Pray for the best: on perinatal health inequalities and health agency

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Abstract

Inequalities in child morbidity and mortality occur in poor societies but also in prosperous societies that have free and high quality care in place. Much needs to be done to ameliorate the conditions of parents-to-be who live in underprivileged neighborhoods within prosperous societies. The improvement of the material and social conditions of these parents-to-be however, is but part of the solution to perinatal health inequalities. We argue that the effects of life in underprivileged neighborhoods on the health agency of parents-to-be have to be considered as well in order to successfully counteract perinatal health inequalities. That is, parents-to-be who live in underprivileged neighborhoods tend to adapt their preferences regarding their own and their offspring's health so these match the unfortunate conditions in which they live. This adaptation curtails their 'capacity', 'feeling of control' and 'experienced freedom' to seek and make use of care available to them. We therefore propose a 'bare-bones-perfectionism' approach to counteract perinatal health inequalities which, as we will argue, follows from the demands of justice.

Introduction: Raising aspirations beyond adaptations

> "[A]ll experience has shown, that mankind is more disposed to suffer, *while evils are sufferable*, than to right themselves by abolishing the forms to which they are accustomed. [emphasis added]" (The Declaration of Independence)

There is an important distinction between 'injustice' and the 'experience of injustice', between what one 'aspires' and what one 'is made to aspire'. Especially in destitute societies in which the odds to have poor health are overwhelming, people tend to *adapt* their health-related preferences so to acquiesce in their unescapable deprived living conditions.(1-4) This phenomenon is known as 'adaptive preferences'; describing the tendency to curtail one's (health-related) aims and ambitions so they match one's unfortunate conditions, which then cease to be a source of frustration. The more one accepts underprivileged conditions as part of one's life the less likely one is to imagine a better life.

Individuals living in prosperous societies are also not immune to adaptive preferences. We, for one, are troubled by the peculiarity that a prosperous country such as the Netherlands, that has free[9] and high-quality health care as well as a robust public health policy in place, has a persistent high number of poor pregnancy outcomes compared to many other European countries.(5-7) In addition to these poor baseline numbers, inequalities in pregnancy outcomes between neighborhoods –especially in the city of Rotterdam– are alarmingly high.(8, 9) Despite these poor pregnancy outcomes and perinatal health inequalities (PHI), research shows that parents(-to-be) who face higher risks to have a problematic pregnancy, bear an unhealthy baby or even to lose their baby(10), typically do not appraise themselves as being more exposed to these risks or they accept these increased risks as a given.(11-13)

Asking a group of vulnerable mothers(-to-be) whether they felt well prepared for pregnancy, one of them gave a response that adequately captured the overall sentiment namely: "in the end, what can we do but pray for the best?"(11) Rather than praying for the best, we will consider the appropriate response to PHI in prosperous societies that is warranted by the demands of justice.

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9 Free as in Universal healthcare. The Netherlands has a mandatory private insurance scheme with Government subsidies for individuals with a low income

This essay will continue as follow. First we present the case of PHI in prosperous societies. We take the situation in the Netherlands as the paradigmatic example of a prosperous society in which a decent minimum of social and political arrangements such as free and high quality pregnancy-related care is available. Yet there exist substantial PHI, the most disquieting being those recorded in the city of Rotterdam. We will use the recent insights from epigenetics and the Developmental Origins of Health and Disease paradigm (DOHaD) to describe the way social and political misfortunes become biologically impinged and consequently lead to avoidable poor pregnancy outcomes.

We then present two mutually reinforcing sources of PHI, which are (i) the 'corrosive conditions(14)' in which disadvantaged parents-to-be prepare for (if they do so) and fulfill their parenthood and (ii) the 'adaptive preferences' of parents-to-be with regard to the health of their children-to-be. We will argue that from a normative viewpoint the 'corrosiveness' of (i) and the 'adaptive preferences' of (ii) impair what we call the 'health agency' of parents-to-be. That is, what makes corrosive environments in which parents(-to-be) live and the adaptive preferences parents(-to-be) have troubling from a normative viewpoint, is that they impair **1.** the *capacity* to form health-goals one has reason to value, **2.** the perceived control over achieving those health-goals and **3.** the freedom(s) they have to achieve those health-goals, in sum, *health agency*.

Given that our health agency concept is primarily concerned with the impaired freedoms parents(-to-be) (from here on parents) have to choose health goals for their offspring and the severe and lifelong debilitating consequences of avoidable poor pregnancy outcomes, we will base this concept on the capabilities approach. Capability scholars such as Amartya Sen and Martha Nussbaum have been extensively concerned with the detrimental impact corrosive conditions and adaptive preferences have on individuals' agency and capabilities that are necessary for human flourishing.(4, 15-18) Their research however, has mostly focused on countries that face desperate poverty and destitution. Still, to our mind, the capabilities approach also offers the appropriate tools to address the challenge of counteracting PHI in prosperous societies.

We will argue that justice requires the promotion of the health agency of parents. This entails that ultimately, the measure of success with which parents are able to convert available (health) care into actual good pregnancy outcomes should be adopted as the appropriate 'currency' of justice regarding PHI. Notwithstanding human diversity, we defend the view that when it comes to the lifelong health of newborns, some basic preferences such as the preference to invest in the prevention of avoidable poor pregnancy outcomes *are* or *should be* held by parents, care professionals, policy makers and society as a whole. Adaptive preferences can curb these basic preferences. We will call

the approach that holds that adaptive preferences are inconsistent with basic human flourishing 'bare-bones perfectionism'. We will show how this approach can improve health agency by counteracting underlying adaptive preferences and how it can be used as a model to develop policy aimed at improving pregnancy outcomes. This approach will help parents to raise their aspirations beyond their adaptations.

We will conclude by presenting two caveats regarding our perfectionist approach. First, is that our proposal to improve the level of health agency of parents to a level of sufficiency is intentionally *underspecified*. What ultimately counts as sufficient should be determined through deliberation within the community that seeks to achieve this level of sufficient health agency for all parents.(19) Second, is that adaptive preferences never justify the condescending view that parents living in underprivileged neighborhoods are unable to formulate and pursue their own ends.(20) This entails that parents living in underprivileged neighborhoods should never be excluded from public deliberation on the suitability and content of agency-promoting interventions.

Perinatal health inequalities in Rotterdam

It is unfair that by dint of the circumstances in which they enter the world children run the risk to be deprived of good health and the fruits of good health. Few would disagree. This unfairness is arguably more disquieting when it occurs in societies in which these circumstances are not shaped by unfortunate chance such as the destitute conditions in poor countries, but rather by amendable choice. The Netherlands for example, a prosperous country in which free and high quality health care is readily available, has relatively high and persistent poor pregnancy outcome numbers compared to other European countries.(5-7) In addition to these poor baseline numbers, inequalities in pregnancy outcomes between neighborhoods –especially in the city of Rotterdam– are alarmingly high. Research done by Poeran et al. has found that: "[In Rotterdam] [t]he neighborhood-specific perinatal mortality rates varied from 2 to 34 per 1000 births, for congenital abnormalities from 10 to 91 per 1000 births, for IUGR [measure for poor fetal growth] from 38 to153 per 1000 births, for preterm birth from 34 to 157 per 1000 births and for low Apgar [measure for physical condition of a newborn immediately after birth] score from 4 to 37 per 1000 births. The highest mortality rates were observed in deprived neighborhoods."(21) This shows the disquieting impact of neighborhood inequalities on the lifelong health of newborns. Being born in an underprivileged neighborhood in Rotterdam is tantalizing as the prevention of avoidable diseases is in sight yet for too many newborns out of reach.

Much needs to be done to ameliorate the conditions of parents living in underprivileged neighborhoods. Research has identified a sum of 'barriers' to prepare for pregnancy as a source of PHI. Some of these barriers pertain to the corrosive conditions associated poverty.(13) These range from low income levels(22), poor housing(9) air and noise pollution(23) to maternal stress(24) and domestic violence(25). To improve pregnancy outcomes in underprivileged neighborhoods, policy that addresses these corrosive conditions is of paramount importance.(26)

Although the PHI in Rotterdam are caused by poverty, it is not comparable to the desperate poverty people living in developing countries face. Moreover, free and high-quality pregnancy related care is available in Rotterdam; although in underprivileged neighborhoods the access to available care should still be improved. In this article however we want to focus on a special category of barriers. These are the barriers parents living in underprivileged neighborhoods *unintentionally* erect for themselves. That is, the adaptive preferences that arise in the corrosive conditions present in underprivileged neighborhoods.

Consider that PHI are also caused by an accumulation of poor health-related choices such as smoking, drinking, unhealthy nutrition and a lack of physical activity; choices that are associated with living in underprivileged neighborhoods.(27) These choices can be ill-informed, unreflective or even involuntary, especially when they are made in underprivileged neighborhoods. But choices they remain. Consider also that no elaborate ethical analysis is needed to see that being born and living in a desperately poor society is unfair. The choice to prepare for a healthy pregnancy is simply unavailable to many people living in such a society. In prosperous societies like the Netherlands however, the choice to prepare for pregnancy is available, even to those living in underprivileged neighborhoods. It may be less readily available, may require a greater sacrifice in terms of resources and time from parents. It may require a greater awareness of the benefits of pregnancy preparation; but available it is. Moreover, initiatives aimed at increasing the awareness of pregnancy preparation and the availability of pregnancy related care[10] have been launched, unfortunately with limited success.(29, 30) Although parents living in underprivileged neighborhoods appraise the goals of pregnancy related care, they typically do not identify themselves as the target audience that faces higher risks to have poor pregnancy outcomes.(13) This results in parents who could greatly profit

10 Preconception care in particular. Preconception care is concerned with identifying biomedical, behavioral and psychosocial risk factors prior to conception to improve pregnancy outcomes. 28. Atrash H, Jack BW, Johnson K. Preconception care: a 2008 update. Current Opinion in Obstetrics and Gynecology. 2008;20(6):581-9.

from available care not seeking this care, to the disappointment of many well-willing caregivers (in Rotterdam).(13, 31)

This is what makes addressing PHI in prosperous societies so challenging (and frustrating). On the one hand, the recorded PHI are disquieting and demand a response from parents, caregivers, policy makers and society as a whole. Avoidable PHI that are mediated by neighborhood inequalities are the epitome of injustice pertaining to health. No newborn deserves her poor health. On the other hand, care and help are available (although there still is much room for improvement!) for those who seek it. Unfortunately, few parents benefit from this availability. To formulate an appropriate response to PHI in prosperous societies it is, we will argue, of great importance to consider how the corrosive conditions in which parents live adapt the preferences they have regarding the health of their offspring. To bolster the strength of this consideration we will first shortly describe the importance of adequate pregnancy preparation for the long-life health of newborns.

Developmental Origins of Health and Disease and epigenetics

The period surrounding pregnancy is taking center stage in the endeavor to unveil the 'origins of health and disease'. (32-35) The findings of David Barker in particular propelled research that focuses on the ways in which the impaired development of the fetus is linked to chronic diseases later in life.(33, 36-38) This focus on the 'Developmental Origins of Health and Diseases' (DOHaD), ushered in a paradigm shift in which the paramount importance of a healthy pregnancy is recognized. The burdens of stunted fetal development are not only carried by newborns who become more prone to be born unhealthy. A stunted fetal development entails a life-long increased vulnerability to develop chronic diseases such as cardiovascular diseases, certain types of cancer and type 2 diabetes.(39) In other words, an impaired development in utero hits twice.

Research shows that so called 'epigenetic mechanisms' (partly) underpin the development of the fetus (39). Epigenetics is described as the mechanism that regulates the gene expression and thus health outcomes, without changing the DNA sequence. (40). An increasing number of clinical and epidemiological studies describe how preconceptional, prenatal and early life conditions of parents affect the epigenomic regulation of the fetal gene expression and thus consequently fetal health outcomes. (41-44) What is of particular interest is that the study of developmental processes and epigenetic mechanisms are increasingly elucidating the pathways through which social disadvantages become biologically impinged. Poor living environments, starting

from the environment in utero, translate into poor health. Although pathways such as aging, stochastic events and genotype are beyond human control, environmental and behavioral factors are to a large extent controllable. These factors include exposure to pathogens and pollutants, housing, work, nutrition and lifestyle.(45, 46) These factors are associated with parental socioeconomic status and their detrimental effects are strongest during the period surrounding pregnancy.(39, 47-52)

The fields of public health policy and ethics are taking interest in DOHaD and epigenetics. Following the new scientific insights, researchers are calling for a shift towards preventive policy focusing on the mother-child pair especially during the preconception and prenatal period and the first few years of post-natal life.(53-55) The implications for the demands of justice have also been addressed, notably the implications from a Rawlsian and luck-egalitarian perspective.(52, 56-58) The ethical literature available on 'epigenetics and justice' converges towards the idea that to the extent that epigenetic disadvantages, especially in the period surrounding pregnancy, are avoidable or amendable, justice requires the development of policy that aims at avoiding or amending these disadvantages. Preconception care has been put forward as a promising strategy to adequately prepare for pregnancy and thereby reduce poor pregnancy outcomes associated with epigenetic disadvantages.(59-61) Researchers also advise caution and conscientiousness when it comes to the ethical and policy implications of epigenetics. (52, 62) Following this caveat, we understand the insights from DOHaD and epigenetics as scientific insights that elucidate the way social misfortunes become biologically impinged and lead to lifelong disease or increased vulnerability to disease. These insights are relevant to determine the demands of justice regarding PHI, whatever theory of justice one adheres to. With these new scientific insights in mind, we move now to the question of what the demands of justice are regarding PHI in prosperous societies.

Some remarks on justice and equality

At the heart of every theory of justice lies a claim to equality. Sen writes: "[T]he major theories of social arrangement [theories of justice] all share an endorsement of equality in terms of *some* focal variable, even though the variables that are selected are frequently very different between one theory and another".(15) For example, utilitarians want to give equal weight to the equal interests of all individuals,(63) Rawlsians strive for equal liberty and an equal (and fair) distribution of primary goods(64) and Nozickians demand equality of libertarian rights(65). All claim equality of something.

Consider also that Rawls's egalitarianism was a response to utilitarianism and Nozick's libertarianism a response to Rawls's egalitarianism (his difference principle in particular). That is, theories of justice do not only differ in the variable of *equality* they *endorse*. They also differ in the variable of *inequality* they find *unacceptable*. Rawls found inequalities in liberties and primary social good unacceptable, which are prima facie tolerable for utilitarians. Nozick found inequalities in libertarian rights unacceptable which are prima facie tolerable for Rawlsians. And isn't that an opportune starting point for any deliberation about justice? The observation that some forms of inequality are unacceptable.

This is also our starting point. The observation that PHI in prosperous societies are unacceptable. Why? Because the vulnerabilities and disadvantages newborns born in underprivileged neighborhoods face –to the contrary of healthy newborns born one zip code away– deprive them of good health or burden them with a greater and life-long risk to become ill. This, to us, is unfair; an example of an unacceptable inequality.

To effectively tackle PHI, we have to identify the appropriate focal variable. That is, we need to identify the variable which can be connected to PHI and which is appropriate to be corrected by the demands of justice. This also known as the identification of the correct 'currency of justice' or the correct *equalisandum;* the 'good' justice seeks to equalize. Typical candidates are: primary social goods, utility, well-being, liberties, rights, resources, opportunities and capabilities. Given we aim to counteract PHI in prosperous societies, the best course of action would be to first focus on the sources of these inequalities. These can subsequently inform us about the correct equalisandum.

Corrosive conditions

There are conditions in which parents live that expose them to disadvantages that are likely to compound further disadvantages. Wolff and De-Shatlit call these disadvantages 'corrosive disadvantages'.(14) We call conditions in which these disadvantages are more likely to be present 'corrosive conditions'.

Consider this hypothetical but realistic portrayal. Parents living in underprivileged neighborhoods are more likely to have a lower educational attainment (a corrosive disadvantage). This increases the chance of having a low income job. A low income limits

the resources parents preparing for pregnancy have to buy healthy food[11]. Moreover, the lower educational attainment also makes parents less likely to be aware of the effects of poor nutrition on their own and their offspring's' health. This in turn makes parents less likely to want to improve their (possibly) unhealthy diet; an improvement for which they have limited resources.

In addition, low income jobs are often also risky jobs that typically put employees and consequently their offspring at an increased health risk. In combination with an unhealthy diet, which these parent are more likely to have, these job-related health risks are more likely to develop into diseases. Parents that have low income jobs are also more likely to develop stress(66), which can have significant impact on their health and which in turn can affect their offspring, and so on and so forth…(67, 68)

Slowly a web of compounding disadvantages starts to manifest when we consider the conditions that parents living in underprivileged neighborhoods face. The many ways in which parents living in underprivileged neighborhoods are disadvantaged have been observed and recorded manifold.(69-72)

Together, corrosive disadvantages expose and re-expose parents to greater health risks for themselves and their offspring *and* they curb the parents' abilities, preferences and ambitions necessary to counteract these increased risks for their own and their offspring's health. In other words, together, corrosive disadvantages are 'risk multipliers' and 'agency reducers'. Yet PHI in prosperous societies are hard to address because viewed separately, corrosive disadvantages are not necessarily unjust. Having a low income can be a corrosive disadvantage but as long as it is above the minimum wage threshold, it isn't necessarily unjust[12]. A low educational attainment can be a corrosive disadvantage but as long as one has finished compulsory education, it isn't necessarily unjust. Having a risky job can be a corrosive disadvantage but it isn't necessarily unjust. However, as our portrayal shows, it is the compounding effect of these "just" corrosive disadvantages that result in an unjust corrosive condition; a condition in which PHI are perpetuated and possibly exacerbated.

So given these corrosive condition, what should the response from a justice perspective be to counteract PHI? Especially in prosperous societies it is clear that it can't be only a matter of (re-)allocating goods. It can't be only a matter of increasing the *availability of*

11 Healthy food is not everywhere more expensive than unhealthy food but it is typically less convenient to prepare as opposed to ready-to-eat meals.

12 This obviously depends on whether the minimum wage threshold allows people to satisfy their basic needs in a given society.

and *access to* care, decent housing, decent wages, decent education and other goods necessary for making poor pregnancy outcomes less neighborhood-dependent. Of course, policy should be in place to correct for the possible lack of these essential goods; that much is clear. But what to do with the adaptive preferences that parents develop living in underprivileged neighborhoods?

This is the trait that enables them to bear their underprivileged living condition but also the trait that curbs their capacity to form health-goals they have reason to value. Correcting for the deficit of goods does not necessarily correct the deficit of this capacity. Due attention needs thus to be given to addressing the capacity people have to convert health-promoting goods into actual good pregnancy outcomes. To go back to our question about the appropriate equalisandum, we propose that this should be (a) the *capacity* to form health-goals they have reason to value, (b) the perceived control over achieving those health-goals and (c) the freedom(s) they have to achieve those health-goals, in sum, –an equality of sufficient *health agency*–.[13] The importance of considering the capacity individuals have to convert goods into actual well-being is of course the cornerstone of the capabilities approach.(73)

Capabilities and health agency

Within the justice discourse the 'capabilities approach' is a normative framework with which the demands of justice vis-à-vis social and political arrangements can be assessed. Whether a social or political arrangement is just then depends on the extent to which individuals have substantial freedoms "to do and be what they have reason to value"(74)These freedoms to achieve goals one has reason to value are called 'capabilities'. Amartya Sen, a distinguished capabilities scholar, argues that "one's freedom to achieve those things that are constitutive of one's own well-being"(15), is one's capability set or *well-being freedom*. Sen also argues that one can have reasons to value other goals than the sole promotion of one's own well-being.(75) Parents for example, typically pursue the promotion of the health and well-being of their children even if it comes at some cost of their own. Sen calls the freedom necessarily to pursue valuable goals other than one's own promotion of well-being *agency freedom* and the corresponding goals *agency goals*.(75)

13 We thus propose a baseline equality of health agency, or equality of sufficient health agency. This is a 'suffcientarianist' view which is compatible with our equality view.

As we are dealing with PHI, the capacity parents have to avoid preventable poor pregnancy outcomes is thus better described as a matter of 'agency freedom' than as a matter of 'well-being freedom' or 'capabilities'. And, as we are discussing the capacity to improve the *health* of newborns (which is an important element of the well-being of the newborn) the qualification *health agency* seems most appropriate. That is, although our normative analysis is capability-based, discussing the capacity parent have to promote the health of their offspring is better captured in terms of health agency than it is in terms of –say– health capability.

Taking stock, we have shown that PHI occur in prosperous societies such as the PHI in the city of Rotterdam and these can be partly explained by the adaptive preferences of parents living in underprivileged neighborhoods. We shortly described the ways birth and life in an underprivileged neighborhood translate into poor pregnancy outcomes and lifelong increased risk for chronic diseases. Then we argued that corrosive conditions found in underprivileged neighborhoods not only increase health risks but also reduce health agency. Therefore, in addition to securing health-related goods we argued that justice also demands the equalization of sufficient health agency of parents. Lastly, we based our health agency concept on the capabilities approach and on Sen's concept of agency. Because adaptive preferences can curb parents' agency and we propose health agency as the appropriate equalisandum of justice we will now further develop our health agency concept. This more comprehensive description can aid caregivers and policymakers to counteract PHI in correspondence with the demands of justice.

Health agency and adaptive preferences

Capacity

We have argued that in underprivileged neighborhoods within prosperous societies, adaptive preferences can impair parents' health agency. So what exactly is being impaired by adaptive preferences when we claim that health agency is impaired? To answer this question, we need to 'unpack' the concept of health agency. Now consider for example the preference *to quit smoking before pregnancy* to achieve the goal of *benefiting the health of one's future baby.*

X has this preference and makes an effort to stop smoking.

Y has this preference but makes no effort to stop smoking.

To start, it isn't unreasonable to assume that many women who smoke would do in fact want to stop smoking for the benefit of their future child. They can however, differ in the 'type of preference' they have regarding smoking cessation. Consider that X makes an effort to stop smoking. Therefor she has at least: a) identified 'smoking cessation for the benefit of her future child as a goal worth pursuing. She has also acted in accordance with that goal. I.e. she made an effort to stop smoking. Therefore, it is reasonable to conclude that her preference to stop smoking was based on the goal of benefiting the health of her future baby. This is a goal she has reason to value. She wants to bear a healthy baby.

But not all preferences are created equally. People prefer being rich over being poor. People prefer the freedom to enjoy the day as they see fit over long and arduous days at work. People prefer to be healthy over being unhealthy. And people prefer to have healthy children over having unhealthy children. However, as long as these preferences are not based on *goals one has reason to value* these preferences do not exceed the level of unattainable wishes. This is not to say that health is not a goal people have no reason to value. Quite the contrary. It is to say that goals one has reason to value have an important precondition. This precondition is that these goals have to be –in the mind of the agent– within reach, sooner or later. As a precondition, we tend to value those goals that are (eventually) attainable and *adapt* our preferences when goals are unattainable. This is the lesson of adaptive preferences. People living in underprivileged conditions tend to curtail their aspirations for a better and healthier life so they match their unfavorable circumstances. What one *needs* is then not adequately mirrored in what one *prefers*.

The same goes for Individual Y. Of course she has the 'preference' to stop smoking. This preference however is closer to the preferences one has regarding unattainable dreams (e.g. being rich or a Maria Callas-like prima donna) than to preferences which are based on goals one perceives to be both valuable and achievable. Under unfavorable conditions Y's preferences have adapted in such a way that her living conditions are no (longer) a source of frustration. This acquiescence however also stultifies her (health-related) aspirations, making it less likely for her to consider the health of her offspring as an attainable goal worth pursuing. Which reasons does she in these circumstances have to give up smoking? "In the end, what can we do but pray for the best?"(11)

Coming back to our concept of health agency we have formulated condition a) as: X has identified 'smoking cessation for the benefit of her future child' as a goal worth pursuing. To generalize this health agency condition we will formulate it as: **1.** the *capacity* to form health-goals one has reason to value. The importance of this capac-

ity condition for (health) agency is typically found in the capabilities approach based literature(75-77)

Control

Given that X has made an effort to stop smoking, it is furthermore reasonable to assume that she has perceived that she had (some) *control* over achieving the goal she has reason to value. Control is typically considered to be an important condition for agency. When we act as agents we tend to feel 'in charge' of what we do and what happens to us. This experience of –being in charge–, or the lack of, has been described in the psychological literature as the 'locus of control'. Locus of controls entails that (health-related) behavior is predicated on whether individuals view the attainment of a goal as being either within their control (internal) or beyond their control (external). (78-80) Therefore it is of significant importance to the concept of (health) agency. An individual who attributes success (such as having good health) in her life to the choices she made will be more likely to make an effort to pursue other goals worth valuing (such as bearing a healthy baby). She has an internal locus of control. Adaptive preferences are in this sense characterized as a way to come to terms with one's lack of internal locus of control. Those goals that are perceived to be beyond one's control (external) are then less likely to be worth pursuing. There is evidence suggesting that women living in underprivileged neighborhoods do experience limited control over their pregnancy and the health of their offspring. (11, 13) Although this group of women is open to receiving help and care, they tend not to seek it because of their perceived limited control over their pregnancy and their pregnancy outcomes. This brings us to our second condition for health agency which is **2.** the perceived control over achieving health-related goals one has reason to value.

Freedom

The perception of control however is not enough. In line with Sen we argue that *freedom* is also an indispensable condition for agency and therefore also for health agency. Sen describes 'agency freedom' as "what the person is free to do and achieve in pursuit of whatever goals or values he or she regards as important"(75) For Sen agency freedom consist of two elements namely 'control' and 'power'. The former has been discussed in the previous paragraph and our account of control converges with his account. The latter element, power, is surprising enough a familiar concept within the healthcare debate. It typically appears as claims about the importance of em*power*ment of individuals to improve their health (and the health of their offspring). (81-83) When it comes to health agency we also endorse the idea of freedom as a power or –if you will– empowerment. Especially when health-related goals require "complex self-management tasks"(84) such as comprehensive life-style changes, the power to

actually *carry out the changes* one values and perceives as being under one's control matter. This 'freedom as power' comes close to the concept of 'executive autonomy'. This concept refers to "the capacity to perform complex self-management tasks, especially those related to treatment planning and implementation."(84) The freedom condition of health agency thus refers to the freedom to actually do what is necessary to achieve the health goals one has reason to value. It is for example, the freedom to stop smoking; today, tomorrow and preferably forever if one values smoking cessation. Thus our last condition for health agency is **3.** the freedom one have to achieve health-goals one has reason to value.

It is important to consider that although these three conditions (capacity, control and freedom) of health agency are distinct as concepts, in the agent's mind they are interdependent. If one's capacity to form health-goals one has reason to value is compromised it is also likely that her perception of control will be compromised and vice versa.

We have proposed that the demands of justice regarding PHI in prosperous societies are best captured by the claim that the health agency of parents should be equalized, at least until they meet the threshold of sufficiency. Now we have given a more comprehensive account of health agency the question that remains is: when is health agency *sufficiently* equalized?

Bare-bones perfectionism

We propose that health agency is sufficiently equalized when the preferences of parents living in underprivileged conditions match the preferences they would endorse in conditions conducive to their own and their offspring's health and basic well-being. These preferences might differ on a practical level. There are for example, numerous ways to try to improve one's lifestyle in the period surrounding pregnancy. On a basic level however, these preferences are to some extent predictable. They are based on a goal we can reasonably expect to be endorsed by parents, caregivers and society as a whole, that is, the goal of improving the health of newborns and reducing PHI. Therefore, health agency is sufficiently equalized when the preferences of parents regarding pregnancy and offspring converge towards the goal of preventing avoidable poor pregnancy outcomes. Based on the relatively good pregnancy outcomes, we expect that parents living in conditions conducive to their own and their offspring's health to have these preferences.

This goal does not have to be achieved by any means and at any cost. Moreover, conditions necessary for preventing avoidable poor pregnancy outcomes, such as access to social services and adequate care, have to be in place. As we are considering PHI in prosperous societies we have, for the sake of argument, assumed that these are to a reasonable extent in place. This is not to say that there is still much to do to provide these material and social conditions for example in a city like Rotterdam. Rather, it is to say that even when these material and social conditions are met, health agency affected by adaptive preferences, can hinder the conversion of these conditions into actual good health for newborns. The mere fact that help is available does not necessarily entail that people who would benefit from it will seek that help.

We proposed that the goal of improving the health of newborns by avoiding preventable poor pregnancy outcomes, especially in underprivileged neighborhoods, is a goal worth valuing and pursuing by all members of the moral community. We base this goal on what is known in the ethical and philosophical literature as 'perfectionism'. We will now shortly explain why this is the case and what type of perfectionism we have in mind.

When we make claims such as: 'it is better for a baby to be born healthy than to be born ill' and 'we should aspire to equalize the health agency of parents, at least to a level of sufficiency' we have an idea of the Good in mind. That is, good health for newborns and sufficient health agency for parents are goals we as a society have reason to value and therefore pursue, i.e. base policy on. The value of good health for newborns for example, is not predicated on whether parents, viewed separately, actually prefer or desire their baby to be healthy. It would be a strange state of affairs if *hypothetical* sadistic individuals who vehemently desire that their babies are born with poor health would affect the value we as a moral community attribute to good health for newborns. Rather, in this value we find expressed 'an idea of the Good'; which is that as a moral community it matters to us how well the life of a newborn goes. And if that life is plagued by preventable poor health we have a responsibility to cure and prevent.

The idea that there are some goals we as a community have reason to value and therefore pursue because they generally make our life go better, irrespective of individual preferences is our bare-bones version of what is called (moral) 'perfectionism'.(85) Educating children for example, is a goal we as a community have reason to value and therefore pursue because, generally speaking, education makes the lives of children go better. This goal is mirrored by the corresponding preference most (if not all) parents have, namely that their children are properly educated. Consequently, children have to go to school even if some parents or children would prefer otherwise.

In cases where adaptive preferences cause and/or perpetuate instances of injustice such as PHI, policy responses based on bare-bones perfectionism are very much worth considering. Policy that is aimed at improving the health agency of parents living in underprivileged neighborhoods is worth considering because it aims at achieving a goal we can reasonably expect parents to have reason to value and pursue. This goal is the prevention of avoidable poor pregnancy outcomes. We will now formulate two important caveats to our bare-bones perfectionism approach to counteract PHI in prosperous societies.

Two caveats

First, our proposal to improve the level of health agency of parents to a level of sufficiency is intentionally *underspecified*. What ultimately counts as sufficient should be determined through deliberation within the community that seeks to achieve this level of sufficient health agency for all parents. An overly specified top-down view of which goals we as a community have reason to value and how we ought to pursue them have been fiercely criticized and for good reasons. Such perfectionism-based policies disallow the plurality of views on which (health-related) goals are worth valuing and pursuing (86) and justify coercion of people who are not acting in accordance with the goals worth valuing and pursuing.(85) Coercing people to commit to one view of the "good life" and act accordingly is itself a source of much harm and many evils in the world. This is not what we have in mind.

The importance of public deliberation to establish which goals (and which capabilities) are worth valuing and pursuing within a society has been stressed on multiple occasions by capability scholars such as Sen and Nussbaum(18, 87). To our mind, deliberation is especially important to establish justified policies to improve health agency as we cannot imagine that deliberation would result in the refutation of goals such as the improvement of the health of newborns and the health agency of parents. The ways to achieve this improvement however is clearly up for debate. The suitability and exact content of interventions such as: lowering the prices of healthy products, taxing unhealthy products, encouraging a pro-active disposition of caregivers, rewarding healthy pregnancy preparation and embedding topics such as perinatal health and the effects on long-life health within local and national Governmental policies and education, should be determined by public deliberation.

From this follows our second caveat. Adaptive preferences never justify the condescending view that parents living in underprivileged neighborhoods are unable to formulate

and pursue their own ends.(20) This entails that parents living in underprivileged neighborhoods should never be excluded from public deliberation on the suitability and content of agency-promoting interventions. Adaptive preferences are not irrational or unreasonable. If anything it is perfectly understandable that one adapts her aspirations so they align with her material, social and medical conditions. Adaptive preferences can justify the raising of questions about an unjust state of affairs such as PHI. By themselves however, they never justify detailed policy to counteract this unjust state of affairs. A serious engagement with parents is necessary to unfold the underpinnings of their adapted preferences as well as the 'barriers' and 'facilitators' to improve their health agency.(13, 88, 89) These insights are necessary to counteract PHI in prosperous societies because ultimately it are the parents that have to "own"(20) the alternative preferences which are based on an improved health agency.

Conclusion

We have argued that PHI in prosperous societies are partly caused by adaptive preferences. These PHI are an example of unacceptable injustice. To counteract these adaptive preferences, we proposed that the health agency of parents living in underprivileged conditions should be improved at least to the level of equal sufficiency. The level of sufficiency is achieved when parents adopt the prevention of avoidable pregnancy outcomes as a goal worth valuing and pursuing; although not at all costs and by any means.

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