främst beror på en ohälsosam livsstil, orsakar etisk debatt kring förhållningssätt och ansvar. Dessutom ger den ökande ojämlikheten när det gäller hälsa upphov till oro.

Frågor som rör hälsofrämjande åtgärder och förebyggande av sjukdomar hos befolkningen har inte funnits på dagordningen inom traditionell bioetik, vilken främst har berört frågor som rör modern bioteknik och dess tillämpningar. Autonomi har varit det centrala begreppet, men som enda värde passar det inte särskilt väl in i "folkhälsostrategin". Vidare är man inom medicinsk etik mest intresserad av förhållandet mellan läkaren och patienten i den kliniska miljön.

En klassisk text från 1920 definierar folkhälsa som "vetenskapen om och konsten att förebygga sjukdom, förlänga liv och främja fysisk hälsa och förmåga, genom det organiserade samhällets insatser för en hygienisk miljö, kontroll av infektioner, spridandet av kunskaper om personlig hygien, organisation av läkar- och sjuksköterskeservice för att tidigt kunna ställa diagnos och genomföra förebyggande behandling av sjukdomar, samt utveckling av ett socialt nätverk som för varje individ ska säkerställa en levnadsstandard som är tillräcklig för upprätthållande av hälsa" (Winslow 1920, s. 30).

Inom samtida diskurs är man intresserad av jämlikhet och rättvisa när det gäller hälsa. UNESCO införde principen om socialt ansvar och hälsa i artikel 14 i den *Allmänna deklARATIONEN om bioetik och mänskliga rät-*

¹² Till exempel ägnade WHO sin *Bulletin* i augusti 2008 åt etik och folkhälsa. Samma år gavs den första volymen av den internationella tidskriften *Public Health Ethics* (Folkhälsoetik) ut av Oxford Journals.

tigheter år 2005. Med denna artikel utvidgade UNESCO tillämpningsområdet för bioetik med en social dimension. Faktum är att många politiska områden är relevanta för folkhälsan: handel och ekonomi, miljöfrågor, jordbruk, social politik, säkerhetsfrågor, bara för att nämna några. För några år sedan introducerades initiativet "Health in all policies" under Finlands EU-ordförandeskap (Ståhl et al., 2006). Ett par år senare offentliggjorde WHO:s *Kommission för sociala bestämningsfaktorer för hälsa* sitt slutbetänkande (CSDH 2008). I själva verket har också begreppet "befolkningshälsa" (Population Health) föreslagits (Young 2005) för att ge ett mer tvärvetenskapligt akademiskt synsätt på folkhälsa: förutom epidemiologi och dess kvantitativa verktyg, använder "befolkningshälsa" kvalitativa metoder från samhällsvetenskap och humaniora, såsom demografi, antropologi, historia och etik, för att förstå folkhälsa och utveckla förhållningssätt. Fortfarande är dock terminologin för de olika begreppen långt ifrån klar.

Nordisk kommitté för bioetik arrangerade en konferens i Reykjavik i augusti 2010 för att höra experters synpunkter och diskutera etiska frågor som berör folkhälsa. Programmet var indelat i tre sessioner: 1) Individens frihet och folkhälsa, 2) Hälsa, ansvar och livsstil samt 3) Social jämlikhet och rättvisa. Talarna erbjöd ett brett vetenskapligt perspektiv på dessa frågor. Jag känner mig privilegierad att få vara redaktör för denna bok till vilken de flesta av talarna sänt sina värdefulla bidrag. Strukturen i boken följer programmet för konferensen.

Den första sessionen under konferensen angav ramarna för temat, och gav insikter i den klassiska etiska spänningen mellan individuella fri- och rättigheter och samhällets nödvändiga åtgärder för att skydda folkhälsan. *Haraldur Briem* tar upp den etiska frågan om hur man ska skydda människor från farliga smittsamma sjukdomar, samtidigt som man tar hänsyn till individuella rättigheter och fri rörlighet. *Kalle Grill* försvarar tesen att frihet är ett viktigt värde, men utan anspråk på prioritet. *Helena Kääräinen* diskuterar screening av befolkningen genom att ta upp neonatal screening av genetiska sjukdomar som exempel. Det stora problemet i programmen gäller kvaliteten. Således betonar hon att screening av befolkningen kräver noggrann planering och korrekt information innan man påbörjar ett program. *Stefán Hjörleifsson*, å sin sida, utreder för- och nackdelar med screeningsprogram. Enligt hans åsikt överväger fördelarna vanligtvis inte olägenheterna och kostnaderna.

Den andra sessionen fokuserade på ansvar för hälsa och livsstil. Många av dagens betungande hälsoproblem är relaterade till livsstil och korrelerar också tyvärr ofta med lägre socioekonomisk status. Men vem bär sist och slutligen ansvaret för individernas hälsa? I vilken utsträckning kan staten använda paternalistiska åtgärder för att få människor på rätt kurs? *Ole Faergeman* anser att alltför lite uppmärksamhet ägnas åt klimatförändringarnas effekter på hälsan. Han menar att politikernas misslyckande med att reagera på klimatförändringarna delvis beror på övergripande strukturer i samhället. *Bjørn Hofmann* undersöker frågan "Har människor rätt att leva ett ohälsosamt liv?" Även om många teorier rättfärdigar offentliga fohälsoringrepp för att motivera och påverka människor att välja ett hälsosammare liv, verkar svaret inte lätt; icke minst på grund av svårigheterna att definiera nyckelbegreppen. *Ástrídur Stefánsdóttir* föreslår i sitt bidrag att en stor epidemi i vår tid, fetman, i första hand bör ses som ett socialt problem, eftersom ett ökande antal barn och vuxna lever i en miljö som gör det allt svårare att föra ett hälsosamt liv. *Tinna Laufey Ásgeirsdóttir* hävdar att effektivitet är en av flera tänkbara etiska barometrar som vi kan använda för vägledning av och rådgivning för individer och samhälle. Enligt hennes uppfattning är etiska och ekonomiska analyser två sätt att beskriva eller väga de olika möjligheterna till optimalt beslutsfattande, den ena som en del av den andra. *Pekka Louhiala* reflekterar i sin text över om det är nödvändigt att vara frisk för att kunna leva "ett gott liv". Lycka kan inte mätas med vetenskapliga termer, konstaterar han, utan måste baseras på värden som formas i sociala sammanhang.

Under konferensens tredje session, Social jämlikhet och rättvisa, identifierades fattigdom som en av de viktigaste orsakerna till dålig hälsa och ökande ojämlikhet beträffande hälsa. Den övergripande utmaningen gäller rekommendationer och åtgärder på alla områden: dagliga levnadsvillkor, miljöförhållanden, lika fördelning av resurser, marknadsansvar. Dessutom bör dessa vara inriktade på ett livslångt perspektiv. Särskild fokus bör riktas mot marginaliserade eller utsatta befolkningsgrupper. Men framför allt, framhölls det, måste åtgärderna för ett effektivt förbättrande av hälsa vara evidensbaserade. I den tredje delen av denna bok utvecklas dessa idéer ytterligare. *Geir Gunnlaugsson* betonar vikten av de första åren för barnets utveckling och senare hälsa i vuxen ålder. Han konstaterar också att låg social ställning i själva verket är en viktig faktor i sig, eventuellt på grund av stress och de konsekvenser den har på människokroppen. *Janne*

Nikkinen hävdar att den nordiska välfärdsstaten inte har kunnat hantera socioekonomiska faktorer som påverkar barndomen tillräckligt väl: ojämlikhet inom hälsa existerar och ökar i de nordiska länderna. Slutligen behandlar *Ketil Lennart Hansen* frågan om hur samerna som lever i de nordiska länderna upplever fördomar och diskriminering både som individer och som grupp.

Texterna i denna bok kastar sig rakt in i de viktigaste av dagens utmaningar gällande folkhälsa. Intressant nog hävdar flera texter att dagens politiker misslyckas med att se orsakerna i de djupare politiska strukturer som resulterar i stora folkhälsoproblem. Det är uppenbart att ytterligare diskussion och mer forskning om detta behövs i samhället för att förbättra folkhälsan och för att upprätthålla förtroendet för den nordiska välfärdsstaten.

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Public Health – ethical issues

The Nordic Committee on Bioethics organised a conference in Reykjavik in August 2010 to discuss ethical issues relating to public health. The speakers of the conference have contributed to this book, which offers wide multidisciplinary perspectives on themes around Individual Freedom and Public Health, Health Responsibility and Life Style, and Social Equality and Justice.

