BEFORE YOU WERE BORN

A moral exploration of parental and societal responsibilities for the health of children-to-be

Hafez Ismaili M'hamdi

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Ismaili M'hamdi H.

This thesis is a result of a research project funded by the ZonMw program Pregnancy and Birth: Ethical Issues in Preconception Care (project number 209040004)

ISBN: 978-94-6050-016-9

Cover design: Optima Grafische Communicatie (www.ogc.nl)
Printing: Optima Grafische Communicatie (www.ogc.nl)

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Nog voor jij geboren was:
een morele verkenning van de verantwoordelijkheden van ouders en de samenleving voor de gezondheid van toekomstige kinderen.

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de
rector magnificus

Prof.dr. R.C.M.E. Engels

en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
woensdag 21 november 2018 om 11.30 uur

door

Hafez Ismaili M'hamdi

geboren te Weert

Erasmus University Rotterdam

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DISSERTATION

to obtain the degree of Doctor at Erasmus MC Rotterdam,
on the authority of the Rector Magnificus Prof. dr. Rutger Engels,
and a degree of Doctor of Medical Science at the Hasselt University,
on the authority of the Rector Prof. dr. Luc De Schepper,
in accordance with the decision of the Board of Deans,
to be defended in public on Wednesday 21st of November at 11.30 hours
in Rotterdam

by Hafez Ismaili M'hamdi

Depotnummer: *D/2018/2451/84.*

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For my parents,
who came with nothing
yet gave me everything.

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PART 1

MATERNAL AND PARENTAL RESPONSIBILITIES

1

GENERAL INTRODUCTION

Introduction

Moral birth

A baby is born twice. Its *biological* birth occurs approximately nine months after conception; its *moral* birth however, quite some time before. Moral birth denotes the moment the needs of the child-to-be enter the world. The most elementary of these needs and corresponding responsibilities pertain to the survival and health of the newborn. For its health and therefore its wellbeing, a newborn needs healthy nourishment and adequate care. We primarily look to the parents to respond to these 'health needs' as they are expected to protect, maintain and promote the health and wellbeing of their children. Parents however, are not the only ones who carry responsibility for the health needs of their children-to-be. In fact, a baby is never only born to a mother, a father or into a family; it is also born into a society. That society also carries responsibility for the child. For example, when society has the means to do so, it has the responsibility to make decent and accessible pregnancy related care - such as preconception, prenatal and maternity care - available. If a mother-to-be carries the responsibility to invest in having a healthy pregnancy for the benefit of the health and wellbeing of her child-to-be, then surely society carries the responsibility to make the access to decent pregnancy related care readily available.

This raises the question: when have parents and society responded adequately and satisfactory to the health needs of children-to-be? The moral exploration of the parental and societal responsibility to satisfy the health needs of children-to-be is the central theme of this dissertation.

Ambitious as this exploration may at first glance seem, this wide scope is, as I will argue, in fact necessary. There is reason to be optimistic about the fulfillment of parental and societal responsibility for the health of children-to-be. The perinatal mortality in the Netherlands for example, has decreased substantially these last decades.(1) Insights into the harmful effects of smoking and drinking and advances in gynecological and obstetric care have reduced the number of adverse pregnancy outcomes significantly. Yet, when we consider the *avoidability* of poor pregnancy outcomes in the Netherlands on the one hand and the staggering *inequalities* in the chances of having healthy pregnancy outcomes between neighborhoods on the other(2, 3) it becomes clear that questions about the responsibility for the health of children-to-be are of paramount importance. As an example of these staggering inequalities, consider 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."

Needs

It is a good idea to begin at the beginning. So when do responsibilities for the health of the newborn, both from parents and society, 'begin'? The period of time in which behavior, action and policy can have a significant impact on the health of newborns seems a reasonable starting point. This is not the moment of conception. An increasing amount of scientific evidence points towards the period before conception (4, 5)–the *pre*conception period– as the appropriate window of opportunity to start considering the health of the newborn. Embryonic development is a key determinant for the health of a newborn.(6) Conventional antenatal care (which typically begins between the 8th and 12th week of pregnancy) is ill-equipped as it is delivered too late to prevent a possible suboptimal embryonic development as many key events in the development of the embryo have already taken place when the mother has her first consultation. (7) Preconception care however, care for couples who contemplate pregnancy, is aimed at preventing the suboptimal embryonic (and fetal) development by addressing the underlying risk factors before conception. Moreover, preconception care is also aimed at improving the health of the mother-to-be.(8) Interventions that aim to improve women's intake of sufficient folic acid in the preconception period to decrease the risk for newborns to have a neural tube defect (9) belong to the best-known examples of preconception care. What is more, in addition to the *direct* benefits to the health of the newborn and the mother, preconception care can actually benefit the subsequent *lifelong* health of that newborn Studies building on the so called 'Developmental Origins of Health and Disease' paradigm show that one's risk to develop chronic diseases such as cardiovascular disease and diabetes later in life is associated with one's development in utero.(10, 11) Thus in sum, for its health and wellbeing a newborn needs its parents to prepare for pregnancy.

Responsibilities

Having introduced (some of) the basic health needs of children-to-be I turn now to the corresponding responsibilities. Avoidable adverse pregnancy outcomes in general and perinatal health inequalities in particular are unnecessary and unfair to the extent that they, for one, require a response from parents, the mother in particular as her pregnancy preparation affects the health of the child-to-be the most. Changes in behavior before conception such as smoking and alcohol cessation, dietary improvements and the use of folic acid supplementation improve the chances of giving birth to healthier babies. These opportunities for improvement give rise to responsibilities. Although not

by any means or at any cost, mothers-to-be have, by virtue of these opportunities, a responsibility to prepare for pregnancy. This responsibility is felt strongly by mothers-to-be themselves as they are typically interested in the opportunities to improve the health and wellbeing of their children-to-be.(12) Adequate pregnancy preparation can however, be quite demanding. For example, it may require mothers-to-be to make substantial lifestyle changes such as resisting an addiction such as smoking or postponing pregnancy, that is, resisting her strong desire to have a baby because, for example, of a complicated medical or obstetric history.

Therefore, the 'demandingness' of maternal responsibility has to be established in order to develop, organize and deliver of pregnancy-related care in an ethically justified manner. Are, after ethical scrutiny, only those pregnancy-related interventions justified that inform, give advice to and encourage mothers(-to-be) to make choices that benefit the health of their children(-to-be)? Or are, with an appeal to the health of the newborn and the corresponding responsibility of the mother, interventions that rely on the steering of unreflective behavior (i.e. nudges), coercion or even force justified? In this dissertation I aim to answer these questions by considering the justifiability of two types of pregnancy-related interventions at the opposite of the 'demandingness spectrum'. On the one side there are the so called 'nudges' that aid mothers-to-be to prepare for pregnancy for example by making healthy choices such as visiting a preconception consultation the default. On the other side there is the use of force against mothers-to-be for the benefit of the health of the fetus. A classic case is that of the 'forced cesarean' where pregnant women are forced to submit to cesarean surgery to save the fetus in distress. The analysis of the justifiability of force in this classic case can serve as an ethical guideline for the use of force in other forms pregnancy-related care.

Considering the responsibilities of parents and mothers in particular is, as already stated, only part of the picture. The impact of the socioeconomic environment of the parents-to-be on the health of children-to-be, an impact which cannot be adequately captured by referring to parental responsibilities, is considerable. Most risk factors associated with poor pregnancy outcomes have significant socioeconomic components which are typically *not* or only *to a limited extent* a matter of parental choice. The highest risks of poor pregnancy outcomes are in fact recorded in deprived neighborhoods where parents-to-be struggle – even in a prosperous society like the Netherlands– with the burdens of poverty.(13) Poor housing, air and noise pollution, maternal stress and a suboptimal availability and access to pregnancy-related care are examples of risk factors that are associated with poor pregnancy outcomes over which mothers-to-be living in underprivileged neighborhoods have but limited control.(14-17) Addressing these

risk factors is a matter of public policy and governmental organization of (health) care. In other words, it is a matter of social responsibility to make resources for pregnancy-related care (e.g. monetary investments in preconception care) available. However, society has to balance the claim on resources for the benefit of children-to-be with its (many) other societal responsibilities. It is simply unattainable and even ethically unjustifiable to direct all of society's resources to combat poor pregnancy outcomes; some form of prioritization of scarce resources is necessary. So what can we reasonably ask from society when it comes to resource allocation aimed at benefiting the health of children-to-be? This is a question of distributive and social justice. In this dissertation I aim to address this question by considering what the demands of justice pertaining to the health and wellbeing of children-to-be do (and do not) entail.

Aims

The aims of this dissertation are:

- To identify and describe the views of parents and caregivers on the responsibilities for the health of children-to-be in general and the responsibility to prepare for pregnancy in particular.
- To provide an ethical analysis of the justifiability of unreflective behavioral interventions (nudges) aimed at benefiting the health of children-to-be.
- To provide an ethical analysis of the justifiability of the use of force in pregnancy related care by considering the case of the justifiability of forced cesareans.
- To identify and present the demands of justice pertaining to the improvement and securing of the health of children-to-be.

Methods

Questions in bioethics and medical ethics are typically complex as they consist of 'real-world' empirical elements as well as more abstract philosophical and normative elements. A 'mixed method' approach, in which literature research, qualitative interview studies and ethical analysis are combined is considered to be an appropriate method to tackle questions within these domains.(18) This will also be the method used in this dissertation. The views of the stakeholders, those being (vulnerable) mothers(-to-be), caregivers and researchers, on the responsibility for the health and wellbeing of children-to-be are of key importance. These views will be identified through qualitative interview studies and an expert meeting. Central in these studies and meeting is the question of responsibility and the barriers and facilitators to fulfill this responsibility.

To answer the normative question on responsibility for the health of children-to-be there will be an emphasis on critical ethical analysis in this dissertation We use the (narrow) reflective equilibrium. (19) This is a method in which the principles one is committed to are tested for their coherence against one's intuitions and considered judgments. We use this method explicitly to establish the responsibility of caregivers for the health of pregnant women and children-to-be. The analysis of the demands of justice pertaining to the health of children-to-be will be based on Rawls's idea of justice as fairness(20) and Sen and Nussbaum's capabilities approach(21, 22). Both focus on the important distinction between interpersonal duties, in our case parental responsibilities towards their children(-to-be), and duties of justice, in our case societal responsibilities towards children(-to-be).

Outline

Part I 'Maternal and Parental Responsibilities'

In *Chapter 2* we report on the barriers and facilitators to adequate pregnancy preparation according to healthcare professionals.

In *Chapter 3* we report on the perceptions vulnerable mothers-to-be have on their responsibility to prepare for pregnancy.

In *Chapter 4* we introduce the concept of other-regarding nudges; behavioral interventions that are aimed at promoting the health and wellbeing of someone else than the person who is being targeted by the behavioral intervention. The conventional ethical justification for nudges i.e. Libertarian Paternalism is replaced by an ethical justification which is suited for explaining why one person (e.g. a mother) can be justifiably targeted to be nudged for the benefit of another person (e.g. her child-to-be).

In *Chapter 5* we discuss the limits of maternal responsibility for the health of her child-to-be by considering the justifiability of forcing pregnant women to submit to surgery when this would save the life of their child-to-be. We argue that although pregnant women have a serious and robust responsibility to promote the health and wellbeing of their children-to-be, they should not be *forced* to fulfill this responsibility.

Part II 'Societal Responsibilities'

In *Chapter 6* we report on the conclusions reached in a multidisciplinary expert meeting in which the definition and distribution of roles and responsibilities of caregivers and the organization of preconception care were discussed.

In *Chapter 7* we provide an ethical analysis of the problem of inequalities in pregnancy outcomes in prosperous societies such as the Netherlands and it is proposed that justice demands the equalizing the 'health agency' of parents(-to-be) to a sufficient level.

In *Chapter 8* we discuss the insights of the Developmental Origins of Health and Disease and epigenetics and how these insights should be used to establish the societal responsibilities towards the health and wellbeing of children-to-be.

In *Chapter 9* I summarize and discusses the main findings of this dissertation.

References

1. CBS. Deaths; important causes of death: diseases in the perinatal period Overledenen; belangrijke doodsoorzaken : Aandoeningen v.d. perinatale period. 2017
2. Vos AA, Posthumus AG, Bonsel GJ, Steegers EA, Denktaş S. Deprived neighborhoods and adverse perinatal outcome: a systematic review and meta-analysis. Acta obstetricia et gynecologica Scandinavica. 2014;93(8):727-40.
3. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EAP. Urban perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2011;24(4):643-6.
4. van der Zee B, de Beaufort I, Temel S, de Wert G, Denktas S, Steegers E. Preconception care: an essential preventive strategy to improve children's and women's health. J Public Health Policy. 2011;32(3):367-79.
5. Atrash HK, Johnson K, Adams MM, Cordero JF, Howse J. Preconception care for improving perinatal outcomes: the time to act. Maternal and child health journal. 2006;10(1):3-11.
6. Steegers E. Embryonic health and preconception care: importance for current and future generations. Nederlands tijdschrift voor geneeskunde. 2014;158:A7373-A.
7. van Voorst S. Preconception care: from policy to practice and back2017.
8. van der Zee B. Preconception Care: Concepts and Perceptions: An ethical perspective2013.
9. Steegers-Theunissen RP, Boers GH, Trijbels FJ, Finkelstein JD, Blom HJ, Thomas CM, et al. Maternal hyperhomocysteinemia: a risk factor for neural-tube defects? Metabolism-Clinical and Experimental. 1994;43(12):1475-80.
10. Barker D. Developmental origins of adult health and disease. Journal of epidemiology and community health. 2004;58(2):114.
11. Gluckman PD, Hanson MA, Low FM. The role of developmental plasticity and epigenetics in human health. Birth Defects Research Part C: Embryo Today: Reviews. 2011;93(1):12-8.
12. de Jong-Potjer LC, De Bock GH, Zaadstra BM, De Jong ORW, Verloove-Vanhorick SP, Springer MP. Women's interest in GP-initiated pre-conception counselling in The Netherlands. Family practice. 2003;20(2):142-6.
13. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EA. Urban perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2011;24(4):643-6.
14. de Graaf JP, Steegers EA, Bonsel GJ. Inequalities in perinatal and maternal health. Current Opinion in Obstetrics and Gynecology. 2013;25(2):98-108.
15. Genereux M, Auger N, Goneau M, Daniel M. Neighbourhood socioeconomic status, maternal education and adverse birth outcomes among mothers living near highways. Journal of Epidemiology & Community Health. 2008;62(8):695-700.
16. Hobel CJ, Goldstein A, Barrett ES. Psychosocial stress and pregnancy outcome. Clinical obstetrics and gynecology. 2008;51(2):333-48.
17. M'hamdi HI, van Voorst SF, Pinxten W, Hilhorst MT, Steegers EA. Barriers in the Uptake and Delivery of Preconception Care: Exploring the Views of Care Providers. Maternal and Child Health Journal. 2016:1-8.
18. Childress J. Methods in bioethics. 2009.
19. Arras JD. The way we reason now: reflective equilibrium in bioethics. 2007.
20. Rawls J. A Theory of Justice. Mass: Harvard University. 1971.

21. Paul Anand PD. Equity, Capabilities and Health. Social Science & Medicine. 2005;60(2):219-22.
22. Nussbaum MC. Women and human development: The capabilities approach: Cambridge University Press; 2001.

2

BARRIERS TO THE UPTAKE AND DELIVERY OF PRECONCEPTION CARE: EXPLORING THE VIEWS OF CARE PROVIDERS

HAFEZ ISMAILI M'HAMDI, SABINE F. VAN VOORST, WIM PINXTEN, MEDARD T. HILHORST, ERIC A. P. STEEGERS (2017).

BARRIERS TO THE UPTAKE AND DELIVERY OF PRECONCEPTION CARE: EXPLORING THE VIEWS OF CARE PROVIDERS *MATERNAL AND CHILD HEALTH JOURNAL*, *21*(1), 21-28.

Abstract

Objectives: To examine the health care professionals' views on their role and responsibilities in providing preconception care and identify barriers that affect the delivery and uptake of preconception care.

Methods: Twenty health care professionals who provide preconception care (PCC) on a regular basis were interviewed using semi-structured interviews.

Results: We interviewed twelve community midwives, three General Practitioners, three obstetricians, one cardiologist specialized in congenital heart diseases and one gastroenterologist. We identified four barriers affecting the uptake and delivery of preconception care: 1) lack of a comprehensive preconception care program; 2) Most future parents are unaware of the benefits of PCC. GP's are hesitant about the necessity and effectiveness of PCC; 3) poor coordination and organization of preconception care; 4) conflicting views of health care professionals on pregnancy, reproductive autonomy of patients and professional responsibility.

Conclusion: We have identified four types of barriers in the uptake and delivery of preconception care. Our findings support the timely implementation of a comprehensive program of PCC (already advocated by the Health Council of the Netherlands) and increasing awareness and knowledge of PCC from care providers and future parents. We emphasize the need for further research on how organizational barriers lead to suboptimal PCC and how interdisciplinary collaboration and referral can lead to optimally tailored intervention approaches.

Significance

What is already known about this subject? Despite persistent adverse pregnancy outcomes and even though the benefits of preconception care have been established, the uptake and delivery of preconception care remain low. Health care professionals play an important role in the uptake and delivery of preconception care.

What this study adds? This study identifies barriers perceived by health care professionals. These barriers need to be addressed to improve the uptake and delivery of preconception care.

Introduction

An increasing amount of research links fetal development with perinatal morbidity and mortality as well as the development of chronic diseases in later life (1, 2). Many risk factors for perinatal mortality and morbidity and associated diseases in adulthood are already present during the periconception period – the period before and shortly after conception– (3). Targeting the periconceptional period opens opportunities to prevent later risks. Preconception care (PCC) – care and advice given before pregnancy – offers such an opportunity as it is offered before risk factors can exert negative effects on the developing fetus. A substantial body of evidence supports the benefits of PCC interventions on pregnancy outcomes (4-7) and influenced national and international recommendations and guidelines for the uptake and delivery of PCC (8-10) Most recommendations endorse the use of a standardized risk assessment which includes both medical and non-medical risks. (11, 12)

Despite persistent adverse pregnancy outcomes and although the benefits of PCC have been established, the delivery and uptake of PCC remain low. In 2007, in response to the relatively high perinatal mortality and morbidity rates in the Netherlands, the Dutch Health Council published an advisory report entitled 'Preconception care: a good beginning.' The report emphasizes the importance of introducing a PCC program that is initiated and coordinated by the government. (13)Guidelines for general practitioners and midwives (8) as well as risk assessment instruments have been developed (14), and the Dutch government recognized the importance of introducing PCC as a standard component of perinatal care (15). Despite these recommendations, no comprehensive PCC program has been introduced and only few healthcare professionals are currently delivering PCC.(16).

Healthcare professionals who deliver PPC (e.g., community midwives, general practitioners (GPs), obstetricians and other medical specialists) have the potential to significantly influence the uptake of PCC (17, 18). But even though primary care setting, hospital setting, community outreach programs and youth health centers all offer opportunities to address and offer PCC (19), healthcare professionals do not systematically discuss the availability and benefits of PCC in such settings (16, 20).

The views held by those who provide PCC in different clinical settings influence the way in which they engage in PCC activities, discuss PCC with, and deliver PCC to future parents. A better understanding of the views of PCC providers regarding their role and responsibility towards PCC may help explain why the uptake is low.

The aim of this study is to explore the views, identify the barriers and provide recommendations to optimize the uptake and delivery of PCC.

Methods

We conducted qualitative interviews with healthcare professionals who provide PCC in the Netherlands. As PCC is implemented on a small scale and there is no overview of where it is delivered, a convenience sample was selected for this interview study. The convenience sample consisted of GPs, midwives, and specialists who deliver PCC on a regular basis (for our purposes defined as having delivered PCC at least 5 times in the previous year). We included specialists who deliver specialist PCC in order to compare whether their views differ from those of GPs and midwives who deliver regular PCC.

The selected midwives delivered PCC on a weekly basis in midwifery practices. All selected GPs offered PCC in an opportunistic way. The familiarity with their patients offers them opportunities to discuss PCC at strategic moments, such as the removal of an IUD.

Both GPs and midwives were selected from the list of participants of the 'Healthy Pregnancy 4 All' study (21); a study that evaluates the effectiveness of a preconception care program in urban and rural multi-ethnic communities from 14 municipalities in the Netherlands. In the 'Healthy Pregnancy 4 All' study, midwives and GPs were recruited to deliver PCC to requesting patients, thereby automatically making them eligible for our study by fulfilling the inclusion criterion of having delivered PCC at least 5 times within the previous year.

Specialists affiliated to the same university hospital as the authoring team and known to deliver hospital based PCC were invited to participate. Included specialists comprised of gynecologists, gastrointestinal specialist and cardiologists, all working at the Erasmus Medical Center Rotterdam, which delivers care to a multi-ethnic urban population. As university hospital employees, these specialists are involved in more complex PCC cases, sometimes after referral from GPs, midwives, or other specialists.

Interviews were performed using a semi-structured questionnaire. In developing the questionnaire, we carefully attended to the form and content of the questions. The form of the questionnaire was based on of the Theoretical Domains Framework developed by Michie and colleagues (22). This framework has been developed to enhance understanding of behavior change processes amongst health care professionals, which is an

Table 1. *Form: based on the theoretical domain framework developed by Michie et al.*

Domain	Questions
Knowledge	· Are you familiar with the Dutch preconception guidelines? · What do you think about the current organization of PCC? Is it feasible for you to perform your task as a preconception caregiver? · How effective do you think PCC is? Do you think the goals of PCC are attainable?
Skills	· How and with what aim do you ask the future parents about their medical and obstetric history? Other domains as well (Informative, directive (paternalistic), deliberative, shared decision making(23)) · What problems have you encountered when asking about the medical and obstetric history and how did you try to solve them? Can you give an example of such a problem? (And how were you able to solve the problem)
Social/professional role and identity	· Do you encounter situations in which you think pregnancy should be postponed or discouraged because of the social economic conditions? Can this lead to a tension between your personal convictions and professional responsibility? (E.g. Personally I would advise against it however as a professional I feel obliged to advise and counsel)
Beliefs about capabilities	· What problems have you encountered when delivering PCC in general? · What problems have you encountered when asking about the medical and obstetric history and how did you try to solve them? · How do you deal with the fact that working conditions can be hard to change, even if it is better for the health of the future parents and child?
Beliefs about consequences	· Are you optimistic about the likelihood of tobacco, alcohol and drugs cessation? · Do you think the current organization of PCC is adequate to help you solve the problems you encounter? · How does the fact that these conditions (working conditions/ social economic position) are hard to modify influence your delivery of PCC?
Motivation and goals	· How valuable is PCC? Do you subscribe the goals of PCC and do they motivate you to do your job as a preconception caregiver? · Does the social economic situation alter your motivation or goals when delivering PCC?
Memory, attention and Decision processes	· How much preparation do you need to deliver a preconception consultation and is it in balance with the perceived reward? (Reward can be a good consultation, health benefits for the future parents or monetary reward)
Environmental context and resources	· What do you think about the current organization of PCC? Is it adequate for you to perform your task as a preconception caregiver? (Is there sufficient time and are there sufficient resources to perform your tasks as a preconception caregiver?)
Social influences	· Do you feel sufficiently recognized valued in your work as a preconception caregiver by your patients and your peers?
Emotion regulation	· Do you encounter situations in which you think pregnancy should be postponed or discouraged because of the medical or obstetric history? Can this lead to a tension between your personal convictions and professional responsibility? (E.g. Personally I would advise against it however as a professional I feel obliged to advise and counsel)
Behavioral regulation	· What do you think about the current organization of PCC? Is it adequate for you to perform your task as a preconception caregiver
Nature of the behavior	· Do you encounter any problems and what would help to overcome these problems?

important determinant for the success of the clinical implementation of evidence-based practice such as PCC in the healthcare domain. It consists of a list of consensus-based theoretical domains (e.g., caregivers' knowledge, skills, motivation and goals), which are essential for achieving a successful evidence-based implementation. Structuring our questions according to these domains enabled us to systematically identify the limiting factors for the delivery and uptake of PCC. That is, this framework offered the opportunity to link PCC barriers perceived by participants to a specific domain known to affect the uptake and delivery of healthcare. For each domain, sample questions were provided to evaluate implementation (table 1).

The content of the questions was based on the Dutch guideline for GPs. (8). This is a broad guideline for general comprehensive PCC that describes several risk domains that should be covered during preconception consultations for couples from the general public. This guideline includes the assessment of medical and obstetrical history, genetic risks, life style risks (including tobacco, alcohol and drug use, and risk exposure at work), genetic disorders, and socioeconomic factors (see Online Resource 1). We incorporated all these risk domains in our questionnaire.

To ensure consistency, only one interviewer (HI) conducted the interviews. Interviews had a duration of approximately 45 minutes. The semi structured interview format ensured that the preselected items were discussed but allowed to deviate from the interview format to explore new themes that were considered to be relevant by participants. The interviews were audiotaped and transcribed ad verbatim. All participants' details were removed and the transcripts were de-identified to protect confidentiality.

Three authors (HI, WP, and MH) read the transcriptions independently from each other, and subsequently discussed content to identify and compare the key barriers to PCC. The participants' responses were classified using a deductive thematic method of analysis, in which the framework provided domains to organize the barriers mentioned by participants. Microsoft Excel software was used to organize these barriers.

Results

Twelve community midwives, three general practitioners, three obstetricians, one cardiologist specialized in congenital heart diseases and one gastroenterologist were interviewed. The community midwives and GPs interviewed deliver general preconception consultation services, which cover the risk domains mentioned in the Dutch guideline for PCC. All the interviewed midwives and GPs indicated that they use Zwangerwijzer,

a validated PCC questionnaire. The online version of Zwangerwijzer allows to generate an overview of the respondents' risk profile. The interviewed midwives and GPs use this risk profile to deliver PCC as effectively and efficiently as possible. Only the GPs offered PCC opportunistically (i.e. when women request removal of an intrauterine device). Midwives indicated that the midwifery setting does not often allow to offer PCC opportunistically because parents-to-be typically rarely visit a midwifery before conception. The interviewed specialists deliver specialist preconception consultation services. These consultations typically aim to address complex medical issues that expose the patient and her future child to substantial health risks. All interviewed participants were aware of the Dutch guideline of PCC and shared the view that the delivery of PCC is of upmost importance when preparing for pregnancy. They also shared the view that despite this importance, the uptake of PCC remains disappointingly low.

The participant's answers in combination with the domains from Michie's framework provided the identification of four barriers that affect the uptake and delivery of preconception care. 1) Lack of a comprehensive PCC program; 2) Most future parents are unaware of the benefits of PCC. GP's are hesitant about the necessity and effectiveness of PCC; 3) Poor organization and coordination of PCC; 4) Health care professionals' conflicting views on pregnancy, reproductive autonomy of patients and professional responsibility.

1. Lack of a comprehensive PCC program

The lack of a centrally coordinated and comprehensive offer of PCC (that is the lack of a PCC program in which contents of PCC is standardized) was raised as an important cause of the unfamiliarity with, and low knowledge of PCC amongst future parents. This unfamiliarity amongst future parents was thought to be the main reason for the low uptake of PCC. In addition, the low uptake of PCC also makes it difficult for healthcare professionals to develop a routine and build experience in the delivery of PCC.

> *(Knowledge, belief about capabilities) "Due to the low uptake, the frequency with which we do preconception consultations is low. Therefore we lack the opportunity to develop experience and routine in delivering PCC." (Midwife)*

All participants expressed the concern that future parents who would benefit the most from PCC are the ones who are the hardest to reach. Participants specifically identified future parents with low socioeconomic status, people living in poverty or deprived neighborhoods and non-western immigrants as hard to reach groups.

(Beliefs about capabilities) "PCC is simply unknown to a lot of people, especially to those who would benefit the most…I think that the people who would benefit the most are those who smoke, drink and are obese and live in deprived neighborhoods."(Obstetrician)

(Beliefs about capabilities) "Especially people with a low SES perceive that they should only start seeking care once they are pregnant. The fact that they can optimize their health before pregnancy is unknown to them."(Obstetrician)

Midwives perceived the current lack of a fee (no financial compensation) in combination with the labor-intensiveness as a barrier to deliver PCC.

-(Environmental context and resources, motivation and goals) "The preconception consultation is very time consuming and we do not get paid for it."(Midwife)

Delivery of PCC is perceived to be time consuming because it is a new form of care and because of the substantial amount of risk factors that should be addressed during a consultation. Interviewed GPs and medical specialists indicated that they have insufficient time to deliver PCC. This lack of time was partly due to the fact that consultations are time consuming and partly because of competing preventive care which also needs to be delivered. Participants also indicated that future parents were not always willing to invest the required time and effort to adequately prepare for pregnancy.

(*Environmental context and resources)* "I *often have to use all the time available to address the patient's medical questions, so the time to ask about the desire to have children or to discuss PCC is lacking… Because of time and resource constraints, PCC has to compete with other preventive care. That may also be a barrier." (GP)*

-(Beliefs about capabilities, beliefs about consequences) "I would like to see my patients invest more time in following my advice. It takes time to follow the advice I give them, like changing their medication or visiting another medical specialist for a checkup. When I ask them to come see me again in three months they sometimes are reluctant to do so because they want to get pregnant as quickly as possible."(Obstetrician)

2. Care providers' and future parents' lack of knowledge of preconception care.

Participants indicated that the future parents' as well as healthcare professionals' perceptions about PCC are important determinants for the uptake and delivery of PCC. The lack of familiarity with and knowledge of PCC of future parents and caregivers

were perceived as barriers. GP's in particular were somewhat hesitant to deliver PCC because, according to them, it is a time consuming form of care that still has to prove to be effective.

> *- (Knowledge) "My patients' knowledge about their health and about pregnancy is generally limited. They do not experience the need for PCC. This is a barrier for them to seek PCC." (GP)*

> *-(Knowledge)"There is still a lot of uncertainty surrounding PCC. I am in favor of preventive healthcare interventions however I don't know how evidence based some PCC interventions are…. excluding folic acid supplementation, tobacco and alcohol cessation and a good diet" (GP)*

> *(Knowledge, Social/professional role and identity, memory attention and decision processes) "PCC is a relatively new form of care and, I think, not well known to many caregivers. And this unfamiliarity of caregivers with PCC is reflected in the amount of future parents seeking PCC." (Midwife)*

3. Poor organization and coordination of preconception care

The proper delivery of PCC can be challenging because perinatal risk factors are multifactorial. Risk assessment and the subsequent timely referral to the appropriate caregiver are paramount. GPs and specialists indicated that in general, the healthcare professionals' ability to timely identify all the different healthcare needs of future parents needs improvement. Women who have a substantial risk to experience complications during pregnancy, are too often not referred to the appropriate specialist. The inability of non-specialists to identify patients who need tailored PCC was perceived as a barrier. In addition, the poor or even lack of communication between the different healthcare disciplines that offer PCC was also identified as a cause for insufficient referral of patients to the appropriate caregiver and perceived as a barrier.

> *(Social influences, beliefs about capabilities)" It is really important that patients are referred in time to the right caregivers which unfortunately doesn't always happen… the communication between the different disciplines of PCC seems to be fragmented which makes the provided care suboptimal and less efficient."(GP)*

> *-(Social influences, beliefs about capabilities)"In this hospital we have cardiologists who are specialized in managing congenital heart defects in young people, also during pregnancy. This includes delivering tailor-made PCC. A general cardiologist has less experience and expertise to provide this specific care. Although we encour-*

age the referral of these patients to a hospital that can provide the required care, this unfortunately doesn't happen enough." (Cardiologist specialized in congenital heart diseases)

-(Social influences, beliefs about capabilities) "Midwives, GP's and obstetricians have insufficient expertise about inflammatory bowel disease to provide adequate care for patients who have a desire to become pregnant. However, these patients who should be seen by me or one of my colleagues are too often not referred to us." (Gastroenterologist)

4. Ethical barriers

The future parents' medical history or non-medical risks can lead to situations where healthcare professionals would advise to postpone pregnancy or even advise against it. However, healthcare professionals also want to respect the clients' and patients' right to autonomously choose when to become pregnant. An ethical dilemma can arise when a patient persists in her wish to conceive against the advice of the healthcare professional and in spite of medical grounds to postpone or stall pregnancy. The tension between personal beliefs about pregnancy and the wellbeing of the future child on the one hand and the professional responsibility to provide the best care possible for patients while respecting the reproductive autonomy of the future parents on the other hand, was perceived as a barrier. However, all participants stated that they would, under no circumstance, forfeit their professional responsibility to provide care for their patients once they are pregnant.

-(Social/professional role and identity, emotion regulation, motivation and goals) "A barrier is that sometimes you personally think that, considering the patient's medical history, it might be better for her not to get pregnant. However as a caregiver my task is to advise and guide her regardless of my personal view." (GP)

-(Social/professional role and identity, emotion regulation, motivation and goals)"Sometimes you see cases where for example the patient lives in squalid conditions, has financial debts or is bedridden. These are difficult situations. I would ask my patient how she would take care of her child once it is born. The hope is that through discussion you can give an honest view of how difficult it would be for her to raise a child in her situation and perhaps persuade her to postpone or give up her desire to have a child. However, if she decides to become pregnant I will advise and guide her as good as possible."(Obstetrician)

Discussion

The results of our study suggest that there are four types of barriers to the uptake and delivery of PCC. 1) Due to a lack of a comprehensive PCC program, the future parents' and caregivers' limited familiarity with and knowledge of PCC is perpetuated. This barrier is particularly worrisome because the groups who would benefit the most from PCC such as future parents with a lower SES and non-western future parents, are the ones who are the hardest to reach with PCC. 2) Most future parents are unaware of the benefits of PCC. GP's are hesitant about the necessity and effectiveness of PCC. 3) Perinatal risk factors are multifaceted. It is important that future parents receive care from the proper caregiver. GPs and medical specialists expressed the concern that too often patients who need specialized care are not referred or are referred too late to them. 4) There are situation where women trying to conceive are well advised to postpone pregnancy, but may choose to become pregnant regardless. Even when participants thought that choosing to become pregnant for a patient was the wrong choice, all participants clearly expressed that they would favor their professional responsibility and the patients' reproductive autonomy over their own personal views.

This study shows that there is an unfamiliarity with and lack of knowledge about PCC. The participants of this study indicate that both the unfamiliarity and lack of knowledge towards PCC are reasons why the uptake towards such care remains low. The low uptake due to lack of knowledge about PCC was also observed by Hosli and colleagues (24) and van der Zee and colleagues (25). The GPs indicate that time and resource constraints as well as competing preventive care were barriers to deliver PCC. This was also observed by Mazza and colleagues (26). Our study draws attention to the barriers that result from the lack of a comprehensive PCC program. This barrier was anticipated by the Dutch Health Council that advised to set up a governmentally initiated and coordinated program of PCC, sustaining that this approach will reach the greatest number of future parents and create the most favorable conditions for monitoring the effectiveness, efficiency and social consequences of PCC (13). Unfortunately, the advice to set up a PCC program has not yet lead to the implementation of a comprehensive and coordinated PCC program in the Netherlands.

Participants, especially the GPs and specialists, pointed out that even though timely referral of patients with complex medical and obstetric history to adequate caregivers is paramount, such patients are too often not referred or are referred too late.

We do stress the need for further studies to look into the ways in which these organizational barriers lead to suboptimal PCC delivery and into how interdisciplinary

collaboration can result in optimally tailored PCC. However, because the inadequate referral of patients is an urgent matter we recommend the implementation of a PCC program as was suggested by the Dutch Health Council. We also support the inclusion of PCC in the academic curriculum of future healthcare professionals. We suggest that the implementation of a PCC program and the inclusion of PCC in the curriculum of future caregivers will increase overall knowledge about, and awareness of, PCC in general, and will promote adequate referral of future parents with a complex medical history. Education about PCC should include evidence-based findings of research on PCC. This is of particular importance because, as our study shows, GP's remain hesitant about the effectiveness and efficiency of PCC. This hesitation is a barrier for the (opportunistic) offering of PCC in healthcare settings.

Furthermore, efforts to train and educate caregivers should not end at graduation, especially in the case of PCC. The participating midwives pointed out that the low uptake of PCC reduces opportunities to gain the necessary experience in delivering PCC. This barrier was also identified by (27). In their study, they describe that barriers to provide PCC include a lack of contact with women planning to conceive. In addition, Van Heesch and colleagues (28) also reported that few midwives had received any training on PCC after qualifying in their discipline. In their study they show that midwives seem willing to play an active role in the provision of preconception care in the future, but that 'there is a great need for continued training with practicing healthcare providers'

In some cases, patients with complex medical conditions or with difficult financial and social problems do wish to become pregnant, even against the caregiver advices to postpone pregnancy. Caregivers can personally feel that these patients are making an incorrect decision when they insist on pregnancy. However, our results do not indicate that the caregivers' personal considerations lead to a suboptimal uptake or delivery of PCC. Nevertheless, we recommend that the curriculum of PCC caregivers should include ethical education and guidance so that in practice caregivers will be more competent in dealing with these dilemmas.

Strengths

Incorporating risk domains mentioned in the Dutch guideline preconception care and composing the questionnaire for this study according to the framework Michie and colleagues ensured quality and relevance of the questionnaire. Furthermore, given the fact that the participants in our study were all experienced in the delivery of PCC according to the Dutch guideline, they were ideally positioned to report on barriers on the uptake and delivery of PCC. Finally, the variety of disciplines in which the participants included in our study practiced allowed to identify barriers experienced

in PCC as a whole. Ultimately, in accordance to the views of participants, PCC requires a multidisciplinary approach. This requires knowledge about barriers perceived by the whole ambit of healthcare professionals who deliver PCC.

Limitations

The small number of participants, which is common in qualitative studies, limits the generalizability of our findings. However, interviews were conducted until saturation of responses was achieved. We do recommend the confirmation of our results by other studies.

Conclusion

Our study has identified four barriers for the optimal uptake and delivery of preconception care. Given the explorative nature of our study, we recommend that further research is done to gain a better understanding of these barriers and to determine which barriers should be prioritized for intervention. In addition, we highlight the need for further research into ways in which organizational barriers lead to suboptimal PCC delivery and how interdisciplinary collaboration can result in optimally tailored intervention approaches.

However, the recommendation for further research should not hinder the introduction and integration of PCC as a government coordinated program since the benefits of PCC interventions such as folic acid supplementation, alcohol and tobacco cessation and the promotion of a healthy diet have provided sufficient evidence to be made a priority in healthcare.

References

1. Gluckman PD, Hanson MA, Cooper C, Thornburg KL. Effect of in utero and early-life conditions on adult health and disease. New England Journal of Medicine. 2008;359(1):61-73.
2. Jaddoe VWV, de Jonge LL, Hofman A, Franco OH, Steegers EAP, Gaillard R. First trimester fetal growth restriction and cardiovascular risk factors in school age children: population based cohort study. Bmj. 2014;348:g14.
3. Steegers-Theunissen RP, Twigt J, Pestinger V, Sinclair KD. The periconceptional period, reproduction and long-term health of offspring: the importance of one-carbon metabolism. Hum Reprod Update. 2013;19(6):640-55.
4. Shannon GD, Alberg C, Nacul L, Pashayan N. Preconception health care and congenital disorders: mathematical modelling of the impact of a preconception care programme on congenital disorders. Bjog. 2013;120(5):555-66.
5. van der Zee B, de Beaufort I, Temel S, de Wert G, Denktas S, Steegers E. Preconception care: an essential preventive strategy to improve children's and women's health. J Public Health Policy. 2011;32(3):367-79.
6. Jack BW, Atrash H, Coonrod DV, Moos M-K, O'Donnell J, Johnson K. The clinical content of preconception care: an overview and preparation of this supplement. American Journal of Obstetrics and Gynecology. 2008;199(6):S266-S79.
7. Temel S, van Voorst SF, Jack BW, Denktaş S, Steegers EAP. Evidence-based preconceptional lifestyle interventions. Epidemiologic reviews. 2014;36(1):19-30.
8. de Jong-Potjer L BM, Bogchelman M, Jaspar AHJ, Van Asselt KM. . Preconception care guideline by the Dutch Federation of GP's Dutch College of General Practitioners (NHG); 2011.
9. Freda MC, Moos M-K, Curtis M. The history of preconception care: evolving guidelines and standards. Maternal and Child Health Journal. 2006;10(1):43-52.
10. Johnson K, Posner SF, Biermann J, Cordero JF, Atrash HK, Parker CS, et al. Recommendations to improve preconception health and health care—United States. Morbidity and Mortality Weekly Report. 2006;55(4):1-23.
11. Temel S, van Voorst SF, de Jong-Potjer LC, Waelput AJM, Cornel MC, de Weerd SR, et al. The Dutch national summit on preconception care: a summary of definitions, evidence and recommendations. Journal of community genetics. 2015;6(1):107-15.
12. Williams JL, Abelman SM, Fassett EM, Stone CE, Petrini JR, Damus K, et al. Health care provider knowledge and practices regarding folic acid, United States, 2002–2003. Maternal and child health journal. 2006;10(1):67-72.
13. Health Council of the Netherlands. Preconception care: a good beginning. The Hague2007.
14. Landkroon AP, De Weerd S, van Vliet-Lachotzki E, Steegers EAP. Validation of an internet questionnaire for risk assessment in preconception care. Public Health Genomics. 2010;13(2):89-94.
15. Vos AA, van Voorst SF, Steegers EAP, Denktaş S. Analysis of policy towards improvement of perinatal mortality in the Netherlands (2004-2011). Social Science & Medicine. 2016.
16. van Voorst S, Plasschaert S, de Jong-Potjer L, Steegers E, Denktaş S. Current practice of preconception care by primary caregivers in the Netherlands. The European Journal of Contraception & Reproductive Health Care. 2016:1-8.

17. de Weerd S, van der Bij AK, Cikot RJLM, Braspenning JCC, Braat DDM, Steegers EAP. Preconception care: a screening tool for health assessment and risk detection. Preventive medicine. 2002;34(5):505-11.

18. Shannon GD, Alberg C, Nacul L, Pashayan N. Preconception Healthcare Delivery at a Population Level: Construction of Public Health Models of Preconception Care. Matern Child Health J. 2013.

19. Tuomainen H, Cross-Bardell L, Bhoday M, Qureshi N, Kai J. Opportunities and challenges for enhancing preconception health in primary care: qualitative study with women from ethnically diverse communities. BMJ open. 2013;3(7):e002977.

20. Mazza D, Chapman A, Michie S. Barriers to the implementation of preconception care guidelines as perceived by general practitioners: a qualitative study. BMC health services research. 2013;13(1):1.

21. van Voorst SF, Vos AA, de Jong-Potjer LC, Waelput AJM, Steegers EAP, Denktas S. Effectiveness of general preconception care accompanied by a recruitment approach: protocol of a community-based cohort study (the Healthy Pregnancy 4 All study). BMJ open. 2015;5(3):e006284.

22. Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A. Making psychological theory useful for implementing evidence based practice: a consensus approach. Quality and safety in health care. 2005;14(1):26-33.

23. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. Jama. 1992;267(16):2221-6.

24. Hosli EJ, Elsinga J, Buitendijk SE, Assendelft WJJ, Van der Pal-de Bruin KM. Women's motives for not participating in preconception counseling: qualitative study. Public Health Genomics. 2008;11(3):166-70.

25. van der Zee B, de Beaufort ID, Steegers EA, Denktas S. Perceptions of preconception counselling among women planning a pregnancy: a qualitative study. Fam Pract. 2013;30(3):341-6.

26. Mazza D, Chapman A, Michie S. Barriers to the implementation of preconception care guidelines as perceived by general practitioners: a qualitative study. BMC Health Serv Res. 2013;13:36.

27. Heyes T, Long S, Mathers N. Preconception care practice and beliefs of primary care workers. Family Practice. 2004;21(1):22-7.

28. van Heesch PN, de Weerd S, Kotey S, Steegers EAP. Dutch community midwives' views on preconception care. Midwifery. 2006;22(2):120-4.

Online Resource 1. *Content: based on the Dutch guideline of general practitioners on preconception care*

Domain	Questions
Preconception care in general	· What do you think about the current organization of PCC? Is it adequate for you to perform your task as a preconception caregiver? Do you encounter any problems and what would help to overcome these problems? · How valuable is PCC? Do you subscribe the goals of PCC and do they motivate you to do your job as a preconception caregiver? · How effective do you think PCC is? Do you think the goals of PCC are attainable? · Do you feel sufficiently recognized and valued in your work as a preconception caregiver both by your patients and your peers?
Medical and obstetric history	· In what way and with what aim do you ask the future parents about their medical and obstetric history? (Informative, directive (paternalistic), deliberative, shared decision making(23)) · What problems have you encountered when asking about the medical and obstetric history and how did you try to solve them? · Can you give an example of such a problem? (And how were you able to solve the problem) · Do you encounter situations in which you think pregnancy should be postponed or discouraged because of the medical or obstetric history? Can this lead to a tension between your personal convictions and professional responsibility? (E.g. Personally I would advice against it however as a professional I feel obliged to advise and counsel) · Do you think the current organization of PCC is adequate to help you solve these problems? What kind of adjustments to PCC would ameliorate your capability to deal with these problems?
Genetic disorders	· How and with what aim do you ask the future parents about genetic disorders? · Does the difficulty of the subject matter change your role as a caregiver? (E.g. from informative to directive?)
Exposures at work	· How and with what aim do you ask the future parents about their working conditions? · How do you deal with the fact that working conditions can be hard to change, even if it is better for the health of the future parents and child?
Socioeconomic factors	· How and with what aim do you ask the future parents about their social economic positions? · How does the fact that these conditions are hard to modify influence your delivery of PCC? · Do you encounter situations in which you think pregnancy should be postponed or discouraged because of the social economic conditions? Can this lead to a tension between your personal convictions and professional responsibility? (E.g. Personally I would advise against it however as a professional I feel obliged to advise and counsel) · Does the social economic situation alter your motivation or goals when delivering PCC?
Tobacco, alcohol and drugs	· How and with what aim do you ask about tobacco, alcohol and drugs use? · Are you optimistic about the likelihood of tobacco, alcohol and drugs cessation?

3

PERCEPTIONS OF PREGNANCY PREPARATION IN WOMEN WITH A LOW TO INTERMEDIATE EDUCATIONAL ATTAINMENT: A QUALITATIVE STUDY

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PERCEPTIONS OF PREGNANCY PREPARATION IN WOMEN WITH A LOW TO INTERMEDIATE EDUCATIONAL ATTAINMENT: A QUALITATIVE STUDY. *MIDWIFERY 59*(1), 62-67.

Abstract

Objective

In the promotion of periconceptional health, appropriate attention has to be given to the perceptions of those who are most vulnerable, such as women with a relatively low socioeconomic status based on their educational attainment. The aim of this study was to explore these women's perceptions of pregnancy preparation and the role they attribute to healthcare professionals.

Design

We conducted semi-structured interviews with women with a low to intermediate educational attainment and with a desire to conceive, of which a subgroup had experience with preconception care. Thematic content analysis was applied on the interview transcripts.

Findings

The final sample consisted of 28 women. We identified four themes of pregnancy preparation perceptions: (i) "How to prepare for pregnancy?", which included health promotion and seeking healthcare; (ii) "Why prepare for pregnancy?", which mostly related to fertility and health concerns; (iii) "Barriers and facilitators regarding pregnancy preparation", such as having limited control over becoming pregnant as well as the health of the unborn; (iv) "The added value of preconception care", reported by women who had visited a consultation, which consisted mainly of reassurance and receiving information.

Key conclusions and Implications for practice

The attained insights into the perceptions of women with a low to intermediate education are valuable for adapting the provision of preconception care to their views. We recommend the proactive offering of preconception care, including information on fertility, to stimulate adequate preparation for pregnancy and contribute to improving perinatal health among women who are socioeconomically more vulnerable.

Keywords

Preconception care, educational attainment, qualitative research, pregnancy outcomes, fertility, health behaviour

Introduction

Optimizing preconception health does not only reduce the risk of poor pregnancy outcomes but also the risk of developing non-communicable diseases later in life (1-3). This reduction of risk is paramount as many poor pregnancy outcomes as well as non-communicable diseases are to a great extent preventable. Despite high quality perinatal care in the Netherlands for example, perinatal mortality remains high compared to other European countries (4-6). Moreover, similar to other health outcomes there is a social gradient observable in pregnancy outcomes (7-9). People in the lowest part of the social gradient, typically people who live in a deprived neighbourhood, face substantially higher risks to have poor pregnancy outcomes (10-12). Furthermore, the uptake of obstetric care has been shown to be lower among women who are socioeconomically disadvantaged (13). Therefore, attention has to be given to women who are socioeconomically vulnerable when promoting health at the start of pregnancy. A crucial period for health promotion is the periconception period, defined as the fourteen weeks before and ten weeks after conception, due to the processes of gametogenesis, organogenesis and placental development (14).

An increasing body of evidence suggests that preconception care (PCC) interventions can contribute to better pregnancy outcomes by identifying biomedical, behavioural and psychosocial risk factors prior to conception (15, 16). However, delivery and uptake of preconception care is still low (17, 18). The improvement of the uptake of PCC and of perinatal health outcomes relies partly on the extent to which women prepare for pregnancy. Actively preparing for pregnancy is associated with positively changing lifestyle behaviours (19). The extent to which women prepare for pregnancy is related to their perceptions about pregnancy preparation. As behavioural research indicates, perceptions underpin behaviour to a certain extent, for example pregnancy related behaviour (20, 21). As such, perceptions may influence whether women would prepare for pregnancy and make use of PCC. Based on previous research, we assume that a lacking or an inadequate perception of the need of pregnancy preparation most probably leads to no, or inadequate, pregnancy preparation (22, 23). Women's lack of awareness and their perception of absence of risks have been frequently identified as barriers for PCC use (23). Little is known about the perceptions and motivations of women who have used PCC (24). Besides, most of the studies have focussed on attitudes towards PCC and on subgroups of women with a medical risk (e.g. diabetes), but less on women with a desire to conceive and their general notion of preparing for pregnancy (23, 24).

To study perceptions of pregnancy preparation, we focussed on women with desire to conceive who are socioeconomically more vulnerable for adverse pregnancy outcomes.

We used low to intermediate educational attainment as a proxy measure for low to intermediate socioeconomic status (SES). Educational inequalities, as an indicator of socioeconomic inequalities, have been demonstrated in various pregnancy outcomes, for instance birthweight (25, 26). Assessing the perceptions of women with a relatively low educational background, with and without PCC experience, will provide insights into why and how these women prepare for pregnancy and whether this includes consulting a healthcare professional for PCC. These insights are valuable for the improvement of periconception health, in part via the improvement of the uptake and delivery of PCC. Therefore, the aim of this study was to explore perceptions of pregnancy preparation of women with a relatively low educational attainment and the role they attribute to healthcare professionals. We aimed at achieving this by interviewing women with a desire to conceive, of which a subgroup had received PCC.

Methods

Study population

This study was approved by the Medical Ethics Committee of the Erasmus MC. Written informed consent was obtained from all participants. The study population consisted of two subgroups. One subgroup, the PCC-group, was recruited from the Healthy Pregnancy for All (HP4All) Preconception Care study (27). This study, conducted in 14 Dutch municipalities, aims to assess the effectiveness of a recruitment strategy for PCC and the effectiveness of individual PCC consultations. The recruitment strategy included an invitational letter for PCC from a general practitioner (GP) and/or from the municipality. Women aged 18 to 41 years who applied for a PCC consultation with their GP or midwife were asked to participate in a cohort study. For our study, a selection of eligible participants was made based on the following criteria: consent to be contacted for an additional study, having received a PCC consultation in 2014, and an indication for having a low to middle SES based on a low or intermediate educational attainment (International Standard Classification of Education up to and including level 4). The selection resulted in a sample of 36 participants eligible for an interview. The other subgroup, the non-PCC-group, was recruited using a professional recruitment service specialized in finding suitable participants for scientific research. This service has a database of people willing to participate in scientific research. From this database, participants were identified based on whether they had a low to middle SES, a low to intermediate education attainment (as explained for the PCC-group above) and a desire to conceive in the nearby future. This resulted in a sample of 18 eligible participants.
We aimed at interviewing fifteen participants (thirty in sum) in both the PCC-group and the non-PCC-group, as we expected to reach saturation of responses at that num-

ber. We were able to conduct 15 interviews in each group, but we had to exclude two participants from the PCC-group as they did not meet the inclusion criteria after all (see figure 1).

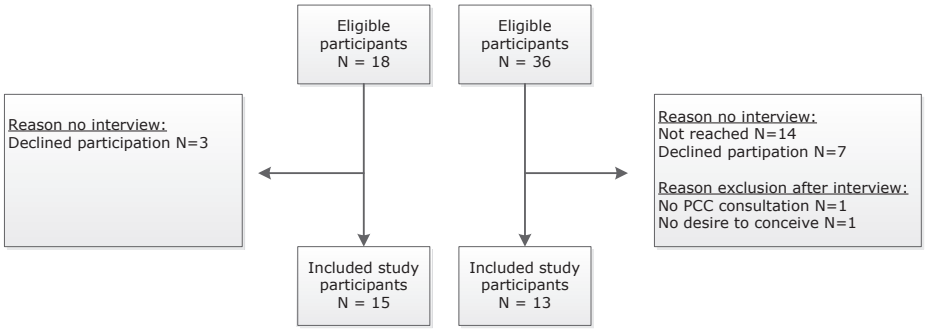

Figure 1: Enrolment of participants

As a result, we had a final sample of 28 participants. Our aim was to have a sample with a variation in participant's characteristics such as age, ethnic background and prior experiences with pregnancy.

Data collection

Semi-structured interviews were conducted in the spring of 2015 by four researchers in close collaboration. The interviews were carried out at the Erasmus MC, at participant's homes, or by telephone if preferred. The semi-structured interviews were conducted using a two-part topic list. The first part focused on perceptions and behaviour with regard to pregnancy preparation. The second part listed questions on perceptions concerning healthcare needs prior to pregnancy. For the PCC-group, this second part included questions about their experience with PCC. The interviews were audio recorded and transcribed verbatim for analysis.

Data analysis

We used an inductive process of thematic analysis as described by Braun and Clarke to identify the key themes of perceptions in the transcriptions (28). Firstly, we familiarised ourselves with the data and generated an initial coding scheme. Together, two researchers with experience in qualitative research adjusted the coding scheme through an iterative process of analysing the transcripts. We used NVivo10 software (QSR International, 2012) for the analysis. Subsequently, based on our coded fragments, themes and sub-themes were mapped in Excel. The two researchers performed this step together to discuss and refine the themes during the process. Representative citations were selected and translated to English.

Results

Study participants' characteristics

With respect to our inclusion criteria of low to intermediate education attainment, our final sample of 28 participants consisted mainly of women who had attained or were currently attaining an intermediate education (n=24). Thirteen women did not have a paying job; three of them because they had not finished their education yet. We achieved variation of other socio-demographic characteristics in our sample, with in both subgroups a similar composition: the women's age ranged from 24 to 41 years in the PCC-group (median 32) and 21 to 38 years (median 29) in the non-PCC-group; four women did not have a Dutch background in the PCC-group and five in the non-PCC-group; six women were mothers at the time of the interview in the PCC-group and eight in the non-PCC-group. The group of non-responders (referred to in figure 1) seemed to have similar background characteristics as the group of participants.

The perceptions

We identified three themes of pregnancy preparation perceptions in both groups which are perceptions about: (1) how to prepare for pregnancy? (2) why prepare for pregnancy? (3) barriers and facilitators regarding pregnancy preparation. We described one more perception theme in the PCC-group: (4) the added value of PCC.

(1) How to prepare for pregnancy?

1.1 Health related preparations

Participants from both groups mentioned similar ways to prepare for pregnancy such as; quitting smoking, moderating or abstaining from alcohol, reducing stress, the timely use of folic acid supplementation, losing weight and having a healthy diet. *"The moment I would like to become pregnant, I wouldn't go 'all out' at a party. I would abstain from drinking alcohol." (Interview 7 non-PCC-group) "First of all I would quit smoking, …. , furthermore I would eat healthy, so that the baby receives good nutrition which the baby needs." (Interview 13 PCC-group)*

1.2 Healthcare related preparations (non PCC-group)

We asked the participants of the non PCC-group about what they perceived to be the role of caregivers, especially the GP, in the period they are trying to conceive. Most participants mentioned that first and foremost it is in fact one's own responsibility to adequately prepare for pregnancy. *"First of all it depends on yourself, whether you go to the GP or midwife for information, because they won't just come to you…. but actually I don't think I would go, because I always think positive, no one thinks that their pregnancy would not go well."*

(Interview 7 non-PCC-group) These participants consider that the future mother should seek care herself when she considers this to be necessary. *"I would contact my GP because I have used contraceptives for years,* ***so I would like to know what the procedure is [emphasis added]*** *…." (Interview 11 non-PCC-group)*

The participants were nevertheless positive about the suggestion of a GP who proactively asks them about their desire to become pregnant, provided that these questions are asked when reproductive issues, such as contraception or teratogenic medications, are being discussed. "*As he [the GP] prescribes medication, he should tell you to be careful with this medication in case you want to become pregnant." (Interview 4 non-PCC-group) "I actually think that a GP, Midwife, and gynaecologist could tell you [about pregnancy preparation], because many women do not know, or are ashamed to ask." (Interview 7 non-PCC-group)* Some participants referred to the mother-to-be and the healthcare professional as having a shared responsibility for the adequate preparation of pregnancy. These participants did however also emphasize that it is the mother-to-be who eventually has to follow the advice of the healthcare professional and therefore the ultimate responsibility falls on her. *"A healthcare professional gives advice, but you have to follow that advice." (Interview 8 non-PCC-group)*

1.3 Healthcare related motivations and expectations (PCC-group)

We asked the PCC-group what their motivations and expectations were when they decided to visit a healthcare provider before pregnancy. For most participants, the PCC invitational letter, which they had received from their GP or municipality, was the trigger to make an appointment. *"We had received a letter… and then I thought let's start with this PCC consultation, and all the information that we can get is welcome." (Interview 6 PCC-group)* However, some participants already had plans to visit their GP because of pregnancy related questions. *"… I had been thinking, should I go to my GP or not, and that same week, a total coincidence, I received a letter about the start of consultations for women with a desire to become pregnant."(Interview 11 PCC-group)* Most women went without specific expectations to their PCC appointment, as they were not familiar with PCC, but they perceived it as a possibility worth exploring. *"I didn't know what it entailed, so I thought there is no harm in trying." (Interview 14 PCC-group)* Some women expected to receive information, an examination, or a general check-up.

(2) Why prepare for pregnancy?

2.1 Questions about conception and fertility

For most participants questions about conception and fertility were the major reason to consider preparing for pregnancy. For both groups, the participants' willingness to

seek pregnancy related care such as consultation from a doctor seemed to increase in case they would experience problems with becoming pregnant. *"Yes, I might go [to the GP]….. for example, if I would face difficulties getting pregnant." (Interview 3 non-PCC-group) "We already had a desire to have child for some time but still had not succeeded. Therefore, we wanted an appointment with the GP…" (Interview 13 PCC-group)* In the PCC-group, questions about fertility and fertility problems were for about half the group the main reason to actually visit the healthcare professional for a PCC consultation.

2.2 Assuring health of the mother and child

In both groups, some participants mentioned that they would consider pregnancy preparation as it may benefit their own health and the health of their future children. In response to their miscarriage for example, two participants mentioned that they would explore ways to adequately prepare for pregnancy in light of possible future pregnancies. *"Well yes [visiting a doctor] because of my miscarriage, see what is there, blood tests or something, check whether my belly is healthy, I assume it is, but you never know." [When would you do that?] "Well, anyway before you are pregnant… I think maybe a month ahead, but yeah, you cannot really determine that." (Interview 12 non-PCC-group)* The participants' perceptions of adequate preparation consisted of checking their vitamin status, as well as making sure components of oral contraceptives and tobacco smoke were, as they phrased it, "*cleared out of the body*." Working with potential harmful substances was also mentioned by a veterinary assistant as a reason to inform her employer about her desire to conceive and as a reason to have visited a PCC consultation. *"Because of my work [as a veterinary assistant] I wasn't sure about what I could and could not do…. anaesthesia, x-rays….sedation using gas, is that dangerous? these kind of questions.."(Interview 12 PCC-group)*

(3) Barriers and facilitators regarding pregnancy preparation

3.1 Facilitator

Most participants from both groups mentioned that they felt adequately prepared for pregnancy. They mentioned that ample information about pregnancy preparation is available, especially on the Internet, which enables them to adequately prepare for pregnancy. *"Yes [having sufficient possibilities to prepare for pregnancy], nowadays you can find everything on websites, health websites, Google, everywhere really." (Interview 1 non-PCC-group)*

3.2 Barriers

Despite the fact that most participants felt adequately prepared for pregnancy, many also perceived barriers in terms of having limited control over their chances to conceive and the course of their pregnancy. *"You just hope, you cannot say 'I want', but you actually hope that God lets you become pregnant". (Interview 2 non-PCC-group)* They also mentioned

that they had limited control over their ability to ensure good health for their future children during pregnancy. *Well as far as I know you cannot do anything about it [actual pregnancy going well], but you can help it a bit." (Interview 1 non-PCC-group)* The latter perception was more pronounced in the non-PCC-group than in the PCC-group.

Some participants, mainly of the non-PCC-group, mentioned that they experienced preparing for pregnancy and accessing pregnancy-related information as stressful and burdensome. *"I do not go looking for answers on the internet, because then I go crazy. (Interview 14 non-PCC-group)* This was also mentioned as a reason not to explore or to "*give up*" on ways to prepare for pregnancy, such as giving up folic acid supplementation when it takes too long to become pregnant, finding it difficult to commit to healthy food not knowing how long it takes to become pregnant, and not succeeding in quitting smoking before and during pregnancy. *"I tried taking folic acid for a period, but you know, the longer it took [getting pregnant] the more I forgot taking it. Thus, yeah at a certain time you just stop taking it. (Interview 14 non-PCC-group)" "Yeah I tried quitting smoking but it took so long, so .. yeah… Well my mother also smoked during her pregnancy and here I am, so yeah…" (Interview 10 non-PCC-group)* In the PCC-group, a few participants also referred to the difficulty of committing to for instance a healthy lifestyle, since it may take a while to become pregnant.

Some participants from the non-PCC-group reported that pregnancy was a "natural" event that does not require any special preparation or planning if one is not ill. *"No, no [not going to a doctor before pregnancy unless there is a problem with becoming pregnant], it is different when I would be pregnant, then I would ask right away what I could do." (Interview 3 non-PCC-group) "Otherwise you are just planning all the time, I am against that, you should not plan something like this [pregnancy], if I prepare by for example eating healthy, then I am already planning a bit." (interview 3 non-PCC-group)*

Participants reported to perceive more urgency to be healthy and visit a healthcare provider once they would know they were actually pregnant rather than when they were preparing for pregnancy. *"…when you know you are pregnant, then you can begin, because then you know and then you have to do it [live healthy]." (Interview 12 non-PCC-group)* Furthermore, some women were sceptical about the effects of unhealthy behaviour, such as smoking and drinking alcohol, on pregnancy and the health of the unborn. *"But I did stop drinking alcohol. Regarding smoking, yes I'll consider that when I really am pregnant….I have started to smoke a bit less." (Interview 6 non-PCC-group)* Accordingly, there was a wide range in perceptions with regard to what pregnancy preparation would actually entail ranging from quitting smoking prior to pregnancy to lowering the number of cigarettes during

pregnancy, and ranging from trying to have a healthy weight before pregnancy to not paying attention to weight at all because "*you get fat anyway during pregnancy*".

(4) Added value of PCC

The perceived added value of PCC was only assessed in the group that received a PCC consultation. We asked whether the participants felt that PCC had influenced their pregnancy preparation. Most participants reported that they were already familiar with the information and advice that was provided during the consultation. *"No, it did not really [change anything], but it was actually just a confirmation that the things I did and read were right." (Interview 7 PCC-group)*

However, a few participants mentioned that it changed their perceptions of pregnancy preparation, for example by learning about the importance of folic acid supplementation and quitting smoking. In addition, some participants reported that it influenced their behaviour, e.g. drinking less alcohol and having a healthier diet. "*Yes, I don't drink [alcohol] so much anymore at parties, less alcohol let's put it that way. Not that I drink so much but now I will drink with moderation" (Interview 11 PCC-group)*

When we asked how they valued the PCC consultation, almost all participants were positive about their experience with PCC. They explained the value of PCC in terms of reassurance and confirmation, or receiving information and answers to questions. Knowing now what the consultation entailed, most participants reported that in hindsight they would have visited a PCC consultation again. *"Yes, reassurance, I could ask more questions, I received a lot of information, heard how it all goes, so yes that was nice." (Interview 9 PCC-group)*

Discussion

This study provides new insights into the perceptions on pregnancy preparation of women with a low to intermediate educational attainment. We found that the participants predominantly associate pregnancy preparation with fertility and conception. Many participants perceived limited control over the chance of conception and reported to be motivated to seek care in case of fertility concerns. This finding is in line with the findings of van der Zee, de Beaufort (21), Tuomainen, Cross-Bardell (29) and has been reported in the systematic review on PCC barriers and facilitators of Poels, Koster (23). Our study shows that women with a low to intermediate educational attainment and a desire to become pregnant put an emphasis on fertility and conception during the period they are trying to conceive. As women are more likely to engage in

pregnancy preparation in case those issues that are relevant to them are addressed, we recommend making advice on fertility an important theme of PCC. Correspondingly, PCC could also be integrated in fertility care.

Most participants mentioned relevant and important health related ways to prepare for pregnancy such as the importance of having a good lifestyle and smoking and alcohol cessation. Despite this awareness there were also preconception care related topics that we did not find in our data. These include topics such as over-the-counter drugs, immunizations, sexual risk behaviours, family history, chronic illness, and mental health which are typically included in PCC (16, 30). Frey and Files have also reported on this awareness of important pregnancy related issues on the one hand and what they call "knowledge gaps" on the other hand (31).

Our results suggest that awareness and knowledge alone about adequate pregnancy preparation, e.g. smoking cessation, does not necessarily lead to actual pregnancy preparation, e.g. actual smoking cessation. For example, consider the following response *"Yeah I tried quitting smoking [awareness] but it took so long, so .. yeah…"[actual behaviour] (Interview 10 non-PCC-group) and "I tried taking folic acid for a period [awareness], but you know, the longer it took [getting pregnant] the more I forgot taking it [actual behaviour] (Interview 14 non-PCC-group)."* In other words, we suggest that poor pregnancy preparation is not only a matter of not knowing what to do, as participants typically displayed awareness of and knowledge about pregnancy preparation, but arguably also a matter of not experiencing the urgency to do what is known. Some women for example, were sceptical about the effects of unhealthy behaviour, such as smoking and drinking alcohol, on pregnancy and the health of the unborn and therefore did not stop smoking or drinking in the preconception period. However, the expressed scepticism could also be a form of self-justification. Further research should be done on this gap between knowledge about pregnancy preparation and actual pregnancy preparation in order to better understand, encourage and adequately help women with a desire to conceive to put in to practice the knowledge they have.

In addition, most participants felt sufficiently able to prepare for pregnancy because they could find information, especially on the internet, on pregnancy preparation, when deemed necessary. A conjecture, based on these outcomes, is that the educational background of our participants, and possibly a lower health literacy often associated with having this background, may lead to an underestimation of perinatal risks and an overestimation of abilities to reduce these risks. We based our assertion on responses such as "*Well my mother also smoked during her pregnancy and here I am, so yeah…" (Interview 10 non-PCC-group).* In line with this conjecture, Lupattelli et al. found that low health-lit-

eracy women were more inclined to underestimate the detrimental effects of smoking during pregnancy (32). Moreover, Endres, Sharp (33) have reported on an association between low health literacy in women with pregestational diabetes and a reduced likeliness to prepare for pregnancy, such as taking folic acid supplementation and seeking medical advice before pregnancy. However, more research needs to be done about the relation between health-literacy and the estimation of pregnancy related risks to better understand whether and how health-literacy influences pregnancy preparation. In summary, taking up research on risk estimation is particularly important as women with lower education are more vulnerable to have adverse pregnancy outcomes (25, 26). Furthermore, women living in socioeconomically deprived neighbourhoods have more preconceptional and perinatal risk factors for adverse pregnancy outcomes (34, 35).

Our results show that the participants from the non-PCC-group were open to receiving information about pregnancy preparation from a healthcare professional provided that this information is presented in relevant situations, such as prescribing potential harmful medications. This is in line with the results of de Jong-Potjer et al. who found that women were interested in PCC-consultation of their GP should they decide to have children (36). We therefore recommend healthcare professionals to proactively integrate PCC in their consultations, in particular when pregnancy affecting issues are being discussed. This is warranted as most participants indicate they would not seek PCC without a, in their view, compelling reason to do so. This is in line with the current limited use of PCC and with the results of the PCC-group in which most women also had a compelling reason to seek PCC. However, prudence is required as some participants perceived planned pregnancy preparation as burdensome and stressful. Consideration has to be given to these feelings of burden and stress, as they can become barriers to prepare for pregnancy and seek PCC. The 'naturalness' of pregnancy was also mentioned as a reason not to prepare for pregnancy. This concern regarding naturalness was also reported in the systematic review by Poels, Koster (23). Efforts need to be made to clarify that adequate pregnancy preparation is not at odds with the naturalness of pregnancy.

A remarkable result of our study was the PCC-group's experience of modest but relevant added value of having visited a PCC consultation. This experience may result from the fact that women who visited a PCC consultation may typically be women who were already motivated to prepare for pregnancy and therefore were relatively well-informed. This assertion is supported by the study of Barrett, Shawe (22) who describe different groups of women with three different levels of investment in pre-pregnancy healthcare being the prepared group, the poor knowledge group and the absent pre-pregnancy period group. To increase a sense of relevancy, they argue that individual

groups will likely need different PCC approaches. We also recommend a custom-made approach based on the perceptions, abilities and needs of women.

The fact that half of the participants did visit and the other half did not visit a PCC consultation offered a unique opportunity to explore pregnancy preparation perceptions in both groups. It is important however to emphasize the explorative nature of this research, which is not meant to draw conclusions from any comparison between the two groups. Neither did we intend to draw conclusions on differences related to the level of educational background.

A limitation of our study is that our participants' intention to get pregnant differed (i.e. actively trying to conceive, intention in the nearby future, or only an intention at the time of PCC), which could have influenced their current perceptions. In addition, participants of the PCC-group were included in the broader HP4ALL-study. This may have increased the possibility of participants giving socially desirable answers. However, given that most participants felt unhindered to express only a modest but relevant added value of the PCC-consultation, we assume that participants felt free to give their own opinion during the interview. Participants could also have been influenced in their responses by the different interview settings (i.e. on site, at home, and via telephone), yet we have not been able to detect such differences. We included mainly women with intermediate educational attainment and only a few women with low educational attainment, which may have affected our results. A final limitation is that our study was done in one country with a specific, mainly publicly financed, healthcare system that provides for primary care, which includes PCC. This may influence the perceptions people have about health in general and on pregnancy preparation in particular. That is, perceptions of pregnancy preparation may differ in situations where people have to carry the full financial burden of PCC from situations where this is not the case.

Conclusions

Our study provides insights into the perceptions about pregnancy preparation of women with a low to intermediate educational attainment. Understanding the perceptions of this group is of key importance as they have higher risk for adverse pregnancy outcomes. Based on our results, we recommend the proactive offering of custom-made PCC including information on fertility. Despite mentioning relevant ways to prepare for pregnancy, participants did not mention important topics such as over-the-counter drugs, immunizations, sexual risk behaviours, family history, chronic illness, and mental health. More effort, e.g. in the form of information and education, is required to

bring these topics to the attention of women with a desire to become pregnant. In addition, more research needs to be done about how women can be motivated to prepare for pregnancy as knowledge about pregnancy preparation alone does not necessarily lead to actual pregnancy preparation. Special attention needs to be given to whether and if so, how low-health literacy influences pregnancy preparation. As participants were open to receiving information about pregnancy preparation provided that this information is presented in relevant situations, we also recommend that healthcare professionals proactively integrate PCC in their consultations, in particular when pregnancy affecting issues are being discussed.

References

1. Temel S, van Voorst SF, Jack BW, Denktaş S, Steegers EAP. Evidence-based preconceptional lifestyle interventions. Epidemiologic reviews. 2014;36(1):19-30.
2. Hanson M, Godfrey KM, Lillycrop KA, Burdge GC, Gluckman PD. Developmental plasticity and developmental origins of non-communicable disease: theoretical considerations and epigenetic mechanisms. Progress in Biophysics and Molecular Biology. 2011;106(1):272-80.
3. Gluckman PD, Hanson MA, Buklijas T, Low FM, Beedle AS. Epigenetic mechanisms that underpin metabolic and cardiovascular diseases. Nature Reviews Endocrinology. 2009;5(7):401-8.
4. Mohangoo AD, Hukkelhoven CW, Achterberg PW, Elferink-Stinkens PM, Ravelli AC, Rijninks-van Driel GC, et al. [Decline in foetal and neonatal mortality in the Netherlands: comparison with other Euro-Peristat countries between 2004 and 2010] Afname van foetale en neonatale sterfte in Nederland: vergelijking met andere Euro-Peristat-landen in 2004 en 2010. Ned Tijdschr Geneeskd. 2014;158:A6675.
5. EURO-PERISTAT project with SCPE EUROCAT and EURONEONET. Eruopean perinatal health report. Better statistics for better health for pregnant women and their babies in 2004. 2008.
6. EURO-PERISTAT project with SCPE and EUROCAT. European Perinatal Health Report: The health and care of pregnant women and their babies in 2010. 2013.
7. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P, Consortium for the European Review of Social Determinants of H, et al. WHO European review of social determinants of health and the health divide. Lancet. 2012;380(9846):1011-29.
8. de Graaf JP, Steegers EAP, Bonsel GJ. Inequalities in perinatal and maternal health. Current Opinion in Obstetrics and Gynecology. 2013;25(2):98-108.
9. Poeran J, Maas AF, Birnie E, Denktas S, Steegers EA, Bonsel GJ. Social deprivation and adverse perinatal outcomes among Western and non-Western pregnant women in a Dutch urban population. Social Science & Medicine. 2013;83:42-9.
10. Vos AA, Posthumus AG, Bonsel GJ, Steegers EA, Denktas S. Deprived neighborhoods and adverse perinatal outcome: a systematic review and meta-analysis. Acta Obstet Gynecol Scand. 2014;93(8):727-40.
11. Scholmerich VL, Erdem O, Borsboom G, Ghorashi H, Groenewegen P, Steegers EA, et al. The association of neighborhood social capital and ethnic (minority) density with pregnancy outcomes in the Netherlands. PLoS One. 2014;9(5):e95873.
12. Weightman AL, Morgan HE, Shepherd MA, Kitcher H, Roberts C, Dunstan FD. Social inequality and infant health in the UK: systematic review and meta-analyses. BMJ Open. 2012;2(3).
13. Lindquist A, Kurinczuk JJ, Redshaw M, Knight M. Experiences, utilisation and outcomes of maternity care in England among women from different socio-economic groups: findings from the 2010 National Maternity Survey. BJOG. 2015;122(12):1610-7.
14. Steegers-Theunissen RP, Twigt J, Pestinger V, Sinclair KD. The periconceptional period, reproduction and long-term health of offspring: the importance of one-carbon metabolism. Hum Reprod Update. 2013;19(6):640-55.
15. Atrash H, Jack BW, Johnson K. Preconception care: a 2008 update. Current Opinion in Obstetrics and Gynecology. 2008;20(6):581-9.

16. Temel S, van Voorst SF, de Jong-Potjer LC, Waelput AJ, Cornel MC, de Weerd SR, et al. The Dutch national summit on preconception care: a summary of definitions, evidence and recommendations. Journal of Community Genetics. 2015;6(1):107-15.
17. Shawe J, Delbaere I, Ekstrand M, Hegaard HK, Larsson M, Mastroiacovo P, et al. Preconception care policy, guidelines, recommendations and services across six European countries: Belgium (Flanders), Denmark, Italy, the Netherlands, Sweden and the United Kingdom. Eur J Contracept Reprod Health Care. 2015;20(2):77-87.
18. van Voorst S, Plasschaert S, de Jong-Potjer L, Steegers E, Denktas S. Current practice of preconception care by primary caregivers in the Netherlands. Eur J Contracept Reprod Health Care. 2016;21(3):251-8.
19. Poels M, van Stel HF, Franx A, Koster MPH. Actively preparing for pregnancy is associated with healthier lifestyle of women during the preconception period. Midwifery. 2017;50:228-34.
20. Ajzen I. From intentions to actions: A theory of planned behavior. Action control: Springer; 1985. p. 11-39.
21. van der Zee B, de Beaufort ID, Steegers EA, Denktas S. Perceptions of preconception counselling among women planning a pregnancy: a qualitative study. Family Practice. 2013;30(3):341-6.
22. Barrett G, Shawe J, Howden B, Patel D, Ojukwu O, Pandya P, et al. Why do women invest in pre-pregnancy health and care? A qualitative investigation with women attending maternity services. BMC Pregnancy Childbirth. 2015;15:236.
23. Poels M, Koster MP, Boeije HR, Franx A, van Stel HF. Why Do Women Not Use Preconception Care? A Systematic Review On Barriers And Facilitators. Obstet Gynecol Surv. 2016;71(10):603-12.
24. Steel A, Lucke J, Reid R, Adams J. A systematic review of women's and health professional's attitudes and experience of preconception care service delivery. Family Practice. 2016:588-95.
25. Jansen PW, Tiemeier H, Looman CW, Jaddoe VW, Hofman A, Moll HA, et al. Explaining educational inequalities in birthweight: the Generation R Study. Paediatr Perinat Epidemiol. 2009;23(3):216-28.
26. Daoud N, O'Campo P, Minh A, Urquia ML, Dzakpasu S, Heaman M, et al. Patterns of social inequalities across pregnancy and birth outcomes: a comparison of individual and neighborhood socioeconomic measures. BMC Pregnancy Childbirth. 2015;14:393.
27. van Voorst SF, Vos AA, de Jong-Potjer LC, Waelput AJ, Steegers EA, Denktas S. Effectiveness of general preconception care accompanied by a recruitment approach: protocol of a community-based cohort study (the Healthy Pregnancy 4 All study). BMJ Open. 2015;5(3):e006284.
28. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.
29. Tuomainen H, Cross-Bardell L, Bhoday M, Qureshi N, Kai J. Opportunities and challenges for enhancing preconception health in primary care: qualitative study with women from ethnically diverse communities. BMJ open. 2013;3(7):e002977.
30. Jack BW, Atrash H, Coonrod DV, Moos M-K, O'Donnell J, Johnson K. The clinical content of preconception care: an overview and preparation of this supplement. American journal of obstetrics and gynecology. 2008;199(6):S266-S79.

31. Frey KA, Files JA. Preconception healthcare: what women know and believe. Maternal and Child Health Journal. 2006;10(5 Suppl):S73-7.

32. Lupattelli A, Picinardi M, Einarson A, Nordeng H. Health literacy and its association with perception of teratogenic risks and health behavior during pregnancy. Patient Educ Couns. 2014;96(2):171-8.

33. Endres LK, Sharp LK, Haney E, Dooley SL. Health literacy and pregnancy preparedness in pregestational diabetes. Diabetes Care. 2004;27(2):331-4.

34. Vink-van Os LC, Birnie E, van Vliet-Lachotzki EH, Bonsel GJ, Steegers EA. Determining Pre-Conception Risk Profiles Using a National Online Self-Reported Risk Assessment: A Cross-Sectional Study. Public Health Genomics. 2015;18(4):204-15.

35. Timmermans S, Bonsel GJ, Steegers-Theunissen RP, Mackenbach JP, Steyerberg EW, Raat H, et al. Individual accumulation of heterogeneous risks explains perinatal inequalities within deprived neighbourhoods. European Journal of Epidemiology. 2011;26(2):165-80.

36. de Jong-Potjer LC, De Bock GH, Zaadstra BM, De Jong ORW, Verloove-Vanhorick SP, Springer MP. Women's interest in GP-initiated pre-conception counselling in The Netherlands. Family practice. 2003;20(2):142-6.

4

NUDGE ME, HELP MY BABY: ON OTHER-REGARDING NUDGES

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NUDGE ME, HELP MY BABY: ON OTHER-REGARDING NUDGES *JOURNAL OF MEDICAL ETHICS* 2017;43:702-706.

Abstract

There is an increasing interest in the possibility of using nudges to promote people's health. Following the advances in developmental biology and epigenetics, it is clear that one's health is not always the result of one's own choices. In the period surrounding pregnancy, maternal choice behaviour has a significant influence on perinatal morbidity and mortality as well as the development of chronic diseases later in life. One's health is thus a matter of one's own as well as one's maternal choices. Therefore, self-regarding and other-regarding nudges should be considered as viable strategies to promote health. In this article, we introduce the concept of other-regarding nudges. We use the harm principle and the principle of beneficence to justify these other-regarding nudges. We conclude by stressing the importance of a fair assessment of expectations towards the nudgee, when determining whether a nudge is aimed at preventing harm or promoting a good.

Introducing: other-regarding nudges

Fast and frugal rules of thumb or-heuristics as they are called-are cognitive processes that ignore part of the available information to make efficient decisions.(1) Heuristics are a powerful tool when it comes to making good inferences about the world under limited time and information. (2) Despite their usefulness however, decisions based on heuristics can arguably also be detrimental, for example, to one's health. Choosing unhealthy food despite one's intention to eat healthy and taking the elevator instead of the stairs to one's sedentary office job are examples of this 'surrender' to heuristics.

A well-known strategy that uses heuristics to the benefit of choice-makers is nudging. A nudge is defined as "any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives"(3)There is an increasing interest in the possibility of using nudges to encourage people to make healthier choices.(4) Poor health however, can't always be traced back to one's own choice-behavior. Perinatal morbidity (and mortality) and chronic diseases – two major challenges for healthcare and public health – are at least to a certain extent the result of *other* people's choices, in the cas we discuss, parental choices.(5, 6) Although the origins of perinatal morbidity and chronic diseases are multifactorial with in part unclear causal chains, there is an increasing amount of evidence suggesting that the health of the mother during the period surrounding pregnancy influences the risk of developing these poor health outcomes.(7-9) Policy and interventions aimed at empowering mothers-to-be, have a great potential to promote healthy pregnancies and reduce the risk of developing chronic diseases.(10, 11) This opens up the possibility of introducing nudges that encourage parents, mothers in particular, to make choices that benefit the health of their future children. The aim of this paper is to explore the justification of nudges where the principal but not necessarily sole beneficiary of the nudge is *not* the nudgee, in this case the mother, but her future children. We will call these nudges other-regarding nudges. We will use nudges aimed at promoting the health of the future child as a case study. Therefore the scope of this article will be limited to other-regarding nudges that are aimed at promoting the health of the future child by altering the choice-behavior of the mother. Like all nudges, these other-regarding nudges are not meant to replace but to complement policy, in this case to complement policy to improve maternal and fetal health.

First we provide a short overview of the relation between the development of the unborn, perinatal morbidity and chronic diseases later in life. Subsequently the justification of nudges to improve the health of the future child will be discussed. Because Libertarian Paternalism, the traditional justificatory theory for nudging, only offers a

justification for nudges that benefit the nudgee, an alternative form of justification is required. As the securing of the future child's health involves the prevention of harm, the Harm Principle will be put forward as a justification. Furthermore, not only should harm be prevented. The good, in this context the future child's health, should also be promoted. This duty to promote the good is based on the principle of beneficence. Thaler and Sunstein, do mention 'Libertarian Benevolence' as a justification of other-regarding nudges(12).[1] We aim to present a fuller account of how beneficence justifies other-regarding nudges.

The distinction between the duty to prevent harm resulting from act or omission and the duty to promote the good is notoriously hard to determine. It is important however, to seriously consider this distinction as the duty to prevent of harm is thought to offer necessary and sufficient justification to introduce preventive policy whereas the duty to promote the good does not. As this distinction of duties is based on what we can reasonably expect from others, we conclude by discussing the importance of expectations when assessing whether an act counts as doing harm or failing to promote the good.

From unborn to adult, the development of disease

Despite the fact that many risk factors for chronic diseases such as cardiovascular diseases, cancers, chronic respiratory diseases and diabetes, are to a great extent avoidable, the prevalence of chronic diseases has reached pandemic proportions.(13) Many public health interventions are traditionally introduced in the second half of life because it is assumed that during this period the risk of developing chronic diseases is greatest.(14) This approach however, has had limited success because it leaves the early origins of chronic diseases, unaddressed. Research shows that the development of the unborn is an important determinant for the risk to develop chronic diseases later in life. (15, 16) An impaired fetal development, which is for example associated with a mother's poor diet, smoking, alcohol consumption or sedentary lifestyle in the period surrounding pregnancy, leaves biological traces on the newborn, putting him at higher risk to develop chronic diseases later in life.

The field of epigenetics elucidates the pathways through which social disadvantages become biologically impinged.(17) In tandem, these social and biological traces increase the risk of chronic diseases later in life.(17) This is why the offering of adequate

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<> The difference between benevolence and beneficence is irrelevant for our discussion so for the sake of clarity we will only use beneficence.

pregnancy-related care and the education and empowerment of mothers-to-be is important. We argue in favor of a fair opportunity for mothers-to-be, to make choices which will benefit their own and their future child's health. Because of their non-coercive character, nudges aimed at promoting healthy maternal choice behavior in the period surrounding pregnancy could be considered. In the next section we will examine the moral justification for using these other-regarding nudges.

Beneficence to promote the good, the Harm Principle to prevent harm

A nudge is an intervention that benefits from people's propensity to favor heuristics over deliberation to steer them towards preset choices. For example, Thaler and Sunstein's well-known cafeteria nudge relies on people's tendency to choose food products that are conveniently in reach and thus easy to choose.(12) Libertarian Paternalism is put forward as a justification for nudging. In short, a Libertarian Paternalistic nudge encourages people to choose for their own good in their own eyes. The justification of nudges has been discussed extensively because of their alleged potential to manipulate, infantilize and nanny the targeted nudgees.(18, 19) These concerns also affect the justification of other-regarding nudges. A distinction should be made here between the aim of the nudge, for example helping individuals to eat healthy, and the nudging method which benefits from individual's propensity to make heuristic decisions. We will put forward beneficence and the harm principle as ways to justify other-regarding nudges. The rest of the article will address whether these two principles adequately justify the aims of other-regarding nudges. As regards the method, the justifiability of relying on heuristics is a concern that is not limited to other-regarding nudges, but to nudges in general. If one finds the use of heuristics acceptable, provided that the aim of a nudge is justified, then the use of other-regarding nudges is equally acceptable and vice versa. This is however a matter we cannot settle here. Still, in our view, an assessment of the steering character of the other-regarding nudge (for example does resisting the preset choice involve strenuous effort or high costs) is a pragmatic way to determine the justifiability of the nudging-method. For the rest of this article we will assume that unless the assessment of an other-regarding nudge proves otherwise, the nudging-method is justified.

Regarding other-regarding nudges, one example Thaler and Sunstein discuss is a nudge aimed at increasing the availability of organs.(20) This nudge does not benefit the donors, but individuals who need the donor's organs. In this case Libertarian Benevolence is put forward as justification. This shift from paternalism to beneficence represents the shift from self-regarding to other-regarding benefits.

Why then would it be justified to nudge someone for the benefit of another? In the case of organ donation, the fact that the availability of this valuable good fully depends on the willingness of others to donate, provides at least a strong reason to encourage people to become organ donors. Whether a nudge is appropriate to achieve this encouragement depends on the character of the nudge, for example, whether it sufficiently respects the autonomy of the potential donors.

This dependency on others to promote a good also holds for the health of the future child. The securing and promotion of the health of the future child depends to a certain extent on the choice behavior of the mother. Notwithstanding the fact that maternal obligations are in no way comparable to the beneficent act of donating one's organs, both cases demonstrate that the availability of certain valuable goods depends on the willingness of others to provide them. In these cases, an appeal to beneficence provides strong reasons to use other-regarding nudges that aim to promote the good (OG) In the section "beneficence as justification" we will argue that these strong reasons alone provide necessary but insufficient justification for OG.

There are arguably stronger reasons to prevent harm than to promote the good. Therefore, the well-known Harm Principle can be used to justify other-regarding nudges that aim to prevent harm (OH). We will present the justification of OH based on the Harm Principle in the following section.

The Harm Principle as justification

It is widely accepted that governments have the duty as well as the authority to protect and promote the population's health.(21) The Harm Principle offers a justification for the authority to prevent harm to the population's health. In On Liberty John Stuart Mill argues that ''The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant."(22) Joel Feinberg argues that liberty-limiting interventions aimed at preventing harm to others should be both effective and as less intrusive as possible.[2](23) The ideas of Mill and Feinberg combined offer a basis for identifying the threshold for justified government interventions. In

2 There are two ways an unborn can be harmed. A pregnant woman could *do* harm, for example by taking drugs when she is pregnant. She could also *allow* harm to happen, for example, in the case she is diabetic but doesn't seek care to control her blood sugar. We will follow Feinberg in assuming that the Harm Principle applies to harms brought about both by act (harm done) and omission (failure to prevent harm).

our case, this entails that maternal decisions should be respected by the government except when a decision of a mother places the future child at substantial risk of serious harm. Only then, the most effective and least intrusive interventions are justified.

Regarding OH, the justification based on the Harm Principle raises a serious concern. By definition nudges are not intended to be intrusive or to limit liberty. The Harm Principle justifies far more intrusive interventions than the mere steering character of a nudge. The concern about disproportional intrusiveness however is not a matter of justification, but one of adequacy. For example, if it is indisputably clear that maternal cocaine abuse during pregnancy harms the fetus, a hypothetical cocaine cessation-nudge, which does not block the use of cocaine, is not the adequate intervention to prevent harm. If in this case the only guiding moral principle for introducing an intervention would be the Harm Principle, a far more intrusive intervention would not only be justified but also warranted.

The softer side of harm

In many cases however, patterns of behavior rather than isolated choices cause disease. For example, women are well advised to abstain from drinking alcohol during pregnancy or when trying to conceive. However, it isn't this one and only glass of wine but a pattern of drinking that leads to faltered fetal development. The difference between an isolated choice and a pattern of behavior is, from a moral point of view, important. The Harm Principle offers a prima facie justification to prohibit alcohol and enforce treatment in the cases of pregnant women with a severe alcohol addiction.(24) These interventions however, seem too extreme in the case of a pregnant woman who at times drinks a glass of alcohol. This is not new; it is a repetition of Feinberg's articulation of the Harm Principle. What is new though is that the concepts of proportionality and subsidiarity dovetail nicely with nonintrusive interventions that help the majority of mothers who live relatively healthy lives but who would profit from encouragement to prevent harm to their future children. For example, a nudge that encourages the prevention of drinking an occasional glass of wine is far more appropriate than a legal prohibition of alcohol for women trying to conceive. A nudge that incentivizes smoking cessation in the period surrounding pregnancy rather than a blanket prohibition of smoking, isn't intrusive and it has promising chances to work.(25) An E-health nudge that generates a personal risk profile can encourage and empower women to adequately prepare for pregnancy. (26) Therefore, in our view, OH are justified when the causes of harm viewed separately are morally wrong but not to the extent that they

justify and warrant coercive interventions. In these cases, the Harm Principle offers necessary and sufficient justification for OH.

Beneficence as justification

We have argued that the availability of certain valuable even life-saving goods, such as organs and a healthy prenatal environment for the fetus, depends on the willingness of others to provide them. This dependency on others to attain a valuable good provides strong reasons to encourage individuals to provide these goods by introducing OG. In addition, is some cases, like ours in which we aim to improve the health of the future child by altering the choice-behavior of the mother, it may be argued that the mother has an interest in benefiting her future child. That is, there are stronger reasons for introducing OG when the nudgee has an interest in benefiting the other even if she is not the primary beneficiary of the nudge.

But does the fact that we are dealing with (i) valuable goods whose (ii) availability depends on the willingness of others to provide them and (iii) these others have an interest in providing these goods, provide necessary and sufficient justification for OG?

The noncoercive character of the nudge meshes well with the imperfect (deontological) or moderate (consequentialist) duty to promote the good. The consequentialist and deontological approach to beneficence share the idea that beneficence, contrary to the Harm Principle, isn't an overriding principle.(27-30) That is, there are (prima facie) never good reasons to harm someone whereas there can be good reasons not to promote someone else's good. Therefore, beneficence alone offers a necessary but not sufficient justification for OG. Compelling reasons not to promote the good can trump reasons to promote the good. The best-known constraint on the demands of beneficence is overdemandingness. This refers to the unreasonable duty to "give till in hurts". (29) Over-demandingness however does not disqualify beneficence as a justification because of the non-coercive nature of nudges; when being nudged, no one is required to give till it hurts. For example, an organ donation nudge does neither oblige nor pressure anyone to donate his or her organs. However, there may be other reasons besides over-demandingness that trump the reasons to promote the good.

Take the following example: it is hard for women to combine a high-powered career and children. Suppose that a government introduces as a 2-year pilot an egg-freezing

nudge to stimulate this combination.[3] The government offers companies a financial incentive to stimulate the offering of egg-freezing. This incentive is meant to cover part of the costs of egg freezing. For example, the government pays half and the employer and employee pay the other half. This makes it easier for companies to offer egg-freezing to their employees so that they can choose to become pregnant when they are ready for motherhood. Let's also assume that the intention of the government is to promote the good. The nudge is really meant to offer women a better chance at having a career and children. After two years the number of women freezing their eggs has gone up but less women are working part-time and compared to two years ago, relatively more young women without children are hired than young women with children. In this case, the principle of beneficence offers a necessary but not a sufficient justification. The government nudges companies with (the governmental interpretation of) the good of women in mind. This satisfies the criterion of necessity. However, the reproductive autonomy of the employees could be limited rather than promoted. As it is now, a woman's egg freezing preferences (if she has any in the first place) are her own and she is required neither to choose nor to make her reasons for any decision explicit. With the introduction of this nudge the option of keeping her preferences to herself is lost. Even if she ignores the option, she still *chooses* not to freeze her eggs. In this case –not choosing– is a meaningful option that deserves to be protected, first and for all by the government. In addition, and from a more practical point of view, the evaluation of this nudge reveals detrimental side effects which are: a pressure to postpone pregnancy, less flexible hours for young parents and less career opportunities for young mothers. These concerns show that beneficence is necessary but insufficient as a justification for this OG. This is, of course a fictive example that is only meant to show that ample prudence is required when introducing OG.

The murky waters of preventing harm and promoting the good

We have argued that the Harm Principle offers necessary and sufficient justification for OH and that beneficence offers necessary but not sufficient justification for OG. Thus it is important to determine whether an other-regarding nudge is aimed at preventing harm or at promoting the good.

In theory, a nudge that helps women trying to conceive to start the timely use of folic acid supplementation is easier to justify than a nudge to help women trying to conceive

3 This example is inspired on the controversies surrounding Apple and Facebook's recent offering of egg-freezing to their female employees

to optimize their diet. The former nudge aims at preventing harm whereas the latter aims at optimizing a good. Unfortunately, the murky waters of everyday practice often resist this neat theoretical distinction. It is all but clear where prevention of harm ends and where the promotion of good begins.

Take folic acid supplementation again as an example. Let's consider the case of Amy who is trying to conceive but doesn't use supplementation because she is unaware of its effects on fetal development. A nudge may be introduced to help Amy to optimize her folic acid intake. For example, bread that is fortified with folic acid can be made easily available for her during the period she is advised to use supplementation. Reducing the chance of neural tube defects becomes as easy as eating a sandwich. Because the nudge is aimed at preventing harm the Harm Principle offers necessary and sufficient justification.

Amy's case however, may also be construed, as one of failing to promote a good. Amy isn't putting her future newborn in a more harmful situation than the newborn would be in the first place, a necessary condition for an action (or omission) to count as harm. What she is 'doing' is failing to provide a good, the good being the benefits of supplementation. In this case the justification of the nudge would be based on the principle of beneficence. When considering the introduction of a nudge this difference, although small, does matter. The moral constraint of causing harm is stronger than the moral obligation to promote the good. There are stronger reasons to introduce a supplementation nudge to prevent harm (decrease the chance of neural tube defect) than to promote a good (increase the chance of no neural tube defect). One way to determine whether we are dealing with a situation of harm or a situation of benefit is by assessing what we may reasonably expect from Amy and why.

It is reasonable to claim that women trying to conceive have some maternal obligations towards their future children. These obligations are very likely to inform us about what we may reasonably expect from Amy. Not fulfilling these obligations could be construed as harm. Binge drinking in the period she is trying to conceive for example, would count as harm. There is also a class of actions (or omissions) which are praiseworthy but not obligatory; supererogatory actions. Not acting in a supererogatory way can be construed as failing to provide a good. Even though not visiting a preconception consultation does not does not count as harm, a visit would be recommendable and praiseworthy. In order to distinguish between situations of harm and benefit however, a full account of obligations of women trying to conceive is required. Although giving this full account is beyond the scope of this article, the most important requirement this account should satisfy is that the expected benefits for the future child should

justify the burdens put on women trying to conceive. In the case of the fortified bread nudge, the benefit of substantially reducing the risk of a neural tube defect justifies the "burden" of being encouraged to eat fortified bread instead of normal bread. Therefore, we argue that using folic acid supplementation is a moral obligation and we would classify that nudge as OH. Optimizing one's diet when trying to conceive decreases the chances of disease development of one's future child. The effect of diet optimization on the health of the future child however isn't as clear as in the case of folic acid supplementation. In addition, optimizing one's diet is significantly more burdensome than taking folic acid supplementation or eating a different type of bread. Therefore, it is reasonable to classify diet optimization as beneficence rather than preventing harm. A nudge that encourages women to optimize their diet, such as the earlier mentioned m-Health nudge, would therefore be an OG.

A caveat is that there seem to be a lot of presumptions regarding the duties of mothers (-to-be). How easy and common it is to claim that women should do all they can do to prevent harm to their future children. And how easy and common it is to conflate preventing harm with optimizing health. When the prevention of harm and promotion of good are conflated, everything a mother does that does not *maximize* her child's health or well-being will count as harm. And harm offers necessary and sufficient justification for a whole ambit of interventions. To make sure that the adequate threshold for harm is safeguarded, a fair assessment of benefits and burdens is warranted

Conclusion

We have argued that OH and OG have a place in the array of interventions aimed at preventing harm to and promoting good health of the future child. The Harm Principle offers necessary and sufficient justification for OH. The principle of beneficence offers necessary but insufficient justification for OG. What is expected from nudgees, in this case women trying to conceive, determines whether they are expected to prevent harm or promote the good. Therefore, a fair assessment of these expectations is warranted.

References

1. Gigerenzer G, Brighton H. Homo heuristicus: Why biased minds make better inferences. Topics in Cognitive Science. 2009;1(1):107-43.
2. Gigerenzer G, Goldstein DG. Reasoning the fast and frugal way: models of bounded rationality. Psychological review. 1996;103(4):650.
3. Thaler R.H Sunstein C.R. Nudge: Improving decisions about Health, Wealth and Happiness. London: Penguin Books; 2008, 2009.
4. Quigley M. Nudging for health: on public policy and designing choice architecture. Medical Law Review. 2013;21(4):588-621.
5. Hanson M, Godfrey KM, Lillycrop KA, Burdge GC, Gluckman PD. Developmental plasticity and developmental origins of non-communicable disease: theoretical considerations and epigenetic mechanisms. Progress in biophysics and molecular biology. 2011;106(1):272-80.
6. Barouki R, Gluckman PD, Grandjean P, Hanson M, Heindel JJ. Developmental origins of non-communicable disease: implications for research and public health. Environ Health. 2012;11(42):10.1186.
7. Godfrey KM, Barker DJP. Fetal programming and adult health. Public health nutrition. 2001;4(2b):611-24.
8. Barker DJP, Thornburg KL. The obstetric origins of health for a lifetime. Clinical obstetrics and gynecology. 2013;56(3):511-9.
9. Lu MC, Halfon N. Racial and ethnic disparities in birth outcomes: a life-course perspective. Maternal and child health journal. 2003;7(1):13-30.
10. Wallack L, Thornburg K. Developmental origins, epigenetics, and equity: moving upstream. Maternal and child health journal. 2016;20(5):935-40.
11. Barouki R, Gluckman PD, Grandjean P, Hanson M, Heindel JJ. Developmental origins of non-communicable disease: implications for research and public health. Environmental Health. 2012;11(1):1.
12. Thaler R.H Sunstein C.R. Libertarian Paternalism Is Not an Oxymoron The University of Chicago Law Review. 2003;70(4).
13. Daar AS, Singer PA, Persad DL, Pramming SK, Matthews DR, Beaglehole R, et al. Grand challenges in chronic non-communicable diseases. Nature. 2007;450(7169):494-6.
14. Godfrey KM, Gluckman PD, Hanson MA. Developmental origins of metabolic disease: life course and intergenerational perspectives. Trends in Endocrinology & Metabolism. 2010;21(4):199-205.
15. Gillman MW. Developmental origins of health and disease. The New England journal of medicine. 2005;353(17):1848.
16. Barker D. Developmental origins of adult health and disease. Journal of epidemiology and community health. 2004;58(2):114.
17. Gluckman PD, Hanson MA, Low FM. The role of developmental plasticity and epigenetics in human health. Birth Defects Research Part C: Embryo Today: Reviews. 2011;93(1):12-8.
18. Rebonato R. Taking liberties: A critical examination of libertarian paternalism: Palgrave Macmillan; 2012.
19. Holland S. Public health ethics: John Wiley & Sons; 2015.

20. Richard H. Thaler CRS. Libertarian Paternalism Is Not an Oxymoron The University of Chicago Law Review. 2003;70(4).
21. Childress JF, Faden RR, Gaare RD, Gostin LO, Kahn J, Bonnie RJ, et al. Public Health Ethics: Mapping the Terrain. The Journal of Law, Medicine & Ethics. 2002;30(2):170-8.
22. Mill JS. On liberty: Longmans, Green, Reader, and Dyer; 1869.
23. Feinberg J. Harm to others: Oxford University Press; 1984.
24. Paltrow LM. Governmental Responses to Pregnant Women Who Use Alcohol or Other Drugs. DePaul J Health Care L. 2004;8:461.
25. Volpp KG, Troxel AB, Pauly MV, Glick HA, Puig A, Asch DA, et al. A randomized, controlled trial of financial incentives for smoking cessation. New England Journal of Medicine. 2009;360(7):699-709.
26. Van Vliet-lachotzki E. An electronic preconception checklist on Internet: www. zwanger-wijzer. nl. 2007.
27. Scheffler S. Rejection of Consequentialism: Cambridge Univ Press; 1994.
28. Murphy LB. The demands of beneficence. Philosophy & Public Affairs. 1993:267-92.
29. Noggle R. Give till it hurts? Beneficence, imperfect duties, and a moderate response to the aid question. Journal of Social Philosophy. 2009;40(1):1-16.
30. Hill TE. Beneficence and self-love: a Kantian perspective. Social Philosophy and Policy. 1993;10(01):1-23.

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FORCED CESAREANS: APPLYING ORDINARY STANDARDS TO AN EXTRAORDINARY CASE

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FORCED CESAREANS: APPLYING ORDINARY STANDARDS TO AN EXTRAORDINARY CASE, *JOURNAL OF MEDICAL ETHICS DOI: 10.1136/MEDETHICS-2018-104828*

Abstract

Is it morally justifiable to force non-consenting pregnant women to submit to cesarean surgery to save their fetus in distress? Even though proponents and opponents largely agree on the interests at stake, such as the health and life of the fetus and the respect for bodily integrity and autonomy of pregnant women, they disagree on which moral weight to attach to these interests. This is why disagreements about the justifiability of forced cesareans tend to be pervasive and intractable. To sidestep this deadlock, we will focus on conditions that give rise to the 'cesarean dilemma' in the first place, namely the conflict between inherent norms and values medical professionals are committed to by virtue of being a medical professional. Using the reflective equilibrium, we will we test the opponents' and proponents' considered judgments about forced cesareans against the norms and values they –as medical professionals– are committed to and determine whether they are coherent. Subsequently we will identify the proponents' incoherencies between the considered judgments and norms and values they are committed to and conclude that as long as these incoherencies are in place, forced cesareans are morally impermissible.

Introduction

A is brought into the delivery suites. She is 36 weeks pregnant and is diagnosed with an umbilical cord prolapse. Immediate cesarean section is indicated to save the fetus. Two years ago A was treated for an appendicitis. Her wound got infected and she developed a sepsis. This unfortunate ordeal left A terrified of surgery – especially abdominal surgery. Scared but coherent, she refuses to consent to the cesarean section. After an hour of persistent but fruitless pleas of the doctors, the fetus dies.

Should the doctor in the case of A have forced A to submit to cesarean surgery?[4] Disagreements about the justifiability of forced cesareans are pervasive and intractable. Although opponents and proponents of forced cesareans agree about the interests at stake, they disagree about the moral (and legal) 'weight' that should be given to these interests. Proponents typically acknowledge that women have a right to bodily integrity and autonomy. They claim however, that these rights aren't absolute and the life and health of the fetus should, in dire circumstances, outweigh the right to refuse surgery. (1, 2) Opponents on the other hand acknowledge that the fetus has interests. They claim however, that even though the rights to bodily integrity and autonomy (from here on right to autonomy) aren't absolute, they do protect women against forced surgery.(3) As medical ethics and law stand now, no one can be forced to submit to surgery to save someone else's life. Forcing women to submit to surgery would therefore be an unjustified demand, irreconcilable with the moral and legal standards in the medical domain. Because of these different perspectives on the justification of forced cesareans proponents and opponents are unlikely to reach consensus on an issue that, because of the possible tragic consequences for mother and child, demands it.

We will sidestep this deadlock by focusing on the conditions that give rise to the cesarean dilemma. The cesarean dilemma is precisely –a dilemma– because of the conflict of ethical principles professionals working in the medical domain are committed to. Without this commitment to principles such as 'beneficence' and 'respect for autonomy' the cesarean dilemma would in fact not arise. Therefore, we will test the coherence of the ethical principles medical professionals are committed to and the considered judgments they hold. This is the adage of Rawls's reflective equilibrium (RE).(4) To present the ethical principles professionals are typically committed to in a systematic way, we will use the widely accepted principles of biomedical research of Beauchamp and Childress.(5)

4 In the Netherlands for example, the Dutch group 'Actio Caesarea', consisting of doctors and (former) judges, argues for the possibility to force women, via a court order, to submit to cesarean surgery in cases of medically indicated fetal distress (1).

The use of the RE is appealing because the justifiability of the positions at stake is judged by referring to the principles and considered judgments the opponents and proponents *themselves* are committed to. The RE is thus an instrument that can be of help as it requires the arguments of proponents and opponents to be, at the very least, coherent.

We will conclude that as long as a pregnant woman is competent to consent, proponents face a serious challenge to argue in favor of forced cesareans while at the same time remaining faithful, as professionals, to their own body of considered judgments and ethical principles.

We will start by giving an overview of the arguments typically put forward by proponents and opponents of forced cesareans. Because seemingly the respect for the pregnant woman's *rights* is seemingly in conflict with the duty to bring forth the best *consequences* for the fetus, we will, for the sake of clarity, present the arguments in terms of (i) deontological arguments in favor and against, and (ii) consequentialist arguments in favor and against forced cesareans.

Opponents

Based on most legal and moral literature on the topic, it is surprising that the justifiability of forced cesareans is a matter of controversy. With few exceptions, the literature suggests that a pregnant woman's *right* to autonomy trumps the doctor's *duty* to promote the interests of the fetus and pregnant woman.(6-11) This defense of the pregnant woman's right to refuse surgery typically takes two forms.

First is what we call the *deontological defense*. This line of defense exhibits in a number of ways the importance of respecting a competent patient's right to autonomy, that is, the right to have control over what happens to their body (e.g. in the medical setting) – whatever the consequences of this right may be[5]. One way this right is justified for instance, is by arguing that the right to autonomy is meant to protect the 'intrinsic value' or 'human dignity' of patients. This right to protection brings forth the claim to self-governance and privacy that patients have on medical professionals. This entails that in situations of medical decision-making, a (competent) patient cannot be forced to undergo treatment without her consent even if the consequences are detrimental to herself or a third party. Hence, a pregnant woman may not be 'victimized' through

5 This is not to say that there exist no consequentialist or utilitarian defenses of the right to autonomy.

surgery without consent for the sake of her own or someone else's good. This right is enshrined in the doctor's duty to obtain informed consent.(12) As it is now, the respect for the patient's autonomy and the duty to obtain informed consent are of paramount importance in the medical domain. A legal example that demonstrates the importance of respect for autonomy is the ruling of the Court of Appeal in the UK in the case of S v St George's NHS Trust. The court made it unequivocally clear that a pregnant woman is allowed to refuse medical treatment (cesarean surgery) even if this would likely harm her own health or the health of her unborn "unless she is clearly and properly not sound of mind".(13) The ethical argument underpinning this court order thus is that a pregnant woman's right to autonomy cannot be traded off in pursuance of the best possible consequences for the fetus.

The corollary of this deontological reasoning is a critique of the use of 'greedy' consequentialist reasoning. For example, in her refutation of consequentialism Rhoden writes "If decisions are made for a woman in a way that suggests that it does not matter very much *who she is*, then she has, in a very real sense, been wronged. Of course, courts in these cases do not override women's choices lightly. They are faced with extraordinarily hard decisions in which the threat to the infant must be neither denied nor minimized. But, if the way to avert this threat is to coerce the woman and violate her rights, then the court, *in pursuing the best consequences*, inevitably treats the woman merely as a means to the goal of preserving the infant's health."(10)

Second is what we may call the *consequentialist defense*. This line of defense accepts the assertion that the interests of the mother and the fetus ought to be balanced against one another. When *all* possible consequences are taken into account however, the balance would arguably not tip in favor of the use of force. Here is a list of adverse consequences.

(i) If the option to force women to submit to surgery is accepted, it invites –in addition to the use of force– the use of coercion. Consider the case of Lisa Epsteen who received an email form the chairman of an obstetrics and gynecology department in the U.S. in which he stated: "I would hate to move to the most extreme option, which is having law enforcement pick you up at your home and bring you in, but you are leaving the providers [of the hospital] no choice."(14) The chairman was deeply concerned that Epsteen's refusal to come in for surgery would result in her fetus dying or incurring serious brain damage. His rationale for the email is understandable. However, even if forced cesareans are justified, the coercive offer to bring Epsteen in and potentially force her to undergo surgery requires additional justification.

(ii) The actual enforcement of forced cesareans may lead to humiliating situations. For example, in Chicago a Nigerian woman was hospitalized for the final months of her pregnancy and was advised to have a cesarean section. When she did not agree she was placed by force in leather wrist and ankle cuffs. She reportedly screamed for help and bit through her intravenous tubing in an attempt to get free.(15, 16)

(iii) With the possibility of forced cesareans looming, women, especially those with an obstetric history, may become less likely or even reluctant to seek needed obstetric care.(17)

(iv) The possibility of force is also detrimental to the patient-doctor relation in which it is of crucial importance that a patient feels safe.

(iv) Concerns have also been expressed about the lack of due process for women who would be forced to undergo cesarean surgery. In these cases there is typically an "absence of notice, an absence of adequate legal representation for the pregnant woman and no explicit standard of proof to judge the necessity of a cesarean."(18)

We haven't presented an exhaustive list of adverse consequences of forced cesareans. But these examples should suffice to show that even if a consequentialist line of reasoning is accepted, it remains questionable whether the overall benefits of the use of force do outweigh the burdens for (pregnant) women. We will now present the arguments put forward by the proponents of forced cesareans.

Proponents

Compelling as they may be, the arguments put forward can be disconnected from the 'sense of urgency' felt by doctors who face this dilemma. Research conducted by Samuels et al. found that 51% of the questioned 229 obstetricians and 126 health lawyers were highly likely to support the use of a court ordered cesarean section to protect and promote the health of the fetus.(19) These doctors and lawyers (seem to) hold the view that saving the fetus in distress is a good reason to bypass informed consent. When a child may suffer life-long misery or even die because a mother refuses surgery, feelings of helplessness and despair do arise. With these stakes it is no wonder that some doctors will do all they can to save the fetus, if not by persuasion then by force. Again, we may divide the arguments into a deontological and a consequentialist defense.

First, *the consequentialist defense* is straightforward. Severe harm or death may be prevented at the cost of what is considered to be intrusive but relatively safe and routine

surgery. Therefore, in cases of a medically indicated cesarean, the use of force is justified.

Second, is the *deontological defense*. Once a human life begins it matters how that life goes. This creates a conditional duty [6] to act in such a way that the interests of the (un)born are promoted. Pregnant women have this duty towards their (un)born. This duty includes making some acceptable sacrifices, such as consenting to cesarean surgery, if that would save the life of her (un)born. Chervenak et al. present a similar argument. (1, 20). They argue that if (i) cesarean surgery is medically indicated and the indication is based on (ii) well-founded obstetrical judgment, which should be (iii) replicable by a well-informed competent clinician, a doctor should not be guided only by a mother's refusal but also by his own duty of beneficence. Respecting the refusal of a mother to undergo a medically indicated surgery would be, according to Chervanak et al., "a form of indefensible imprudence."(1)

In short, the justification of forced cesarean sections builds on the beneficence based maternal and professional conditional duties that follow from maternal duty, prudence and well-founded medical judgment. In sum, both opponents and proponents of forced cesareans present reasonable arguments that support their position. The result is a moral deadlock. We will now introduce the RE and explain why and how this method can help to establish whether forced cesareans are justifiable.

The RE

In short, the RE is a method that allows us to align, as well as possible, our most confident moral judgments or intuitions (considered judgments), with the ethical principles we are committed to.(21) This method does not treat considered judgments as unassailable truths nor ethical principles as self-evident axioms. Rather it takes considered judgments as starting points. In order to affirm these considered judgments, they must be coherent with other considered judgments and ethical principles one is committed to. When coherence is achieved, the RE has been reached and there are good reasons to be confident about the soundness of the judgment at hand.

The RE works 'up and down'. Ethical principles are specified in terms of considered judgments. For example, the principle of 'respect for autonomy' is specified as the considered judgment that *it is wrong to perform surgery on A against her will.* Considered

6 A duty resulting from certain relations we have with one another

judgments on the other hand are subsumed under ethical principles. For example, the considered judgment that doctor should save the baby is subsumed under the principle of beneficence. The more one is successful to specify and subsume, the more reason one has to be confident about the judgment at hand.

We emphasize the importance of taking the viewpoint of the professional as they are committed to professional norms and values. Surely a doctor strives to promote the health and well-being of his patients while treating them with due respect –and if he doesn't, he should! We are therefore aiming to find a *narrow* reflective equilibrium in which we take the professional norms and values, which we base on the biomedical principles of Beauchamp and Childress, to be (at least for now) unproblematic. We do so because, the cesarean dilemma does, prima facie, not challenge the whole body of norms and values of the medical domain. Quite the contrary, the cesarean dilemma appears precisely as a dilemma because two cornerstone principles, which are -the duty of beneficence- and -the duty to respect autonomy-, are in conflict. If, say, the duty to respect autonomy wasn't a cornerstone principle, the cesarean dilemma would arguably not arise. The benevolent paternalistic doctor would simply decide what is best for the mother and her fetus. We will now assess the coherence of the considered judgments and ethical principles pertaining to the cesarean dilemma.

The equilibrium at work: the case of A revisited

We begin by formulating a hypothetical equilibrium (HE) which after scrutiny will or will not pass the test of the reflective equilibrium. (HE) *Doctors should have the possibility to force a competent pregnant woman to submit to surgery if according to the best of their professional judgment this would save the life or greatly benefit the health of the fetus without exposing the woman to disproportionate risks.*

Textbox 1
A is brought into the delivery suites. She is 36 weeks pregnant and is diagnosed with an umbilical cord prolapse. Immediate cesarean section is indicated to save the fetus. Two years ago A was treated for an appendicitis. The wound resulting from the appendectomy got infected and she developed a sepsis. This unfortunate ordeal left A terrified of surgery –especially abdominal surgery. Scared but coherent, she refuses to consent to the indicated cesarean section. After an hour of persistent but fruitless pleas of the doctors, the fetus dies.

Let's go back to the situation in which A (textbox 1) is brought into the delivery suites and she adamantly refuses the indicated cesarean.

We start with considered judgment (CJ1) (table 1) *the doctor should force A to submit to surgery.* For (CJ1) to be accepted it should be in equilibrium with other considered judgments as well as the medical ethical principles.

We add (CJ2) *Given that X is a doctor he should try to save the life of the fetus in distress.* As a doctor it is reasonable to hold these two considered judgments because a doctor wants to do good; (P1) *the principle of beneficence.* In RE terms: (P1) is specified by (CJ1,2) and (CJ1,2) are subsumed under (P1).

For a doctor who holds (CJ1,2) to act *fair* (P2) he should force all women in A-like circumstances to submit to surgery because the doctor should treat all equal medical cases equally. Whether that is the case depends of course on what qualifies as an A-like case. A-like cases can be thought to comprise all cases in which competent women refuse a medically indicated cesarean.

Table 1

Hypothetical Equilibrium
(HE) Doctors should have the possibility to force a competent pregnant woman to submit to surgery if according to the best of their professional judgment this would save the life or greatly benefit the health of the fetus without exposing the woman to disproportionate risk
Considered judgments
(CJ1) the doctor should force A to submit to surgery.
(CJ2) Given that X is a doctor he should try to save the life of the A's fetus in distress
(CJ3) forcing A to submit to surgery is justified because the benefit for the fetus outweighs the harm to A.
(CJ4) Forcing A to submit to surgery to benefit the fetus is justified if persuasion fails
(CJ5) Because A's refusal is based on fear, it isn't a reflection of what she really wants; without fear she would consent
Principles based on the principles of biomedical research by Beauchamp and Childress
(P1) the principle of beneficence
(P2) the principle of fairness
(P3) the principle of proportionality
(P4) the principle of subsidiarity
(P5) the principle of respect for autonomy

A-like cases can however also be thought to comprise all cases in which one person has a conditional duty towards another person, like mother and fetus but also father and son, and the prior is in a unique position to save the latter by way of surgery. Consider for example the case in which a father could save his son by donating his kidney which

would come at a risk comparable to a mother having cesarean surgery to save the life of her fetus. If a mother is forced to save the life of her fetus but a father is not forced to save the life of his son, then equal cases are *not* treated equally.[7] (CJ1,2) are not coherent with (P2).

The scenario in which a father is in the unique position to save his son but chooses not do so has, as far as we know, not been recorded. The case that comes closest to this scenario is the case of *McFall v Shimp.*(22, 23) McFall was dying and Shimp, his cousin, was the only person known to have compatible bone marrow. Shimp refused to donate, so McFall attempted to force Shimp to comply on the grounds that his life depended upon the transplantation. The court decided that Shimp could not be compelled to donate. McFall died[8].

From a moral viewpoint, what matters is that moral fiduciaries can be in a unique position to save those under their moral protection. This can be a mother saving her fetus but also a father saving his son (and why stop there and not include McFall?). To single out women as the only targets of force is, from a moral viewpoint, arbitrary. Therefore, we argue that A-like cases should be expanded to all moral fiduciaries who are in the unique position to save those under their protection at a reasonable cost, such as submitting to relatively safe surgery. Consequently, we should either permit force in *all* or in *no* A-like cases. In RE terms: (CJ1,2) are not coherent with (P2) if we only use force against pregnant women.

We will now scrutinize the principle of beneficence (P1). It is understandable that doctors want to use force to save the fetus (CJ1,2) as they have a duty of beneficence (P1). But what is understandable is not necessary justifiable. Especially in the medical domain, the demands of beneficence is not without limits. The case of Angela Carder is a clear example of the danger of the 'overdemandingness' of beneficence.

Carder, who was pregnant, was a bone cancer patient. She became critically ill and the condition of the fetus seemed to deteriorate to such an extent that Angela's family was asked for permission to perform a caesarean section.(24).Because the caesarean might further shorten Carder's life and it would lead to more discomfort in her already precarious situation the family, in accordance with Carder's own desire, decided against

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7 *In this paper we only discuss to the justifiability of forced cesareans. We are however, aware that there is a broad discussion about the justifiability of liberty-restricting measures in cases where maternal behavior may possibly harm children(-to-be).*

8 *It is worth noting that in common law there is a distinction between parents and all others in regard to a duty to rescue.*

surgery. The hospital attorney however felt that the interests of the fetus deserved more consideration. “Balancing Angela Carder’s life expectancy as a cancer-ridden patient against that of the fetus, the court ordered the cesarean.”(25) the surgery was performed, sadly followed in short order by the child’s death and that of its mother.(26) Three years later an appellate court overturned the lower court ruling in order to prevent a precedent.(24) The ruling stated clearly that considerations such as a mother’s prognosis and likelihood of success should not make a difference when protecting a woman’s right to be the decision maker.

To prevent such dramatic situations, the demands of beneficence are regulated by (P3) *proportionality* and (P4) *subsidiarity.* The burdens of cesarean surgery have to be acceptable relative to the benefits for the fetus (P3) and the benefits for the fetus must be achieved using the least intrusive methods (P4). (P3,4) are the ‘checks and balances’ for (P1).

Going back to the case of A we can now add two more considered judgments: (CJ3) *forcing A to submit to surgery is justified because the benefit for the fetus outweighs the harm to A.* (CJ4) *Forcing A to submit to surgery to benefit the fetus is justified if persuasion fails.* We’d like to mention that to our mind persuasion as mentioned in (CJ4) is morally permissible and for the sake of the fetus it is even required. Let us now scrutinize (CJ3,4).

How coherent are (CJ3,4) with (P3,4)? Do the demands of proportionality and subsidiarity allow for the use of force when the use of force brings about benefits for the fetus that outweigh the burdens for the mother? To be clear we are not aiming at finding the conditions in which the benefits for the fetus outweigh the burdens for the mother. Even if it is possible to identify such conditions, *by themselves* these conditions do not justify the use of force as such. For the sake of argument, we will assume that the exchange of benefits and burdens is reasonable and ask whether this is sufficient to justify force.

The use of force in the medical domain is rare. Its use for the benefit of others even rarer. This is not because the options to help each other are limited. Individuals may undergo surgery, donate organs, donate blood or participate in medical research; all for the sake of others. The use of force is limited because it, prima facie, violates (P5) *the principle of respect for a patient’s autonomy*. Yet, one example of the justified use of force for the benefit of others is the use of force when quarantining contagious individuals to prevent serious communal harm.(27) In dire circumstances, quarantine can be the only available measures to stop an outbreak of diseases such as SARS and Ebola. The restriction of movement during the estimated period of communicability is therefore

thought to be a proportionate and subsidiary use of force (P3,4). Let us now compare the risks and burdens pertaining to quarantines and forced cesareans. To be sure we are aware that the (possible) voluntariness of pregnancy and involuntariness of having a contagious disease limit the comparison. However, we may still discuss, in a meaningful way, the burdens and benefits of both interventions.

Without doing injustice to the considerable praiseworthiness of rescuing the potentially lost life of a viable fetus, the prevention of an epidemic (including the potential death of a great many viable fetuses) counts as a 'greater' benefit'. More lives can be saved. The burdens on the other hand are arguably bigger for those who are forced to *submit to surgery* than those whose *movement is restricted* by force. Consider that "in response to concerns about informed consent, HHS/CDC has added regulatory language requiring that the Director advise the individual that if a medical examination is required as part of a Federal order that the examination will be conducted by an authorized and licensed health worker *with prior informed consent*. [emphasis added]"(27) The HHS/CDC rightfully assumes that medical examination without informed consent is a greater intrusion on one's rights than the restriction of movement. In sum, the benefits of quarantine are bigger and the burdens are smaller. Therefore, as we do not force medical examination to save many people from an epidemic, *a fortiori* we shouldn't force surgery on a pregnant woman to save the life of a fetus.

Whether (CJ4) is subsidiary (P4) is more open to debate. One may claim that professionals cannot rely on persuasion as the least intrusive option. A pregnant woman can still refuse. On the other hand, in the overwhelming majority of cases information and persuasion are sufficient to convince women to undergo cesarean surgery. We will now address (P5) *respect for autonomy.*

Is respect for autonomy (P5) reconcilable with the use force in the medical domain? Obviously not; except for two situations. First, when medical disaster can be prevented as we have described in the quarantine case. The use of force is, however, even in that extraordinary situation limited to the restriction of movement. Second, it is permitted when a patient (temporarily) lacks the capacity to make a medical decision. In such a case, medical treatment can be enforced for the good of that patient. A legal example that demonstrates the importance of the capacity to make a decision about cesarean surgery is the case of Ms. A. Pacchieri an Italian35 year old woman who traveled to the UK.(28) Pacchieri who suffered from bipolar disorder had a panic attack and was subsequently detained. At 39 weeks of gestation an application was made to the Court of Protection to perform a cesarean section as this was thought to be in the best interest of Pacchieri. The judge made a declaration that Pacchieri lacked capacity in relation

to this decision and that it was in her best interests for her baby to be delivered by caesarean section, with the use of reasonable restraint in order to achieve that operation safely and successfully.(29)

Given the importance of capacity we add (CJ5) *Because A's refusal is based on fear, it isn't a reflection of what she really wants; without fear she would consent.* If (CJ5) is true, then (P5) offers insufficient reason to not force A to submit to surgery. A is scared and will regret het refusal and thus there is reason to force her to submit to surgery.

If (CJ5) is not true and A's refusal is a reflection of what she really wants, then there is good reason to adhere to (P5) and not allow force. And herein lies the problem. In acute situations such as a cesarean dilemma, it is particularly hard to establish a pregnant woman's decision-making capacity.(30) Moreover, decision-making capacity comes in varying degrees. The additional *normative* question is; which level of decision-making capacity (scalar) is sufficient to establish competence (binary)? (31)

A's decision is obviously affected by her fear for abdominal surgery. Yet fear alone should, in our view, never be the threshold for incompetence. Emotions such as fear, anxiety, anger and despair are part and parcel of the medical domain. Such a threshold would render many patients who are capable of balancing emotion with reason, incompetent. However, it isn't easy to imagine situations in which the refusal of a medically indicated cesarean surgery is based on understandable and appreciable reasons. And these reasons for refusal are important to deflect the sentiment that in the medical domain, we allow for actual life to capitulate to abstract principle. It is at this point, that the 'art of establishing decision-making capacity' plays a crucial role and that our case study of A reaches its limits. We can, of course, construct A's case in such a way that she turns out to be competent –or not. But that does not help to establish the justifiability of forced cesareans.

Conclusion

From here, we turn back to the RE and draw two conclusions. First, we have shown that coherence is lacking between considered judgments (CJ1-5) and principles (P1-5). This suggests that the HE does not pass the test of the RE and should therefore be rejected.

Second, although we reject the HE this is not based on a blind adherence to the principle of respect of autonomy (P5). To understand the adherence to a patient's wish when anxiety and fear may have marred her decision-making capacity as 'respect'

for autonomy is, in our view, questionable and such adherence can, especially in a litigious culture, be a 'moral bailout'. The overwhelming majority of cases show that refusal is an atypical response when cesarean surgery is required to save the fetus. This understandably raises questions about the woman's decision-making capacity. In this dilemma, nothing would be more regrettable than not changing the mind of a mind open to change. Still, the moral norms and standards of the medical domain, in which the use of force to benefit others is close to unthinkable, should also apply to pregnant women and their doctors. The fact that this is an extraordinary dilemma offers on its own no reason to judge it according to extraordinary moral standards.

References

1. Chervenak FA, McCullough LB, Skupski DW. An ethical justification for emergency, coerced cesarean delivery. Obstetrics & Gynecology. 1993;82(6):1029-35.
2. Groot C. A newly discovered procedure: 'Actio Caesarea' (Een nieuw ontdekte procedure: 'Actio Caesarea'). Dutch Lawyers Magazine (Nederlandse Juristenblad). 2015:1656-7.
3. Davenport EP. Court Ordered Cesarean Sections: Why Courts Should Not Be Allowed to Use a Balancing Test. Duke J Gender L & Pol'y. 2010;18:79.
4. Rawls J. A Theory of Justice. Mass: Harvard University. 1971.
5. Beauchamp TL, Childress JF. Principles of biomedical ethics: Oxford University Press, USA; 2001.
6. Draper H. Women, forced caesareans and antenatal responsibilities. Journal of Medical Ethics. 1996;22(6):327-33.
7. Annas GJ. Law and the life sciences: forced cesareans: the most unkindest cut of all. Hastings center report. 1982:16-45.
8. Paltrow LM, Flavin J. Arrests of and forced interventions on pregnant women in the United States, 1973–2005: Implications for women's legal status and public health. Journal of Health Politics, Policy and Law. 2013:1966324.
9. Charles S. Obstetricians and violence against women. The American Journal of Bioethics. 2011;11(12):51-6.
10. Rhoden NK. The judge in the delivery room: the emergence of court-ordered cesareans. California Law Review. 1986;74(6):1951-2030.
11. Morris T, Robinson JH. Forced and Coerced Cesarean Sections in the United States. Contexts. 2017;16(2):24-9.
12. Faden RR, Beauchamp TL. A history and theory of informed consent: Oxford University Press; 1986.
13. St George's Healthcare N. Trust v. R v Collins and other ex parte S [1998] FLR. 1998;728.
14. Diaz-Tello F. Invisible wounds: obstetric violence in the United States. Reproductive health matters. 2016;24(47):56-64.
15. Gallagher J. Prenatal Invasions & Interventions: What's Wrong with Fetal Rights. Harv Women's LJ. 1987;10:9.
16. Minkoff H, Paltrow LM. Melissa Rowland and the rights of pregnant women. Obstetrics & Gynecology. 2004;104(6):1234-6.
17. Annas GJ. Protecting the liberty of pregnant patients. New England Journal of Medicine. 1987;316(19):1213-4.
18. Cherry AL. Detention, Confinement, and Incarceration of Pregnant Women for the Benefit of Fetal Health, The. Colum J Gender & L. 2007;16:147.
19. Samuels T-A, Minkoff H, Feldman J, Awonuga A, Wilson TE. Obstetricians, health attorneys, and court-ordered cesarean sections. Women's health issues. 2007;17(2):107-14.
20. Chervenak FA, McCullough LB. Justified limits on refusing intervention. Hastings Center Report. 1991;21(2):12-8.
21. Arras JD. The way we reason now: reflective equilibrium in bioethics. 2007.

22. Beauchamp TL, Childress JF. Principles of biomedical ethics: Oxford University Press,; 1983.
23. McFall v Shimp, 10 Pa. D. & C.3d 90 1978.
24. In re A.C. 573 A2d: United States Court of Appeals for the District of Columbia Circuit; 1990.
25. Thornton TE, Paltrow L. The rights of pregnant patients: Carder case brings bold policy initiatives. Healthspan. 1991;8(5):10.
26. Minkoff H, Lyerly AD. Samantha Burton and the Rights of Pregnant Women Twenty Years after" In re AC". The Hastings Center Report. 2010;40(6):13-5.
27. Control of Communicable Diseases, (2017).
28. Walmsley E. mama Mia! Serious Shortcomings With Another '(en) Forced'Caesarean Section Case re Aa [2012] Ewhc 4378 (cop). Medical law review. 2014;23(1):135-43.
29. Re AA [2012] EWHC 4378 (COP), (2012).
30. Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. New England Journal of Medicine. 1988;319(25):1635-8.
31. Den Hartogh G. Do we need a threshold conception of competence? Medicine, Health Care and Philosophy. 2016;19(1):71-83.

PART 2

SOCIETAL RESPONSIBILITIES

6

MEETING REPORT: ETHICAL ISSUES SURROUNDING PRECONCEPTION CARE

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MEETING REPORT: ETHICAL ISSUES SURROUNDING PRECONCEPTION CARE *SUBMITTED*

Abstract

Background: Embryonic and fetal development are key determinants for pregnancy outcomes and life-long health. Preconception care aims to identify, manage and counteract risk factors to prevent or limit the impediment of this development. Moreover, it provides an excellent opportunity to improve couples informed decision-making by providing information on reproductive choices. Unfortunately, in most countries the uptake of PCC remains low. Moreover, it is usually provided infrequently and on an opportunistic basis.

Objective: In response to the high prevalence of adverse pregnancy outcomes, especially among vulnerable women, and the poor uptake of PCC, an international and interdisciplinary expert meeting was organized in October 2016. The objective was to (i) discuss the key barriers in the provision, uptake and implementation of preconception care, (ii) to explore the gaps in current research and (iii) to explore the potential of new scientific insights to further improve pregnancy outcomes.

Results: This report presents the most important outcomes of this meeting. These include the provision of tailor-made care; the definition and distribution of roles and responsibilities of caregivers; the inclusion of fertility counseling in preconception care and the development of pathways that cut across the medical and non-medical domains.

Keywords: preconception care, ethics, expert meeting, responsibility, inequity, epigenetics, fertility counseling, nudging

Introduction

Embryonic and fetal development are key determinants for pregnancy outcomes and life-long health.(1-3) Preconception care (PCC) aims to identify, manage and counteract risk factors to prevent the impediment of this development and it aims to improve couples informed decision-making by providing information on reproductive choices.(4) Especially vulnerable women living in deprived circumstances face higher risks to have adverse pregnancy outcomes due to an accumulation of risk factors.(5) There is compelling evidence for the effectiveness of a list of PCC interventions such as folic acid supplementation, smoking cessation and dietary improvement.(6) Given that the risks of adverse pregnancy outcomes can be reduced, the empowerment of mothers-to-be to adequately prepare for pregnancy by offering them PCC is a medical and a moral imperative.

Unfortunately, in most countries the uptake of PCC remains low and it is usually provided infrequently and on an opportunistic basis.(7) In response to the unnecessary high prevalence of adverse pregnancy outcomes especially among vulnerable women, and the poor uptake of PCC, an international and interdisciplinary expert meeting was organized in October 2016. The aim was to (i) discuss the key barriers in the provision, uptake and implementation of PCC, (ii) to explore the gaps in current research and (iii) to explore the potential of new scientific insights to improve pregnancy outcomes. This report presents the most important outcomes of this meeting.

Method

The expert panel of 11 members consisted of clinicians, clinical researchers, medical ethicists, and a representative of a patient- federation (an alliance of 70 patient organizations). The discussion was structured around the following topics: (1) 'The concept of PCC and the role of caregivers' (2) 'reaching those who need care the most' (3) 'societal valorization of new knowledge' and (4) 'translating behavioral insights into PCC'. Each topic was introduced by a member of the expert panel. The subsequent discussions were guided by a list of questions and statements (Table 1). The results of this meeting are presented in the form of four recommendations. All panel members participated in reviewing and providing suggestions related to the content of the manuscript.

Recommendations

1. Reach consensus about the organization of PCC

a. Appoint a PCC-provider responsible for the uptake

Although there is consensus about the content of PCC (4, 8), a uniform strategy about the best ways to maximize the uptake of PCC is largely lacking.(7) This is mainly due to the poor organization of PCC, in which it is unclear who should develop, offer, provide, and fund PCC interventions. According to the expert panel, the poor uptake of PCC can in part be improved by appointing an easily identifiable PCC-provider, who acts as a case manager, responsible for the first contact for entry into PCC. Preferably, this contact should be someone who is easily approachable for parents-to-be, which in many cases is the general practitioner or public health nurse.

b. Provide tailor-made care

A major problem in improving the uptake in PCC, is that those who could benefit most from entering PCC are often unaware of PCC or do not consider themselves as the target public.(9, 10). Barrett et al. reported that different PCC approaches are needed for different groups of women with differing investments in pre-pregnancy health and care.(11) Building on these findings, clinical experts mentioned that it is necessary to consider that parents-to-be are mainly interested in their own personal risks and possible benefits rather than the entire package of PCC aims. For example, patients who were interested in identifying their personal genetic risk, were generally not interested in a general preconception consultation. The need for tailor-made care including personal risk identification and a clear presentation of possible health benefits is thus not only necessary for adequate PCC delivery but also for an improved uptake of PCC. Digital assessment tools such as 'Gabby' (12, 13), the mHealth coaching tool Smarter Pregnancy, (14) and the preconception risk assessment tool 'Preparing for Pregnancy' (15) may prove to benefit the uptake of PCC as they are easily accessible, generate personal risk assessments and provide tailor-made information and advice explaining why the identified risks are a potential problem and how the user can minimize these risks.

c. Define and distribute the roles and responsibilities of caregivers

In accordance with existing research, the panel was in agreement on the fact that PCC encompasses medical and non-medical domains such as gynecology and obstetrics, general medicine, reproductive health, pharmacy, public health, social services and personal lifestyle.(16) Whereas the preconception consultation and the delivery of health care clearly belong to the medical domain, the duty to provide preconception

information and the improvement the socioeconomic determinants of adverse pregnancy outcomes cuts across the medical and non-medical domains. In accordance with existing literature, a shared care model, an approach to care that includes the skills and knowledge of a range of professionals such as pregnancy related healthcare professionals, policy makers, social peer group networks and community social workers, has been proposed to secure the involvement of all relevant stakeholders and ameliorate the fair distribution of the responsibility to improve pregnancy outcomes.(17)

Members of the panel mentioned that the lack of a shared care model sometimes results in the untimely referral of patients to specialist care. For example and in line with existing research(10) they experience that some caregivers tend to treat patients too long and consequently misestimate the appropriate moment of referral. Members mentioned that caregivers tend to only deliver the care relevant to their domain, thereby overlooking other possible risks to pregnancy. For example, not all oncologists mention the possibility of egg freezing to women who will likely lose their fertility after treatment. Likewise, teratogenic medication is too often prescribed to women who might become pregnant without informing them about the reproductive risks. These examples reinforce the need for a shared care model.

2. Reach those who need care the most

a. Include fertility counseling in PCC

Most members mentioned that parents-to-be are highly motivated to explore issues related to fertility during the period before pregnancy. One clinical expert mentioned that discussing fertility as part of PCC, would offer an opportunity to engage men as well. Van der Zee et al. and Tuomainen et al. also report that fertility is an important subject for women with a desire to become pregnant.(18, 19) The gains of fertility care –achieving pregnancy or not– are moreover clear and visible, whereas the gains of PCC that deals with prevention are less clear to parents-to-be and perhaps also less clear to caregivers. Therefore, including fertility counseling in PCC may improve the uptake as couples are arguable most motivated to hear about PCC when fertility issues will also be discussed.

b. Develop pathways that cut across the medical and non-medical domain to address health inequalities

The observed inequalities in perinatal morbidity and mortality and the socioeconomic gradient which describes these inequalities raised questions of social justice and health equity.(20) One clinical expert mentioned that some women have such an accumulation of social and economic problems that they have lost self-governance and

autonomy which makes them powerless; unable to overcome their problems without help from social workers and caregivers. The member mentioned the 'Mothers of Rotterdam initiative' as an example of care that cuts across the medical and non-medical domain, not only guiding women towards the appropriate healthcare providers but also guiding women towards debt management plans, housing services, educational plans and employment agencies.(21) In short, tailor-made help is offered to vulnerable women with the aim of helping them to regain control over their lives. Although all members supported such initiatives, the question was raised about what the exact role of the health care professional should be. There was however consensus on the suggestion that PCC-providers should at least identify non-medical problems and refer women to the appropriate institutions. 'Care pathways' should be in place to facilitate these referrals to non-medical institutions.

c. Emphasize the importance of PCC and care pathways as a medical imperative and as a demand of social justice

Members also mentioned that inequalities in perinatal health outcomes deserve special attention as these are often the result of existing injustices such as poverty, racism and lack of access to high quality care for a vulnerable group of parents-to-be.(22-25) Moreover, if these inequalities remain unaddressed they perpetuate and exacerbate poor pregnancy outcomes, possibly over generations, as one's ability to escape deprivation and poor health is curbed by the very inequality one is trying to escape. Inequality begets greater inequality if left unaddressed. This makes the provision of PCC not only a medical imperative but a demand of social justice, as although PCC cannot address inequalities directly, it can mitigate the detrimental effects on pregnancy.

3. Societal valorization of new knowledge

a. Use new scientific insights to promote PCC and public health policy in general

The panel agreed on the fact that PCC could gain from new scientific insights such as those from the field of epigenetics. One clinical expert mentioned that epigenetics offered an interesting and appealing 'frame' to raise awareness about the importance of the preconception period for adequate pregnancy preparation. In addition, the effects of adverse changes to the epigenome that may result from generations of social, economic and cultural insults can insufficiently be addressed through only the delivery of PCC as a clinical form of care and require a concerted effort from other domains such as public health, education and social welfare as well.(26, 27) Therefore, it is quite possible that "the future of PCC will require an innovative multigenerational approach to health promotion for women and men to achieve optimal reproductive health outcomes." (28)

b. Include the discussion on epigenetics and social inequities in the overall strategy to counteract adverse pregnancy outcomes

Epigenetics is a new and burgeoning field that attracts a lot of attention. Careless and oversimplified interpretations of epigenetics however, suggesting that mothers are the sole responsible for the health of their children, are unwarranted. Moreover, epigenetics has the potential to open up the discussion on the social determinants of adverse pregnancy outcomes. Epigenetic insights suggest that social inequities can become biologically impinged to the detriment of the health and wellbeing of newborns. Therefore, the improvement of maternal (and paternal) and child health involves not only the provision of adequate pregnancy related care. Discussing how social injustices affect maternal and child health should become part of a comprehensive strategy to counteract adverse pregnancy outcomes.

c. Valorize new insights in the form of pregnancy-related policy and interventions

The experts mentioned that scientific researchers have a duty to valorize new scientific insights which should lead to interventions that benefit parents- and children-to-be.(29) Although caution is well advised regarding the translation of new scientific insights into policy, passivity from policy makers based on incomplete evidence is not always warranted. The dire situation of vulnerable parents-to-be in combination with reasonable scientific predictions should temper the requirement of conclusive scientific evidence before introducing pregnancy related policy.

4. Translating behavioral insights into PCC interventions

a. Explore the potential of incentives and nudges such as E-health and m-Health tools to promote PCC

Members discussed the potential of behavioral insights to increase the uptake of PCC. In addition to information and education about the benefits of an adequate pregnancy preparation, parents-to-be could also be incentivized or 'nudged' to seek PCC.(30) Nudges use people's propensity to apply heuristics and biases, which are 'mental rules of thumb', when making decisions, such as decisions about lifestyle or decisions about seeking care. Behavioral interventions such as an opt-out rather than an opt-in system for organ donation and financial rewards to quit smoking were mentioned as successful interventions, in the sense that the aim of the intervention was achieved.(31, 32)

Possibilities for PCC were discussed. For example, people tend to favor immediate small gains over future bigger gains (hyperbolic discounting). Therefore, a future gain, for example child benefits (in the Netherlands) could be paid in advance, for example when visiting a PCC consult, to increase the uptake of PCC. As people tend to make

decisions based on availability (availability bias) and people use the internet 'en masse', the possibility of incentivizing parents-to-be through E-Health and m-Health tools was also discussed. "Gabby", "Preparing For Pregnancy" and "smarter pregnancy" which are digital E-health and m-Health tools, were mentioned as successful digital tools that provide tailor-made risk assessments, health advice and can incentivize parents-to-be to seek PCC on the basis of a personal risk assessment.(12, 14, 33)

b. Ethical justification of these interventions is needed to avoid charges of paternalism, infantilization and reliance on incentives

Behavioral insights which can be used to 'nudge' parents-to-be towards PCC need to be ethically justified to prevent charges of paternalism and infantilization.(30) In addition, the problem with relying on incentives is that when the incentive disappears the effect, in this case an expected increase of uptake, may also disappear as the use of incentives does not increase the intrinsic motivation to adequately prepare for pregnancy.

Conclusion

The main recommendations of the expert panel are: the provision of tailor-made care; the definition and distribution of roles and responsibilities of caregivers; the inclusion of fertility counseling in PCC, and the development of pathways that cut across the medical and non-medical domains. Moreover, the discussion on how to promote maternal and child health should include the detrimental effects of social inequities and the potential use of incentives such as E- and mHealth tools.

References

1. van Uitert EM, Exalto N, Burton GJ, Willemsen SP, Koning AH, Eilers PH, et al. Human embryonic growth trajectories and associations with fetal growth and birthweight. Human Reproduction. 2013:det115.
2. Barker DJ, Eriksson JG, Forsén T, Osmond C. Fetal origins of adult disease: strength of effects and biological basis. International journal of epidemiology. 2002;31(6):1235-9.
3. Gluckman PD, Cutfield W, Hofman P, Hanson MA. The fetal, neonatal, and infant environments—the long-term consequences for disease risk. Early human development. 2005;81(1):51-9.
4. Temel S, van Voorst SF, de Jong-Potjer LC, Waelput AJ, Cornel MC, de Weerd SR, et al. The Dutch national summit on preconception care: a summary of definitions, evidence and recommendations. Journal of community genetics. 2015;6(1):107-15.
5. de Graaf JP, Steegers EA, Bonsel GJ. Inequalities in perinatal and maternal health. Current Opinion in Obstetrics and Gynecology. 2013;25(2):98-108.
6. Temel S, van Voorst SF, Jack BW, Denktaş S, Steegers EAP. Evidence-based preconceptional lifestyle interventions. Epidemiologic reviews. 2014;36(1):19-30.
7. Shannon GD, Alberg C, Nacul L, Pashayan N. Preconception Healthcare Delivery at a Population Level: Construction of Public Health Models of Preconception Care. Matern Child Health J. 2013.
8. Organization WH. Meeting to develop a global consensus on preconception care to reduce maternal and childhood mortality and morbidity: World Health Organization Headquarters, Geneva, 6–7 February 2012: meeting report. 2013.
9. Poels M, Koster MP, Boeije HR, Franx A, van Stel HF. Why do women not use preconception care? A systematic review on barriers and Facilitators. Obstetrical & Gynecological Survey. 2016;71(10):603-12.
10. M'hamdi HI, van Voorst SF, Pinxten W, Hilhorst MT, Steegers EA. Barriers in the Uptake and Delivery of Preconception Care: Exploring the Views of Care Providers. Maternal and Child Health Journal. 2016:1-8.
11. Barrett G, Shawe J, Howden B, Patel D, Ojukwu O, Pandya P, et al. Why do women invest in pre-pregnancy health and care? A qualitative investigation with women attending maternity services. BMC pregnancy and childbirth. 2015;15(1):236.
12. Jack B, Bickmore T, Hempstead M, Yinusa-Nyahkoon L, Sadikova E, Mitchell S, et al. Reducing preconception risks among African American women with conversational agent technology. The Journal of the American Board of Family Medicine. 2015;28(4):441-51.
13. Boston University Medical Campus Family Medicine. Meet Gabby 2015 [
14. Van Dijk MR, Huijgen NA, Willemsen SP, Laven JS, Steegers EA, Steegers-Theunissen RP. Impact of an mHealth Platform for Pregnancy on Nutrition and Lifestyle of the Reproductive Population: A Survey. JMIR mHealth and uHealth. 2016;4(2):e53.
15. Landkroon A, De Weerd S, van Vliet-Lachotzki E, Steegers E. Validation of an internet questionnaire for risk assessment in preconception care. Public Health Genomics. 2010;13(2):89-94.
16. Jack BW, Atrash H, Coonrod DV, Moos M-K, O'Donnell J, Johnson K. The clinical content of preconception care: an overview and preparation of this supplement. American journal of obstetrics and gynecology. 2008;199(6):S266-S79.

17. Denktaş S, Bonsel G, Van der Weg E, Voorham A, Torij H, De Graaf J, et al. An urban perinatal health programme of strategies to improve perinatal health. Maternal and child health journal. 2012;16(8):1553-8.

18. van der Zee B, de Beaufort ID, Steegers EA, Denktas S. Perceptions of preconception counselling among women planning a pregnancy: a qualitative study. Fam Pract. 2013;30(3):341-6.

19. Tuomainen H, Cross-Bardell L, Bhoday M, Qureshi N, Kai J. Opportunities and challenges for enhancing preconception health in primary care: qualitative study with women from ethnically diverse communities. BMJ open. 2013;3(7):e002977.

20. Braveman P. What is health equity: and how does a life-course approach take us further toward it? Maternal and child health journal. 2014;18(2):366-72.

21. Mothers of Rotterdam Program & Research Fact Sheet, [Available from: https://www.moedersvanrotterdam.nl/wp-content/uploads/Factsheet-Moeders-van-Rotterdam-ENG-nummering-def2.pdf.

22. Zhang S, Cardarelli K, Shim R, Ye J, Booker KL, Rust G. Racial disparities in economic and clinical outcomes of pregnancy among Medicaid recipients. Maternal and child health journal. 2013;17(8):1518-25.

23. Dominguez TP, Dunkel-Schetter C, Glynn LM, Hobel C, Sandman CA. Racial differences in birth outcomes: the role of general, pregnancy, and racism stress. Health psychology. 2008;27(2):194.

24. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EA. Urban perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2011;24(4):643-6.

25. de Graaf JP, Ravelli AC, de Haan MA, Steegers EA, Bonsel GJ. Living in deprived urban districts increases perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2013;26(5):473-81.

26. Wallack L, Thornburg K. Developmental origins, epigenetics, and equity: moving upstream. Maternal and child health journal. 2016;20(5):935-40.

27. Barouki R, Gluckman PD, Grandjean P, Hanson M, Heindel JJ. Developmental origins of non-communicable disease: implications for research and public health. Environmental Health. 2012;11(1):1.

28. St. Fleur M, Damus K, Jack B. The future of preconception care in the United States: multigenerational impact on reproductive outcomes. Upsala Journal of Medical Sciences. 2016;121(4):211-5.

29. Steegers EAP, Barker ME, Steegers-Theunissen RPM, Williams MA. Societal Valorisation of New Knowledge to Improve Perinatal Health: Time to Act. Paediatric and perinatal epidemiology. 2016;30(2):201-4.

30. M'hamdi HI, Hilhorst M, Steegers EA, de Beaufort I. Nudge me, help my baby: on other-regarding nudges. Journal of Medical Ethics. 2017:medethics-2016-103656.

31. Blumenthal-Barby JS, Burroughs H. Seeking better health care outcomes: the ethics of using the "nudge". Am J Bioeth. 2012;12(2):1-10.

32. Quigley M. Nudging for health: on public policy and designing choice architecture. Medical Law Review. 2013;21(4):588-621.

33. Vink-van Os LC, Birnie E, van Vliet-Lachotzki EH, Bonsel GJ, Steegers EA. Determining Pre-Conception Risk Profiles Using a National Online Self-Reported Risk Assessment: A Cross-Sectional Study. Public health genomics. 2015;18(4):204-15.

Table 1

Description sessions

Session 1 'The concept of PCC and the role of caregivers'

Introduction:	Prof Eric Steegers and Prof Inez de Beaufort on the concept of preconception care, is there consensus about what it entails and why it is an important form of care (10 min)
Perspective:	The role of caregivers and their reported barriers : Hafez Ismaili M'hamdi (10 min)
Discussion:	Chair Prof Inez de Beaufort, discussion on the basis of cases. **Case 1.** PCC, one concept, one form of care (Is there consensus about PCC and what are the barriers to achieve consensus? What are the barriers that result from a lack of consensus? Who is primarily responsible for reaching consensus? How does reaching consensus about PCC promote the goals of PCC?)
Case 2.	The proactive role of the caregiver (How to promote proactivity of caregivers? what can we reasonably expect from caregivers? How to overcome the barriers they experience, perceived lack of evidence-based interventions/ competition with other practices of preventive care? Which caregiver is the gatekeeper of PCC?) **Case 3.** Late referral to adequate caregiver (Why are parents-to-be who need specialist care referred (too) late to the specialist? Are there examples of well-organized referral to adequate caregiver in general and to the specialist in particular? What can be done to advance timely referral?) **Case 4.** What to do with non-medical risks? (Poor socio- economic circumstances are recognized as risk factors. Are caregivers sufficiently able to identify non-medical risks? What can/should a caregiver do when a non-medical risk factor is identified? Can, as it is now organized, PCC adequately address non-medical risks?) **Case 5.** No directivity, no care? (How to offer PCC to women/couples who would be well-advised to postpone their desire to become pregnant? How to offer PCC to high-risk women/couples who do not perceive any urgency? How far can a caregiver go on behalf of the unborn/ future child? Is non-directive counseling/advising of couples effective/adequate/sufficient?)

Session 2 'Reaching those who need care the most'

Introduction: Meertien Sijpkens, presentation results qualitative research on perceptions of vulnerable women with a desire to become pregnant (10 min)

Perspective: Prof Eric Steegers, why are we, despite all efforts, not succeeding at increasing the uptake of PCC? (10 min)

Discussion: Chair Medard Hilhorst, discussion on the basis of questions. **Question 1** Should pregnancy and birth be perceived as medical events by future parents and what are the advantages and disadvantages of such a perception?

Question 2 Which measures have already been taken to increase the uptake? **Question 3** Which of these measures are successful or unsuccessful? **Question 4** What is the adequate measure of PCC uptake, consultation visits/delivery of care/ maternal-parental-fetal-newborn health? **Question 5** How to deal with the discrepancy between perceived subjective health of parents-to-be and their actual objective health with respect to adequate pregnancy preparation? how do we overcome this discrepancy in a responsible and ethically justified way? **Question 6** How should we counteract pregnancy outcome inequalities? Is it justified to target higher risk groups (especially when they do not perceive themselves as high risk groups) for extra care. **Question 7** The most vulnerable future parents tend to have an accumulation of non-medical/socio- economic risk factors. How well equipped is PCC/ are caregivers to counteract these risk factors? ""*Why treat people and send them back to the conditions that made them sick?"* (M. Marmot chair of WHO social determinants of health)

Session 3 'Societal valorization of new knowledge'

Introduction: Prof Eric Steegers, presentation of new scientific knowledge (DOHaD and epigenetics) and the ways in which this can be translated into policy (10 min)

Perspective: Hafez Ismaili M'hamdi, how does new scientific knowledge influence ethical and philosophical ideas about perinatal health inequalities, parental responsibility and social justice? (10 min)

Discussion: Chair Prof Wim Pinxten, discussion on the basis of statements.

Statement 1 As long as knowledge is not translated in sound evidence based interventions, it has no use for PCC. **Statement 2** Insights from DOHaD and epigenetics show that pregnancy outcome inequalities are the result of socio economic inequalities rather than a lack of individual responsibility of parents-to-be. **Statement 3** There is a real danger that insights from DOHaD and epigenetics will be used to shift too much responsibility for a healthy pregnancy on to the mother. **Statement 4** The potential of PCC to play an important role in reducing chronic diseases which manifest in adult life is currently underused.

Session 4 'Translating behavioral insights into PCC'

Introduction: Hafez Ismaili M'hamdi, bounded rationality and other-regarding nudges (10 min)

Perspective: Professor Regine Steegers-Theunissen, presentation on the potential of E-health/m-Health (10 min)

Discussion: Chair Prof Inez de Beaufort, discussion on **Issue 1** is there reason to believe that future parents make decisions based on bounded rationality to their and their future children's detriment? **Issue 2** What types of interventions are ethically justified to counteract bounded rationality? Nudges? Directive counseling? Paternalistic policy? **Issue 3** How can e-Health/ m-Health tools promote healthy pregnancies? **Issue 4** What are the pitfalls when poor pregnancy outcomes are framed as results of bounded rationality/ is it adequate to perceive the problem of poor pregnancy outcomes as one of poor choice behavior on the part of mothers-to-be?

7

PRAY FOR THE BEST: ON PERINATAL HEALTH INEQUALITIES AND HEALTH AGENCY

HAFEZ ISMAILI M'HAMDI, ERIC A. P. STEEGERS, INEZ DE BEAUFORT.

SUBMITTED

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.

References

1. Elster J. Sour grapes: studies in the subversion of rationality. Cambridge {Cambridgeshire}. New York: Cambridge University Press; 1983.
2. Sen A. Resources, values, and development: Harvard University Press; 1997.
3. Sen A. Freedom as development. Oxford University Press, Oxford; 1999.
4. Nussbaum MC. Women and human development: The capabilities approach: Cambridge University Press; 2001.
5. Mohangoo A, Buitendijk S, Hukkelhoven C, Ravelli A, Rijninks-van Driel G, Tamminga P, et al. Higher perinatal mortality in The Netherlands than in other European countries: the Peristat-II study. Nederlands tijdschrift voor geneeskunde. 2008;152(50):2718-27.
6. Zeitlin J, Wildman K, Bréart G, Alexander S, Barros H, Blondel B, et al. PERISTAT: indicators for monitoring and evaluating perinatal health in Europe. European Journal of Public Health. 2003;13(suppl_3):29-37.
7. Zeitlin J, Mohangoo AD, Delnorn M, Alexander S, Blondel B, Bouvier-Colle MH, et al. European perinatal health report. The health and care of pregnant women and babies in Europe in 2010: Euro Peristat; 2013.
8. de Graaf JP, Ravelli AC, de Haan MA, Steegers EA, Bonsel GJ. Living in deprived urban districts increases perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2013;26(5):473-81.
9. de Graaf JP, Steegers EA, Bonsel GJ. Inequalities in perinatal and maternal health. Current Opinion in Obstetrics and Gynecology. 2013;25(2):98-108.
10. Timmermans S, Bonsel GJ, Steegers-Theunissen RPM, Mackenbach JP, Steyerberg EW, Raat H, et al. Individual accumulation of heterogeneous risks explains perinatal inequalities within deprived neighbourhoods. European journal of epidemiology. 2011;26(2):165-80.
11. M'hamdi HI, Sijpkens MK, de Beaufort ID, Rosman AN, Steegers EA. Perceptions of pregnancy preparation in women with a low to intermediate educational attainment: a qualitative study. Midwifery. 2018.
12. Hosli EJ, Elsinga J, Buitendijk SE, Assendelft WJJ, Van der Pal-de Bruin KM. Women's motives for not participating in preconception counseling: qualitative study. Public Health Genomics. 2008;11(3):166-70.
13. Poels M, Koster MP, Boeije HR, Franx A, van Stel HF. Why do women not use preconception care? A systematic review on barriers and Facilitators. Obstetrical & Gynecological Survey. 2016;71(10):603-12.
14. Wolff JaD-s. Disadvantage. New York: oxford University press; 2007.
15. Sen A. Inequality reexamined: Oxford University Press; 1992.
16. Sen A. Why health equity? Health Economics. 2002;11(8):659-66.
17. Sen A. Health: perception versus observation: Self reported morbidity has severe limitations and can be extremely misleading. BMJ: British Medical Journal. 2002;324(7342):860.
18. Nussbaum MC. Frontiers of justice: Disability, nationality, species membership: Harvard University Press; 2009.
19. Khader SJ. Adaptive preferences and women's empowerment: OUP USA; 2011.
20. Khader SJ. Must theorising about adaptive preferences deny women's agency? Journal of Applied Philosophy. 2012;29(4):302-17.

21. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EAP. Urban perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2011;24(4):643-6.
22. Weightman AL, Morgan HE, Shepherd MA, Kitcher H, Roberts C, Dunstan FD. Social inequality and infant health in the UK: systematic review and meta-analyses. BMJ open. 2012;2(3):e000964.
23. Genereux M, Auger N, Goneau M, Daniel M. Neighbourhood socioeconomic status, maternal education and adverse birth outcomes among mothers living near highways. Journal of Epidemiology & Community Health. 2008;62(8):695-700.
24. Hobel CJ, Goldstein A, Barrett ES. Psychosocial stress and pregnancy outcome. Clinical obstetrics and gynecology. 2008;51(2):333-48.
25. Shah PS, Shah J. Maternal exposure to domestic violence and pregnancy and birth outcomes: a systematic review and meta-analyses. Journal of women's health. 2010;19(11):2017-31.
26. Atrash HK, Johnson K, Adams MM, Cordero JF, Howse J. Preconception care for improving perinatal outcomes: the time to act. Maternal and child health journal. 2006;10(1):3-11.
27. Vos AA, Posthumus AG, Bonsel GJ, Steegers EA, Denktaş S. Deprived neighborhoods and adverse perinatal outcome: a systematic review and meta-analysis. Acta obstetricia et gynecologica Scandinavica. 2014;93(8):727-40.
28. Atrash H, Jack BW, Johnson K. Preconception care: a 2008 update. Current Opinion in Obstetrics and Gynecology. 2008;20(6):581-9.
29. Denktas S, Bonsel GJ, Steegers EA. [Perinatal health in Rotterdam, the Netherlands—experiences after 2 years of 'Ready for a baby']. Ned Tijdschr Geneeskd. 2012;156(29):A4289.
30. Van Der Zee B, De Beaufort I, Temel S, De Wert G, Denktas S, Steegers E. Preconception care: an essential preventive strategy to improve children's and women's health. Journal of public health policy. 2011;32(3):367-79.
31. M'hamdi HI, van Voorst SF, Pinxten W, Hilhorst MT, Steegers EA. Barriers in the uptake and delivery of preconception care: exploring the views of care providers. Maternal and child health journal. 2017;21(1):21-8.
32. Fleming T, Watkins A, Velazquez M, Mathers J, Prentice A, Stephenson J, et al. Origins of lifetime health around the time of conception: causes and consequences. The Lancet. 2018.
33. Barker D. Developmental origins of adult health and disease. Journal of epidemiology and community health. 2004;58(2):114.
34. Barker DJ. Fetal origins of coronary heart disease. BMJ: British Medical Journal. 1995;311(6998):171.
35. Barker DJ, Eriksson JG, Forsén T, Osmond C. Fetal origins of adult disease: strength of effects and biological basis. International journal of epidemiology. 2002;31(6):1235-9.
36. Gillman MW. Developmental origins of health and disease. The New England journal of medicine. 2005;353(17):1848.
37. Godfrey K. The'developmental origins' hypothesis: Epidemiology. 2006.
38. Godfrey KM, Gluckman PD, Hanson MA. Developmental origins of metabolic disease: life course and intergenerational perspectives. Trends in Endocrinology & Metabolism. 2010;21(4):199-205.

39. Hanson M, Godfrey KM, Lillycrop KA, Burdge GC, Gluckman PD. Developmental plasticity and developmental origins of non-communicable disease: theoretical considerations and epigenetic mechanisms. Progress in biophysics and molecular biology. 2011;106(1):272-80.
40. Holliday R. Epigenetics: a historical overview. Epigenetics. 2006;1(2):76-80.
41. Zeisel SH. Epigenetic mechanisms for nutrition determinants of later health outcomes. The American journal of clinical nutrition. 2009;89(5):1488S-93S.
42. Gluckman PD, Hanson MA, Cooper C, Thornburg KL. Effect of in utero and early-life conditions on adult health and disease. New England Journal of Medicine. 2008;359(1):61-73.
43. Liu X, Chen Q, Tsai HJ, Wang G, Hong X, Zhou Y, et al. Maternal preconception body mass index and offspring cord blood DNA methylation: exploration of early life origins of disease. Environmental and molecular mutagenesis. 2014;55(3):223-30.
44. Steegers-Theunissen RP, Obermann-Borst SA, Kremer D, Lindemans J, Siebel C, Steegers EA, et al. Periconceptional maternal folic acid use of 400 μg per day is related to increased methylation of the IGF2 gene in the very young child. PloS one. 2009;4(11):e7845.
45. Ober C, Vercelli D. Gene–environment interactions in human disease: nuisance or opportunity? Trends in genetics. 2011;27(3):107-15.
46. Dolinoy DC, Jirtle RL. Environmental epigenomics in human health and disease. Environmental and molecular mutagenesis. 2008;49(1):4-8.
47. Godfrey KM, Lillycrop KA, Burdge GC, Gluckman PD, Hanson MA. Epigenetic mechanisms and the mismatch concept of the developmental origins of health and disease. Pediatric Research. 2007;61:5R-10R.
48. Messer LC, Boone-Heinonen J, Mponwane L, Wallack L, Thornburg KL. Developmental programming: priming disease susceptibility for subsequent generations. Current epidemiology reports. 2015;2(1):37-51.
49. López-Jaramillo P, Silva SY, Rodríguez-Salamanca N, Duran A, Mosquera W, Castillo V. Are nutrition-induced epigenetic changes the link between socioeconomic pathology and cardiovascular diseases? American journal of therapeutics. 2008;15(4):362-72.
50. Tehranifar P, Wu H-C, Fan X, Flom JD, Ferris JS, Cho YH, et al. Early life socioeconomic factors and genomic DNA methylation in mid-life. Epigenetics. 2013;8(1):23-7.
51. Steegers EAP, Barker ME, Steegers-Theunissen RPM, Williams MA. Societal Valorisation of New Knowledge to Improve Perinatal Health: Time to Act. Paediatric and perinatal epidemiology. 2016;30(2):201-4.
52. M'hamdi HI, de Beaufort I, Jack B, Steegers E. Responsibility in the age of Developmental Origins of Health and Disease (DOHaD) and epigenetics. Journal of developmental origins of health and disease. 2018;9(1):58-62.
53. Barouki R, Gluckman PD, Grandjean P, Hanson M, Heindel JJ. Developmental origins of non-communicable disease: implications for research and public health. Environmental Health. 2012;11(1):42.
54. Rozek LS, Dolinoy DC, Sartor MA, Omenn GS. Epigenetics: relevance and implications for public health. Annual review of public health. 2014;35:105-22.
55. Burdge GC, Lillycrop KA. Bridging the gap between epigenetics research and nutritional public health interventions. Genome medicine. 2010;2(11):80.
56. Loi M, Del Savio L, Stupka E. Social epigenetics and equality of opportunity. Public health ethics. 2013;6(2):142-53.

57. Meloni M. Epigenetics for the social sciences: justice, embodiment, and inheritance in the postgenomic age. New Genetics and Society. 2015;34(2):125-51.
58. Rothstein MA, Cai Y, Marchant GE. Ethical implications of epigenetics research. Nature Reviews Genetics. 2009;10(4):224.
59. Shawe J, Delbaere I, Ekstrand M, Hegaard HK, Larsson M, Mastroiacovo P, et al. Preconception care policy, guidelines, recommendations and services across six European countries: Belgium (Flanders), Denmark, Italy, the Netherlands, Sweden and the United Kingdom. The European Journal of Contraception & Reproductive Health Care. 2015;20(2):77-87.
60. van Voorst SF, Vos AA, de Jong-Potjer LC, Waelput AJM, Steegers EAP, Denktas S. Effectiveness of general preconception care accompanied by a recruitment approach: protocol of a community-based cohort study (the Healthy Pregnancy 4 All study). BMJ open. 2015;5(3):e006284.
61. Temel S, van Voorst SF, Jack BW, Denktaş S, Steegers EAP. Evidence-based preconceptional lifestyle interventions. Epidemiologic reviews. 2014;36(1):19-30.
62. Huang JY, King NB. Epigenetics Changes Nothing: What a New Scientific Field Does and Does Not Mean for Ethics and Social Justice. Public Health Ethics. 2017.
63. Hare RM, Sen A, Williams B. Ethical theory and utilitarianism1982.
64. Rawls J. A Theory of Justice. Mass: Harvard University. 1971.
65. Nozick R. State, anarchy, and utopia. Malden, Mass: Basic Books. 1974.
66. Kivimäki M, Leino-Arjas P, Luukkonen R, Riihimäi H, Vahtera J, Kirjonen J. Work stress and risk of cardiovascular mortality: prospective cohort study of industrial employees. Bmj. 2002;325(7369):857.
67. Lobel M, Cannella DL, Graham JE, DeVincent C, Schneider J, Meyer BA. Pregnancy-specific stress, prenatal health behaviors, and birth outcomes. Health Psychology. 2008;27(5):604.
68. Su Q, Zhang H, Zhang Y, Zhang H, Ding D, Zeng J, et al. Maternal stress in gestation: birth outcomes and stress-related hormone response of the neonates. Pediatrics & Neonatology. 2015;56(6):376-81.
69. Timmermans S, Bonsel GJ, Steegers-Theunissen RP, Mackenbach JP, Steyerberg EW, Raat H, et al. Individual accumulation of heterogeneous risks explains perinatal inequalities within deprived neighbourhoods. European Journal of Epidemiology. 2011;26(2):165-80.
70. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EA. Urban perinatal health inequalities. The Journal of Maternal-Fetal & Neonatal Medicine. 2011;24(4):643-6.
71. Garcia-Subirats I, Pérez G, Rodríguez-Sanz M, Muñoz DR, Salvador J. Neighborhood inequalities in adverse pregnancy outcomes in an urban setting in Spain: a multilevel approach. Journal of Urban Health. 2012;89(3):447-63.
72. Luo Z-C, Wilkins R, Kramer MS. Effect of neighbourhood income and maternal education on birth outcomes: a population-based study. Canadian Medical Association Journal. 2006;174(10):1415-20.
73. Robeyns I. The Capability Approach: a theoretical survey. Journal of Human Development. 2005;6(1):93-117.
74. The Capability approach [Internet]. Edward N. Zalta (ed.),. (Summer 2011 Edition). Available from: URL = <http://plato.stanford.edu/archives/sum2011/entries/capability-approach/>. .
75. Sen A. Well-being, agency and freedom the Dewey lectures 1984. Justice and the Capabilities Approach: Routledge; 2017. p. 3-55.

76. Ruger JP. Rethinking equal access: agency, quality, and norms. Global Public Health. 2007;2(1):78-96.

77. Abel T, Frohlich KL. Capitals and capabilities: Linking structure and agency to reduce health inequalities. Social science & medicine. 2012;74(2):236-44.

78. Lefcourt HM. Locus of control: Academic Press; 1991.

79. Wallston BS, Wallston KA, Kaplan GD, Maides SA. Development and validation of the health locus of control (HLC) scale. Journal of consulting and clinical psychology. 1976;44(4):580.

80. Cobb-Clark DA, Kassenboehmer SC, Schurer S. Healthy habits: The connection between diet, exercise, and locus of control. Journal of Economic Behavior & Organization. 2014;98:1-28.

81. Wallerstein N. Powerlessness, empowerment, and health: implications for health promotion programs. American journal of health promotion. 1992;6(3):197-205.

82. Tengland P-A. Behavior change or empowerment: on the ethics of health-promotion goals. Health Care Analysis. 2016;24(1):24-46.

83. Hanson M, Barker M, Dodd JM, Kumanyika S, Norris S, Steegers E, et al. Interventions to prevent maternal obesity before conception, during pregnancy, and post partum. The Lancet Diabetes & Endocrinology. 2017;5(1):65-76.

84. Naik AD, Dyer CB, Kunik ME, McCullough LB. Patient autonomy for the management of chronic conditions: a two-component re-conceptualization. The American Journal of Bioethics. 2009;9(2):23-30.

85. Hurka T. Perfectionism: Oxford University Press on Demand; 1996.

86. Rawls J. Political liberalism: Columbia University Press; 2005.

87. Sen A. The idea of justice: Harvard University Press; 2011.

88. Mazza D, Chapman A, Michie S. Barriers to the implementation of preconception care guidelines as perceived by general practitioners: a qualitative study. BMC health services research. 2013;13(1):1.

89. Lia-Hoagberg B, Rode P, Skovholt CJ, Oberg CN, Berg C, Mullett S, et al. Barriers and motivators to prenatal care among low-income women. Social Science & Medicine. 1990;30(4):487-94.

8

RESPONSIBILITY IN THE AGE OF DOHAD AND EPIGENETICS

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RESPONSIBILITY IN THE AGE OF DEVELOPMENTAL ORIGINS OF HEALTH AND DISEASE (DOHAD) AND EPIGENETICS. *JOURNAL OF DEVELOPMENTAL ORIGINS OF HEALTH AND DISEASE, 9*(1), 58-6

Abstract

Insights from the Developmental Origins of Health and Disease paradigm and epigenetics are elucidating the biological pathways through which social and environmental signals affect human health. These insights prompt a serious debate about how the structure of society affects health and what the responsibility of society is to counteract health inequalities. Unfortunately, oversimplified interpretations of insights from Developmental Origins of Health and Disease and epigenetics may be (mis)used to focus on the importance of individual responsibility for health rather than the social responsibility for health. In order to advance the debate on responsibility for health, we present an ethical framework to determine the social responsibility to counteract health inequalities. This is particularly important in a time where individual responsibility often justifies a passive response from policymakers.

Keywords*: responsibility, DOHaD, epigenetics, ethics, justice*

Introduction

Insights from the Developmental Origins of Health and Disease (DOHaD) paradigm and epigenetics are elucidating the biological pathways through which social and environmental cues affect human health. These insights do not only advance biological and medical knowledge. They also lay bare the biological effects of social inequities on the health and well-being of individuals, therefore raising serious ethical concerns.

In this article we present these ethical concerns. Insights from DOHaD and epigenetics describe how social deprivation and poverty become biologically impinged.[1] Adverse fetal and childhood exposures such as poor environmental quality, stress, smoking, drinking and poor nutrition all of which are typically associated with life in an underprivileged environment, leave developmental and epigenetic traces on the developing fetus. Together, these socio-biological traces not only maintain but also exacerbate the effects of social deprivation, thereby propagating the persistence of health disparities, from early life to adulthood.[2] Moreover, "there is a strong rationale to consider developmental and epigenetic mechanisms as links between early life environmental factors like maternal stress during pregnancy and adult race-based health disparities in diseases like hypertension, diabetes, stroke, and coronary heart disease."[3] These adverse factors have durable and even transgenerational influences thereby propagating existing race-based health inequalities.[3]

Despite this knowledge about the possible social and racial underpinnings of health inequalities, health is increasingly being described and presented as a matter of individual responsibility; thereby suggesting that one's health mirrors one's efforts to be healthy. This view on health encourages a passive response from policy makers. We warn against this oversimplified view on individual responsibility for health which may be reinforced by an oversimplified interpretation of new developmental insights. We will present a basic ethical framework to help determine the responsibility for health which takes serious the insights of DOHaD and epigenetics. We will argue that the concepts *avoidability* and *fairness* are of critical importance for the proper assessment of responsibility. Building on the work of political philosopher John Rawls we will present a philosophical distinction between individual responsibility and social responsibility which follows from the Rawlsian principles of justice. We will focus especially on the responsibility for the health and well-being of *parents-to-be* and *newborns* as the effects of inequality have a significant and long-lasting impact on the groups. We conclude by presenting two initiatives that empower mothers-to-be to take responsibility for their own and their (future) children's health.

Responsibility

A deep rooted moral intuition is that one has to accept (some) responsibility for one's actions. Incentives encouraging healthy behavior, penalties for unhealthy behavior, taxing of unhealthy products,

variable health insurance premiums and the prioritizing of organs based on accountability are examples of how this moral intuition about individual responsibility is manifested in healthcare and public health policy. Insights from DOHaD and epigenetics can be used to strengthen this view of responsibility. These insights describe the possible long-term detrimental effects of poor maternal lifestyle choices such as smoking, drinking alcohol, having a poor diet and having a sedentary lifestyle, on the development and health of the newborn. Therefore, mothers(-to-be) have a serious and robust responsibility towards their (future) children to promote their health through healthy choice-behavior, or so the argument goes. This view is seen in multiple headlines in the popular press stating: "'Mother's diet during pregnancy alters baby's DNA' (BBC), 'Grandma's Experiences Leave a Mark on Your Genes' (Discover), and 'Pregnant 9/11 survivors transmitted trauma to their children'" (The Guardian)[4]

This emphasis on individual responsibility for health presents serious concerns. First, colloquial and careless interpretations of DOHaD and epigenetic insights are at risk of unfairly targeting mothers as being primarily responsible for the health of their children.[4] For example, although it is true that a mother's nutrition influences the development of her fetus, insights from DOHaD and epigenetics do not suggest a mono-causal pathway from a mother's dinner to a newborn's disease. Fetal development and epigenetic programming are both complex processes, steered by a myriad of endogenous and exogenous factors such as nutrition, hormones and environmental toxins that *together* affect the risk of disease development. The translations of these new scientific insights for a lay audience will require some simplification. However, the complex and multifactorial nature of disease development is itself an important insight that should not be compromised for the sake of clarity. If anything, the complexity of disease aetiology shows that the exact causes of, for example, chronic diseases are hard to establish. To oversimplify this complexity for the sake of clarity is to alter the insights of DOHaD. The tendency to *solely* focus on mothers as irresponsible subjects, blameworthy for the poor health of their offspring, is thus unwarranted

This focus on individual responsibility also draws attention away from an arguably more important question. As one's social and environmental conditions have deep and pervasive effects on one's health, what responsibility does society have vis-à-vis

individuals living in that society? In the next sections we will clarify this question and aim to answer it by presenting a basic ethical framework.

From insights to avoidability

DOHaD research describes how the environmental factors before conception up to the first two years after birth affects fetal development and consequently both *child* and *adult* health.[5] Epigenetic research describes how social and environmental cues affect the way genes are expressed and thereby how susceptibility for disease is to a certain extent 'programmed under one's skin.'[6] These biological insights corroborate decades of epidemiological research where a stable association has been observed between people's social conditions and their health.[7] This association, which is widely known as the social determinants of health, is observable both in perinatal and adult health inequalities.

Understanding the developmental sources of poor health outcomes alone however, does not make them avoidable. Avoidability depends on the possibility to mitigate the effects of detrimental sources on health. In other words, fascinating as they are, insights from DOHaD and epigenetics are of little help to the promotion of child and adult health if they are not used as the scientific base for the development and evaluation of actual pregnancy related interventions. This gives rise to the academic responsibility to determine the degree of avoidability (figure 1). That is, given that (i) perinatal and adult health inequalities present a serious healthcare and public health challenge and (ii) the responsibility to avoid these poor health outcomes hinges on their degree of avoidability, there is an academic responsibility to determine the avoidability of these poor health outcomes.

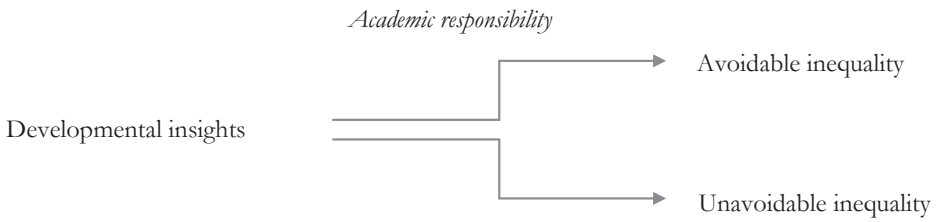

Figure 1

There are good reasons to believe that addressing developmental risk factors during the period surrounding pregnancy increases the avoidability of poor pregnancy outcomes and many chronic diseases that manifest in adult life. Insights from DOHaD and

epigenetics indicate that the risk of these diseases is set during fetal development.[6] Therefore, a shift towards preventive measures which focus on the mother-child pair during the periconceptional period has been called for.[8] "Measures which improve nutrition, and reduce exposures to environmental chemicals, from all environmental compartments (air, water, soil) and in food and consumer products, are likely to improve child and maternal health significantly over the short term, as well as reduce disease incidence and the cost of health care overall…"[8] Illustrative of the academic responsibility to determine the degree of avoidability of poor health outcomes is the 'Healthy Pregnancy 4 All' study. The 'Healthy Pregnancy 4 All' study, combines insights from public health and epidemiological research to ameliorate the offering of adequate preconception and antenatal care, thereby determining the avoidability of the relatively high prevalence of poor pregnancy outcomes in the Netherlands.[9]

Avoidability and fairness

Determining the avoidability of a health inequality alone is not sufficient to determine the social responsibility to counteract this inequality. The degree to which avoidable inequalities are *unfair* also determines the moral urgency, that is the responsibility, to counteract this inequality. Michael Marmot , chair of the WHO commission on social determinants of health writes "Health inequalities that could be avoided by reasonable means are unfair"[10].To claim that a health inequality is unfair is to say that the inequality is the result of morally arbitrary factors. That is, if we agree that morally arbitrary factors such as race and socioeconomic background should not increase the risk of disease but developmental insights provide evidence that they do, then the resulting health inequalities are unfair (figure 2).

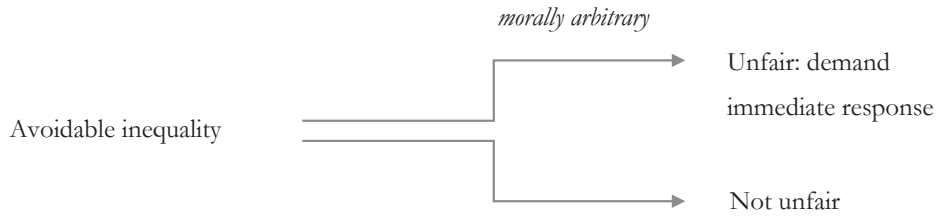

Figure 2

To appeal to fairness is, as philosopher Thomas Nagel states, "*to claim priority over other values. [Unfairness] is not just another cost; it is something that must be avoided, if not at all costs, then at any rate without counting the costs too carefully*"[11] Unfair health inequalities have the highest priority to be mitigated, the corollary being that a passive response to

this inequality is morally indefensible. This raises the question: ' to which extent are perinatal and adult health inequalities unfair?' or, more precisely, 'which factors that result in avoidable inequalities are morally arbitrary?' Factors like race and socioeconomic background are obviously morally arbitrary; they ought not to matter. However, cigarette smoking, drinking alcohol, the use of drugs, having an unhealthy lifestyle and not seeking free and high-quality care in the period surrounding pregnancy are *prima facie* not morally arbitrary. That is, people can be held, to some extent, responsible.

For example, in Rotterdam inequality in perinatal mortality, "as tip of the iceberg of perinatal morbidity"[12] in neighborhoods ranges between 2 and 34 per 1000 births.[13] Women with a low socioeconomic status and with a non-Western background face the highest risk for poor pregnancy outcomes. On the other hand however, the Netherlands offers free and high quality pregnancy related care. One might ask "to what extent are these perinatal health inequalities unfair and to what extent are they a matter of parental responsibility –given that pregnancy related care is in place. The resolution of this moral dilemma requires the assessment of both the scientific component (the degree of avoidability) and of the ethical component (the degree of unfairness) as shown in figure 3.

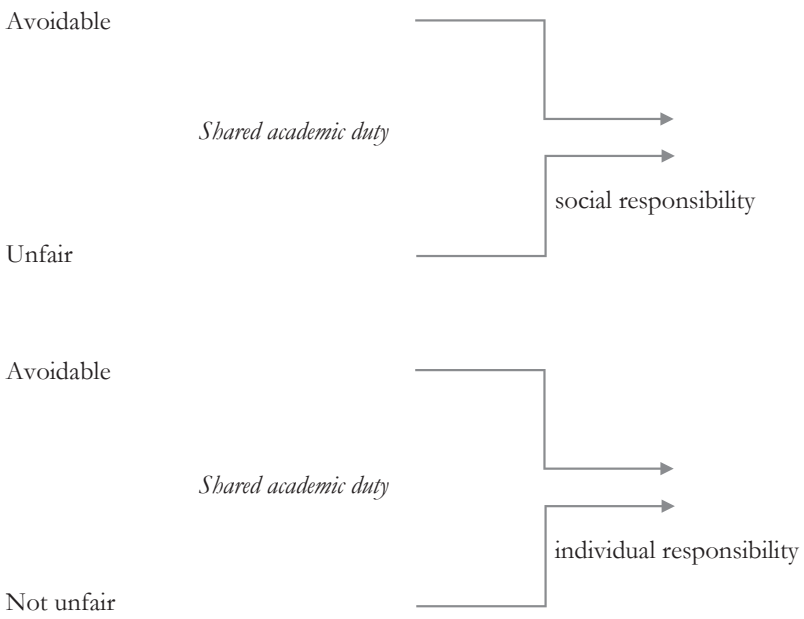

Figure 3

The pivotal question to determine responsibility is 'when exactly are inequalities unfair?' In answering this question, John Rawls's philosophical ideas about 'justice as fairness' and insights from DOHaD and epigenetics come together

Justice as fairness

In his book 'A theory of justice' John Rawls aims to identify and describe 'the principles of justice' which are the principles upon which a just society should be based upon. In his search for these principles Rawls writes: "the principles of justice for institutions must not be confused with the principles which apply to individuals and their actions in particular circumstances. These two kinds of principles apply to different subjects and must be discussed separately."[14](p.47) Rawls ponders about whether the principles of justice should be responsive to judgements of individual conduct. Consider for instance whether the offering of pregnancy related care should be responsive to the way parents-to-be typically prepare for pregnancy. From a Rawlsian point of view, the answer is no, as the reasons to introduce pregnancy related care which are: "the principles of justice for institutions should not be confused with the principles that apply to individuals and their actions…" namely, the way they prepare for pregnancy. In other words, it is a 'category mistake' to base a policy response to health inequalities on judgments about individual responsibility for health. Rawls gives three reasons for making the category distinction between the 'principles of justice' (e.g. health care and public health policy) and the principles that apply to individuals and their conduct (e.g. individual responsibility for health).[14]

First, the principles applied to shape society, (e.g. health care and public health policy), have profound and far-reaching effects and inequalities resulting from people's initial social position are likely to be deep and pervasive.[8] Second, these principles affect the way people shape their character, desires, aims, and aspirations making them 'more' or 'less' likely to escape their initial position of poor health and destitution. Third, given the scale and complexity involved in shaping society (e.g. healthcare) it is not feasible to expect that the principles of individual conduct are adequate to counteract unjust states of affairs resulting from an unfairly shaped society. In sum, Rawls argues that the principles of justice should "secure just background conditions against which the actions of individuals and associations take place. Unless this structure is appropriately regulated and adjusted, an initially just social process will eventually cease to be just, however free and fair particular transactions may look when viewed by themselves"[15] (p.266) That is, because the ability to take individual responsibility for health depends on contingent social factors, it is mistaken not to improve these social factors (such

as health care and public health), however irresponsible one may judge individual conduct to be. Simply stated: the duty to help the marginalized communities should not depend on their conduct.

Claims about the influence of environment and social background on individuals' well-being and life prospects have since moved beyond philosophical assertions. They are now a scientific fact, corroborated by developmental insights as depicted in figure 4.

Social background →	periconceptional factors →	epigenetic marks →	phenotype →	risk of disease
Underprivileged neighborhood/ poverty/ racism	Poor maternal diet/ maternal stress/ poor working conditions	Hypo- or hypermethylation at regulatory region of gene	Altered metabolic functioning/ altered cognitive development	Low birthweight/ chronic disease risk/ cognitive impairment
Social contingent factors/ unchangeable through individual conduct (Rawls's third reason)	Morally arbitrary from the POV of the future child	Morally arbitrary factors become biologically impinged	Far reaching effects on health and well-being (Rawls's first reason)	Influence on character, desires aims and aspirations in life (Rawls's second reason)

Figure 4

Together, ethical reflection and developmental insights show that perinatal and adult health inequalities are to a significant extent the result of contingent social and environmental factors which are morally arbitrary (or even reprehensible such as racism). These health inequalities are avoidable, unfair and unsolvable solely through individual conduct and therefore demand an active response from the academic community (figures 1,2 and 3) as well as from policy makers (figure 4) as they can improve socially contingent factors such as the provision of public health and healthcare.

Discussion

In the healthcare and public health debate, individual responsibility and social responsibility tend to be erroneously pitted against one another. Taking responsibility however calls for social and environmental conditions in which individuals can be reasonably expected to make responsible health-related choices. Insights from DOHaD and epigenetics are sufficiently robust to show that more needs to be done to improve these conditions. Rather than viewing mothers(-to-be) as targets of blame, culpable for the poor health of their offspring, special attention for the conditions of the parents-to-be is required.

Here are two initiatives that depict how taking social responsibility creates the right conditions in which mothers-to-be to are empowered to take individual responsibility. The Special Supplemental Nutrition Program for Women, Infants and Children (WIC), which provides disadvantaged families with regular supplies of food essential for physical and cognitive development, has improved the quality of maternal and child nutrition, and the physical and cognitive development of children.[16] This demonstrates how a coordinated care program benefits the health of mothers and newborns. The 'Mothers for Rotterdam' initiative, in which women living in deprived neighborhoods are assisted and guided in addressing their medical and non-medical conditions, is another example.[17] Young mothers are aided through mediation in cases of evictions, supported in the acquisition of proper health insurance and assisted in finding education and employment. In this way mothers are empowered, giving them and their children a fairer chance to prevent poor health and escape their destitute situation. Michael Marmot writes:" *Why treat people and send them back to the conditions that made them sick?"*[18] This statement poignantly captures the social dimension of the health inequality problem we are facing. Some ideas ought to cut across social, cultural and political beliefs. Securing the conditions for good health and well-being of newborns, regardless of how culpable one judges parents to be, is a prominent one.

References

1. Hanson M, Godfrey KM, Lillycrop KA, Burdge GC, Gluckman PD. Developmental plasticity and developmental origins of non-communicable disease: theoretical considerations and epigenetic mechanisms. *Prog Biophys Mol Biol.* 2011;106(1):272-280.
2. Messer LC, Boone-Heinonen J, Mponwane L, Wallack L, Thornburg KL. Developmental Programming: Priming Disease Susceptibility for Subsequent Generations. *Current Epidemiology Reports.* 2015:1-15.
3. Kuzawa CW, Sweet E. Epigenetics and the embodiment of race: developmental origins of US racial disparities in cardiovascular health. *Am J Hum Biol.* 2009;21(1):2-15.
4. Richardson SS, Daniels CR, Gillman MW, et al. Society: Don't blame the mothers. *Nature.* 2014;512:131-132.
5. Barker D. Developmental origins of adult health and disease. *J Epidemiol Community Health.* 2004;58(2):114.
6. Gluckman PD, Hanson MA, Low FM. The role of developmental plasticity and epigenetics in human health. *Birth Defects Research Part C: Embryo Today: Reviews.* 2011;93(1):12-18.
7. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P. WHO European review of social determinants of health and the health divide. *The Lancet.* 2012;380(9846):1011-1029.
8. Barouki R, Gluckman PD, Grandjean P, Hanson M, Heindel JJ. Developmental origins of non-communicable disease: implications for research and public health. *Environ Health.* 2012;11(42):10.1186.
9. Denktas S, Poeran J, van Voorst SF, et al. Design and outline of the healthy pregnancy 4 all study. *BMC Pregnancy Childbirth.* 2014;14(1):253.
10. Marmot M, Bell R. Fair society, healthy lives. *Public Health.* 2012;126:S4-S10.
11. Nagel T. Justice and nature. *Oxford J Legal Stud.* 1997;17:303.
12. Steegers EAP, Barker ME, Steegers-Theunissen RPM, Williams MA. Societal Valorisation of New Knowledge to Improve Perinatal Health: Time to Act. *Paediatr Perinat Epidemiol.* 2016;30(2):201-204.
13. Poeran J, Denktas S, Birnie E, Bonsel GJ, Steegers EAP. Urban perinatal health inequalities. *The Journal of Maternal-Fetal & Neonatal Medicine.* 2011;24(4):643-646.
14. Rawls J. A Theory of Justice (Cambridge. *Mass: Harvard University.* 1971.
15. Rawls J. *Political liberalism.* Columbia University Press; 2005.
16. Jackson MI. Early childhood WIC participation, cognitive development and academic achievement. *Soc Sci Med.* 2015;126:145-153.
17. Erasmus Medical Centre Department of Obstetrics and Gynecology Bureau Frontlijn Municipality of Rotterdam. Mothers of Rotterdam. https://www.moedersvanrotterdam.nl/wp-content/uploads/Factsheet-Moeders-van-Rotterdam-ENG-nummering-def2.pdf. Accessed 6-4-2016.
18. Marmot M. *The health gap: the challenge of an unequal world.* Bloomsbury Publishing; 2015.

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GENERAL DISCUSSION

The first aim was: *to identify and describe the views parents and caregivers on the responsibility for the health of children-to-be in general and the responsibility to prepare for pregnancy in particular*

Maternal responsibility

Our study, in which we interviewed socioeconomic underprivileged mothers-to-be, has shown that this group of women does feel responsible for the health of their newborns also before birth and even before conception.(1) Most women we interviewed mentioned the timely intake of folic acid supplementation, alcohol and smoking cessation, dietary improvements and the increase of physical activity as changes they (if relevant) *should* make for the benefit of the health of their children-to-be. Although advice from caregivers such as the GP about adequate pregnancy preparation was typically welcomed, the behavioral changes as such were thought to be, ultimately, a matter of maternal responsibility. According to these women, caregivers can thus play an important supportive role in empowering women to fulfill their responsibility. This supportive role was thought to be more important as the required changes were of an increasing medical character. For example, the role of the caregiver was in the eyes of this group more important when women took medication which was possibly teratogenic or when women had an obstetric history such as a miscarriage. In these cases, cases in which medical expertise contributes significantly to an adequate pregnancy preparation, it was though that mothers-to-be and caregivers *shared* the responsibility for the health of the children-to-be.

This view on the maternal responsibility is promising as women are in principle open to pregnancy preparation for the benefit of their children-to-be. Leaving aside women who are adequately prepared for pregnancy, there are however, barriers that need to be overcome in order to go from the 'experience of responsibility' to 'actual pregnancy preparation.' For one, mothers-to-be typically feel sufficiently prepared for pregnancy.(1-3) This feeling can be caused by a combination factors such as previous experiences with pregnancy, the experiences of relatives and friends with pregnancy and the availability of online pregnancy-related information. When we consider these factors together with the general unfamiliarity with pregnancy preparation and preconception care in particular (4, 5) and the tendency of mothers-to-be to underestimate the risk factors they have for poor pregnancy outcomes(1-3, 6), the feeling of 'being prepared' is understandable. Thus, although the feeling of responsibility for the health of the newborn is present, the fulfillment of this responsibility does not necessarily require professional health care interventions, according to the women we interviewed.

It seems to me that this feeling of being prepared warrants response. First, there ought to be a response from the scientific community. We have argued(7) and I argue once more that apart from its academic aims, scientific research on pregnancy preparation has a significant societal function. This function is to raise awareness and to set the societal agenda in order to make the avoidable adverse pregnancy outcomes a prominent topic in the public discourse. Topics are not important until they are made important. Hence, the scientific community (a) carries the burden of proof to show that this feeling of preparedness is in fact a barrier to adequate pregnancy preparation and better pregnancy outcomes(1, 4) (b) has a duty translate scientific insight into actual interventions that aid women in preparing for pregnancy and lead to better pregnancy outcomes (8) and (c) has a burden of proof to show that women who receive preconception care are truly better prepared for pregnancy and have a better chance at avoiding adverse pregnancy outcomes.(9) This last consideration present a serious challenge. In our study, women who received a preconception care consultation mentioned that although they were positive about the consultation they were also already aware of most information and advice given.(1) Consider that even if this group of women was somewhat overestimating their knowledge prior to the consultation, a good topic for future research, the problem of the *perception* of a limited added-value of the preconception care consultation remains. This suggests that for an increased uptake, the delivery of preconception care has to make bigger impact on the perception of preparedness of women.

Second, pregnancy preparation as a topic should be better imbedded within the educational system in order for women (and men) to have a better notion of what it entails. It is peculiar that although many women felt relatively prepared for pregnancy our research, which is in with line other studies, suggests that most women are unfamiliar with preconception care.(1, 2, 4) This might be the result of women associating pregnancy preparation (not preconception care) for the most part with fertility(1, 3) and hence conception represents a successful pregnancy preparation. The 'cross-pollination' of knowledge about the importance of pregnancy preparation for health and the knowledge about fertility is an idea worth exploring. This entails, first, that in addition to lessons on fertility and sexual health, lessons on pregnancy preparation for the health of the mother and should be included newborn in the educational curriculum. With the appropriate knowledge in mind, women will be far better able to estimate their preparedness for pregnancy and decide on better grounds whether to seek preconception care or not. Second, fertility as a topic should be a marked feature within preconception care. This may encourage women to seek preconception care as the important topic in which they are interested –fertility– will also be discussed.

In addition to the feeling of preparedness, skepticism was also expressed about the controllability of the course of pregnancy and the health of their child-to-be. Statements such as "[w]ell as far as I know you cannot do anything about it [actual pregnancy going well], but you can help it a bit."(1) denote the utero as a 'black box' of sorts in which the 'difficult to influence' development of the child-to-be unfolds. Well-known claims such as 'my mother smoked during my pregnancy and I am just fine' reinforce this idea; in the end there is little we can do to influence let alone improve the course of pregnancy. This skepticism meshes well with the idea of the 'naturalness of pregnancy'. This idea of pregnancy as being natural, has for our discussion two relevant meanings. First, the 'naturalness of pregnancy' can refer the perceived limited controllability as just described. If pregnancy is perceived to be natural in this sense, then human interference such as preconception care will have little impact on the outcome of pregnancy. Second, the 'naturalness of pregnancy' can in addition also describe an ideal. Natural pregnancy in this sense refers to 'pregnancy with as little (medical) interference as possible' as something worth achieving. This ideal is not uncommon within the pregnancy domain as the increasing popularity of home deliveries in the Netherlands seems to suggest. Research has been done on the topic of 'medicalization' (10) in which the soundness of the 'naturalness of pregnancy as a reason not to seek care' argument has been discussed (and refuted). Yet, to my mind, important questions about the *phenomenology*[14] *of pregnancy* remain unanswered. Why is there a tendency to perceive pregnancy as something which should be shielded from medical intervention in the first place? What are the reasons for setting the 'naturalness of pregnancy' against 'medical interventions'? What is the phenomenological distinction between eating more broccoli and taking folic acid pills to prevent neural tube defects? Unless we understand the reasons and more importantly the sentiments behind the skepticism about 'the controllability of pregnancy' and the idea of the 'naturalness of pregnancy' –two sides of the same coin– studies on medicalization will most likely only resonate with academic peers. Public deliberation and research is needed to enrich the concept of naturalness in the domain of pregnancy so that the image of natural pregnancy is no longer mainly underpinned (and thus dominated) by unreflective sentiments and perceptions. To my mind, there is in essence nothing good or bad about naturalness as such.

Lastly, it is important to also mention the responsibility of the father-to-be for the health of his child(ren)-to-be. Although this responsibility is typically indirectly beneficial to the health of his child(ren)-to-be, it is nevertheless not unimportant. Lifestyle

14 Phenomenology is the study of structures of experience or consciousness as experienced from the first-person point of view. For example, what is it like to prepare for pregnancy?

changes associated with pregnancy preparation such as alcohol and smoking cessation and eating healthier are made and sustained easier when the prospective mother and father join forces in achieving these aims. What is good for the goose is good for the gander. The father-to-be can also play a supportive role when it comes to preconception care. Taking interest in pregnancy preparation, encouraging his partner to seek care and joining her during consultations are all admirable manners to fulfill his responsibility as a father-to-be.

The caregiver's responsibility

The awareness of, or better yet, the knowledge about the benefits of pregnancy preparation and preconception care in particular is an important precondition to assume responsibility for the health of children-to-be. Caregivers do typically have knowledge about the benefits of pregnancy preparation such as the importance of folic acid supplementation, yet significant knowledge gaps do exist.(5, 11) Our research confirmed and gave a more detailed account of this 'knowledge gap barrier' to the uptake of preconception care.(5) The lack of a government coordinated preconception care program in the Netherlands and the poor organization of preconception care are both detrimental to making preconception care more familiar and lead to situations in which necessary care is either delivered too late or not at all.(5) Statements such as: *" It is really important that patients are referred in time to the right caregivers which unfortunately doesn't always happen… the communication between the different disciplines of PCC* [preconception care]*seems to be fragmented which makes the provided care suboptimal and less efficient."(GP)* and *"Midwives, GP's and obstetricians have insufficient expertise about inflammatory bowel disease to provide adequate care for patients who have a desire to become pregnant. However, these patients who should be seen by me or one of my colleagues are too often not referred to us." (Gastroenterologist)* attest to the missed opportunities to deliver much needed preconception care. That is, they attest to opportunities missed by caregivers to assume and fulfill their responsibility to secure and promote the health of children-to-be.

This barrier and its possible solution was also discussed during our expert meeting. According to the expert panel, the appointment of an easily identifiable preconception care provider who acts as a case manager of sorts and thus assumes responsibility for the pregnancy preparation from the caregivers' perspective would be a good strategy worth exploring.(12) The GP or public health nurse were put forwards as possible candidates. What is more, given that preconception care encompasses both the medical and non-medical domain(13) an additional recommendation of the panel was to define and distribute the different roles and responsibilities of caregivers. A shared

care model, a model of care that includes the skills and knowledge of a range of professionals such as pregnancy related healthcare professionals, policy makers, social peer group networks and community social workers, was proposed to secure the involvement of all relevant stakeholders and improve the fair distribution of the responsibility to improve pregnancy outcomes.(12, 14)

Yet, arguably the most important barrier for caregivers to fulfill their professional responsibility towards women contemplating pregnancy and children-to-be is that mothers-to-be who would benefit the most from preconception care are the hardest to reach.(4, 5, 12) The unreachability of those who need care the most remains the bane of the preconception care professional. Especially women who have accumulated medical, obstetric, social and economic misfortunes can greatly benefit from the whole array of possible preconception care interventions; but unfortunately too few are reached to deliver this care. One way to better reach these vulnerable women who contemplate pregnancy, I assume, is by emphasizing the non-medical interventions which are available (and should to a greater extent be made available) through preconception care. A, in my view remarkable initiative that does exactly this, is the Mothers of Rotterdam project where vulnerable mothers living in deprived neighborhoods are 'taken by the hand' to address their medical problems (e.g. by making appointments for these women with the appropriate healthcare professionals and go with to the appointment if necessary) as well as their non-medical problems (e.g. by guiding these women towards debt management plans, housing services, educational plans and employment agencies)(15) To my mind, preconception care can play a more distinctive role when it goes beyond the *identification* of non-medical (and medical) risk factors and problems. To play this role, preconception care should be able to set in motion the appropriate social and economic interventions that are necessary to help women who, because of their accumulation of problems, are at risk of losing self-governance. Introducing so called 'care pathways' that facilitate necessary referrals to non-medical caregivers would be conducive to achieve this, in my view, 'fleshed-out' version of preconception care.(12) I would be more optimistic about the ability to reach vulnerable women with well-functioning care paths in place. In other words, widening the scope so that social and economic problems are included would be, in my view, an improvement of preconception care. Yet, if preconception care ventures out in the world of non-medical risks and problems it has the responsibility to respond to the risks and problems it encounters, for example by guiding women towards the help and care they needed. Pointing out problems without providing some, for vulnerable women, attainable solution would indeed be quite unhelpful.

Lastly I would like to shortly discuss the disposition of caregivers who *deliver* or *should deliver* preconception care in relation to their professional responsibility. Our research as well as other research has reported on the relatively reticent (as opposed to proactive) disposition of caregivers when it comes to pregnancy preparation and preconception care. (5, 11, 16) This ties in with the earlier mentioned views on the lack of sufficient awareness of and sufficient knowledge about preconception care as well as the unclear definition and distribution of responsibilities as expressed by caregivers. Moreover, caregivers who could deliver preconception care reported that preconception care consultations are time consuming –especially if one is unable to deliver them on a regular base– and the delivery of preconception care has to compete with the delivery of other forms of (preventive) care.(5, 11) Statements such as *"The preconception consultation is very time consuming…"(Midwife)*(5) and "*I often have to use all the time available to address the patient's medical questions, so the time to ask about the desire to have children or to discuss PCC* [preconception care] *is lacking… Because of time and resource constraints, PCC has to compete with other preventive care. That may also be a barrier." (GP*) (5) demonstrate these barriers as perceived by caregivers. The lack of a proactive disposition by caregivers regarding the offering of preconception care is thus understandable. I recommend the provision of education to equip professionals with the necessary awareness and knowledge for a proper deliver of preconception care, the organization of preconception care (preferably coordinated by the government) for it to have a less 'impromptu' character and thus to be of better quality and less time consuming and a clear distribution of the caregivers' roles and responsibilities for the offering and delivering of preconception care as ways to address these barriers.

I would moreover like to draw attention to phenomenology once more. I do think that the fact that we are dealing here with those who are not-born (yet), makes an important difference in the experience –in the phenomenology– of responsibility, harm and delivery of care. It is in our human nature to feel more committed towards the concrete and tangible rather than to the hypothetical and things of abstract nature.[15] As was also mentioned during the expert meeting, the benefits of adequate pregnancy preparation, preconception care and prevention in general are intangible, abstract and only noticeable as a statistic. The abstract nature of the benefits of prevention and preconception care in particular may be reflected in the experience of urgency caregivers (but also parents-to-be) have regarding pregnancy preparation. That is, the fact that the aim is to prevent hypothetical harm, benefiting a hypothetical child, may influence the experience of urgency and hence the commitment to offer and deliver preconception care.

15 The speculative nature of our economic system, which seems to serve abstract market-related goals rather than actual people however, seems to suggest otherwise.

Of course, this is a hypothesis from my side, but one which calls for further research. Moreover, this observation on the hypothetical nature of prevention and its effects on the experience of urgency is not meant as a reason to discard the barriers to the offering and delivery of preconception care perceived by caregivers. These are quite real and need to be addressed. It is meant to show that if we want to address the barriers caregivers experience, as we should, we should take into consideration how caregivers balance the hypothetical harms to hypothetical children against other medical and preventive interventions in which the harms and benefits are more obvious. It seems to me that the crucial difference between 'those who are more' and 'those who are less' committed to preconception care boils down the perception one has on the harms that can be prevented and the benefits that can be gained by preparing for pregnancy, that is, a difference in phenomenology.

The second aim was to: *To provide an ethical analysis of the justifiability of unreflective behavioral interventions (nudges) aimed at benefiting the health of children-to-be*

Drawing lessons from nudging

Research into the way we make choices has drawn much attention from scientists and ethicists, not least since the publication of Daniel Kahneman's 'Thinking Fast and Slow'(17) and Richard Thaler and Cass Sunstein's 'Nudge: Improving Decisions About Health, Wealth, and Happiness'(18) The central theme in behavioral research in general and these two books in particular is the question of how people make everyday choices. People typically face choices everywhere and all the time. And for life not to become overwhelmingly burdensome many choices in daily life are made quickly and without (significant) deliberation. Decisions about everyday choices such as what to eat and what to drink, how to work-out, what time to set the alarm, which road to take to the office and many more seem to effortlessly 'pop up' into our mind. Cognitive 'rules of thumb' or 'heuristics' as they are called underpin these unreflective decisions we tend to make. The tendency to stick with the default (default bias) or the overestimation of available information (availability bias) are examples of these heuristics that influence or sometimes even determine our choice behavior.

The way these heuristics play out depends on the way a choice is designed and presented. If for example, the 'choice architecture'(18) is designed in such a way that a magazine subscription is automatically renewed, the chances that one remains a paying subscriber for years are significantly increased. Thus the basic equation is, combine a heuristic with a certain choice architecture and the result is a predictable outcome.

Given that heuristics are close to impossible to change[16] and choice architectures are ubiquitous[17], the best way to arrive at this predictable outcome is by the deliberate design of the choice architecture. Choice architectures that have been designed deliberately so to steer people to a predictable outcome are what are known as 'nudges'. Or as Thaler and Sunstein define it: "A nudge, is any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives." The potential of these nudges generated great interest also from policy makers tasked with encouraging individuals to lead healthier lives.(19)

Before I move to the discussion of the possibilities of nudging for health and pregnancy preparation I want to emphasize an underappreciated insight. As mentioned already, behavioral insights shed light on people's propensity to make heuristic-based choices in everyday life. Life would be quite unbearable if we would have to reflect on every choice we make, so heuristics are in this sense '*necessary* cognitive illusions' The entrenched-ness of our mental rules of thumb provides the 'cognitive room' for the deliberation about the choices that require careful thought. With the easy choices out of the way, we can focus on the important matters at hand.

However, when our heuristics steer us towards unfavorable outcomes and we want to change the corresponding choice behavior, the entrenched-ness of these heuristics becomes painfully clear. It can be truly hard to change choice behavior that is underpinned not by deliberation, but by mental rules of thumb. Consider for example the lifestyle changes recommended for a healthy pregnancy such as dietary changes. Research has shown that there is an association between having a diet containing vegetables, fruit, whole grains and fish and having a lower risk of preterm delivery. (20) Now consider women who have a fast-food based diet. The 'choice' to eat fast-food several times a week is not very likely to be a well-thought out decision but rather a simple and convenient way to solve the problem that one has to eat.[18] Fast food is readily available and in line with the 'availability bias' therefore likely to be chosen. It is an easy heuristic-based fix to the problem of having to eat every day.

Now if we ask these women to adopt a healthier diet when they are contemplating pregnancy, we are asking them to replace an easy heuristic-based approach which requires a minimal cognitive effort with reflective approach that requires (a) a cognitive investment, e.g. making an effort to decide what to cook and how to cook it,

16 which is not to say that they cannot be resisted e.g. through deliberation about a choice
17 choices have to always be presented in one way or another
18 This is in no way meant as a moral judgment of women who regularly eat fast-food

(b) an investment in terms of time, e.g. when to go to the supermarket to buy all these healthy products and (c) a commitment to this dietary change, i.e. resisting the appeal of fast-food and sustain her change in diet. Upholding this dietary change is not impossible. But it surely is not an easy aim to achieve. More generally speaking, changing heuristic-based behavioral patterns is quite a challenge. Everyday behavior becomes entrenched in our mind and changing these patterns of behavior is though not impossible particularly hard as fast, unconscious and convenient solutions have to be replaced by solutions that require reflection and are typically more difficult to achieve. This is exactly why help in the form of nudges and mHealth tools such as 'Smarter Pregnancy', which aims to lower the threshold to preconception care and make it easier to have a healthier diet and lifestyle is being explored.(21)

We have to keep this in mind when judging mothers-to-be with regards to their pregnancy preparation.

Nudge me, help my baby

I turn now to the possibility of using nudges to make the choices conducive to a healthy pregnancy preparation easier. The possibility of using nudges to improve people's health has been discussed in the scientific and ethical literature.(19) Nudges such as: serving alcoholic and sugar sweetened drinks in smaller glasses, keeping cigarettes, lighters and ashtrays out of sight and making salad rather than fries the default side dish in a meal are all meant to make healthier choices easier.(22) So why not use nudges to make choices pertaining to a healthy preparation for pregnancy easier? My short answer would be: indeed, why not. There are to my mind no fundamental moral objections to not consider nudges for pregnancy preparation and preconception care in particular. This entails that I do not think that nudges are freedom limiting or autonomy thwarting to the extent that they are morally unjustifiable as some of the ethical literature on this topic seems to suggest.(23-25) Given the inescapable influence of any choice architecture and the fact that proper nudges never eliminate choice, that is, the 'Libertarian Paternalist' justification for nudging(26), choice, freedom and autonomy are, in my view, sufficiently safeguarded. Moreover, the goals pursued through nudging, in our case the improvement of health of children-to-be (and the mother-to-be), are innocuous and more than likely to be in line with the aims of the 'nudgee'. We may safely assume that nudging women towards healthier pregnancies is 'for their own good in their own eyes'.(27)

However, an interesting challenge presents itself when we consider the use of nudges for the benefit of the health of children-to-be. The justification of nudging as offered by Libertarian Paternalism, only applies to cases in which the benefit of the nudge is to be gained by the individual being nudged. When *I* am nudged, *my* biases are utilized so to benefit *me* according to *my* standards of what counts as a benefit. In the case of a pregnancy preparation nudge however a woman is nudged for the benefit of her child-to-be. This is not an account of paternalism but an account of beneficence; doing good for the benefit of the other. One possible response to this challenge is to point to the benefits of pregnancy preparation for the mother. Although it is true that many (though not all) ways to prepare for pregnancy are also good for the health of the mother, the justification as such is not compelling. In the end, a pregnancy preparation nudge is primarily aimed at benefitting the health of the child-to-be even if it does also benefit the mother-to-be and the primacy of this aim should be accounted for in the justification offered for that nudge.

This is why we introduced the concept of the 'other-regarding nudge', a nudge that is meant to benefit the other (even if it also benefits the individual being nudged).(27) We have argued that although Libertarian Paternalism fails as the justificatory principle, the Harm Principle and the principle of beneficence provide sufficient justification for these other-regarding nudges.(27) More specifically, other-regarding nudges that are aimed to prevent harm are justified using the Harm Principle and other-regarding nudges that are aimed to bestow some benefit or good are justified using the principle of beneficence.

An interesting discussion that, in my view, follows from the distinction between preventing harm and bestowing a good is how to morally label certain actions or omissions pertaining to pregnancy preparation. Does an informed mother-to-be who does not take preconceptional folic acid supplementation harm her child-to-be or is she only failing to bestow a good? And the same question goes for smoking, alcohol, visiting a preconception consultation and so on. This is a relevant question as harm is typically met with stronger moral disapproval than not bestowing a good. For example, there are stronger reasons to nudge women who contemplate pregnancy to quit smoking than to nudge them to visit a preconception consultation; although there are good reasons for the latter as well. It seems to me that smoking while trying to conceive is an example of a possible harm whereas not visiting a preconception care consultation is not; it is a matter of failing to bestow a good.

To my mind this is more than a philosophical puzzle. It raises the more fundamental question of what we can reasonable expect from women contemplating pregnancy.

(27) Consider the danger of construing every deviation from an optimal pregnancy preparation (whatever that may be) as a form of harm. We are then at risk of reducing mothers-to-be to 'fetal containers', instrumental vessels that are valued largely in terms of their pregnancy-related efforts and investments. (28) Consequently, the need for justification for a whole array of pregnancy-related interventions becomes minimal as the prevention of harm to others typically warrants intrusive interventions let alone nudging. Therefore, a fuller account of the responsibilities of women trying to conceive towards their children-to-be is required in which the expected benefits to the child are reasonably balanced against the burdens for the woman. To be clear, my claim here is that the justification for other-regarding nudges involves 'moral labels', i.e. the prevention of harm or the promotion of the good, that we have to apply with great care in order not to consider every deviation from a perfect pregnancy preparation as a form of harm.

I will end this section with two caveats pertaining to the use of nudges for the benefit of children-to-be. First, we have to be aware that although choices can be mediated through heuristics, poor choice behavior should not be automatically attributed to (only) some flaw of the human mind. Not every poor choice is a matter of corruptive heuristics. Adverse pregnancy outcomes are largely the result of the structure of society, living in deprived neighborhood, rather than the structure of the mind. This brings me to the second caveat. I do believe that nudges can be conducive to pregnancy preparation. However, poor pregnancy outcomes are ultimately not the result of a 'lack of rationality' but rather a lack of knowledge, education as well as a lack of medical and social support. No nudge will overcome these deficiencies. Thus in the end, nudging is, I argue, an interesting strategy to consider when it comes to supporting women to prepare for pregnancy. Nudging however, should not replace the comprehensive care and policy necessary to counteract avoidable pregnancy outcomes.

The third aim was to: *provide an ethical analysis of the justifiability of the use of force in pregnancy related care by considering the case of the justifiability of forced cesareans*

Why consider force?

In general terms, pregnancy-related research shows that the health of children-to-be is becoming less a matter of chance and more a matter of choice. Adequate preconception, prenatal and maternity care can all contribute to the reduction or prevention of avoidable adverse pregnancy outcomes thereby promoting and securing the health of children-to-be. The corollary of this increased 'controllability' of the course of preg-

nancy is that more can be done to achieve healthier pregnancies that result in the birth of healthier babies. 'More *can* be done', but does this without question imply that 'more *ought* to be done?' To some extent I would say –yes–. An increase in knowledge leads to an increase of responsibility. Now we know that many neural tube defects can be prevented by preconceptional folic acid supplementation, this knowledge gives rise to the responsibility to use supplementation before (and during the first weeks of) pregnancy. Knowledge alone however, is not enough to determine responsibility. The burdens associated with pregnancy preparation and the expected benefits to the child-to-be should also be accounted for when determining the responsibility of mothers-to-be for her child-to-be. I have discussed the question of determining responsibility of the mother-to-be in the previous section. The question I want to address here is: 'what response is justified when a mother-to-be does not fulfill her responsibility?"

Surely we should not force women into taking folic acid supplementation. This would amount to a moral outrage. Yet mothers-to-be who knowingly or even because of 'weakness-of-will' forgo the regular use of supplementation are doing wrong and perhaps even harm to their child-to-be. So what is the adequate response to this wrongdoing and doing harm? A provisional answer would be that the more harm to the child-to-be can be prevented, the more intrusive the intervention can be that prevents this harm. So for example, the soft steering character of a pregnancy preparation nudge is justified by the hypothetical harms it aim to prevent.(27)[19] But is the use of force then justified if acute and life-threatening harm for the child-to-be can be prevented? For the case of pregnancy preparation, this question comes too early; no acute and life threatening harm can be prevented. The risks of harm can be reduced, that much is clear. But the risk of harm is different from actual harm and it is the latter I wish to discuss. Does the prevention of inevitable acute and life-threatening harm justify the use of force against women? To my mind the best way to answer this question is by looking to cases in which this question actually arises. One such case is the that of the forced cesarean. Is it morally justifiable to force a pregnant woman to submit to cesarean surgery, if she does not consent to a medically indicated cesarean, necessary to save her fetus in distress? The line of argumentation used to answer this question provides, so I believe, valuable insights in the moral permissibility of force in pregnancy-related care in general.

19 or hypothetical goods they aim to bestow

Forced cesarean

In the discussion on the 'cesarean dilemma'[20] proponents and opponents typically do agree on the interests at stake, the respect for autonomy of pregnant women on the one hand and the duty to save the life of the unborn on the other, yet they disagree on the moral weight that should be attached to these interests. We have argued that given this disagreement on the 'weight' the weighing of benefits and burdens is unlikely to succeed as a strategy to overcome this dilemma.(29) As an alternative we proposed to test the considered judgments of the professionals in the medical domain against the norms and values these professionals –by virtue of being professionals– are committed for their coherence. This method is widely known as the (narrow) reflective equilibrium. (30) Basing our analysis on the four cardinal principles of medical ethics[21](31) as the moral depictions of the norms and values professionals working in the medical domain ought to be committed to, we concluded that the justification for forced cesareans leads to too much incoherency between the considered judgments that underpin it[22] and the principles of medical ethics that should justify it[23]. Therefore, the use of force is, we argued, morally impermissible.(29)

I believe that the analysis that lead to this conclusion (as well as the conclusion itself) is (are) relevant for our discussion on the responsibility caregivers and mothers-to-be have towards children-to-be. For one, it demonstrates that narrowing the scope so to include only the health and the interests of the child-to-be or the freedom and autonomy of mothers-to-be is insufficient to do a sound ethical analysis on which pregnancy preparation interventions are justifiable and which ones are not. I often do think that there is a pitfall to being in the 'preconception care business' as we tend to, for perfectly understandable reasons, narrow our focus to the health and interests of the child-to-be. The improvement of the health and wellbeing of children-to-be is such a praiseworthy goal that we run the risk of discounting what we ask mothers-to-be to do in order to achieve this goal. The use of the reflective equilibrium in our analysis of the justifiability of forced cesareans offers a way to widen this scope by 'forcing' us to reconcile the duties and demands we attribute to mothers-to-be with the duties and demands we attribute to others who are also in the position to prevent harm to and do significant good for the health of children-to-be. Just think of the significant harms to children-to-be that are caused by tobacco companies, fast-food companies, unnecessary poverty and poor parenting to name just a few. Demanding an adequate pregnancy

20 Is the use of force against pregnant women justified when it can save the life of their unborns?
21 These are the principles of: respect for autonomy, beneficence, non-maleficence and justice
22 the justification of forced cesareans.
23 Idem

preparation from mothers-to-be in a society filled with possible harms for children-to-be is like fixing the window to subsequently burn the house. To be sure, I am not claiming that until all social and economic sources of harm are abolished, mothers-to-be carry no responsibility for their children-to-be. I am claiming that we should be 'test' our intuitions and considered judgments regarding the pregnancy-related interventions (which may or may not allow force) for their fairness and reasonableness by assessing how coherent they are with other intuitions, considered judgments, norms and values we are committed to.

The fourth aim was: *to identify and present the demands of justice pertaining to the improvement and securing of the health of children-to-be*

Why justice?

I turn now to the societal responsibilities for the health of children-to-be, that is, the demands of justice. Let me start by pointing to an important debate in the field of political philosophy which revolves around the question of whether the moral rules applied for interpersonal conduct should be the same as the moral rules applied for realizing social values such as fairness, equality and justice. Let me explain. It is clear that by any reasonable standard of evaluation, people within a society, even a prosperous society like the Netherlands, live lives of (significantly) varying quality. Individuals belonging to different socioeconomic positions differ in their quality of health, nutrition and lifestyle, life expectancy, access to medical care and education and their vulnerability to stress, violence and abuse. This is nothing new.

Those who have the good fortune to belong to the more privileged strata of society can surely be moved by the ill-faith of those less fortunate, yet, in general, they look not primarily to themselves to alleviate their burdens. For example, for a privileged[24] individual it is a matter of personal responsibility to rescue a drowning infant from death in a pool but *not* or at best *significantly less* a matter of personal responsibility to counteract inequalities in infant deaths observed in the city of Rotterdam. In other words, there seems[25] to be a difference in the way we ought to treat one another and respond to each other's needs on a small-scale and the way we ought to respond to large-scale societal problems such as perinatal inequality. In the literature this is referred to as the 'division of moral labor'.(32) This dissertation also contains a division of moral labor. On the

24 in fact, any individual who can swim or call for help
25 caution is in order as some political and ethical theories such as libertarianism and utilitarianism do not make this distinction

one hand I discussed the responsibilities of mothers-to-be, parents-to-be and caregivers for the health of children-to-be. These responsibilities are comprehensive but they do not include the large-scale problems pertaining to the health of children-to-be which have to do with the number of avoidable adverse pregnancy outcomes is general and perinatal health inequalities in particular. In the next section I will turn to the responsibility of society to address these large-scale problems, that is, the demands of justice.[26] Before doing so I want to stress the importance of this moral division of labor. There is a tendency to pit small-scale responsibilities against large-scale responsibilities in societies that (over)emphasize the individual responsibility for health.(7) In light of the insights provided by the DOHaD paradigm and epigenetics there exists a serious risk that mothers-to-be become the target of blame and shame in the discussion on avoidable infant disease and death; from the mother's dinner to a newborn's disease.(7) This is both unwarranted and it draws attention away from the demands of justice pertaining to health of children-to-be. If it's the mother then it can't be society, or so the fallacy goes. Having mentioned this fallacy, I turn now to the demands of justice to counteract avoidable pregnancy outcomes in general and perinatal health inequalities in particular.

Adverse pregnancy outcomes and the demands of justice

Adverse pregnancy outcomes occur everywhere in the world. The ones I discussed however, are particularly disquieting because of one special feature; they are observed in prosperous societies. The Netherlands for example, has free and high-quality (pregnancy-related) care in place yet it has a persistent high number of adverse pregnancy outcomes compared to other European countries.(33) Moreover, staggering inequalities in pregnancy outcomes between neighborhoods have also been observed.(34) Insights from the DOHaD paradigm and epigenetics show that a suboptimal embryonic growth which leads to many adverse pregnancy outcomes also increases the risk of attracting non-communicable diseases later in life. An impaired development in utero hits twice.(35) These insights emphasize the importance of a good embryonic and fetal development and thereby the importance of adequate pregnancy preparation as well as the availability of accessible pregnancy-related care.

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26 Responsibilities of society to address large-scale problems can also be based on solidarity rather than on determining the demands of justice. This is however typically considered to be a less principled and therefore less compelling way. Still, the healthcare system in the Netherlands for example, is based on solidarity and not on the principles of justice.

So what to do to counteract these high number of adverse pregnancy outcomes and perinatal health inequalities in a prosperous society such as the Netherlands? Or more precisely, what does justice demand in this situation? We have argued that although much more can be done to improve the availability and accessibility of care in deprived neighborhoods this will most probably not be enough as the problem of adverse pregnancy outcomes cannot only be traced back to a 'deficit of goods' (such as availability of care) but also a 'deficit of capacity'; the capacity individuals living in deprived neighborhoods have to set health-related goals worth pursuing.(35) It has been widely observed that people living in deprived circumstances tend to *adapt* their (health-related) preferences, goals and aspirations so they match their unfortunate living conditions so that these conditions cease to be a source of frustrations. This 'mechanism of acquiescence' is widely known as 'adaptive preferences'.(36, 37) Research on adaptive preferences has typically focused on people living in countries that face severe poverty and destitution. Our own research(1) however, suggests that these adaptive presences can also occur in deprived neighborhoods in prosperous societies; even if the level of poverty is incomparable between those worst-off living in the Netherlands and those worst-off living in –say– India. Our observation can be seen as an invitation to further research into the ways life in deprived circumstances within a prosperous society curb the health-related preferences, goals and aspirations of mothers-to-be.

We have argued that to meet the demands of justice we should focus on counteracting these adaptive preferences that are caused by living in a deprived neighborhood by investing in interventions that improve what we called the 'health-agency' of mothers-to-be.(35) We described health agency as "**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)* one has to achieve those health-goals.(35)" One can think of interventions that aim to improve health-agency as 'anti-nudges'[27] as they are aimed at empowering women in order for them to set health-related goals *they have reason to value.* Unlike nudging these interventions require serious societal investments in education and tailor-made care so that mothers-to-be are encouraged to raise their health-related expectations for themselves and their children-to-be beyond their adaptations. To be sure, this will most likely be a slow and arduous process. Helping mother-to-be to set 'giving birth to a healthy baby' as a *valuable* and *achievable* goal rather than merely 'praying for the best'(35) is ambitious and requires social dedication. But as we have argued, justice demands nothing less.

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27 This is not to say that the potential of nudging as a way to encourage women to better prepare for pregnancy should not be explored but only that more is needed than nudging namely anti-nudging as well.

Strengths and limitations

The subtitle of this dissertation is: 'a moral *exploration* of the responsibilities of parental and societal responsibilities for children-to be' and an exploration it is. The aim was to explore topics that matter greatly in the discussion on adverse pregnancy outcomes, pregnancy preparation and preconception care; topics such as the responsibility of the mother-to-be and society for the health of children-to-be; topics have always there in the background but should also take center stage. I am optimistic that the identification, exploration and argumentation offered here on novel topics such as 'nudging and pregnancy preparation' and 'the demands of justice pertaining to the health of children-to-be' are conducive to finding comprehensive answers to the problem of avoidable infant illness and death. It seems to me that ethical and philosophical refection is indispensable in order to improve pregnancy outcomes in a manner that is respectful towards mothers-to-be and based on moral arguments we all have reason to be convinced by. It is my hope that this dissertation has made a contribution to this reflection.

As is with most explorations however, it leads not to fine-grained discoveries. As opposed to the recommendations for caregivers and policymakers, this dissertation was, *not* tailor-made. Although we have identified 'health-agency' as an important trait that enables mothers-to-be to set the good health of their children-to-be as a goal worth pursuing we have not specified which interventions are most likely to achieve the empowerment of health agency. We have justified the use of nudges for the benefit of the health of children-to-be but not yet given a specified account of the content of a pregnancy preparation nudge. The interview studies we did yielded interesting insights on the self-reported responsibility of caregivers and mothers-to-be for the health of children-to-be. More studies on the views of mothers-to-be and caregivers are however required to reaffirm and expand on our findings.

Recommendations

<u>Recommendations for research</u>

- The views, ideas and sentiments of mothers-to-be underpinning the feeling of preparedness for pregnancy should be researched
- The views, ideas and sentiments of mothers-to-be underpinning the purported 'naturalness of pregnancy' should be researched
- The views and ideas of caregivers on the added-value and effectivity of preconception care should be researched.

- Research is needed to arrive at a fair and reasonable idea on what counts as harm and what counts as failing to provide a benefit in the case of pregnancy preparation. It is important to include within this deliberation the responsibilities we attribute to others (e.g. fathers, caregivers, fast-food companies) for the health of children so to 'calibrate' the responsibility to avoid harm and to provide benefits to children-to-be by the mother-to-be. I recommend our distinct use of the reflective equilibrium as the appropriate method for this research.
- Research is needed on the way life in depraved neighborhoods curbs the preferences, aims and aspirations of mothers-to-be regarding the health of their children-to-be.

Recommendations for caregivers, researchers and policymakers

- Invest in the translation of scientific insight into actual pregnancy preparation interventions
- Embed pregnancy preparation and preconception care within the educational system
- Include fertility care in preconception care
- Appoint a 'case manager', who can function as the primary responsible caregiver for preconception care. The GP or public health nurse are good candidates
- define and distribute the different roles and responsibilities of caregiver
- Include pathways to non-medical care in preconception care and make these pathways better known to mothers-to-be.
- Offer more education to caregivers on the topic of pregnancy preparation and preconception care
- Make preconception care a governmental coordinated form of preventive care
- Explore the possibilities of nudges for pregnancy preparation, in particular in the domains of E-Health and mHealth
- Invest in interventions that empower women to (re)gain their health agency

Recommendation for fathers-to-be

- Help your partner to prepare for pregnancy

Recommendation for mothers-to-be

- Prepare for pregnancy

References

1. M'hamdi HI, Sijpkens MK, de Beaufort ID, Rosman AN, Steegers EA. Perceptions of pregnancy preparation in women with a low to intermediate educational attainment: a qualitative study. Midwifery. 2018.
2. Hosli EJ, Elsinga J, Buitendijk SE, Assendelft WJJ, Van der Pal-de Bruin KM. Women's motives for not participating in preconception counseling: qualitative study. Public Health Genomics. 2008;11(3):166-70.
3. van der Zee B, de Beaufort ID, Steegers EA, Denktas S. Perceptions of preconception counselling among women planning a pregnancy: a qualitative study. Fam Pract. 2013;30(3):341-6
4. Poels M, Koster MP, Boeije HR, Franx A, van Stel HF. Why do women not use preconception care? A systematic review on barriers and Facilitators. Obstetrical & Gynecological Survey. 2016;71(10):603-12.
5. M'hamdi HI, van Voorst SF, Pinxten W, Hilhorst MT, Steegers EA. Barriers in the Uptake and Delivery of Preconception Care: Exploring the Views of Care Providers. Maternal and Child Health Journal. 2016:1-8.
6. Lupattelli A, Picinardi M, Einarson A, Nordeng H. Health literacy and its association with perception of teratogenic risks and health behavior during pregnancy. Patient education and counseling. 2014;96(2):171-8.
7. M'hamdi HI, de Beaufort I, Jack B, Steegers E. Responsibility in the age of Developmental Origins of Health and Disease (DOHaD) and epigenetics. Journal of developmental origins of health and disease. 2018;9(1):58-62.
8. Steegers EAP, Barker ME, Steegers-Theunissen RPM, Williams MA. Societal Valorisation of New Knowledge to Improve Perinatal Health: Time to Act. Paediatric and perinatal epidemiology. 2016;30(2):201-4.
9. van Voorst SF, Vos AA, de Jong-Potjer LC, Waelput AJ, Steegers EA, Denktas S. Effectiveness of general preconception care accompanied by a recruitment approach: protocol of a community-based cohort study (the Healthy Pregnancy 4 All study). BMJ open. 2015;5(3):e006284.
10. Zee Bvd. Preconception care: Concepts and Perceptions, an ethical perspective. Rotterdam: Erasmus University; 2013.
11. Poels M, Koster MP, Franx A, Stel H. Healthcare providers' views on the delivery of preconception care in a local community setting in the Netherlands. BMC health services research. 2017;17(1):92.
12. M'hamdi HI, Sijpkens MK, Inez de Beaufort, Hilhorst M, Jack B, Pennings G, et al. Meeting Report: Ethical Issues Surrounding Preconception Care. submitted.
13. Jack BW, Atrash H, Coonrod DV, Moos M-K, O'Donnell J, Johnson K. The clinical content of preconception care: an overview and preparation of this supplement. American journal of obstetrics and gynecology. 2008;199(6):S266-S79.
14. Denktaş S, Bonsel G, Van der Weg E, Voorham A, Torij H, De Graaf J, et al. An urban perinatal health programme of strategies to improve perinatal health. Maternal and child health journal. 2012;16(8):1553-8.
15. Erasmus Medical Centre Department of Obstetrics and Gynecology Bureau Frontlijn Municipality of Rotterdam. Mothers of Rotterdam [Available from: https://www.moeders-

vanrotterdam.nl/wp-content/uploads/Factsheet-Moeders-van-Rotterdam-ENG-nummering-def2.pdf.

16. Mazza D, Chapman A, Michie S. Barriers to the implementation of preconception care guidelines as perceived by general practitioners: a qualitative study. BMC health services research. 2013;13(1):1.
17. Kahneman D. Thinking Fast and Slow: Farrar, Straus and Giroux; 2011.
18. Thaler R.H Sunstein C.R. Nudge: Improving decisions about Health, Wealth and Happiness. London: Penguin Books; 2008, 2009.
19. Quigley M. Nudging for health: on public policy and designing choice architecture. Medical Law Review. 2013;21(4):588-621.
20. Englund-Ögge L, Brantsæter AL, Sengpiel V, Haugen M, Birgisdottir BE, Myhre R, et al. Maternal dietary patterns and preterm delivery: results from large prospective cohort study. Bmj. 2014;348:g1446.
21. van Dijk MR, Oostingh EC, Koster MP, Willemsen SP, Laven JS, Steegers-Theunissen RP. The use of the mHealth program Smarter Pregnancy in preconception care: rationale, study design and data collection of a randomized controlled trial. BMC pregnancy and childbirth. 2017;17(1):46.
22. Marteau TM, Ogilvie D, Roland M, Suhrcke M, Kelly MP. Judging nudging: can nudging improve population health? BMJ: British Medical Journal (Online). 2011;342.
23. Mitchell G. Libertarian Paternalism is an Oxymoron. Northwestern University Review. 2005;99(3).
24. Grüne-Yanoff T. Old wine in new casks: libertarian paternalism still violates liberal principles. Social Choice and Welfare. 2012;38(4):635-45.
25. White M. The manipulation of choice: Ethics and libertarian paternalism: Springer; 2013.
26. Thaler RH, Sunstein CR. Libertarian paternalism. American Economic Review. 2003:175-9.
27. M'hamdi HI, Hilhorst M, Steegers EA, de Beaufort I. Nudge me, help my baby: on other-regarding nudges. Journal of Medical Ethics. 2017:medethics-2016-103656.
28. Purdy LM. Are pregnant women fetal containers? Bioethics. 1990;4(4):273-91.
29. M'hamdi HI, de Beaufort I. Forced cesareans: not all is fair in love. submitted. 2018.
30. Arras JD. The way we reason now: reflective equilibrium in bioethics. 2007.
31. Beauchamp TL, Childress JF. Principles of biomedical ethics: Oxford University Press, USA; 2001.
32. Scheffler S, Munoz-Dardé V. The division of moral labour. Proceedings of the Aristotelian Society, Supplementary Volumes. 2005:229-84.
33. Mohangoo A, Buitendijk S, Hukkelhoven C, Ravelli A, Rijninks-van Driel G, Tamminga P, et al. Higher perinatal mortality in The Netherlands than in other European countries: the Peristat-II study. Nederlands tijdschrift voor geneeskunde. 2008;152(50):2718-27.
34. de Graaf JP, Steegers EA, Bonsel GJ. Inequalities in perinatal and maternal health. Current Opinion in Obstetrics and Gynecology. 2013;25(2):98-108.
35. Hafez Ismaili M'hamdi, Eric Steegers, Beaufort Id. Pray for the best: on perinatal health inequalities and health agency. *Submitted*.
36. Elster J. Sour grapes: studies in the subversion of rationality. Cambridge {Cambridgeshire}. New York: Cambridge University Press; 1983.

37. Sen A. Health: perception versus observation: Self reported morbidity has severe limitations and can be extremely misleading. BMJ: British Medical Journal. 2002;324(7342):860.

ADDENDA

Summary

Children have certain needs that enter the world before they do. The overall aim of this thesis is to provide a moral exploration of the responsibilities mothers-to-be, fathers-to-be, caregivers, policymakers and society as a whole have to meet the most elementary of these needs; the health-related needs of children-to-be. Such a moral exploration is warranted given the high number of avoidable adverse pregnancy outcomes in prosperous societies such as the Netherlands and the recorded inequalities of these adverse pregnancy outcomes. An increasing body of scientific evidence shows that an adequate pregnancy preparation can significantly decrease the chances of adverse pregnancy outcomes. The delivery of preconception care in particular can play a key role in improving the chances of mothers-to-be to have a healthy pregnancy. As welcome as they are, these opportunities to improve pregnancy outcomes do however raise moral questions. What are the views of parents-to-be and caregivers on the responsibilities for the health of children-to-be in general and the responsibility to prepare for pregnancy in particular? Is it justifiable to use nudges to help women prepare for pregnancy? Is the use of coercion or force against women justified if this would greatly benefit the health children-to-be or fetuses? What are the demands of justice pertaining to the improvement and securing of the health of children-to-be? These questions, which were introduced in *chapter 1,* need to be answered in order to improve pregnancy outcomes in a morally acceptable manner.

In *chapter 2* we examined the views of health care professionals regarding their responsibility to deliver preconception care. We interviewed twenty health care professionals who provide preconception care on a regular basis. These interviews yielded four barriers to the uptake and delivery of preconception care those being: (i) a lack of a comprehensive preconception care program; (ii) most future parents are unaware of the benefits of preconception care. GP's are hesitant about the necessity and effectiveness of preconception care; (iii) poor coordination and organization of preconception care; (iv) conflicting views of health care professionals on pregnancy, reproductive autonomy of patients and professional responsibility. These barriers need to be addressed in order to increase the uptake and improve the delivery of preconception care.

In *chapter 3* we argued that in order to improve pregnancy outcomes, appropriate attention has to be given to the perceptions of those who are most vulnerable, such as women with a relatively low socioeconomic status. To determine these perceptions, we conducted interviews with women with a low to intermediate educational attainment and with a desire to conceive, of which a subgroup had experience with preconception care. We identified four themes of pregnancy preparation perceptions: (i) "How to

prepare for pregnancy?", which included health promotion and seeking healthcare; (ii) "Why prepare for pregnancy?", which mostly related to fertility and health concerns; (iii) "Barriers and facilitators regarding pregnancy preparation", such as having limited control over becoming pregnant as well as the health of the unborn; (iv) "The added value of preconception care", reported by women who had visited a consultation, which consisted mainly of reassurance and receiving information.

Our key findings were that the participants were unfamiliar with important pregnancy preparation topics such as over-the-counter drugs, immunizations, sexual risk behaviors, family history, chronic illness, and mental health. Therefore, more effort, e.g. in the form of information and education, is required to bring these topics to the attention of women with a desire to become pregnant. In addition, more research needs to be done about how women can be motivated to prepare for pregnancy as knowledge about pregnancy preparation alone does not necessarily lead to actual pregnancy preparation. Special attention needs to be given to whether and if so, how low-health literacy influences pregnancy preparation. As participants were open to receiving information about pregnancy preparation provided that this information is presented in relevant situations, we also recommend that healthcare professionals proactively integrate preconception care in their consultations, in particular when pregnancy affecting issues are being discussed.

In *chapter 4* we turned to the topic of nudging. Given the increasing attention from policy makers to make healthier choice-behavior easier, that is, to nudge people towards better health, we analyzed the moral justifiability of using nudges to help mothers-to-be to better prepare for pregnancy. We started by arguing that Libertarian Paternalism, the standard justificatory principle for nudging, does not justify the nudges we have in mind. The nudges we have in minds are distinctive in the sense that, contrary to conventional nudges, the person who benefits from the nudge is *not* the same person that is being nudged. We called these nudges other-regarding nudges. We used the harm principle and the principle of beneficence to justify these other-regarding nudges. We concluded by stressing the importance of a fair assessment of expectations towards the nudgee, when determining whether a nudge is aimed at preventing harm or promoting a good. For our purpose this entails that a fair assessment of the responsibility of mothers-to-be for their children-to-be is warranted in order not to construe every deviation from optimal pregnancy preparation as a form of harm.

After considering nudging, a relatively soft and nonintrusive intervention we focused on the other side of the demandingness spectrum. In *chapter 5* we explored the justifiability of the use of force in pregnancy related care. To do this, we considered whether

it is justified to use force to submit a pregnant woman to cesarean surgery when this would save the life of her fetus. We argued that even though proponents and opponents largely agree on the interests at stake, such as the health and life of the fetus and the respect for bodily integrity and autonomy of pregnant women, they disagree on which moral weight to attach to these interests. This is why disagreements about the justifiability of forced cesareans tend to be pervasive and intractable. To sidestep this deadlock, we focused on conditions that give rise to the 'cesarean dilemma' in the first place, namely the conflict between inherent norms and values medical professionals are committed to by virtue of being a medical professional. Using the reflective equilibrium, we tested the opponents' and proponents' considered judgments about forced cesareans against the norms and values they –as medical professionals– are committed to. Subsequently we identified the proponents' incoherencies between the considered judgments and norms and values they are committed to and concludes that as long as these incoherencies are in place, forced cesareans are morally impermissible.

In *chapter 6* we reported on an expert meeting on the ethical issues surrounding preconception care which was held in October 2016. The aim of this meeting was to (i) discuss the key barriers in the provision, uptake and implementation of PCC, (ii) to explore the gaps in current research and (iii) to explore the potential of new scientific insights to improve pregnancy outcomes. The expert panel of 11 members consisted of clinicians, clinical researchers, medical ethicists, and a representative of a patient- federation (an alliance of 70 patient organizations). The discussion was structured around the following topics: (1) 'The concept of PCC and the role of caregivers' (2) 'reaching those who need care the most' (3) 'societal valorization of new knowledge' and (4) 'translating behavioral insights into preconception care interventions'. Each topic was introduced by a member of the expert panel. The main recommendations of the expert panel were: the provision of tailor-made care; the definition and distribution of roles and responsibilities of caregivers; the inclusion of fertility counseling in preconception care, and the development of pathways that cut across the medical and non-medical domains. Moreover, the discussion on how to promote maternal and child health should include the detrimental effects of social inequities and the potential use of incentives such as E- and mHealth tools.

In *chapter 7* we claimed that 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 argued 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 proposed a 'bare-bones-perfectionism' approach to counteract these adaptive preferences.

We concluded that perinatal health inequalities 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.

In *chapter 8* we discussed the insights from the Developmental Origins of Health and Disease paradigm and epigenetics. These insights are elucidating the biological pathways through which social and environmental signals affect human health. These insights, we argued, prompt a serious debate about how the structure of society affects health and what the responsibility of society is to counteract health inequalities. Unfortunately, oversimplified interpretations of insights from Developmental Origins of Health and Disease and epigenetics may be (mis)used to focus on the importance of individual responsibility for health rather than the social responsibility for health. In order to advance the debate on responsibility for health, we presented an ethical framework to determine the social responsibility to counteract health inequalities, perinatal health inequalities in particular. This is, in our view, certainly important in a time where individual responsibility often justifies a passive response from policymakers.

We concluded that in the healthcare and public health debate, individual responsibility and social responsibility tend to be erroneously pitted against one another. Taking responsibility however calls for social and environmental conditions in which individuals can be reasonably expected to make responsible health-related choices. Insights from Developmental Origins of Health and Disease and epigenetics are sufficiently robust to show that more needs to be done to improve these conditions. Rather than viewing mothers(-to-be) as targets of blame, culpable for the poor health of their offspring, special attention for the conditions of the mothers-to-be is required.

We called attention to wo initiatives that depict how taking social responsibility creates the right conditions in which mothers-to-be to are empowered to take individual responsibility. The Special Supplemental Nutrition Program for Women, Infants and Children (WIC), which provides disadvantaged families with regular supplies of food essential for physical and cognitive development, has improved the quality of maternal and child nutrition, and the physical and cognitive development of children. This demonstrates how a coordinated care program benefits the health of mothers and newborns. The 'Mothers for Rotterdam' initiative, in which women living in deprived neighborhoods are assisted and guided in addressing their medical and non-medical conditions, is the other example.

In *chapter 9* I summarized and discussed the main findings of this dissertation. I argued that efforts to prevent avoidable infant disease and death are necessary and praiseworthy. This becomes even more clear when we consider the significant detrimental impact social circumstances have on the prospective health and wellbeing of children-to-be, even in a prosperous society such as the Netherlands. We have tools at our disposal to mitigate the effects of deprivation on the health of children-to-be namely 'pregnancy preparation' and 'preconception care'; now we have a job to do. Yet to prevent overzealous attempts to counteract adverse pregnancy outcomes and to distribute the responsibilities for the promotion and securing of the health of children-to-be in a reasonable and fair manner, caution and ethical reflection are of paramount importance.

Central to the health of the child-to-be, is the health of the mother-to-be. The healthier she is, the healthier her child will likely be. This simple but important 'equation' creates both opportunities and risks. There are opportunities for mothers-to-be to seek preconception care in order to prepare for pregnancy. And these opportunities create duties, the duty to prepare for pregnancy. That much is true. Yet, when we see every deviation from an *optimal* pregnancy preparation as an instance of harm; as a serious moral shortcoming of women in the fulfillment of their maternal duties, we risk stigmatizing mothers-to-be, unfairly targeting them as subjects of blame. Moreover, the fact that the health of children-to-be is, biologically speaking, mostly influenced by the health of the mother-to-be may, without diligent deliberation, lead to an overemphasis on the responsibility of mothers-to-be and an underappreciation of the responsibility of fathers, caregivers, policymakers and society as a whole. Apart from its health benefits, the organization and implementation of a coordinated preconception care program, which I recommend, also invites the discussion on who carries which responsibilities for children-to-be.

Insights from the behavioral sciences can be valuable in the pursuit of better pregnancy outcomes. Nudges are good candidates to consider as interventions that make adequate pregnancy preparation easier. However, the same insights also explain why changing choice-behavior, a necessary constituent of pregnancy preparation, is so difficult to achieve. Patterns of choice-behavior pertaining to lifestyle become 'entrenched' in the less-reflective parts of our mind. And it is the improvement of exactly these daily patterns of behavior, –smoking, drinking, eating, working out and so on– that benefit the health of the child-to-be the most. Advising mothers-to-be to improve these rooted patterns of behavior, something most mothers-to-be are willing to do even if they do not always succeed, is in my view justified but also demanding. And it is the demandingness of the request to prepare for pregnancy combined with the fruits of adequate pregnancy preparation for the child-to-be that make encouraging, rewarding, and nudging mothers-to-be ideas worth exploring.

Still, the downside of incentive-based interventions is that they do not encourage individuals to do the 'right thing for the right reasons'. This is why nudges are not meant to replace comprehensive policy but to supplement it. It is of course great if it turns out that nudges can in fact help women to adopt a healthier lifestyle during the period surrounding pregnancy. But ultimately, the improvement of the mother-to-be's lifestyle should result from (i) the value she attaches to the goal of 'improving the health of her child-to-be' as well as (ii) her experience of control and (iii) her experience of freedom she has over achieving that goal *she has reason to value.* That is, it should be the result of women's 'health agency'. The possibility for mothers-to-be to do those things they have reason to value depends on two conditions; external and internal. The external conditions have to do with the availability and accessibility of care and education to adequately prepare for pregnancy. It is disquieting that in a prosperous society such as the Netherlands, poverty still prevalent and is even increasing. This is also reflected in the suboptimal availability and accessibility of pregnancy-related care. Investing in the improvement of these external adverse socioeconomic conditions is of paramount importance. Poverty however, gets under one's skin. It can curb preferences, aims and aspirations for a healthier and better life. The constrained *external* conditions associated with poverty become, much like the workings of the epigenetic mechanism, *internalized* so that one's aspirations match one's socioeconomic limitations. In other words, facing the difficulties of poverty, underprivileged mothers-to-be are more likely to accept the increased risk of adverse pregnancy outcomes as a given: "in the end what can we do but pray for the best?"(40)

A proper response to the problem of avoidable adverse pregnancy outcomes has to, in my view, address this phenomenon of acquiescence. This response cannot only be

a matter of improving the availability and accessibility of care. It is also a matter of supporting mothers-to-be so they may think beyond their deprived circumstances. This is why in pursuit of better pregnancy outcomes, fostering health agency, primarily through the long and arduous process of education, is, in my view indispensable.

Samenvatting

Kinderen hebben bepaalde behoeften die de wereld in komen nog voor dat zij zelf geboren zijn. In dit proefschrift wordt de morele verkenning gepresenteerd van de verantwoordelijkheden die toekomstige moeders, toekomstige vaders, zorgverleners, beleidsmakers en de samenleving in haar geheel hebben om aan de meest elementaire behoeften van toekomstige kinderen te voldoen; de gezondheidsgerelateerde behoeften. Zo een morele verkenning is belangrijk gezien het grote aantal vermijdbare slechte zwangerschapsuitkomsten in Nederland –een welvarende samenleving- en de ongelijkheid van deze slechte zwangerschapsuitkomsten. Steeds meer wetenschappelijk onderzoek laat zien dat een adequate zwangerschapsvoorbereiding de kansen op slechte zwangerschapsuitkomsten aanzienlijk kan verminderen. Het verlenen van preconceptiezorg in het bijzonder kan een belangrijke rol spelen bij het verbeteren van de kansen op een gezonde zwangerschap. Alhoewel deze kansen op het verbeteren van zwangerschapsuitkomsten welkom zijn roepen ze tegelijkertijd ook morele vragen op. Welke opvattingen hebben toekomstige ouders en zorgverleners over de 'verantwoordelijkheid voor de gezondheid van toekomstige kinderen' en 'de verantwoordelijkheid om je op zwangerschap voor te bereiden?' Is het toegestaan om 'nudges' te gebruiken om vrouwen te helpen bij de zwangerschapsvoorbereiding? Is het inzetten van dwang tegen vrouwen gerechtvaardigd in gevallen waarin dit bijzonder gunstig zou zijn voor de gezondheid van toekomstige kinderen of de foetussen? Wat zijn de rechtvaardigheidseisen die betrekking hebben op het bevorderen en veiligstellen van de gezondheid van toekomstige kinderen? Deze vragen, die wij in *hoofdstuk 1* hebben geïntroduceerd, behoeven antwoord om zwangerschapsuitkomsten op een moreel acceptabele manier te bevorderen.

In *hoofdstuk 2* hebben we de opvattingen van zorgprofessionals over hun verantwoordelijkheid om preconceptiezorg te verlenen onderzocht. We hebben twintig zorgprofessionals die op regelmatige basis preconceptiezorg verlenen geïnterviewd. Met behulp van deze interviews hebben we vier 'barrières' geïdentificeerd die de 'uptake' en het verlenen van preconceptiezorg belemmeren. Deze zijn: (i) het ontbreken van een uitgebreid preconceptiezorgprogramma, (ii) de meeste toekomstige ouders zijn zich niet bewust van de voordelen van preconceptiezorg. Huisartsen twijfelen over de noodzaak en effectiviteit van preconceptiezorg, (iii) slechte coördinatie en organisatie van preconceptiezorg, (iv) conflicterende opvattingen van zorgverleners over zwangerschap, de reproductieve autonomie van de patiënten en de verantwoordelijkheid van de zorgprofessionals. Deze barrières moeten worden aangepakt om de uptake en het verlenen van preconceptiezorg te verbeteren.

In *hoofdstuk 3* hebben we beargumenteerd dat voor het verbeteren van zwangerschapsuitkomsten, passende aandacht gegeven moet worden aan de perceptie van die vrouwen die het meest kwetsbaar zijn, bijvoorbeeld vrouwen met een lage sociaaleconomische status. Om deze percepties vast te stellen hebben we vrouwen met een laag sociaaleconomische status met een kinderwens geïnterviewd. We hebben vier thema's die betrekking hebben op zwangerschapsvoorbereiding geïdentificeerd: (i) 'Hoe voor te bereiden op zwangerschap', waaronder het verbeteren van de gezondheid en medische zorg zoeken vielen. (ii) 'Waarom voorbereiden op zwangerschap', dit had het meest betrekking op vruchtbaarheid en zorgen over de gezondheid. (iii) ''Barrières' en 'facilitators' die betrekking hebben op zwangerschapsvoorbereiding', hier werden het hebben van een beperkte controle over de zwangerschap en de gezondheid van het kind genoemd. (iv) 'De meerwaarde van het preconceptieconsult" waarbij vooral geruststelling en het krijgen van informatie genoemd werden.

Onze belangrijkste bevindingen waren dat de deelnemers onbekend waren met belangrijke onderwerpen die over zwangerschapsvoorbereiding gaan zoals, vrij verkrijgbare geneesmiddelen, risicovol seksueel gedrag, de familiegeschiedenis, chronische ziekten en de geestelijke gezondheid. Daarom moet er meer gedaan worden, bijvoorbeeld met behulp van informatieverstrekking en onderwijs, om deze onderwerpen onder de aandacht te brengen bij vrouwen die een kinderwens hebben. Bovendien is er meer onderzoek nodig naar hoe we vrouwen kunnen motiveren om zich voor te bereiden op zwangerschap aangezien de kennis over zwangerschapsvoorbereiding alleen niet noodzakelijkerwijs tot leidt tot zwangerschapsvoorbereiding. Aandacht is in het bijzonder nodig voor de invloed van 'health literacy' op het voorbereiden van zwangerschap. Omdat de participanten open stonden voor het ontvangen van informatie over zwangerschapsvoorbereiding, mits deze informatie verschaft werd tijdens een relevante situatie, raden wij ook aan dat zorgprofessionals preconceptiezorg ter sprake brengen tijdens hun consultaties, juist wanneer er zwangerschapsgerelateerde zaken besproken worden.

In *hoofdstuk 4* richtten we ons op het onderwerp 'nudging'. Gezien de groeiende aandacht van beleidsmakers voor 'makkelijker maken van gezond gedrag', of te wel, het 'nudgen' van mensen richting gezond gedrag, hebben we de morele rechtvaardiging van het gebruik van nudges om toekomstige moeder te helpen zich beter voor te bereiden op zwangerschap, geanalyseerd. Allereerst beargumenteerden we dat 'Libertarian Paternalism', het principe dat de standaard nudge rechtvaardigt, ongeschikt is voor de nudges die wij in gedachten hebben. De nudges die wij in gedachten hebben, onderscheiden zich van de standaard nudges doordat de persoon die voordeel heeft van de nudge, anders dan bij de standaard nudge, niet dezelfde persoon is als degene

die daadwerkelijk 'genudged' wordt. Wij noemen deze nudges 'other-regarding nudges'. We hebben het 'Harm Principle' en het principe van weldoen gebruikt om deze other-regarding nudges te rechtvaardigen. We eindigden met het benadrukken van het belang van een eerlijke beoordeling van de verwachtingen die wij hebben ten aanzien van degene die genudged wordt om zo op een juiste manier te kunnen vaststellen of de nudge bedoeld is om schade te voorkomen of om wel te doen. In ons geval betekent dit dat een eerlijke beoordeling van de verantwoordelijkheden van de toekomstige moeder voor de gezondheid van haar toekomstige kind nodig is om niet elke afwijking van een optimale zwangerschapsvoorbereiding te begrijpen als het schaden van het toekomstige kind.

Na het bespreken van nudges, een relatieve zachte en niet-intrusieve interventie, richtten wij ons op de meer dwingende interventies. In *hoofdstuk 5* verkenden wij de rechtvaardiging van het gebruik van dwang binnen de zwangerschapsgerelateerde zorg. Om dit te doen onderzochten we de morele toelaatbaarheid van het dwingen van vrouwen tot een keizersnede als dit het leven van de foetus zou redden. We beargumenteerden dat alhoewel voorstanders en tegenstanders het eens zijn over de belangen die op het spel staan, namelijk het leven en de gezondheid van de ongeborene en het recht op lichamelijke integriteit en autonomie van de zwangere vrouw, ze het niet eens zijn over welk gewicht ze deze belangen moeten toekennen. Daarom is de verdeeldheid over de rechtvaardiging van de gedwongen keizersnede tussen voor- en tegenstanders vaak diep en onoverbrugbaar. Om voorbij deze impasse te komen richtten wij ons op de voorwaarden die ten grondslag liggen aan het keizersnede dilemma, namelijk het conflict tussen normen en waarden waar zorgverleners –omdat ze zorgverleners zijn– aan gecommitteerd zijn. Vervolgens hebben we incoherenties geïdentificeerd in de intuïties, normen en waarden van de voorstanders van de gedwongen keizersnede en concludeerden wij dat zolang deze incoherenties aanwezig zijn, gedwongen keizersneden niet te rechtvaardigen zijn.

In *Hoofdstuk 6* brachten we verslag uit over een expert bijeenkomst over de ethische kwesties rondom preconceptiezorg die gehouden werd in oktober 2016. Het doel van deze bijeenkomst was: (i) het bespreken van de belangrijkste barrières bij het aanbieden en verlenen van preconceptiezorg. (ii) het identificeren en bespreken van de hiaten in het onderzoek naar preconceptiezorg, (iii) het verkennen van nieuwe wetenschappelijke inzichten die gebruikt kunnen worden om zwangerschapsuitkomsten te verbeteren. In het expert panel dat uit 11 leden bestond waren aanwezig: clinici, wetenschappelijk onderzoekers, medisch ethici en een vertegenwoordiger van de patiëntenfederatie. Het gesprek werd gestructureerd rondom de volgende onderwerpen: (1) 'Preconceptiezorg als concept en de rol van zorgverleners'. (2) 'Het bereiken van

die personen die de zorg het hardst nodig hebben'. (3) 'sociale valorisatie van nieuwe wetenschappelijke kennis en (4) het vertalen van gedragswetenschappelijke inzichten in preconceptiezorg interventies. Elk onderwerp werd geïntroduceerd door een panellid. De belangrijkste aanbevelingen die uit de bijeenkomst volgden waren: het aanbieden van op maat gemaakte zorg, het vaststellen en verdelen van de rollen en verantwoordelijkheden van zorgverleners, de inclusie van advies over vruchtbaarheid in preconceptiezorg en het ontwikkelen van zorgpaden met aandacht voor medische en niet-medische problematiek. Bovendien moeten in de discussie over het bevorderen van de gezondheid van moeder en kind de schadelijke effecten van sociale onrechtvaardigheden en de mogelijkheden om incentives in te zetten zoals E-health en mHealth tools ook besproken worden.

In *hoofdstuk 7* claimden we dat ongelijkheden tussen kindermorbiditeit en –sterfte voorkomen in zowel arme samenlevingen als in welvarende samenlevingen die gesubsidieerde en kwalitatief goede zorg aanbieden. Er moet nog veel gedaan worden om de omstandigheden van toekomstige ouders die in kansarme wijken in welvarende samenlevingen wonen, te verbeteren. Toch is het verbeteren van de materiele en sociale omstandigheden van deze toekomstige ouders maar een deel van de oplossing. We betoogden dat de effecten van het leven in kansarme wijken op de 'health agency' van toekomstige ouders ook bekeken moet worden om perinatale gezondheidsverschillen tegen te gaan. Toekomstige ouders die in kansarme wijken wonen zijn geneigd hun preferenties betreffende hun eigen gezondheid en de gezondheid van hun toekomstige kinderen 'te adapteren' zodat deze beter aansluiten bij de onfortuinlijke condities waarin zij leven. Deze adaptie beperkt het 'vermogen', het 'gevoel van controle' en 'de vrijheid die men ervaart' om gebruik te maken van beschikbare hulp en zorg. Wij hebben daarom een zogenaamde 'bare-bones perfectionism' aanpak voorgesteld om deze adaptieve preferenties tegen te gaan.

Om deze adaptieve preferenties tegen te gaan stelden we voor om de 'health agency' van toekomstige ouders die in kansarme wijken wonen te verbeteren tot aan het niveau van 'toereikende gelijkheid'. Het niveau van toereikende gelijkheid wordt bereikt wanneer toekomstige ouders het voorkomen van vermijdbare slechte zwangerschapsuitkomsten als nastrevenswaardig doel zien, al hoeft dit doel niet koste wat kost bereikt te worden.

In *hoofdstuk 8* bespraken we de inzichten vanuit het Developmental Origins of Health and Disease paradigma en de epigenetica. Deze inzichten beschrijven de biologische paden waarlangs sociale en omgevingsfactoren de gezondheid beïnvloeden. Deze inzichten roepen op tot een serieus debat over hoe de structuur van de samenleving de

gezondheid van mensen beïnvloedt en wat de verantwoordelijkheid van de samenleving is om ongelijkheden in gezondheid tegen te gaan. Helaas kunnen over gesimplificeerde interpretaties van deze inzichten gebruikt worden om te focussen op het belang van de individuele verantwoordelijkheid voor de gezondheid in plaats van de sociale verantwoordelijkheid voor de gezondheid. Om het gesprek over verantwoordelijkheid voor de gezondheid verder te brengen presenteerden wij een ethisch raamwerk dat het mogelijk maakt de sociale verantwoordelijkheid om ongelijkheden in gezondheid en ongelijkheden in perinatale gezondheid in het bijzonder tegen te gaan, vast te stellen. Dit is, zo vinden wij, belangrijk in een tijd waarin het beroep op individuele verantwoordelijkheid een passieve attitude van beleidsmakers lijkt te rechtvaardigen. Wij concludeerden dat in het gezondheidszorgdebat individuele en sociale verantwoordelijkheid tegen elkaar worden uitgespeeld. Het nemen van verantwoordelijkheid behoeft sociale condities waarin redelijkerwijs van individuen te verwachten valt dat zij gezonde keuzes kunnen maken. De inzichten vanuit het Developmental Origins of Health and Disease paradigma en de epigenetica zijn voldoende robuust om aan te tonen dat er meer gedaan moet worden om juist deze condities te verbeteren. In plaats van toekomstige moeders als schuldigen aan te wijzen voor de slechte gezondheid van hun toekomstige kinderen moet er meer aandacht komen voor de sociale condities van toekomstige moeders. Wij hebben speciaal aandacht gevraagd voor twee initiatieven die laten zien hoe het nemen van de sociale verantwoordelijkheid de juiste voorwaarden schept waarin toekomstige moeders in staat worden gesteld om hun individuele verantwoordelijkheid te nemen. Het Special Supplemental Nutrition Program for Women, Infants and Children, dat kansarme gezinnen voorziet van regelmatige voeding die essentieel is voor de fysieke en cognitieve ontwikkeling, heeft de kwaliteit van voeding verbeterd voor deze groep mensen. Het Moeders van Rotterdam initiatief, waarin kwetsbare moeders geholpen worden bij het oplossen van hun medische en niet-medische problemen is het andere voorbeeld.

In *hoofdstuk 9* heb ik de belangrijkste bevindingen van dit proefschrift samengevat en besproken waarbij ik betoogde dat inspanningen om vermijdbare kindermorbiditeit en mortaliteit te voorkomen prijzenswaardig zijn. Dit wordt nog duidelijker als we kijken naar de schadelijke invloed die een slechte sociale omgeving heeft op de gezondheid en welzijn van toekomstige kinderen, zelfs in een welvarende samenleving als Nederland. We beschikken over de instrumenten om de effecten van armoede op de gezondheid van kinderen te beperken; nu moeten we dit ook echt doen. Echter, om overijverige maar ondoordachte pogingen om ongunstige zwangerschapsuitkomsten te voorkomen en om de verantwoordelijkheden voor het verbeteren en veiligstellen van de gezondheid van toekomstige kinderen op een redelijke en eerlijke manier te verdelen, zijn voorzichtigheid en ethische reflectie onontbeerlijk.

De gezondheid van de toekomstige moeder is belangrijk voor de gezondheid van het toekomstige kind; hoe gezonder de moeder hoe gezonder haar kind waarschijnlijk zal zijn. Deze eenvoudige maar belangrijke 'vergelijking' creëert zowel mogelijkheden als risico's. Er zijn mogelijkheden voor toekomstige moeders om zich met behulp van preconceptiezorg goed voor te bereiden op hun zwangerschap. Deze mogelijkheden creëren uiteraard ook plichten, de plicht om je ook daadwerkelijk voor te bereiden op de zwangerschap. Maas als we elke afwijking van een *optimale* zwangerschapsvoorbereiding zien als een tekortkoming van toekomstige moeders dan lopen we het risico om hen te stigmatiseren. Bovendien, het feit dat de gezondheid van toekomstige kinderen, biologisch gezien, het meest beïnvloed wordt door de gezondheid van hun toekomstige moeders kan, bij gebrek aan reflectie, leiden tot het teveel benadrukken van de verantwoordelijkheid van de toekomstige moeder en het te weinig aandacht besteden aan de verantwoordelijkheid van toekomstige vaders, zorgverleners en de samenleving. De organisatie en implementatie van een gecoördineerd preconceptiezorgprogramma, wat ik aanbeveel, heeft naast de voordelen voor de gezondheid van toekomstige kinderen ook als voordeel dat het de discussie op gang kan brengen over wie welke verantwoordelijkheden draagt voor de gezondheid van toekomstige kinderen.

In het nastreven van betere zwangerschapsuitkomsten kunnen inzichten uit de gedragswetenschappen waardevol zijn. Nudges zijn bijvoorbeeld goede kandidaten om adequate zwangerschapsvoorbereiding makkelijker te maken. Diezelfde inzichten echter maken ook duidelijk waarom het veranderen van gedrag, een noodzakelijke voorwaarde voor zwangerschapsvoorbereiding, zo lastig is. Patronen van gedrag die betrekking hebben op leefstijl raken 'ingebed' in de minst reflectieve delen van ons verstand. En het zijn precies deze patronen –roken, drinken, eten, bewegen en zo voorts– die verbeterd moeten worden om het belang van het toekomstige kind te dienen. Het adviseren van toekomstige moeders om deze patronen van gedrag te verbeteren, iets wat de meeste toekomstige moeders bereid zijn om te doen, is, wat mij betreft, gerechtvaardigd maar het is ook veeleisend. En juist deze veeleisendheid in combinatie met de voordelen van een goede zwangerschapsvoorbereiding voor het toekomstige kind maken dat het aanmoedigen, belonen en nudgen van toekomstige moeders ideeën zijn die verkend zouden moeten worden.

De keerzijde van deze interventies is echter dat zij individuen niet aanmoedigen om 'het juiste te doen omwille van de juiste redenen'. Dit is waarom nudges nooit bedoeld zij om beleid te vervangen, ze zijn bedoeld om het aan te vullen. Het is natuurlijk geweldig als blijkt dat nudges inderdaad vrouwen kunnen helpen bij het aanmeten van een gezondere leefstijl in de periode rondom de zwangerschap. Maar uiteindelijk

zou het verbeteren van de leefstijl van de toekomstige moeder het resultaat moeten zijn van (i) de waarde die zij hecht aan het 'verbeteren van de gezondheid van haar toekomstig kind' alsmede (ii) 'haar ervaring van controle' en (iii) 'de vrijheid die zij heeft om dat doel -waar ze zelf redenen voor heeft om daar waarde aan te hechten- te bereiken.' In andere woorden, het moet het resultaat zijn van de 'health agency' van de vrouw. De mogelijkheid die toekomstige moeders hebben om die doelen te bereiken waar ze redenen voor hebben om daar waarde aan te hechten zijn afhankelijk van twee voorwaarden, een externe en een interne voorwaarde. De externe voorwaarden hebben te maken met de beschikbaarheid en de toegang tot zorg en onderwijs die het mogelijk maken om je goed voor te bereiden op zwagerschap. Het is verontrustend dat in een welvarende samenleving zoals de Nederlandse samenleving, armoede nog steeds voorkomt en zelfs steeds vaker voorkomt. De suboptimale beschikbaarheid en toegang tot zwangerschapsgerelateerde zorg laat dit ook zien. Het investeren in bestrijden van deze externe ongunstige sociaaleconomische omstandigheden is van zeer groot belang. Armoede echter 'kruipt onder je huid.' Armoede beteugelt de voorkeuren, doelen en aspiraties voor een gezonder en beter leven. De ongunstige *externe* condities die geassocieerd worden met armoede raken, vergelijkbaar met het epigenetisch mechanisme, *geïnternaliseerd* zodat een ieders aspiraties aansluiten bij diens sociaaleconomische limitaties. In andere woorden, al kampend met armoede, zijn toekomstige moeders meer geneigd hun grotere risico's op het hebben van ongunstige zwangerschapsuitkomsten te zien als een gegeven: "wat kunnen we uiteindelijk doen behalve hopen op het beste?"

Een adequaat antwoord op de problematiek van de vermijdbare ongunstige zwangerschapsuitkomsten moet, volgens mij, dit 'berustingsprobleem' het hoofd bieden. Dit antwoord kan niet alleen een kwestie zijn van het verbeteren van de beschikbaarheid en toegankelijkheid van zorg. Het is ook een kwestie van het ondersteunen van toekomstige moeders zodat zij voorbij hun achterstandspositie kunnen denken. Daarom is in het streven naar betere zwangerschapsuitkomsten het bevorderen van de 'health agency' aan de hand van onderwijs dat uiteraard veel tijd en moeite vraagt, volgens mij, onontbeerlijk.

Dankwoord

Mijn dank betuigen enkel in gezelschap van een kille monitor is een exercitie die gedoemd is te falen, maar ik probeer het toch.

Allereerst wil ik mijn promotoren en begeleiders bedanken voor hun geduld, de ruimte die ze mij gegund hebben om het onderzoek naar eigen (gebrek aan) inzicht uit te voeren en de hulp die zij mij door de jaren heen geboden hebben waarzonder ik –dat is zeker waar– dit proefschrift nooit had kunnen schrijven. In het bijzonder:

Eric, heel veel dank voor uw scherpe en nuchtere kijk op mijn schrijfsels. Door uw expertise en uw ervaring in het begeleiden van promovendi zijn mij, een leek, veel blamages gespaard gebleven. Ik vind uw onverstoorbare strijd om kinderen een gezonde en eerlijke start te geven bewonderenswaardig. Ik ben erg blij dat de samenwerking niet ophoudt bij dit proefschrift.

Medard, jij was mijn begeleider tijdens de eerste jaren van mijn promotie. Dat kan niet makkelijk voor jou zijn geweest. Mede door jouw kunde om mijn 'proto-argumenten' te identificeren en op basis daarvan mij aan te moedigen om verder te schrijven werd het doen van onderzoek aanzienlijk minder pijnlijk. Bovendien was het een voorrecht om begeleid te worden door een Homo Universalis (hij is onder andere: ethicus, filosoof, wiskundige en dominee)

Inez, heel veel dank dat jij, menig maal na een hectische dag, het vooruitzicht op een rustige treinrit liet sneuvelen om samen met mij in de auto te kletsen over onderzoek en safarireisjes, over filosofie en lekkere hapjes, over alle mooie en minder mooie dingen in de wereld. Ik ben blij dat jij naast jouw rol als promotor ook de dagelijkse begeleiding op je nam in de laatste fase van de promotie. Jouw aandringen om minder "eclectisch" zoals jij het noemde (en je bedoelde natuurlijk op basis van van-de-hak-op-de-tak-logica) te schrijven, heeft mij enorm geholpen om artikelen te produceren die *eindelijk* ergens over gingen. Maar belangrijker nog, ik heb me mede door jou altijd ontzettend welkom en thuis gevoeld op de afdeling. Ik voel me op mijn plek en ik ben jou dankbaar dat ik mag blijven.

Suzanne, jij bent echt super lief. Wie maakt dat nou mee dat hij, een simpele promovendus, wekelijks bij de hoogleraar mag komen eten zodat hij met een vol maagje avondcollege kan gaan geven. Jouw gastvrijheid, openheid en welwillendheid om te helpen en adviseren vind ik hartverwarmend. **Hannie,** ontzettend veel dank dat jij mij van begin aan af hebt gestimuleerd om mij in het onderwijs te verdiepen. En alhoewel

jij mooie en uitgekristalliseerde ideeën hebt over de meerwaarde en doelen van het ethiekonderwijs heb jij mij (maar eigenlijk iedereen) altijd de ruimte gegeven om het onderwijs zelf in te vullen. Dank je wel voor dat vertrouwen. Jij, –onderwijs-orkaan– hebt ook mij niet onberoerd gelaten en ik ben ontzettend blij dat ik als onderwijscoördinator mag blijven samenwerken met jou. **Ineke,** wie had dat nou kunnen bevroeden dat mijn scriptiebegeleider in Utrecht mijn collega in Rotterdam zou worden. En die collega een maatje zou worden waarmee ik gezellig in de kroeg over alles en niets kon praten. En dat vervolgens die collega die een maatje werd, wederom collega werd op de plek waar zij mijn scriptiebegeleider was. Dat bedenk je toch niet? Maar wat ben ik blij dat het zo gelopen is! **Yrrah,** ik ben blij dat ik je heb leren kennen. Je bent indrukwekkend slim en ik zie uit naar jouw promotie volgende week. **Jona,** ik kijk met veel plezier terug op onze gesprekken. Ik ben blij dat wij konden discussiëren over kunst, politiek, literatuur, filosofie en de wereld. Jouw genuanceerde kijk op zaken is benijdenswaardig en ik heb altijd het gevoel dat er een wereld van betekenis schuilt achter elk woord dat jij gebruikt. Ik ben nog lang niet uitgediscussieerd; nog lang niet klaar met kletsen met jou. Ik hoop jij ook niet. **Eline**, ik ben blij dat wij collega's zijn en blijven en ik hoop dat wij op een gegeven moment intensiever kunnen samenwerken. Ik steek namelijk veel op van jouw serene doeltreffendheid. **Karin,** wat zouden de eerste jaren van mijn promotie saai zijn geweest zonder jou! Dank je wel voor alle fijne gesprekken. We deden drankjes, we doen drankjes, en drankjes zullen we blijven doen! **Krista,** in menig dankwoord staat dat "het schrijven van dit proefschrift zou nooit mogelijk zijn geweest zonder persoon X" Maar in dit geval is het letterlijk, figuurlijk, overdrachtelijk, feitelijk en metaforisch, kortom in de meest volledige zin van het woord, *waar.* Dank je wel Krista voor al je hulp en voor alle gezelligheid. **Sabine en Meertien** ik ben dankbaar dat jullie mij wegwijs hebben gemaakt in de wereld van de preconceptiezorg. Ik vond het leuk om jullie te irriteren met mijn rare filosofische ideeën en ben blij dat jullie ondanks mijn 'ethische fratsen' enorm hebben bijgedragen aan de empirische stukken van dit proefschrift.

Dascha en Sem, jullie zijn intimiderend intelligent en ontzettend leuk en lief. Dank jullie wel dat jullie me wegwijs hebben gemaakt in Utrecht.

Rogier en Wendy, mijn paranimfen. Wendy, jij bent de beste kamergenoot! Dank je wel voor jouw openheid en eerlijkheid. Rogier, wij kennen elkaar al zo lang. Samen in het conservatorium op de trap gitaar spelen. Samen in Leiden een MOOC over 'Music and Society' ontwikkelen. Samen bij mij thuis discussiëren over Coltrane, computer games en onze snode plannen om de wereld over te nemen. Ik prijs mij gelukkig met een vriend als jij!

Elco, dank je wel dat je me eraan herinnert –keer op keer– dat de wereld veel verder rijkt dan de muren van de academie, dat de wereld veel verder rijkt dan de muren van het verstand.

Ik wil mijn lieve neefjes **Yasin** en **Elias** bedanken. Door hen voel ik me telkens weer een trotse oom. Ik hou heel veel van jullie! **Layla, Nabila en Fadoua**. Het is eindeloos veel moeilijker dan het schrijven van een proefschrift om uit te drukken hoe dankbaar ik jullie –mijn parels van zusjes– ben, voor alle steun en liefde. Allerliefste **Jihane**. Promoveren was zwaar voor mij, maar misschien nog wel heel veel zwaarder voor jou. Ik was er weinig en als ik er was, was ik er maar een beetje. Ik ben je dankbaar dat je genoegen nam met een halve Hafez en ik ben je dankbaar voor jouw geduld en jouw steun. Ik ben dankbaar dat ik mijn leven met jou mag delen. Ik hou van jou met heel mijn hart.

Papa en mama. Jullie kwamen met niets, helemaal niets. Jullie gaven mij alles, echt alles.

Curriculum Vitae

Hafez Ismaili M'hamdi is born on August 13th, 1981 in Weert, the Netherlands. He finished secondary school in 2000 and went to study jazz guitar at the Codarts conservatory in Rotterdam and the Royal Conservatory in The Hague where he graduated in 2006. Subsequently he started working as a music performer and a music teacher and he started studying philosophy at the Leiden University. There he obtained his Bachelor's degree in 2010. He did his Master in Applied Ethics at the Utrecht University and obtained his Master's degree in 2013. This is when he decided to give up his career as a music performer and a music teacher and pursue an academic career. He started his PhD project at the department of Medical Ethics and Philosophy of Medicine of the Erasmus MC in 2013 under the supervision of prof. Inez de Beaufort and prof. Eric Steegers who are his promoters. A year later he was invited to become a university lecturer in Music and Philosophy at the Leiden University where he developed courses and lectured on the topic of music and society. These courses included honors-classes and an E-learning module.

In 2017 he became a university lecturer in medical ethics at the department of Medical Ethics and Philosophy of Medicine of the Erasmus MC and at university lecturer in practical philosophy at the department of Philosophy and Religious Studies of the Utrecht University. Currently he is still working at both universities as a university lecturer. Together with his colleague Wendy Koster he was recently awarded a ZonMW grant to do further research on how to help women, in a morally justified way, to better prepare for pregnancy.

PhD Portfolio

Name PhD student: Hafez Ismaili M'hamdi
Erasmus MC Department: Medical Ethics and Philosophy, Hasselt University
Research School: OZSW

PhD period: 2013 – 2018
Promotor(s): I.D. (Inez) de Beaufort, E.A.P Steegers
Supervisor: I.D. de Beaufort, W.Pinxten

1. PhD training	Year	Workload (ECTS)
PhD research and academic courses		
- Systematic Literature Retrieval in PubMed and other databases, Endnote, Medical Library Erasmus MC	2013	1.0
- Ethics of Care and Health	2014	6.0
- Integrity in research, Erasmus MC	2017	2.0
- OZSW Winter School "Ethical Theory & Applied Ethics"	2013	6.0
- BKO: Basic Teaching Qualification for Higher Education, certificate obtained June 2016	2015 – 2016	5.0
National conferences		
- Oral presentation Congres Grootstedelijke perinatale gezondheid 3, De Doelen, Rotterdam	2015	2.0
- Oral presentation Congres SCEM preconceptiezorg Driebergen	2014	2.0
- Integrity in Research congress, Erasmus MC Rotterdam. Oral presentation: *"Nudging"*	2014	2.0
International conferences		
- Oral presentation 3rd European Congress on Preconception Health and Care in Uppsala (awarded first price for best oral presentation)	2016	2.0
- IAB World Congres Mexico	2014	1.0
- Oral presentation IAB World Congres Edinburgh	2016	2.0
- Group session presentation IAB World Congres Edinburgh	2016	2.0
Reading groups, seminars, and workshops		
- Reading group, Department of Medical Ethics and Philosophy, Erasmus MC	2013 – 2018	3.0
- Reading group "Ethics and health", OZSW	2013	1.0
- Expert meeting 'Ethical issues surrounding preconception care'	2016	2.0
2. Teaching activities		
- Diversity of ethical dilemmas, BA1 Medicine	2013 – 2017	8.0
- Academic writing and argumentation, BA2 Medicine	2015 – 2018	4.0
- Essay writing, BA2 Medicine (lecture, preparatory classes, grading)	2016 – 2018	4.0
- Bachelor essay, BA3 Medicine (grading)	2013 – 2018	10.0
- Medical ethics, BA1 Justice in health care	2015 – 2018	6.0
- Minor 'mystery of creation' lecture "The ethics of preconception care"	2014 – 2018	8.0
- Minor Ethics of Healthcare lecture "Justice and healthcare"	2015 – 2018	6.0
- Minor Ethics of Healthcare lecture "Ethical issues surrounding pregnancy"	2015 – 2017	4.0
- Supervision of theses, minor ethics of health care	2015 – 2018	3.0
- Supervision of theses, minor Mystery of Creation	2015 – 2018	3.0
- Lecture "Justice in Healthcare", Erasmus University College	2015 – 2016	4.0
	2015 – 2017	4.0