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.

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