Preconception Care: Concepts and Perceptions

An ethical perspective

Boukje van der Zee

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Preconception Care: Concepts and Perceptions
An ethical perspective

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Een ethisch perspectief

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Een verhaal begint

De wereld is nooit klaar
voor de geboorte van een kind.

(Wislawa Szymborska, 'Een verhaal begint', *Einde en Begin*, 1998)

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Chapter 1

General Introduction

To say that having a baby is one of life's richest, most rewarding experiences is a cliché that is nevertheless true. There is just nothing else quite like bringing new life into the world- the waiting, the wonder, the magic of creating enduring bonds of intimacy and sharing love. … For such an overwhelmingly important area of our lives, pregnancy, across the board, is stumbled and bumbled into. … There is, thankfully, a much better, safer, saner way to go to about this. We call it Prepregnancy Medicine.[1]

Please notice: preconception care is not directed at prospective parents expecting a baby, but at prospective parents wishing to become pregnant. The time that one could become pregnant easily, pleasantly and happily is over. All that currently matters is getting a healthy baby.[2]

Preconception care at a glance

General individual preconception care is a new strategy to improve the health of future children and their mothers –and to a lesser extent the prospective fathers' health- through primary intervention.[3] Improving their health through preconception care comprises two component actions. The first is to impart relevant information to prospective parents, thereby improving knowledge. The second is to modify individual behaviour based on the knowledge gained.[4] General individual preconception care anticipates on both these components and entails risk assessment, health promotion, counselling, and interventions. Risk assessment is the systematic identification and evaluation of risk factors for so-called adverse 'pregnancy outcomes'. Risk factors vary widely and include not taking folic acid supplements, using medication that can cause malformations or functional damage to an embryo, overweight, smoking, diabetes or having an inheritable disease. Health promotion means informing and educating couples on how to improve their health in order to improve the future child's health, including avoiding alcohol and tobacco, and the importance of proper nutrition and exercise. Prospective parents are counselled about additional screening, diagnostic tests, and specialist consultations that may be necessary if risks are identified. Intervention refers to efforts to modify or eliminate risk factors.[5]

Forms of preconception care

The recent development of general individual preconception care takes place in addition to other forms of preconception care, which have existed for some time: specialist individual preconception care and collective measures.[3] The term 'collective measures' is used when actions are aimed at a group of people as a whole and not individually tailored. An example of a collective measure with an impact on preconception care is an education campaign concerning the use of folic acid. Some of these measures apply to all women (and often also to men), regardless of whether or not they wish to have children.[3] *Specialist* individual preconception care may be offered to couples at increased risk of adverse effects on the child's health, including couples with complicated medical, obstetrical, or family histories. *General* individual preconception care may be offered to all people of reproductive age or focused on couples planning to become pregnant.[5] In this thesis, general individual preconception care is discussed, focused on couples planning to become pregnant.

Goals and beneficiaries of preconception care

Preconception care aims to improve the health of future children and their mothers and to a lesser extent the prospective fathers' health. Furthermore, it aims to improve couples' informed decision-making by providing information on reproductive options. It aims as well at improvements and cost savings at the public health level.

Following these goals, three beneficiaries of preconception care can be distinguished. The primary beneficiary of preconception care is the child, as it optimises the conditions for intrauterine growth and development. In general, antenatal care starts after the 12th week of pregnancy, neglecting the first gestational weeks, during which key embryonic growth and development take place and may be associated with adverse effects on the child's health.[6-8] To improve prospective parents' knowledge of these first weeks being crucial for the child's health, it is important that prospective parents are informed about potential risks *before* pregnancy. Preconception care, therefore may be a good way to assure appropriate actions to avoid risks in early pregnancy.

Additionally, preconception care can be seen as a window of opportunity to women's health, as through preconception care the woman may optimally prepare her body for a pregnancy. In addition, the changes induced by preconception care are also usually beneficial to the prospective parents' health. Furthermore, preconception care may increase awareness of possible health risks, contributing to a healthy lifestyle, also later in life.[9,10] Also, receiving information through preconception care consultation increases the prospective parents' options in the process of becoming pregnant, as it enables them to make informed choices: they will be informed if they choose to be informed; they can choose whether or not to live according to the lifestyle advice given; and in case of a severe inheritable disease, they may choose not to intervene at all, choose for medically assisted conception in combination with embryo selection, choose to forego parenthood, or they may choose to adopt a child.

Another benefit of preconception care is the improvement of public health, which is a result of the improvement of the individual's (prospective parents' and future children's) health. Furthermore, preconception care serves as an opportunity to screen for current and future health threats like malnutrition and obesity. As a public health strategy, preconception care may be a rewarding and cost-effective preventive strategy. The former Dutch Minister of

Health estimated the annual costs of implementing preconception care consultations, if all future pregnant women were interested, at €7 million.[11] In light of the many preventable adverse outcomes and the potential for preconception care to prevent significant lifetime costs for affected children, preconception care is likely to be cost-effective in the Netherlands.[12]

Organisation of preconception care

The organisation and content of preconception care depend on the national health-care infrastructure, insurance systems, and socio-economic factors. For example, in the United States, where only 50 percent of pregnancies are planned,[13] preconception care is placed in a continuum of women's health-care strategies, with the aim to 'catch' women with reproductive potential at any time they meet with a health-care provider.[14] In the Netherlands, however, 85 percent of pregnancies of native Dutch women are planned[I], making it possible to provide preconception care in individual consultations.[3]

The Health Council advised in 2007 to integrate general individual preconception care in the health care system.[3,15] The Council emphasised the importance of providing preconception care in a single package, to guarantee that all components ranging from risk assessment to intervention are covered. It was further argued that all these components would have to be easily accessible, enabling tailor-made care. There have been some initiatives regarding preconception care in the Netherlands: several pilot studies have been performed,[16-20] some midwifery practices offer preconception care, and some health care insurances cover preconception care consultation. However, to date preconception care has not been implemented in the Dutch health care system.

This thesis: preconception care from an ethical perspective

Although the health of our children is considered to be of the utmost importance, discussing the implementation of general individual preconception care in order to improve the health of children that are yet to be conceived has proven to be controversial. Ethical issues will in all likelihood influence the uptake and the success of preconception care. Therefore, a careful ethical analysis is needed. This study focuses on the evaluation of preconception care from an ethical perspective.

[I] At the 2nd European congress on Preconception Care and Health that was held in Rotterdam 4-5 October 2012 there was debate about the estimation of 80 percent of pregnancies being planned. According to some, this is way too optimistic and would the percentage reflect the pregnancies that are wanted, but not necessarily planned.

As the implementation of general individual preconception care is a new development, when the project started the literature on the ethics of preconception care was near to non-existent. It provided a unique opportunity to study ethical issues with an open view and from the very beginning of the practice. Moreover, an ethical evaluation on time makes it possible to influence the development of the implementation of general preconception care.

There are many arguments in favour of and against preconception care based on a variety of notions. In this thesis two ethical key themes are distinguished: arguments relating to the moral responsibilities for future children and arguments regarding the fear of medicalising the process of becoming pregnant.

With respect to the theme of moral responsibilities, this thesis will explore what can reasonably expected of prospective parents. Furthermore, it will discuss to what extent care-givers should be allowed to encourage prospective parents to modify risk factors, if deemed necessary for the health of the future child. It will also consider the moral responsibilities of governments with respect to the implementation of preconception care.

In addition, this thesis looks into the theme of medicalisation, a process by which non-medical problems become defined and treated as medical problems.[21] The argument of medicalisation is often used to criticize new developments in health care and it seems to function as a barrier for the implementation of preconception care as well. Several underlying issues will be identified.

Furthermore, women's and men's ideas about the process of becoming pregnant and preconception care are empirically investigated. It is discussed how these perspectives relate to an ethical evaluation.

Objectives

This thesis aims to provide an overview of the important ethical issues regarding preconception care and to systematically analyse those issues in order to further the debate on the implementation of preconception care on a wide scale. The main questions include:

- Which parties carry a moral responsibility with respect to preconception care? And what efforts may be reasonable expected of these parties?
- Is the argument of medicalisation a valid argument against the widespread implementation of preconception care and for not seeking preconception care?
- To what extent are prospective parents willing to engage in preconception care and what determines their intention?
- Would it be morally justifiable to include information about screening for Down syndrome in preconception care consultation and why (not)?

Methods

To answer these questions, this study relies both on ethical theory as well as on the practice of preconception care. Ethical analysis is closely linked with the practice of preconception care and based on the idea that a thorough analysis in applied ethics must be grounded in real life and contextualized so that it is sensitive to the lived experiences of the people whom the theorizing would affect once applied.[22] To facilitate the interaction between theory and practice, we used the method of the reflective equilibrium, because it does not assign a preferential status to either of them. The reflective equilibrium approach includes various elements, such as relevant background theories, principles, considered moral judgments and empirical data. All elements have an equal status at the start of the reflection and the method seeks to reach coherence between them. Some elements need to be altered or removed, others kept. The equilibrium reached is a dynamic one; it can change due to new elements in the reasoning process.[23-25]

This relation between practice and ethical theory gives the thesis an interdisciplinary character involving the fields of general practice, midwifery and obstetrics as well as the domain of medical ethics. As is common in multidisciplinary research, in this thesis a mixed methods approach is used, combining literature research, qualitative and quantitative research, and ethical reasoning.

The PhD project started with exploring the practice by observing several individual preconception care consultations taking place in the Erasmus University Medical Center and interviewing several providers of preconception care. Ethical evaluation was performed of the literature regarding the central ethical concepts ‘moral responsibility’ and ‘medicalisation’. Qualitative and quantitative research of women’s and men’s perceptions of the process of getting pregnant and preconception care provided empirical data, which are considered from a moral perspective. Furthermore, during the project three expert meetings were organised to present, discuss and refine preliminary study results. These meetings were attended by professionals engaged in the practice of preconception care, ethicists and policy makers. (Appendix, chapter 9) Finally, in the general discussion recommendations are provided for an ethically sound policy and practice of preconception care.

Terminology

The concept of ‘preconception care’ covers a broad range of applications in practice, from publicity campaigns and education for students, to genetic screening and programs to quit smoking. In this thesis preconception care is interpreted, unless mentioned otherwise, as general individual preconception care as a single package (referred to as preconception care consultation, preconception counselling or a pre-pregnancy clinic) that is directed at all couples wishing to become pregnant.

'Couples wishing to become pregnant' are also referred to as 'want-to-be parents', 'future parents' or 'prospective parents'. In chapter 3 'future parents' are explicitly distinguished from 'want-to-be parents' in the sense that the latter category intends to become pregnant, while this is not necessarily the case for 'future parents'. This distinction is not continued throughout the thesis and all terms mentioned may be used interchangeably.

Most of this thesis reports on women and their responsibilities, arguments, perspectives and preferences. This is mainly due to the scarcity of evidence on preconception care for men. Still, a moral reflection on paternal responsibilities is important. It should be noted that preconception care creates opportunities for both women and men, therefore, whenever applicable, this thesis means to include both prospective parents, 'the couple', also when not explicitly mentioned.

When referring to the health of future children, sometimes the rather alienating term 'pregnancy outcomes' is used. This term originates in the academic medical vocabulary. It originally includes not only the health of the child but also, for example a miscarriage, and the effects of the pregnancy on the mother. However, we use 'pregnancy outcome' and 'health of the future child' interchangeably throughout this thesis.

As discussed, the idea behind preconception care is that risk factors for adverse effects on the health of the future child are assessed and reduced in a timely manner, so that the chance of potential harm to future children is minimized. Throughout this thesis various kinds of risk factors are discussed. Some risk factors are considered separately or used as an example, for example not-using folic acid, the consumption of alcohol, overweight, diabetes and paternal smoking. Risk factors vary in many ways. The distinction that was made by the Dutch Health Council between risk factors that can and risk factors that cannot be influenced is one way in which risk factors may differ. In chapter 3 and 4 of this thesis the most essential aspects of risk factors are distinguished. Although not limited to lifestyle risk factors, the focus throughout this thesis is mostly on these lifestyle risk factors. Genetic risk factors are sometimes touched upon, however, ethical issues regarding genetic risks and genetic screening are not explicitly discussed (see for an ethical discussion of genetic risks for example De Wert, Dondorp, Knoppers[26])

Outline

Part I 'Concepts' (chapters 2,3,4,5) introduces and discusses the central concepts of this thesis.

Chapter 2 provides an introduction into the concept of preconception care: the benefits, the situation in the Netherlands and worldwide, several potential approaches and challenges.

Chapter 3 discusses moral responsibilities of prospective parents towards their future children to prevent them from harm by modifying potential risk factors before pregnancy. A risk-responsibility analysis is used to allocate moral responsibilities.

Chapter 4 focuses on a potential conflict between providing preconception care for men and the scarcity of evidence. We will elaborate on the risk-responsibility analysis of chapter 3 and introduce the evidence-modifiability-effort-severity-probability ratio to determine how much effort may be expected of future fathers and caregivers.

Chapter 5 morally evaluates the argument of medicalisation with respect to preconception care. Several underlying moral issues will be identified and it is discussed whether the argument of medicalisation is a valid argument for prospective parents not to seek out preconception care and for governments not to implement preconception care.

Part II 'Perceptions' (chapters 6,7,8) empirically investigates women's perceptions of the process of becoming pregnant and on preconception care. Findings are discussed from an ethical perspective.

Chapter 6 reports on a web-based survey that examines women's intention to seek preconception counselling after filling out the Zwangerwijzer ('Preparing For Pregnancy'), a national web-based risk assessment questionnaire. In addition it investigates the association between women's intention on seeking counselling and their risk profiles and personal motives.

Chapter 7 describes and reflects on in-depth interviews with women wanting to become pregnant. There seems to be a contradiction between what women think of preconception care in general and how they envisage preconception care in their personal situation. This chapter aims to explain this contradiction by analysing women's attitudes and perceptions with respect to the preconception period and preconception consultation.

Chapter 8 examines the desirability of extending the content of preconception care with information about prenatal screening for Down syndrome. First, women's perceptions are investigated by using a questionnaire. Then, from an ethical perspective, pros and cons are discussed and weighed.

Finally, Chapter 9 summarizes and discusses the main findings of the thesis, as well as the strength and limitations of the studies. Recommendations will be provided for the practice and policy of preconception care, and for further research.

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Part I

Concepts

Chapter 2

Preconception care: An essential preventive strategy to improve children's and women's health

Based on*: Boukje van der Zee, Inez de Beaufort, Sevilay Temel, Guido de Wert, Semiha Denktas, Eric Steegers. Journal of Public Health Policy 2011;32(3): 367–379

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* Changes in the chapters that have previously been published as articles have been made for stylistic reasons only

Abstract

Reproductive health has improved little in the last few decades. The Netherlands, particularly in large cities, has relatively high perinatal death rates compared with other European countries. Lack of improvement in reproductive outcomes despite improved quality of and better access to prenatal care strongly suggests that prenatal care alone is insufficient. We discuss how preconception care offers new strategies for improving reproductive health, how it usefully connects the life course of the affected individual and many health-care disciplines, and the benefits of combining a top-down policy structure and bottom-up organisation around caregivers. Given the likely benefits and cost savings calculated for the Netherlands, we conclude that failing to facilitate preconception care would reflect a breakdown of both professional and governmental responsibilities.

Introduction

Reproductive health results have not improved recently. In the United States, maternal mortality has decreased only modestly,[1] whereas increasing in the Netherlands.[2] In urban regions, perinatal health differs from the national average, especially in deprived areas of larger cities.

Reproductive health focuses on perinatal conditions related to risk of death: preterm birth, intrauterine growth restriction, congenital anomalies, and a sub-optimal start at birth. Researchers have explained these poor perinatal outcomes by the overrepresentation of non- Western women, women of low socio-economic status, and women living in deprived areas of the city–all associated with an accumulation of risk factors.[3,4] The lack of improvement in reproductive outcomes despite improved quality of and better access to prenatal care strongly suggests that prenatal care alone is insufficient[.5]

Preconception care may be a promising approach to improve both newborn and maternal health.[6,7] Chamberlain described preconception care as a specialty service for women, who had previously experienced a poor reproductive outcome.[8,9] Today, the importance of preconception health is becoming better understood. Studies and guidelines worldwide elucidate components of preconception care. With the exception of Hungary, we found no comprehensive national policies.

First, we define and list benefits of preconception care. Then, we consider the implementation of preconception care, paying special attention to the Netherlands, where perinatal death rates are high compared to other European countries.[10] We discuss alternative approaches to improve preconception health, then argue that preconception care should be organised through top-down, as well as bottom-up initiatives. Finally, we foresee a number of challenges that may accompany the implementation of preconception care.

Defining Preconception Care

Preconception care aims to optimise the health of the future child and to improve maternal health through primary interventions.[11] Preconception care entails risk assessment, health promotion, counselling, and interventions. Risk assessment is the systematic identification and evaluation of risk factors for so-called adverse pregnancy outcomes. If risks are identified, additional screening, diagnostic tests, and specialist consultations may be necessary. Health promotion means informing and educating couples on certain health-promotion issues and measures, including folic acid supplementation, avoiding alcohol, tobacco, and other drugs, and the importance of proper nutrition. Intervention refers to efforts to modify or eliminate risk factors. Specialist individual preconception care may be offered to women at increased risk of adverse pregnancy outcomes, including women with complicated medical, obstetrical, or family histories; those who have chronic diseases and conditions such as congenital cardiac defects. General individual preconception care may be offered to all women of reproductive age or focused on women planning to become pregnant.[12] We assess general individual preconception care focused on women planning to become pregnant.

Every couple is likely to have at least one risk factor for an adverse pregnancy outcome;[13] thus, every couple may benefit from preconception care. Preconception care can be seen as a window of opportunity to improve, at the same time, children's and women's health. We refer to evidence for several components of preconception care found in recommendations from the US Centers for Disease Control working group and three journal supplements in the American Journal of Obstetrics and Gynecology, the Maternal and Child Health Journal, and Women's Health Issues.[1,14–16]

The primary beneficiary of preconception care is the child. Preconception care is important for optimal intrauterine growth and development. Currently, antenatal care generally starts after the 12th week of pregnancy, neglecting the first gestational weeks, during which key embryonic growth and development take places and may be associated with an adverse pregnancy outcome.[17–19] Preconception care, therefore, is the best way to assure appropriate actions to avoid risks in early pregnancy. Surely a woman's lifestyle before pregnancy is the strongest predictor of her lifestyle during pregnancy.[20]

Preconception care may improve women's health before, during, and after pregnancy. A woman also optimises her fertility by adopting a healthy lifestyle.[21] In preconception care, women receive individual advice to enable them to make informed choices about getting pregnant. Women may change their lifestyle to optimize their chances of a good pregnancy outcome. The Health Council of the Netherlands considers this informed choice an important aim of preconception care.[11]

Preconception care may also increase awareness of possible health risks, contributing to a healthy lifestyle later in life.[22] Similar considerations hold, mutatis mutandis, for the father, whose lifestyle may also influence the health of the child: he shares parental responsibility for the child and may himself profit from a healthy lifestyle.[23] The woman may benefit directly, for example, when her partner stops smoking, or indirectly by receiving his support.

People receiving lifestyle guidance during preconception care may be more motivated to comply, not only for their health, but also for the health of the future child.

The Netherlands: A Single Package

In the Netherlands in 2007, the Health Council advised integrating general preconception care in the health care system.[11,24] The Council emphasised the importance of providing preconception care in a single package, to guarantee that no component be neglected. All would be easily accessible, enabling tailor-made care. According to the Council, the healthcare system would make preconception care part of a continuum – supported by developing guidelines for referrals, and keeping comprehensive records. Midwives, general practitioners, gynaecologists, and the maternal and child health services might be involved. The former Dutch Minister of Health recognised the importance of implementing preconception care, and asked a commission installed to advise on Dutch perinatal health (Stuurgroep Zwangerschap en Geboorte) to explore also the possibilities for implementing it. In 2010, before leaving that position, he acted upon the commission's recommendations, called on professional groups to establish preconceptional guidelines, and agreed to include preconception care consultations in health insurance packages.[25] The current Minister of Health advised, however, to evaluate the effectiveness of preconception care for high risk groups first.

Studies in the Netherlands looked at how to improve preconception nutritional lifestyle,27,28 folic acid supplementation,[29–31] and cystic fibrosis carrier screening.[32] Others studied comprehensive general preconception care as a single package.[33–36] In 2007, the city of Rotterdam conducted a pilot study.[37] Through public campaigns, parents-to-be were encouraged to complete a pre-pregnancy checklist on the Internet (www.zwangerwijzer.nl) and to send the results to a caregiver. Zwangerwijzer ('Preparing For Pregnancy') is a medically validated, freely accessible, web-based instrument for completion by the user. It identifies individual risk factors, and provides background information and advice about appropriate preventive measures.[38,39]

Some couples may not have easy access to the Internet or may have difficulties using it, especially those from lower income communities, who are non-Dutch speaking immigrants. They can visit a midwife practice, which organises preconception consultations, or ask their general practitioner to assist with completing the form. An additional risk assessment by trained professionals may be necessary to verify certain items, and to further explore identified risk factors. Using this information, the caregiver (generally the midwife or general practitioner) provides preconception advice and other health promotion information. Depending on the risk factors, the caregiver may refer the couple to a specialist, usually a hospital-based gynecologist or clinical geneticist. During the public campaign in Rotterdam, Zwangerwijzer website use increased, but not for preconception consultations, probably because of the campaign's short duration.

In 2009, the municipal council of Rotterdam and the Erasmus University Medical Centre started a citywide urban perinatal health programme to improve outcomes. Preconception care is a key element of this 10-year programme. Two preconception projects in two districts with deprived neighbourhoods began in 2009 and 2010. The planners adapted preconception care to the relatively low socioeconomic population: (1) collective campaigns using specific instruments (multi-lingual posters, leaflets, advertisements, and columns in the local media); followed by (2) a preconception education programme tailored to specific target groups (short courses for men/women about healthy pregnancy and the importance of preconception care); and (3) individual preconception counselling by a midwife or general practitioner combined with social services for parents-to-be.

In the Netherlands, researchers assessed the costs and effects of a mass campaign and of a single preconception consultation. They looked at folic acid supplementation and smoking cessation for all couples contemplating pregnancy. They based estimates on 200 000 women approached each year with an uptake rate of 50 per cent. Effectiveness and potential savings were based on hospital costs associated with neural tube defects and very low birth weight attributable to maternal smoking. If 50 per cent of women sought preconception counselling and if 15 per cent of those gave up smoking after counselling, and if 80 per cent of those women who had not done so started taking folic acid: 22 neural tube defects, 98 low-birth-weight infants, 10 very-low-birth- weight infants, and seven perinatal deaths could be avoided. Preventing neural tube defects and smoking-related morbidity alone could recover approximately 30 per cent of the costs of a preconception care mass campaign and consultations. The net costs were estimated between €3 million (uptake 50 per cent) and €4.1 million (uptake 75 per cent).[40] Recently, the former Dutch Minister of Health estimated the annual costs of implementing preconception care consultations, if all future pregnant women were interested, at €7 million.[25] In light of the many other preventable adverse outcomes and the potential for preconception care to prevent significant lifetime costs for affected children, preconception care is likely to be cost-effective in the Netherlands.[40]

Other Potential Approaches

Hungary, Belgium, Italy, Poland, France, United Kingdom, and Portugal in Europe have studied general preconception care.[11,41] In 2008, the first 'Central and Eastern European Summit on Preconception Health and Prevention of Birth Defects' was organised in Hungary, and in October 2010, the first 'European Congress on Preconception Care and Preconception Health' took place in Belgium.

In the United States, several organisations actively promote general preconception care – the Centers for Disease Control and Prevention (CDC), the March of Dimes, and the American College of Obstetricians and Gynecologists[42–44] – and their efforts led to two national summits.[45,46] An Expert Panel convened by the CDC published recommendations on preconception care.16 Canadian efforts also led to national guidelines.[47]

The organisation and content of preconception care depend on the national healthcare infrastructure, insurance systems, and socio- economic factors. In the Netherlands, for example, 85 per cent of pregnancies are planned,[11] whereas in the United States only 50 per cent are planned.[48] This alone could be why, in the United States, the proponents presented preconception care as a separate strategy, placing it in a continuum of women's healthcare strategies, with the aim to 'catch' women with reproductive potential at any time they meet with a healthcare provider.[43] To enhance awareness and health promotion, it might be possible to extend the target population and provide information to high school students.[49]

To increase awareness of the importance of preconception health and to extend basic knowledge such as the need for periconception folic acid supplementation, mass campaigns continue to be necessary. In the Netherlands, the rate of neural tube defects fell from 12.3 per 10000 children in 1997 to 6.3 per 10000 children in 2004,[11] reflecting, in part, an increase in the use of folic acid. In 1997, a one- time mass media campaign in the Netherlands promoted the use of folic acid. Appropriate folic acid use rose from 15 per cent in 1996 to 36 per cent by the end of 1998.[50] Folic acid supplementation in the Netherlands remains lower among non-Dutch women, who have low educational attainment compared to Dutch women.[50] Although successful, the aim of the campaign has not been fully achieved. Establishing changes in attitude probably requires programs that run for a longer period.[51]

To target subpopulations such as women with less education, it might be useful to use marketing tools like audience segmentation. This means dividing a population into smaller segments based on common characteristics so that an intervention can be tailored to a particular audience.[52,53]

Top-down in Addition to Bottom-up

Although preconception care has progressed over the past three decades, there remains room for improvement. In our view, two characteristics of preconception care favour a policy or top-down approach, in addition to initiatives organised by caregivers or bottom-up. First, general preconception care is a rather new concept, requiring a new mindset. Parents-to-be, as well as physicians remain insufficiently aware of pregnancy-related risk factors, possibilities for prevention, and of the role of properly timed, specific risk-reducing behaviour.[33]

Second, preconception care is multifaceted. It should be part of an interlinked chain that creates connections in the course of life – from preconception care through prenatal, neonatal, child, and youth care. And it entails many healthcare disciplines – general practitioners, midwives, obstetricians, clinical geneticists, plus maternal and child health professionals. To avoid bureaucratic barriers and to guarantee a continuum of optimal care these links are crucial.

These characteristics may complicate and slow bottom-up organisation of preconception care because many disciplines must reach a single consensus. Comprehensive national policies can facilitate bottom-up initiatives – by creating conditions to make initiatives work. Policy, for example, might oblige insurance companies to cover a preconception visit. We believe that governments should organise continuing mass campaigns to promote preconception health and preconception health care, and we expect them to be as successful, as was the folic acid campaign.[51]

Challenges

Many challenges and questions about preconception care, on organisational, practical, and ethical issues, must be addressed:[54]

- How best to organise preconception care to obtain optimal health results? No single format exists. Approaches in different countries must be explored and evaluated.
- Does preconception care spoil the naturalness, insouciance, and joy of becoming pregnant and having a child? This ethical objection to medicalization of becoming pregnant and of pregnancy is present in the Netherlands.[11] Medicalization may express many feelings and concerns about pregnancy. Related preventive care should not become an ethical shield against all preconception consultation as preconception care, like other types of preventive medicine, may have substantial health benefits.
- A practical (and perhaps moral) challenge is that the recipient of information and advice may not act on it.[55] Strong habits, addiction, or disbelief may mean that behaviour does not change. Parents-to-be may not want to change their behaviour. So what is their moral responsibility towards their future child? What interference with this choice, if any, is justified by potential dangers for future children? Efforts to set precise limits and allocate responsibility must not paralyse the debate, or the implementation of preconception care. Parents-to-be may be grateful for information, and for the chance to do what is best for the health of their child.
- Factors over which the individual has no control such as ‘inborn’ genetic risks, pose other challenges. Informing people about genetic risks may confront them with complex moral dilemmas. The Health Council of the Netherlands suggests dealing with this problem first by providing only general information on genetic risk factors, then letting women and couples decide whether they want more detailed information, and perhaps testing, to determine, for example, whether one carries a particular autosomal recessive trait.
- How to reach the most vulnerable subpopulations such as immigrants and those of low socio-economic status?[56] This may call for non-conventional methods. The two Rotterdam preconception projects engaged social peer group networks and community social workers as a means of connecting to specific groups. Migrant organisations, for example, used peer group educators.

Conclusions

All women should have an equal opportunity to receive adequate preconception care, taking into account the situation in their countries. As preconception care improves women’s health and that of future generations, not providing preconception care would be a failure of both professional and governmental responsibilities.

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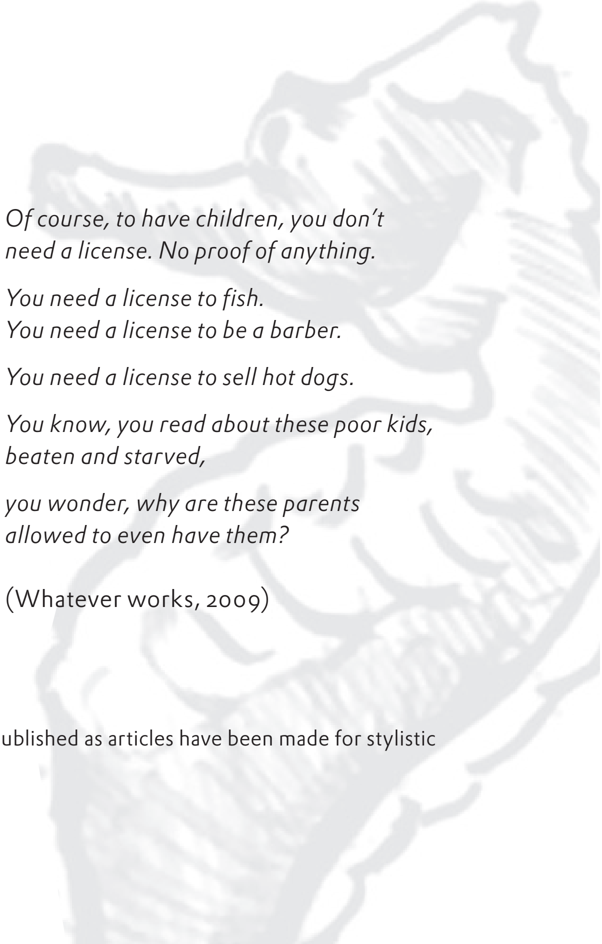
Chapter 3

Preconception care: a Parenting Protocol. A moral inquiry into the responsibilities of future parents towards their future children.

Based on[*]: Boukje van der Zee, Inez de Beaufort. Bioethics 2011;25(8):451-457



Of course, to have children, you don't
need a license. No proof of anything.

You need a license to fish.
You need a license to be a barber.

You need a license to sell hot dogs.

You know, you read about these poor kids,
beaten and starved,

you wonder, why are these parents
allowed to even have them?

(Whatever works, 2009)

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[*] Changes in the chapters that have previously been published as articles have been made for stylistic reasons only

Abstract

In the Netherlands fertility doctors increasingly formulate protocols, which oblige patients to quit their unhealthy lifestyle before they are admitted to IVF procedures. We argue that moral arguments could justify parenting protocols that concern all future parents. In the first part we argue that want-to-be parents have moral responsibilities towards their future children to prevent them from harm by diminishing or eliminating risk factors before as well as during the pregnancy. This is because of the future children's potential to become of a certain type, more specifically: a person that will be the want-to-be parents' child. Want-to-be parents intend to become pregnant and therefore have an additional moral reason to diminish the risks. Also, people who become pregnant unintentionally have the responsibility to prevent their children from harm, unless they become pregnant due to contraception failure. All people not wanting to become pregnant should use contraception methods carefully.

In the second part of this paper we translate the want-to-be parents' responsibilities into practice. We distinguish four determinants of risk factors: modifiability, chance, severity and effort. We examine some evidence-based risk factors based on these variables and deduce levels of responsibility.

In conclusion, formulating informal requirements for want-to-be parents is morally required and therefore also for want-to-be parents in need of medical assistance. The protocols developed by fertility doctors in the Netherlands could be seen as the precursor for a general, informal Parenting Protocol that could be developed on the basis of an extended and thoroughly debated risk-responsibility analysis.

Introduction

In the Netherlands fertility doctors increasingly formulate protocols, which oblige patients to quit their unhealthy lifestyle before they are admitted to IVF procedures. A common objection to this kind of regulation is: ‘Why should the wish for a child of these want-to-be parents be restricted, while others, in potentially worse situations, but not in need of medical assistance, may procreate freely?’ Fertility doctors justify the conditional access to the IVF procedure often by referring to the reduced IVF success rate, as a result of the reduced fertility through unhealthy situations such as overweight or unhealthy habits such as smoking and alcohol consumption. We will argue that the moral arguments concern all future parents.

Preconception care is a new preventive strategy that is directed at all future parents to improve the health of future children. The idea is that want-to-be parents are encouraged by public campaigns to visit a preconception care consultation. A preconception care consultation consists of a lifestyle and family history risk assessment and is accompanied by advice on how to diminish or eliminate the risks. If necessary, the couple is referred to a specialist.

We suggest that all those people who want to become pregnant have a moral responsibility towards their future offspring and therefore should reduce their individual risk factors. Firstly, we will argue that want-to-be parents are responsible for their future children by referring to the moral principle to prevent harm, the potential of becoming a person and the importance of the future parent-child relationship. Then, we will carry this idea of responsibility into the practice of preconception care. We will define preconception care and discuss some important evidence-based risk factors, which could be diminished or eliminated before the pregnancy. We will show that there are some levels of responsibility, dependent on four determinants of the risks: modifiability, chance, severity and effort. We conclude that preconception care is a useful way to practise what we preach.

1. Parental responsibilities

The notion that parents have responsibilities towards their children is not at all controversial. We hold parents responsible for the wellbeing of their child; we expect them not only to prevent harm and provide the basics for survival but also to take loving care of their offspring. Parents have particular responsibilities towards their children, which they do not have towards everyone else.

That people who are expecting a baby have a responsibility towards the unborn[I] is not very controversial either, assuming that they want to bring the pregnancy to term. Most people know that for example alcohol consumption may harm the unborn and it is common knowledge that pregnant women should not smoke. Also, Murray argues that the timing of harm is irrelevant: 'An act resulting in harm to a not-yet born person (who will eventually be a full-fledged person according to everyone's moral theory) is as great a harm as if it were done later.'[1] Potential persons should be protected from being harmed in their capacity of being future persons. That means that pregnant women have a moral responsibility not to harm the unborn child. But how should responsibilities towards future children be approached?

Future parents

The non-identity problem

Can the statement that the timing of harm is irrelevant be extended to the period before conception? One may wonder how children who do not yet exist, future children, could be harmed. Here, we have to face Parfit's famous non-identity problem: How can someone ever harm a potential person when each time there is the smallest difference, a completely different person will come into existence? As a result, we should balance a life that is not perfect against not living at all. Unless existence would be less than the minimal welfare standard, existence would always be preferred to non-existence.[2] It seems counter-intuitive, however, not to assign future parents any responsibility towards future children to prevent them from harm. Feinberg gives an example that makes clear the counter-intuitive character of the non-identity problem: someone places a bomb in a kindergarten, which will go off six years later. The act would lead to harming persons, independently of their non-existence at the time of the act. This shows that someone can be harmed by an act carried out before he was even conceived.[3]

In this paper we will not discuss this debate exhaustively, but we will shortly mention one of the solutions offered by Disilvestro and include a personal aspect. Disilvestro makes a distinction between the non-identity problem and the non-person problem. The main difference between the two is that the former is related to actual wrong-doing, whereas the latter relates to whether one could be wronged. The non-person problem is relevant for our analysis. The solution can be found in that it is the wronging of the person as a 'type' that matters, not the wronging of this particular 'token' person. Accordingly, he concludes that human organisms could be wronged, because they all have the capacities to become a person, and that the timing, before or after conception, is irrelevant.[4]

[I] We refer to the 'unborn' to avoid the complexities of the moral status of the embryo and the foetus. In our argument the emphasis lies on the decision to carry the pregnancy to term

In the solution we offer, the future child could be seen as a Disilvestro's 'type', complemented by a personal element. The 'type' reflects not only the future person but also the future parent-child relationship.

We acknowledge that a different person may come into existence after doing something different before the conception, but unlike Parfit, we do not consider that to be a problem. However, the genetic 'material' is not unlimited; we can speak of the 'collective of potential persons of parents A and B'. That 'collective' may be afflicted by harm resulting from the unhealthy behaviour of the prospective parents. One could define this as an impersonal as well as a personal relationship. It is impersonal in the sense that there will come into existence an unknown person, who may be influenced e.g. by certain life style changes, by genetic screening, or even by environmental exposures. However, it could be regarded as personal when understanding this unknown person as the future child of parents A and B. The collection of genes involved is enormous, but limited to those of A and B. And although the exact set of personal genes will be influenced by the preconception behaviour of the parents, the future relationship is crystal clear and unchangeable: the most intimate relationship possible, that between a parent and his or her child.

Want-to-be parents

So far, we have argued that future parents have a moral responsibility for the prevention of harm inflicted upon their future children. Translating this idea into practical choices, we face another problem: the (un)intentionality of getting pregnant. Because contraceptive measures are not fully reliable, one cannot completely exclude a pregnancy (except from accepting a celibate life). However, it is not realistic to expect all fertile people to behave responsibly towards future children. It would be excessive to judge all fertile people irresponsible when consuming alcohol, smoking or not taking folic acid supplements when they engage in sexual activities while taking all reasonable precautions not to get pregnant.

We propose therefore to draw a line using the concept of intention. When people intend to conceive children, then these want-to-be parents may be held morally responsible for the health of their offspring (to a certain extent, we will come back to this in the second part). This concept is more than a practical concept to limit the group of people that could be held responsible for future offspring: it is morally relevant as well. The moral concept of preventing harm is the same, but because want-to-be parents procreate intentionally and would usually prefer begetting a healthy child, the moral pressure to minimize risks is increased. O'Neill describes how, in her opinion, parental obligations arise: 'A standard way of acquiring obligations is to undertake them, and a standard way of undertaking parental obligations is to decide to procreate.'[5]

So, deciding to try to get pregnant is accompanied by a responsibility towards the future child to prevent it to a certain extent from being harmed. When a woman becomes pregnant unintentionally because contraception failed, she cannot be held responsible for harm that is inflicted upon the child before it was conceived, for example by smoking. When the prospective parents get to know that they are expecting a child and decide to continue the pregnancy, these responsibilities do fall upon them, which makes them responsible for preventing harm from that moment on.

There is a category of people that falls between these categories of getting pregnant intentionally and unintentionally. These people do not use contraceptives carefully and wouldn't really mind when they become pregnant, but do not strive for it. There may be several reasons for this ambivalent behaviour; one may be to prevent themselves from becoming obsessed about getting pregnant. In our view, these people could be blamed for not taking responsibilities with regard to the prevention of the future child from being harmed. When they really want this in-between solution, they should acknowledge the increased chance of getting pregnant and therefore make some lifestyle changes (see second part).

2. Parental responsibilities with regard to preconception care practice

In the foregoing we have drawn some analogies with parents and their existing children, parents-to-be and their potential children, future parents and their future children and ended up with want-to-be parents and their future children. We argued that in all these cases the parents are responsible for preventing the child from harm, irrespective of the timing.

Preconception care

In the Netherlands after the publication of the report of the Health Council on preconception care[6] the general reaction in the media was negative. People were complaining in the media and on the Internet that preconception care was 'carrying it too far' and that the pregnancy and the process of getting pregnant should be natural. They argued that this intervention is an intrusion into one's privacy and that doctors by offering preconception care impose medical values on people. We think that preconception care is not going too far, but instead offers the opportunity for want-to-be parents to behave responsibly. By stating this we assume that most want-to- parents prefer to have a healthy child and that knowledge about the existence of risks and how to modify them is often lacking. Currently, it is quite common that people try to change their lifestyle once pregnant, and for the duration of the pregnancy. Women often say: "I will quit smoking as soon as I know that I am pregnant." This argumentation makes clear that people lack important information, namely that their lifestyle before the pregnancy already influences the health of the future child. (And this also holds for the behaviour of the father.)

Kumar (cited by Disilvestro) also argues that one of the things that can be legitimately expected of prospective parents 'is that they undergo various preconception tests, in order to minimize the risk of their child being born with limiting disabilities or diseases.' And accordingly: 'Culpably failing to complete the required preconception testing would be to wrong their child, for it is their child whom they would be putting at risk by their failure.'[4]

Risk-responsibilities analysis

Unplanned pregnancies can be seen as a serious public health concern.[II] This might lead to the moral message that all pregnancies should be planned. Many other factors are expected to influence the health of the future child. More and more evidence is becoming available. Future parents are to a certain degree responsible for controlling their risk factors, insofar as these are based on evidence.

The risk factors for which the strongest evidence is available as analysed in the report of the Dutch Health Council will be discussed.[6] Recommendations for preconception care from the Centers for Disease Control and Prevention will provide this discussion with additional input.[7] (See these two documents for exact references.) The following risk factors mentioned have an increased change of an adverse pregnancy outcome:

- Folic acid deficiency: Daily use of folic acid (0,4 mg, for example in a vitamin supplement), starting at least four weeks before the desired conception and continuing for eight weeks thereafter, reduces the incidence of neural tube defects by two-thirds.
- Smoking: Smoking (active or passive) is associated with preterm birth, low birth weight and "cot death". These and other adverse perinatal outcomes associated with maternal smoking in pregnancy can be prevented if women stop smoking before or during early pregnancy. Because only 20% of smoking women successfully control tobacco dependence during pregnancy, cessation of smoking is recommended before pregnancy.
- Alcohol consumption: Alcohol consumption prior to conception adversely affects the fertility of women and men. Alcohol consumption during pregnancy is associated with fetal alcohol syndrome, spontaneous abortion and fetal death. Harm can occur early, before a woman has realized that she is or might be pregnant. Fetal alcohol syndrome and other alcohol- related birth defects can be prevented if women cease intake of alcohol before conception.
- Exposure to chemicals: Lead, methyl mercury compounds, cadmium salts, chromium VI and some of its compounds, metallic mercury and nickel salts are harmful to the unborn child. Avoidance could prevent these harms.

[II] In the Netherlands 85% and in the United States 50% of pregnancies are planned.

- Overweight and obesity: Overweight and obesity in pregnant women are associated with an increased risk of adverse pregnancy outcomes (e.g. pre-eclampsia and congenital abnormalities in the child). Obese women have an increased probability (1.5–3.0) of giving birth to a child with a neural tube defects and mortality among newborns is increased (2.5–3.4). Weight loss before pregnancy reduces these risks.
- Diabetes: Preconception care with close monitoring of blood sugar around the time of conception (and during pregnancy) could reduce the number of congenital abnormalities in this group of children. The three-fold increase in the prevalence of birth defects among infants of women with type 1 and type 2 diabetes is substantially reduced through proper management of diabetes.
- Anti-epileptic drugs: The use of anti-epileptic drugs by expectant mothers is associated with an increased risk (two- to threefold) of congenital abnormalities. Want-to-be mothers with epilepsy should, if possible, be switched to monotherapy during the preconception phase or the medication should be tapered down under the supervision of a neurologist.

Responsibilities should be tuned to the risks factors, which vary widely, but at least in four ways: modifiability, chance, severity and effort. The grading of these determinants of the risk factor is relevant for the level of responsibility. We need to emphasize that the following risk-responsibility analysis should be considered as a starting point; we do not endeavour to present an exhaustive and indisputable analysis. We explored some risk factors, for which very strong evidence is available. Other risk factors could also be analysed, but an 'uncertainty' factor should then be incorporated. Psychological risk factors such as stress, for example, are increasingly recognized to be important to the health of the future child's wellbeing. We are not a priori against incorporating psychological components in the analysis. However, we think that this needs to be considered carefully, because the consequences are potentially more intrusive into women's lives.

Modifiability

Firstly, there are differences in the extent to which the risk factor can be modified. A risk factor with regard to lifestyle can be changed, although it may not be effortless. Women who suffer from chronic diseases, such as diabetes and epilepsy have – an increased chance of harming the future child, mainly through medication-use. Proper disease management could reduce these risks. Some genetic predispositions, however, may harm the child severely, while there is not much one can do about it. The Health Council considers it to be important to offer proper information and, if necessary, genetic screening and counselling in order to enable want-to-be parents to make timely and well-informed reproductive choices. In the end, even when a genetic risk is found, several options remain: 'pre-implantation or prenatal diagnosis, donor insemination, adoption, or the decision not to have children.'[6]

Chance

The chance that the harm will occur matters as well, and accordingly, how much that chance could be reduced. For example, we know that heavy smoking is likely to lead to (very) preterm birth and (very) low birth weight. Therefore smoking cessation is very rewarding with respect to the health of the future child and determines the level of responsibility. The fact that we have to deal with a risk calculation resulting in chances that can be very small, instead of clear causality may make it more difficult to modify the risk factor. When not using folic acid supplements the risk of neural tube defects is still less than 1 percent (although it could be reduced by two-thirds by using supplements in the correct period). Although the risk is small, the severity of harm that could be prevented is immense.

Severity

The severity of harm that could be prevented is also relevant to the level of responsibility. This is quite complicated, given the uncertainties with regard to predicting and measuring the degree of harm. Firstly, although evidence increases, in many cases we do not know exactly what the effects of certain behaviour, medication use or chronic diseases are. In addition, potential negative effects could be very subtle, for example preconceptional alcohol consumption could have a negative effect on intelligence. These subtle effects are hard to measure. It is even getting more complicated, since recent research indicated that we should understand the risk factors from a life course perspective: e.g. maternal smoking appears to be an important indicator of aggressive behaviour in adolescence. Despite the lack of evidence with respect to some potential risk factors, other things are clear-cut; we can reason easily, that drinking a glass of wine may not be good for the future child, but that drinking a bottle undisputedly presents a risk of greater harm to the future child.

Effort

The efforts necessary to eliminate or diminish a risk factor are also a variable of risk factors that partly determines the level of responsibility. Taking folic acid supplements is relatively easy. It may be very hard, on the other hand, to quit smoking because it is an addiction. Obesity is very hard to take on, because it is related to a complex pattern of causes including social and genetic causes. With regard to the reproductive options that remain when a genetic risk is found, these actions are very demanding and are probably better explained in terms of a 'burden' rather than in terms of 'efforts'.

Allocated responsibilities

The responsibility for reducing risk factors should not only be taken on by the child's future mother. The father is also responsible for the risk factors he is able to control, for example alcohol consumption and not smoking, because of the negative effects of indirect smoking. Governments should also take responsibility; they should create a climate in which it is attractive to live healthily and easy to choose the healthy option instead of unhealthy alternatives. Governments should also organize mass campaigns to create awareness about the importance of preconception health and preconception care. Doctors are responsible for being alert and aware when they provide patients in the reproductive age (women and men alike) for example with medication that is teratogenic. Employers should offer want-to-be parents the opportunity to avoid exposure to chemicals. With respect to the evidence-based risk factors mentioned, we suggest the following responsibilities for future parents:

- Folic acid deficiency: The chance of having a child with a neural tube defect could be reduced (modified) by two-thirds by taking supplements. Although the chances are small, the severity of the harm that could be prevented is immense and the efforts are low. Therefore, we think that future mothers are morally responsible for reducing the risks for neural tube defects.
- Smoking: Stopping smoking reduces many possible adverse effects for the health of the future child. The chances of adverse effects are huge as well is the harm that could be prevented. The efforts are great as well. Responsible future parents should quit smoking. As conquering an addiction is hard the future parents should be offered help.
- Alcohol consumption: Alcohol consumption should be limited and preferably stopped completely to reduce adverse effects on the future child. Consuming alcohol is harmful for the child and the harms are potentially great (depending on the amounts). Addicted people may have a hard time modifying this risk factor, whereas for others it has minimal impact. Responsible future parents (women and men alike) should cease the consumption of alcohol or reduce it to a minimum before conception: when needed, help should be offered.
- Exposure to chemicals: Exposure to chemicals could harm the unborn child. This risk factor is partly modifiable: women could avoid chemicals for example by not painting the baby’s room during or just before pregnancy. Exposure related to working conditions is partly modifiable, as the employer should collaborate as well. Environmental causes of exposure (pollution), for example living near a waste dump, are very hard to modify. The chances and the severity of harm are substantial. The effort that it would take depends on the situation. Refusing work because of exposure, while the employer is not willing to collaborate, with being fired as a result, may perhaps be too much to ask. The same can be said for moving away from the waste dump. Not painting the baby’s room could be regarded as no effort at all. To what extent future parents are responsible for avoiding exposure depends on the situation.
- Obesity: Obesity and being overweight are potentially harmful to the child and the likelihood is apparent. Losing weight could diminish the risk factor. Obesity, however, as mentioned, has a partly genetic basis and losing weight for these people can be even harder than it is for other people to diet. Even so, one could ask if certain genetic predispositions cannot be ‘overcome’ or fought.

- Diabetes: Children of diabetic women have an increased chance of having birth defects. Proper disease management could modify this risk factor, so that the chances decline to one-thirds. 'Birth defects' could differ in severity. However, the effort seems not to be very demanding; diabetic women should inform their caregiver, who will monitor their blood sugar. We judge diabetic want-to-be-mothers responsible for consulting their caregiver.
- Epilepsy: Epileptic drugs are related to an increase (two- to threefold) in malformations in newborns that could be reduced by temporarily altering medicine use. Altering medicine use may not be comfortable because of an increased chance of having an epileptic attack. These efforts should be undertaken anyhow, because of the severe harm that could be prevented.

The terrain of genetics is a very complicated and much debated area, because although the harm that could be inflicted upon the child is often exactly predictable and clear-cut and the severity of the harm can be huge, the modification of the risk factor can be very demanding. In the ultimate case, people could be advised not to become biological parents.

Conclusion: a Parenting Protocol

We have argued that want-to-be parents have moral responsibilities towards their future children to prevent them from harm by diminishing or eliminating risk factors before the pregnancy. This is the case because of the future children's potential to become of a certain type, more specifically: a person that will be the want- to-be parents' child. Want-to-be parents intend to become pregnant and therefore have additional grounds for diminishing the risks. Also, people who become pregnant unintentionally have the responsibility to prevent their children from harm, unless they become pregnant due to contraception failure. All people not wanting to become pregnant should use contraception methods carefully.

In the second part of this paper we translated the want- to-be parents' responsibilities into practice. We distinguished four components of risk factors: modifiability, chance, severity and effort. We examined some evidence- based risk factors using these variables and deduced levels of responsibility.

To conclude, formulating informal requirements for want-to-be parents is morally required and therefore also for want-to-be parents in need of medical assistance. However, this does not justify these want-to-be parents being refused treatment when they are not behaving responsibly. The implementation of formal protocols (legal regulation) is a delicate issue and should be investigated carefully. The protocols that were developed by fertility doctors in the Netherlands could be seen as a precursor for a general, informal Parenting Protocol that could be developed on the basis of an extended and thoroughly debated risk-responsibility analysis.

Discussion

We are aware of some blurry boundaries that may obscure our risk-responsibility analysis. Allocating responsibilities to future parents may result in a slippery- slope scenario, which could evolve into regulations that only accept perfect parents to produce perfect children.

This non-ideal scenario sketch contains three elements. Firstly, should the allocation of moral responsibilities be regulated? LaFollette argues that all parents should be licensed. He mainly discusses a psychological competence for rearing children.[8] In reality, existing parents and pregnant women could be deprived of parental rights; this is not possible before the pregnancy. We think it is undesirable to discipline future parents by punishment after they have not behaved responsibly. Instead, we think that future parents should be informed about reproductive opportunities and preconception care; there are circumstances in which this could be done carefully. We agree with Savulescu's solution; he emphasizes that there is a moral responsibility and that non-directive counselling in this case is not appropriate. Counselling should instead be directive; future parents should be persuaded to behave responsibly, but not be coerced. We would like to add that the degree of persuasion should be adjusted to the results of the risk-responsibility analysis.

Secondly, the 'perfect' part of the scenario sketched. In our risk-responsibility analysis we draw a line by the undisputed principle of 'preventing harm'. Others, however, believe that we have a moral obligation to create the best children.[III] Savulescu, for example, is convinced that our responsibilities for future children exceed the harm principle. He developed the principle of procreative beneficence:[IV] couples should 'select the child of the possible children they could have, whose life can be expected, in light of the relevant available information, to go best or at least not worse than any of the others.'[10] The consequence of Savulescu's principle would mean that 'potential parents can be persuaded into using IVF, PGD and ES, in order to create children who have the best inherited traits, and, as a consequence, the best possible lives.'[10] We are aware of the fact that in some cases there is a thin line between negative and positive engineering. In this paper, however, we discussed the responsibilities of future parents to prevent their future children from harm.

Finally, we suggested that parents would 'produce' children. This refers to the medicalization debate. Preconception care would spoil the natural and romantic process of getting pregnant. It is evident that the process of getting pregnant could lose some of its naturalness. However, these losses are not at all in proportion to the prevention of harm to a innocent dependent third party: their own child. Above all, Purdy is right when she suggests that efforts, or even sacrifices, should be made out of love: 'What I see is the demands of love: to love someone is to care desperately about his or her welfare and to want only good things

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[III] See for this interesting debate e.g. Savulescu, Hayry, Harris, Glover.

[IV] As others have done before him, e.g. J. Harris in Superwoman and Superman for him or her. The thought that I might bring to life a child with serious physical or mental problems when I could, by doing something different, bring forth one without them, is utterly incomprehensible to me. Isn't that what love means?'[11]

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Chapter 4

Ethical aspects of paternal preconception lifestyle modification

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Abstract

This Clinical Opinion points to a potential conflict between the scarcity of evidence on paternal preconception risk factors for adverse pregnancy outcomes and the view that preconception care should be also directed at men. We argue that from an ethical perspective, responsible fatherhood starts already before conception, as long as evidence increases on the benefits of paternal preconception lifestyle (modification). Our explorative study suggests that the strength of the evidence for paternal preconception lifestyle modification is also important for men. We argue that five aspects together determine the moral responsibility of prospective fathers to modify their behavior: the strength of the evidence on which the risk factor is based, the modifiability of the risk, the efforts necessary to eliminate or diminish the risk factor, the severity of harm, and the probability that harm will occur and that it will be prevented by modifying the risk factor.

Introduction

To further improve the health of future children, it is suggested that preconception care should also be directed at men.[1-4] Improving the outcome of pregnancy through preconception care for men comprises two component actions. The first is to inform prospective fathers adequately, thereby improving their knowledge. The second is for these prospective fathers to modify their individual behavior based on the knowledge gained.[5] However, evidence of the effects of paternal preconception lifestyle – and of the modification of that lifestyle – on the health of future children is scarce.[1-4] Moreover, research on men's willingness to engage in preconception care is lacking. This raises the question whether the suggestion to direct preconception care also at men is at odds with the scarcity of evidence.

In this Clinical Opinion we will discuss whether the suggestion to direct preconception care at men and the scarcity of evidence are at conflict. We start with investigating whether there is a moral basis for expecting men to engage in preconception care. Next, we will discuss the findings of our explorative study. Then, we will argue that risk factors for adverse pregnancy outcomes have five aspects that together determine how much effort can be expected of prospective parents to prevent harm inflicted upon the future child: the strength of the evidence on which the risk factor is based, the modifiability of the risk, the efforts necessary to eliminate or diminish the risk factor, the severity of harm, and the probability that harm will occur. We will finally indicate what preconception care for men could look like.

Early responsible fatherhood

Whereas most reproductive interventions are directed at women only (and possibly men in a supportive role), preconception care can involve men as well. Men and women contribute equally at conception by each providing fifty percent of the genetic material. Preconception care provides an opportunity for paternal[I] involvement before pregnancy through offering men information and, if necessary, making interventions. Prospective fathers can contribute to the future child's health by, as recommended in this journal in 2008, "undergoing a comprehensive medical evaluation", and modifying "any high-risk behaviors or poorly controlled disease states before conception is attempted".[6]

There is much literature on fatherhood that reports on absent and uninvolved fathers.[7] In a paper about ways to improve paternal involvement in pregnancy outcomes, Bond et al. define paternal involvement in pregnancy outcomes as "activities or practices by the male partner

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[I] Strictly speaking, during preconception there is not yet a father and thus no 'paternal' involvement. Throughout this Clinical Opinion, however, we also include the preconceptional period when using the term 'paternal' or 'fatherhood'.

and a couple anticipating birth that ideally lead to an optimal pregnancy outcome”.[8] In other words, paternal preconception involvement is the effort made by men to optimize the future child’s health.

The father-as-progenitor and the father-as-carer

Ives et al. argued that men see fatherhood as a dyadic concept: the father-as-progenitor and the father-as-carer. In an interview study they found that men considered the father-as-progenitor as a state of being and the father-as-carer as a state of doing. Only the father-as-carer was valued as moral fatherhood, because it was assumed that men needed to make an effort to be a successful father and failing to do so led to being judged as a bad father. The father-as-progenitor, on the other hand, was not a good or a bad father; he only ‘produced’ children.[9]

According to this view, a man was only a father-as-progenitor before conception. However, if evidence increases and it becomes clear that the prospective father’s preconception health matters as well and that men must make an effort to optimize the health of future children, the moral distinction between these two ‘types’ of fatherhood no longer holds. By generating evidence on the effects of improving men’s preconception health, the distinction between the father-as-progenitor and the father-as-carer disappears: both types of fatherhood have a moral dimension. Thus, from an ethical perspective, responsible fatherhood will already start before conception, as long as evidence increases on the benefits of paternal preconception lifestyle (modification).

Explorative interview study

What views do men have on this perspective of ‘early’ fatherhood? For explorative purposes we interviewed[II] nine men about their attitudes towards paternal preconception lifestyle modification; eight without children who had a latent or active child wish, and one ‘young’ father (see Table 1 for key questions). All respondents perceived birth or the prenatal period as the start of paternal responsibilities. However, when potential benefits of preconception lifestyle modification for their future children’s health were pointed out to them, almost all ($n = 8$) acknowledged that paternal responsibilities could already start before pregnancy.

Another finding of this small inventory was that the majority of respondents demanded strong evidence of the effects of lifestyle and lifestyle modification in order to consider lifestyle modification before pregnancy. They were in principle not unwilling to modify their lifestyle, but they needed to be convinced of the benefits with evidence-based facts, e.g.,

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[II] According to Dutch law, no IRB review is needed for this type of study. All respondents were adequately informed on the study before participating, and all agreed to participate.

Table 1: Key questions

What do you consider to be good fatherhood and what responsibilities come along with it?
When does parental responsibility begin?
What do you do to prepare for fatherhood?
To what extent do you believe that your lifestyle affects your future child's health?
Are you willing to adjust your lifestyle if that is recommended?
Some lifestyle adjustments are expected but not proven to positively affect the birth outcome. Does the lack of proof change your intention to adjust your lifestyle?
Who would you prefer to provide you with paternal preconception lifestyle information?

"I need to be convinced that there is a causal relation and then I will modify my lifestyle. I am a real critic, I can't apply vague assumptions."

The importance of evidence reappeared when asked which provider they preferred for preconception care. The men's answers varied (general practitioner, midwife, gynecologist, special counselor), but the reasons they gave were the same: they wanted to receive information or care from the 'real specialist'. That specialist must be able to convince them with evidence, preferably using exact percentages, and should have answers to all their questions. For example: "I get many contradictory pieces of advice, so it would be useful to attain clarity from an expert."

This exploration suggests that prospective fathers recognize the ethical importance of evidence regarding paternal preconception lifestyle (modification). Motivation for lifestyle changes before conception seems to be based on evidence. When evidence is lacking or weak, this is apparently a barrier.

The prevention of harm

In the following we will further discuss the role of evidence and other aspects that play a role in what one may reasonably expect of prospective fathers. A general moral principle is the principle of non-maleficence, which prescribes the prevention of harm.[10] Applied to the role-specific responsibility of a prospective father, this moral principle prescribes the prevention of harm to his future child as well as harm to his partner, the prospective mother. Because there are many kinds of potential harm, we will first illustrate our argumentation with a case before addressing the question of how much effort we may expect from prospective fathers.

Case: Paternal preconception smoking

For many paternal preconception lifestyle risk factors for adverse pregnancy outcomes such as alcohol use and various occupational exposures, findings are not consistent yet.[4] We here focus on one of the few risk factors for which there is evidence: regular paternal preconception cigarette smoking. In the literature, emphasis lies on the direct harm of smoking. However, from an ethical perspective it is important to distinguish between direct and indirect harm, both with respect to the future child and with respect to the partner.

Direct harm

Cigarette smoking is known to cause DNA damage in sperm.[1,11] Sperm containing DNA lesions can still fertilize an ovum, which may lead to pathology in the offspring.[11] There is an association that seems to be evidence-based between paternal preconception smoking and childhood acute lymphoblastic leukemia (ALL).[11,12] Liu found that the association between preconception smoking and the chance that a child develops ALL is increased with 25%,[12] and Milne found this increase to be 44% for the paternal smoking of ≥20 cigarettes per day around conception.[11] The potential harm to the child caused by a prospective father's preconception smoking behavior, we call direct harm. Smoking fewer cigarettes seems to carry less risk. Adverse effects of preconception smoking are likely to be reversed by removing the exposure.[11]

It should be noted that the studies discussed focus on the relative risk of the behavior, which is the increased chance of the future child developing childhood ALL. The relative risk is considerable (25-44%). However, considering the absolute risk, we must acknowledge that it is very small. Between 1973 and 1998, the incidence rate in the US of ALL for children and adolescents under twenty years old was almost 27 per million (0,0027%).[13] The adjusted incidence rate based on a presumed increase of 25% is about 34 per million (0,0034%).

The smoking behavior of the prospective father may have a direct adverse effect on the prospective mother as well, by exposing her to secondhand smoke.[14] Reducing the number of smoked cigarettes indoors is likely to reduce harm, and smoking outside could bypass this direct harm altogether.

Indirect harm

Although maternal preconception smoking has not been associated with childhood ALL,[11] there is wide consensus that maternal smoking during pregnancy has adverse health effects on both the pregnant woman and the future child, such as prematurity, and mortality.[15,16] To prevent these kinds of harm, women should be encouraged to stop smoking before pregnancy. The prospective mother's smoking behavior is associated with that of the prospective father.[17-19] When a prospective father smokes, chances are smaller that a prospective mother wants and succeeds to stop smoking.[17-19] So paternal preconception cigarette smoking also has indirect adverse effects on the woman's health and therefore on the child's health. Paternal smoking cessation thus reduces the chance that indirect harm is inflicted upon the partner and future child. It should be noted that this indirect harm is only relevant in the case that the mother smokes.

Five aspects of harm: the EMESP-ratio

The principle of non-maleficence prescribes the prevention of harm and we showed that there are two ways in which paternal preconception smoking may cause harm. Could we thus conclude that we may expect prospective fathers to quit smoking? This is not necessarily the case. The risk factor has five aspects that together determine as to whether lifestyle modification may be expected of prospective fathers: the strength of the Evidence on which the risk factor is based, the Modifiability of the risk, the Effort necessary to eliminate or diminish the risk factor, the Severity of harm, and the Probability that harm will occur and that it will be prevented by modifying the risk factor.[20] We will discuss these aspects one by one.

Evidence

The AJOG's special supplement on the clinical content of preconception care includes a recommendation on preconception care for men, stating: "Despite the challenges and barriers, we recommend that each man who is planning with their partner to conceive a pregnancy should undergo a comprehensive medical evaluation for the purposes of disease prevention and detection and preconception education. Management should be optimized for any high-risk behaviors or poorly controlled disease states before conception is attempted".[6] The strength of the evidence for this recommendation was valued as 'fair'. [6] This 'fair' evidence for taking action falls under one of five situations or categories: There is (A) good or (B) fair evidence to include a particular risk factor in preconception care; there is (C) insufficient evidence to decide upon inclusion or exclusion; or there is (D) fair or (E) good evidence to support the recommendation that the risk factor be excluded in preconception care (Table 2).

What do these categories of evidence mean from an ethical perspective? First of all, we consider the distinction between sufficient and insufficient evidence to include or exclude the risk factor to be of major moral importance. Wrongly attributing sufficiency would be unjust,

Table 2: Strength of evidence[6]

Category	Meaning
A	There is good evidence to support the recommendation that the risk factor be considered specifically in a preconception care evaluation.
B	There is fair evidence to support the recommendation that the risk factor be considered specifically in a preconception care evaluation.
C	There is insufficient evidence to recommend for or against the inclusion of the risk factor in a preconception care evaluation, but recommendation to include or exclude may be made on other grounds.
D	There is fair evidence to support the recommendation that the risk factor be excluded in a preconception care evaluation.
E	There is good evidence to support the recommendation that the risk factor be excluded in a preconception care evaluation.

because it would lead to wrongly attributing moral responsibilities, undermining people's confidence and willingness to accept medical advice. Wrongly attributing insufficiency to include a risk factor would be unjust because it may cause harm. Whether evidence is fair or good, is less important, according to us. The precautionary principle is the moral basis for including a risk factor for which the evidence is fair. The principle suggests that when there is reason to believe that someone will be harmed, it would be irresponsible to wait for definitive evidence: it is better to be safe than to be sorry. We suggest making one moral category of the fair and good evidence to exclude a certain risk factor, as it is important to exclude a risk factor when there is reason to believe that it does not result in harm. If not, prospective fathers may be overcharged, and they may wrongly prioritize risk factors, thereby not preventing harm to occur.

Three moral categories can thus be derived from the former five: sufficient evidence to include a certain risk factor, sufficient evidence to exclude a certain risk factor and insufficient evidence. Generally speaking, risk factors that have sufficient evidence for possibly causing harm call for modification. When using a broader interpretation of the precautionary principle, a risk factor for which there is insufficient evidence to be included in preconception care may also occasionally call for modification, e.g., when the chances of modification are good, the effort is small and the potential harm is severe and likely to occur.

Concerning the risk factor 'paternal preconception smoking', we assume that the evidence qualifies as sufficient. This aspect of the risk factor indicates that prospective fathers should indeed modify this risk factor in order to prevent harm both to the prospective mother and the future child.

Modifiability

With regard to the modifiability of the relative risk induced by paternal preconception smoking, the prospective father may decide to smoke outside, to decrease the amount of cigarettes or to quit smoking altogether. Smoking outside bypasses the direct harm to the mother caused by passive smoking. Decreasing the amount of cigarettes decreases the chance of direct harm to the future child and the prospective mother. Smoking cessation would eliminate direct harm to them. If the prospective mother smokes, paternal smoking cessation increases the likelihood that the prospective mother will quit as well and therefore reduces the chance of indirect harm to the mother and child.

Effort

Tobacco use results in true drug dependence in most users, making attempts to quit difficult and relapses common.[14] Only 3 to 5% of people that stopped smoking maintain their quit attempt for 6 months or longer.[21] This indicates that smoking cessation is very hard. Decreasing the number of cigarettes could be considered less burdensome than stopping smoking altogether, but the effort might still be considerable. Smoking outside might be a comparatively small effort for the prospective father.

Severity

Leukemia in future children is indisputably very serious. The direct adverse effects on the health of the prospective mother by secondhand smoke are severe. In the case that the prospective mother smokes, the indirect effects to her future self by continuing smoking are serious as well. Indirect harm to the child by the reduced chance that the mother will stop smoking during pregnancy entails increased morbidity and mortality, and is thus severe.

Probability

As mentioned previously, with respect to the probability (the absolute risk) of harm, ALL is a rare disease. Although the chance that it will occur is increased with 25 to 44% for fathers who smoked preconceptionally, the incidence rate continues to be very small (0,0034%).

We will call the combination of these five aspects the Evidence-Modifiability-Effort-Severity-Probability(EMESP)-ratio. Based on the EMESP-ratio we may draw some tentative conclusions about whether one may expect prospective fathers to modify paternal preconception cigarette smoking.

There is sufficient evidence of the potential direct and indirect harm inflicted upon the future child and prospective mother and of the prevention of this harm through modification. There are three kinds of modification: smoking outside, reducing the number of cigarettes, and smoking cessation. With respect to smoking outside, only direct harm to the prospective mother is modified. The required effort is small and the potential harm is serious and likely to occur. Therefore, the EMESP-ratio suggests that the prospective father may be expected to smoke outside.

The effort required to reduce the number of cigarettes is moderate, so we argued. The prevention of direct harm to the child would still be present after modification, but to a smaller extent. The same holds for direct harm to the prospective mother. The harm both to the future child and the prospective mother are qualified as serious. Although the probability of direct harm to the child is very small, direct harm to the prospective mother is likely to occur. Therefore the EMESP-ratio suggests that prospective fathers should reduce the number of cigarettes they smoke.

Concerning the modification 'smoking cessation', although direct harm both to the future child and the prospective mother may be very serious, the effort is considerable. Furthermore, the absolute direct risk to the child is very low. The probability of direct harm to the mother is likely; however, another modification is possible, i.e., smoking outside, with the same result but requiring less effort. So far, the EMESP-ratio does not suggest that one may expect a prospective father to stop smoking.

This conclusion changes, however, if the prospective mother is a smoker herself. Smoking cessation of the prospective father is the strongest predictor of successful smoking cessation of the prospective mother, which is important for preventing harm to herself and her future child. Paternal preconception smoking cessation thus reduces the chance that indirect harm is inflicted upon the prospective mother and future child. This harm is severe and likely to occur if paternal smoking is continued, and there is no alternative requiring less effort. In addition, direct harm to the prospective mother and the future child is prevented as well through paternal cessation of smoking. In sum, in the case that the mother smokes, although the effort is considerable, the EMESP-ratio suggests that one may expect a prospective father to quit smoking altogether.

Using the EMESP-ratio in preconception care for men

An ethical reflection of the specific content of preconception care falls beyond the scope of this paper. We indicate what preconception care for men could look like in general. Men should receive all relevant information, while an information overload should be avoided. We propose to provide information on the risk factors with an EMESP-ratio above a certain threshold. Therefore, information should be provided on risk factors that are based on sufficient evidence, that can be modified, for which the effort is reasonable, potential harm is severe and the probability that harm will occur is likely. Occasionally, information may also be provided on risk factors for which there is insufficient evidence, but for which the ratio is nonetheless above the threshold if and because the potential harm is severe and likely to occur and/or the effort for the modification is very small.

Responsibilities do not only rest on prospective fathers. Caregivers should provide prospective fathers with relevant information. We consider non-directive counseling[III] to be inappropriate and we favor a directive approach instead. In our view, if the threshold of the EMESP-ratio is met, caregivers should recommend lifestyle modification. Furthermore, if a prospective father is not willing to make an effort to modify his lifestyle, the caregiver may well encourage him to do so. If he does not succeed in lifestyle modification, caregivers should offer advice and help. Regarding the risk factor ‘paternal preconception smoking’, for example, the caregiver needs to emphasize that it is of utmost importance to stop smoking so as to prevent direct and, in the case that the prospective mother smokes, indirect harm both to his future child and the prospective mother. In addition, the caregiver should encourage the prospective father to participate in a program to quit smoking.

[III] A non-directive approach is generally guiding genetic counseling. It is a value-free approach that supports people to make their own decisions, as what is the morally good decision depends on personal values.

Conclusion

This Clinical Opinion opens up a new debate in the rather new field of preconception care for men. We pointed to a potential conflict between the scarcity of evidence on paternal risk factors and the view that preconception care should be directed at men.

We argued that introducing preconception care for men is not necessarily conflicting with the scarcity of evidence. First we showed that from an ethical perspective, responsible fatherhood can already start before pregnancy, if evidence of paternal preconception lifestyle modification increases. The explorative empirical research suggested that men required good evidence in order to be willing to change their preconception lifestyle. We showed that these men were right in requiring evidence, but that they were too demanding: we argued that fair evidence would be good enough.

Furthermore, we argued that one may expect prospective fathers to modify a risk factor when it meets a certain threshold of the EMESP-ratio. Also, caregivers may be expected to provide information about the risk factors that meet that threshold in a directive way, which means that they should encourage prospective fathers to modify their risk factors.

The number of participants of our explorative study was small and therefore more research is needed. In addition, more research should be done on the effects of paternal preconception lifestyle risk factors and the effects of modifying behavior. Generating sufficient evidence is needed to justify incorporating risk factors in preconception care. In addition, this evidence will motivate prospective fathers to modify their preconception lifestyle, which will prevent future children, as well as prospective mothers, from being harmed.

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Chapter 5

Preconception care and medicalisation

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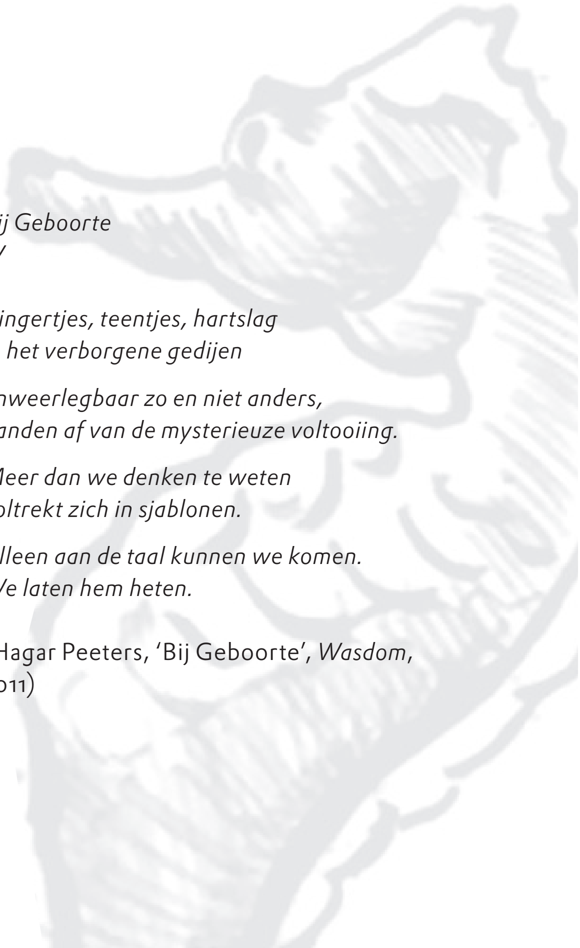

Bij Geboorte
IV

Vingertjes, teentjes, hartslag
in het verborgene gedijen

onweerlegbaar zo en niet anders,
handen af van de mysterieuze voltooiing.

Meer dan we denken te weten
voltrekt zich in sjablonen.

Alleen aan de taal kunnen we komen.
We laten hem heten.

(Hagar Peeters, 'Bij Geboorte', *Wasdom*,
2011)

Abstract

General preconception care is a new preventive strategy that is directed at all prospective parents to improve the health of future children. However, the argument of medicalisation is sometimes used to prevent preconception care from being part of general health care. This argument also functions as a barrier for women to seek out preconception care. The objective of this paper is to morally evaluate this argument of medicalisation with respect to preconception care. The authors identify six underlying moral issues with preconception care: preconception care can be seen as a first or a last step on a slippery slope; preconception care may lead to alienation because of 'health' being the central value of preconception care; prospective parents may not feel free to choose against advice given; preconception care affects women in particular; preconception care may lead to blaming oneself or blaming by others; preconception care could be at odds with the mystery surrounding the process of becoming pregnant. This paper holds that the argument of medicalisation is insufficient to justify refusing to seek out preconception care. Furthermore, not implementing general preconception care is inappropriate, because rejecting preconception care on the basis of presumed moral issues is like throwing the baby out with the bath water. Policymakers and professionals are provided with several recommendations for organising and providing general preconception care in an ethically sound manner.

Introduction

Prospective parents have moral responsibilities towards their future children to prevent them from harm, that fall upon them from the moment they intend to become pregnant, so we argued elsewhere.[1] Preconception care offers the opportunity for prospective parents to take up responsibility.[1]This can be divided in general en specialised preconception care. General preconception care is a new preventive strategy that is directed at all prospective parents to improve the health of future children. The goal of this care is to encourage prospective parents through public campaigns to seek preconception counselling. Counselling consists of a lifestyle, medical and family history risk assessment and is accompanied by advice on how to diminish or eliminate possible risks. If necessary, the prospective parents are offered help or referred to a specialist. Specialist preconception care directs people at a known increased risk for an adverse pregnancy outcome. In 2007 in the Netherlands, the national Health Council advised to implement preconception care.[2]

The argument of 'medicalisation' has been identified as one of the barriers for preconception care.[3-5] Medicalisation can be described as "a process by which non-medical problems become defined and treated as medical problems."[6] The argument may partly explain why prospective mothers seem to be hesitant to engage in preconception care consultation.[7,8] Interestingly, Mazza and Chapman found that some women stated that preconception care over-medicalised a natural human event, while, once pregnant, women felt obliged to go to a general practitioner. The authors are probably right when suggesting that this "may comprise a barrier that, if not more fully understood, will continue to impede the success of efforts to promote family planning and preconception care."[4] The argument of medicalisation does not only function as a barrier for women to seek out preconception care, it is also used not to implement preconception care as part of general health care.[5,9] Because the health of future children is at stake, it is important to understand what the argument of medicalisation comprises. In this paper we will morally evaluate the argument of medicalisation with respect to preconception care.

Criticising, describing, and praising medicalisation

The use of the term medicalisation when criticising preconception care suggests that medicalisation must be something bad. This use of medicalisation is not new. In the past, critics argued that the process of 'making medical' would result in increased medical power, where physical health is at the cost of liberties and moral integrity.[10-12] However, not everyone considers medicalisation to be bad. The sociologist Conrad emphasised that medicalisation is merely a description of a process- by which non-medical problems become defined and treated as medical problems-, which in itself is neutral. Conrad suggested using the term ‘over-medicalisation’ to distinguish critique from the process.6 Occasionally, a third interpretation of medicalisation is put forward, which suggests that the process of medicalisation can also be good.[13-15] Parens states that medicalisation can be a process of empowerment, e.g. by using contraceptives, women use medical technologies to gain control over their lives.[15]

Medicalisation is a convoluted concept that can be considered ‘bad’, ‘neutral’ and ‘good’, and hence it is essential to always clarify whether the term is meant to criticise, describe or praise the process of becoming medical. In the case of preconception care, medicalisation is sometimes used as a critique that seems to function as a barrier for the successful implementation of preconception care.

Moral issues underlying the critique of medicalisation

Verweij argues that the term medicalisation is sometimes used to express moral intuitions people may have regarding the practice of prevention and health promotion.[16] The Health Council of the Netherlands recognised this and used the metaphor of an umbrella to describe how the critique of medicalisation encompasses a whole range of considerations and problems.[2] We agree with it’s proposal to avoid this umbrella concept in an ethical analysis and we will further the debate by identifying and discussing six underlying moral issues.

1. The last or the first step on a slippery slope

Proponents of preconception care emphasise that preconception care should be part of a chain that creates connections over the course of life – from preconception care through prenatal, neonatal, child, and youth care.[9,17] One moral issue underlying the argument of medicalisation can be related to this extended continuum of care. Verweij argued that although one individual practice may not be problematic, a moral problem may arise when individual practices are accumulated.[16] Illich describes how a never-ending story of medical intervention results from individual practices: “life is turned into a pilgrimage through check-ups and clinics back to the ward where it started. Life is thus reduced to a ‘span’, to a statistical phenomenon, which, for better or worse, must be institutionally planned and shaped. This life-span is brought into existence with the pre-natal check-up, when the doctor decides if and how the foetus shall be born, and it will end with a mark on a chart ordering resuscitation suspended.”[12] In the context of generally increased pregnancy related medical care, preconception care may thus be seen as one practice too much – ‘enough is enough’ – or the last step on a slippery slope.

However, one could also argue that preconception care may constitute the start (as opposed to the end) of a medicalisation process. Preconception care is then viewed as a first step on a slippery slope: a first, relatively harmless step in a process that is much more problematic. Scenarios can be sketched in which individuals are not free to refuse preconception care and in which preconception care results in governments or doctors licensing prospective parents and thus decide who is entitled to have children. These scenarios portray the fear that governments will gain too much power and use the medical realm to exert that power.

In both situations, whether preconception care constitutes the end or the beginning of a medicalisation process, preconception care is presented as though prospective parents passively undergo medical care. There are two problems with this characterisation. First, the description of preconception care as only medical is not accurate. The main part of preconception care consists of providing information to prospective parents on potential risk factors for adverse pregnancy outcomes. Part of the risk factors is related to the prospective parents' lifestyles. The other part consists of medical risk factors, which include, for example, chronic or genetic diseases. Furthermore, if needed, prospective parents are offered interventions to modify their risk factors. Second, instead of regarding prospective parents as passive patients, preconception care may well encourage prospective parents to actively influence the health of their future children. Receiving information increases the prospective parents' options in the process of becoming pregnant, as it enables them to make informed choices: women will be informed if they choose to be informed; they can choose whether or not to live according to the lifestyle advice given; and in case of a severe inheritable disease, they may choose not to intervene at all, choose for medically assisted conception in combination with embryo selection, choose to forego parenthood, or they may choose to adopt a child.

Furthermore, although it is important to also consider preconception care as part of a continuum of care, and to be aware of it being a possible step on a slippery slope, it remains critical to consider preconception care for its own merits.

2. Alienation

Preconception care aims to prevent harm to future children, to enable and improve informed decision making and to improve women's health (e.g. by modifying their lifestyle). It is not clear whether these three aims are of equal importance or if there is a certain hierarchy. Verweij argued that preventive medicine may impose the value of health on people, while the value of health may not be the most important consideration to them.[16] He further argues that it may constrain people's autonomy in choosing how they want to live.[16] We agree that it may be wrong (paternalistic) to justify constraining another's autonomy by stating that this will prevent him or her from harm. We also agree that preconception care may indeed contribute to imposing a medical view of the process of becoming pregnant. Even if preconception care may improve informed decision making, we must recognize that all these choices exist in the domain of health. How preconception care may affect thinking about becoming pregnant is illustrated by the medical vocabulary that is used in the academic discourse of preconception care. For example, to speak of a healthy or adverse 'pregnancy outcome' is clearly different from speaking of a healthy or sickly 'baby', and such academic language may therefore alienate people from the non-medical process of getting pregnant. We acknowledge that the health of the future child should not be the only consideration when choosing to become pregnant and that preconception care may contribute to this one-dimensional and alienating view.

However, because the health of prospective parents influences the health of future children and these children depend upon them for their wellbeing, it would not be right to avoid considering the health of a future child during the process of becoming pregnant. Verweij acknowledges it is 'not implausible' that there is a special obligation for women intending to become pregnant to guard their health in order to reduce risks for the future child.[16] He raises – but does not answer – the question of how far this obligation should go. We believe that although the health of the future child should not be the only consideration, it must still be considered. Since the health of vulnerable future children is at stake, we believe that not regarding the process of becoming pregnant from the health perspective of the child would be wrong. In preconception care, it should be recognised that different values play a role in the process of becoming pregnant, including the value of health.

3. Not free to choose against advice given

How does the aim of preventing harm to future children relate to the aim of informed decision making? A condition for informed decision making is that people can freely choose between options, without being pressured. However, in preconception counselling, caregivers may communicate, intentionally or unintentionally, a perceived directive. This means that prospective parents may regard the 'healthy' choice as the right thing to do and may perceive choosing against it as imprudent. As a consequence, although people are in fact free to choose one of several options, prospective parents may not feel free to choose against the advice given.[18]

Should prospective parents be free to choose against the advice given? The answer is twofold. First, yes, people should legally be free to choose against the advice given. There should be no legal directives for prospective parents. Second, no, because the health of vulnerable future children is at stake, the choice is not morally indifferent and therefore a moral appeal may be appropriate. A non-directive counselling approach, as is quite common in reproductive genetic counselling, may therefore not be adequate 17. Thus, when prospective parents do not modify their risk factors, they may be strongly advised to do so after all in order to reduce risks for the health of their future children, although they may not be coerced.

However, the lack of a free choice may become problematic if prospective parents are expected to do everything on behalf of their future child, also when their interests conflict with those of the child. Purdy describes how lifestyle advice given during pregnancy may reflect how foetal interests and the interests of the pregnant woman might diverge.[19] She argues that some potential sacrifices, such as abstinence from certain toxic medication, may be too great to demand from pregnant women: "Imagine a bad cold, let alone more serious illness, without pain relief. Imagine too, foregoing therapy that will cure disease, or being denied … the only drugs that may prolong your life."[19] For the preconception period these examples may be different. However, the central question is similar: if the interests of prospective parents and their future child are at conflict, how much effort may be expected from the prospective parents to prevent their future child from being harmed?

Disregarding that interests may potentially conflict and blindly assuming that women and men will do everything in favour of their child would undermine the 'informed decision-making aim' of preconception care. We are of the opinion, however, that depending on the situation, more particularly, taking account of the strength of the evidence, the severity and probability of the harm, the modifiability of the risk factor and the effort that is needed to modify it,[1,20] sometimes the aim of preventing harm should prevail over the aim of better informed decision making, and sometimes the aim of better informed decision making should prevail over the aim of preventing harm. One must acknowledge that, in practice, these two aims of preconception care may conflict, and thus that there are limitations on what one may ask of prospective parents, and that there are limitations on prospective parents' freedom of choice as they still have moral obligations towards their future children.

4. Unequal burden on women

Feminist critics have argued that medicalisation is an unjust process that affects women in particular. They fear that due to this medicalisation women will be reduced to 'vessels',[21] 'machines'[22] or 'fetal containers'.[19] Most reproductive interventions are indeed directed at women only (and possibly men in a supportive role), and we agree that, for the larger part, women bear the potentially negative consequences. However, this critique does not hold for preconception care, in theory. Preconception care can be directed at prospective parents, and it can include women and men alike, because preconception health of both women and men affects the health of the future child. Having said that, so far, in practice the emphasis lies on women and evidence for paternal preconception risk factors for adverse pregnancy outcomes is scarce.[20] If the emphasis continues to lie on maternal preconception risk factors while there would be (good or fair) evidence of paternal preconception risk factors, this would be unjust. Also, it would be unjust not to perform research to the effectiveness of preconception care for men. However, because this evidence is scarce, we do not consider the current practice of preconception care, which focuses mainly on women, to be unjust.

5. Blaming

A moral issue that may arise from preconception care is that it may suggest there is a guarantee for a healthy child. As a consequence, parents may blame themselves for getting an 'imperfect' child, even when they lived up to the advice given and cannot possibly be to blame. Apart from blaming themselves, others may blame parents for having a child that is less than perfect, because they supposedly could have prevented it by changing their lifestyles or undergoing some other intervention.[16] Many risk factors, their potential coherence and potential modification are nonetheless still unknown, and the health of the future child can only partly be influenced. Therefore, although prospective parents should be pointed to their moral responsibility to modify risks, caregivers should nuance their message by mentioning that the parents' potential influence is limited and that no guarantees can be given. For these reasons, and because the innocent future child may suffer from it, blaming (and certainly punishing) parents for their less than perfect children is almost always unacceptable.[I]

6. Preconception care at odds with the mystery of becoming pregnant

The last issue we identified is the fear of reducing the process of becoming pregnant to a 'technical phenomenon' instead of a 'religious, moral or existential' issue.[14] We think, however, that even if all preconception risk factors become known and the way in which they could be modified becomes clear, the mystery surrounding the process of becoming pregnant would not necessarily be dismissed. One woman trying to get pregnant described her amazement caused by knowledge as follows: "Because I studied biology, I know exactly how conception works. But when I imagine, that if I would become pregnant, what would actually happen in my womb, I am puzzled. I picture these two cells and the whole process. If that would happen in my body: that would be a miracle."[II] The nickname of Louise Brown, the first baby that was born after IVF (which could have been seen as the ultimate medicalisation, because conception was artificially construed), also emphasises the mystery: she was called 'Miracle Baby'.[III] The philosopher Thomä describes the process of becoming pregnant appositely: "They prospective parents may contribute to, but not going beyond, a process that has something incomprehensible and transcendental, something 'mystical'." [23] Following these examples, we may suggest that preconception care is not necessarily at odds with the mystery of becoming pregnant.

[I] There may be situations in which it could be acceptable to blame parents for having 'imperfect' children, for example in the case of a child with fetal alcohol syndrome, caused by high levels of alcohol consumption during pregnancy. However, blaming could only be acceptable if the parental behaviour was chosen freely, which is rarely the case, since women who drink excessively during pregnancy are often addicted. Whether or not punishment is acceptable falls beyond the scope of this paper.

[II] Fragment from an unpublished interview.

[III] Miracle Baby Louise Brown, 1978

Discussion

Medicalisation as a critique is often brought into play when a new kind of care is introduced and it is being used to criticise the implementation of general preconception care as well. Also, women have used the argument of medicalisation to explain their hesitation to engage in preconception care.[4] We identified and discussed underlying moral issues regarding the argument of medicalisation in relation to preconception care: preconception can be seen as a first or a last step on a slippery slope; preconception care may lead to alienation because of 'health' being the central value of preconception care; prospective parents may not feel free to choose against advice given; preconception care unjustly affects women in particular; preconception care may lead to blaming oneself or blaming by others; preconception care could be at odds with the mystery surrounding the process of becoming pregnant. In sum, we reasoned that the argument of medicalisation is not fitting for refusing to seek out preconception care and we regard not implementing general preconception care to be an inappropriate measure for avoiding the presumed moral problems, because that would be like throwing the baby out with the bath water.

However, the medicalisation critique provides policymakers and professionals with moral lessons relevant for the organisation and provision of preconception care in an ethically sound manner:

- Counsellors must realise and discuss with prospective parents that different values play a role in choosing to become pregnant, including the value of the future child's health, and that these values may conflict.
- Counsellors should avoid medical vocabulary and use common language in preconception care consultations.
- Policymakers and providers should recognise that in practice, the three aims of preconception care (prevention of harm to future children, better informed decision making, improvement of women's health) may lead to conflicts, and that there are limitations to what one may ask of prospective parents as well as moral limitations on their freedom of choice, as they still have moral obligations.
- A non-directive approach may be inadequate for preconception counselling and directive counselling may be a better norm when serious harm to the health of the child is likely to occur.
- Preconception care for men should be facilitated, as long as advice given is evidence-based, and providers should involve prospective fathers more in preconception care. Research on the effects of preconception care for men is urgently needed.
- In preconception care it should be communicated that no guarantees can be given.
- Prospective parents must be made aware that preconception care is not by definition at odds with the mystery that surrounds the process of becoming pregnant.

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Part II

Perceptions

Chapter 6

Associations between women's intention to seek preconception counselling, their risk profile and personal motives: a cross-sectional study using a web-based instrument

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Abstract

Objective

To examine women's intention to seek preconception counselling after filling out the Zwangerwijzer ('Preparing For Pregnancy') national web-based risk assessment questionnaire; and to investigate the association between women's intention and their risk profiles and personal motives.

Design and Setting

A cross-sectional study, Internet survey

Population

Women contemplating pregnancy (n=1974) who visited the Dutch web-based risk assessment questionnaire www.zwangerwijzer.nl (Preparing For Pregnancy) between May and November 2008.

Methods

Women who completed Preparing For Pregnancy questionnaire were invited to fill out a short web-based survey on whether they intended to seek preconception counselling and why (not). The association of intention to seek preconception counselling, with risk profile and motives was investigated with binary logistic regression analysis.

Main Outcome Measures

Associations with intention to seek preconception counselling

Results

One third intended to seek preconception counselling. Almost all women (99%) reported at least one risk factor of an adverse pregnancy outcome. None of the women's characteristics or a specific risk profile was specifically associated with the intention to seek preconception counselling. Women's motives were positively associated with the intention. This was in particularly true for general knowledge, intrinsic motivation and, to a lesser extent, motives related to the timing of pregnancy, perceived usefulness and the knowledge on risks. Extrinsic motivation was negatively associated with the intention to seek preconception counselling.

Conclusions

Creation of the awareness of the benefits of preconception care and development of intrinsic motivations to seek preconception care counselling may promote the use of preconception care.

Introduction

Current research increasingly points to the importance of a 'healthy' periconceptional period, i.e. the weeks prior to conception and the first gestational weeks,[1-4] to optimize the health of the future child, mainly through timely improvement of maternal health.[5] It entails risk assessment, that is systematic identification of pregnancy risks; health promotion, that is informing and educating couples on healthy reproductive behaviour counselling, including organisation and weighting of the relevant information; and, if indicated, interventions, i.e. the modification of risk factors.[6] While the primary goal is to advance better reproductive outcomes during this early window of opportunity, the changes induced by preconception care usually are also beneficial to the woman's health.[7] Furthermore, preconception care aims to improve couples' informed decision-making by providing information on options around reproduction.[5]

Preconception care is in its infancy and several approaches are on offer.[6] E-health solutions are considered to be of particular interest.[8,9] They rest on web-based interviewing which offers advantages to paper and pencil questionnaires, and enables the provision of individualized advice.[10]

In 2004 the Erasmus University Medical Center and the Dutch National Genetic Resource and Information Centre developed a free-access national website for individual preconception risk screening and information called 'Zwangerwijzer.nl' ('Preparing For Pregnancy').[11] This paper investigates the yields of Zwangerwijzer.nl, combining individual's risk profiles and stated personal motives to seek preconception care, with women's intention to seek preconception care.

Methods

Participants

In this cross-sectional study conducted between May 22 and November 24 2008 all visitors of the Dutch website www.zwangerwijzer.nl were invited to fill out a short survey on whether they intended to seek preconception counselling, after they had completed the Preparing For Pregnancy risk assessment. All respondents consented to the use of the limited personal data for this study.

Measures

Risk profile

Preparing For Pregnancy is a medically validated[11], freely accessible, web-based instrument for self-report by couples or to support systematic risk assessment by caregivers. Preparing

For Pregnancy is an updated and extended version of the Preconception Health Assessment form, a self-administered screening questionnaire validated in 2002 by De Weerd et al.[12]

For the purpose of analysis we divide the recorded risks into (1) pre-existent individual characteristics, (2) non-modifiable risk factors, (3) modifiable risks factors. Only modifiable risks can be changed by interventions, the remaining risks are important as they may guide the counselling approach to be selected.[4] All risk factors were self-reported. The reported postal code was transformed into the variable 'living in a deprived neighbourhood' through an existing table issued by the Dutch department of Internal Affairs (2007). This assignment rests on a weighted score combining the rates of unemployment, crime, insecurity and poor housing. The label 'deprived' is assigned to 83 of 4878 Dutch postal code areas.[13]

Survey

We added two questions to the Preparing For Pregnancy risk assessment for research purposes only. Question 1: "After the completion of the Internet questionnaire, do you intend to seek preconception counselling at your general practitioner, a midwife, gynaecologist or at a special preconception care consultation?" Response categories: Yes, as soon as possible; Yes, but not right now; No; Don't know yet. Question 2 invited women to tick their motive(s) to do so from a list of 6 to 8 predetermined motives, with more than one motive permitted. A translated version of the questions used for this study is represented in an appendix to this manuscript (Appendix 1).

Data management

Identification of participants

The Preparing For Pregnancy risk profile and the survey data were matched using the computer's IP-number as key. IP-numbers belonging to computers of authors and involved researchers were excluded. When IP-numbers appeared more than once and risk profiles were similar, we only included the most complete series of answers in the analysis. When data were dissimilar, duplication of IP-numbers may occur due to different individuals using the same (public) computer. In this case, we individualized the record by assigning a unique 'personalised' IP-number. After matching, IP-numbers were deleted.

Each reported motive was assigned to one of the following four categories: (1) the timing of pregnancy, (2) the perceived general knowledge of preconception health, (3) the specific knowledge on preconceptional risks, and (4) the perceived usefulness of preconception counselling (see Table 1). A category of motives was coded as being present if a woman reported at least one motive with respect to that category.

Table 1: Categorisation of motives

Category of motives	Question to determine classification
The timing of pregnancy	Is the motive related to the timing of pregnancy?
Perceived general knowledge	Is the motive related to the level of general knowledge, or was knowledge already sufficient?
Risk-specific knowledge	Is the motive related to knowledge with regard to a specific risk factor or risk status? Only when explicitly mentioned, apart from general knowledge.
Perceived usefulness	Is the use or uselessness of preconception care mentioned?
Extrinsic motivation	Was a party other than the woman herself mentioned as motivator?

Next each reported motive was categorized as an 'extrinsic motivation' or 'intrinsic motivation'. We considered a woman to be extrinsically motivated when a party other than the woman herself was mentioned as motivator; otherwise we regarded the motivation as intrinsic (not-extrinsic). To arrive at a summarizing estimate of a woman's degree of extrinsic motivation, we balanced the number of extrinsic and intrinsic motives for each woman individually.

Statistical analysis

A decision to seek care is determined not only by risks but also by attitudes, perceptions, beliefs and motivations.[14,15] The current dataset allowed for explanatory analysis of the factors underlying the intention to seek preconception counselling (dependent variable).

First we removed the records of women who responded "Don't know yet" to the question whether they intended to seek counselling. Then we applied binary logistic regression analysis to estimate the univariate associations (crude odds ratios, OR) between the risks (characteristics, non-modifiable risks and modifiable risk), motives (the timing of pregnancy, perceived general knowledge, risk-specific knowledge, usefulness) and relative degree of extrinsic motivation with this intention. Then we performed stepwise multiple logistic regression analysis. We subsequently added the individual characteristics, the risk profile (either the individual risk factors or the summated score of not-modifiable and modifiable risks), and the five categories of motives as independents to the regression model. Thus 4 models were obtained: I the impact of each individual characteristic separately; II the impact of factors of I to which non-modifiable and modifiable risks were added; III the impact of motives additional to II, IV: the impact of extrinsic/intrinsic motivation in addition to III. Model IV includes the full explanatory set of variables.

A p value < 0.05 (two-sided) was regarded a significant difference.

Results

A total of 1974 participants filled out Preparing For Pregnancy as well as the survey completely. Of these women, 767 (38.9%, 95%CI: 36.7%-41.1%) intended and 1207 (61.1%) did not intend to seek subsequent individual preconception counselling (Figure 1).

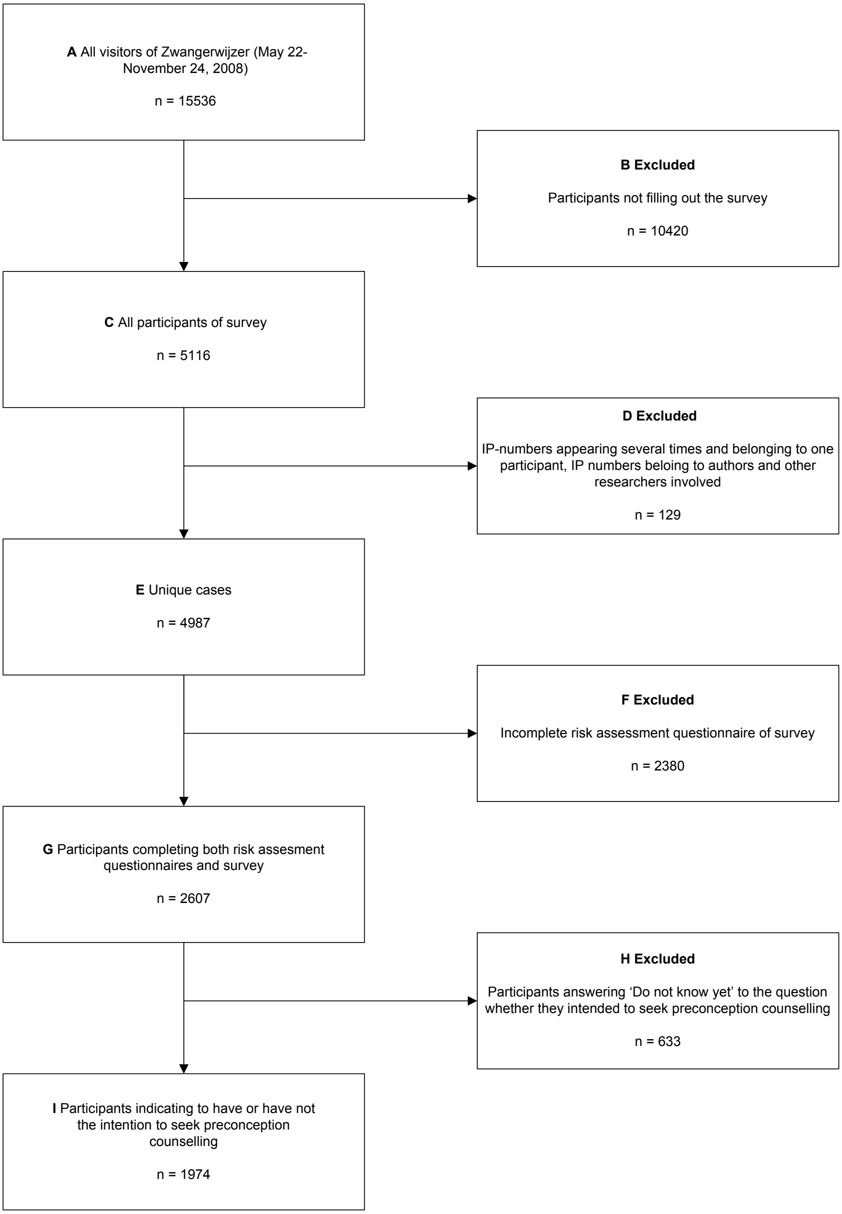

Figure 1: Flow of participants

Table 2: Characteristics of participants (*n*=1974).

	Women who intended to seek pcc (*n*=767)		Women who did not intend to seek pcc (*n*=1207)	
Characteristics	n	%	n	%
Age >36 years of age	78	10,2	108	9,0
Multi parity	264	34,4	409	33,9
Being pregnant	128	16,7	183	15,2
Country of origin other than the Netherlands	62	8,1	123	10,2
Living in deprived neighbourhood	48	6,3	50	4,1

Table 2 shows women's characteristics.

Figure 2 shows the number of modifiable and non-modifiable risk factors per woman. The median number of risk factors was 4 (IQR: 3-6) of which median 3 (IQR: 2-4) modifiable and median 1 (IQR: 0-2) non-modifiable risk factors. 99% of the participants have at least one risk factor.

Table 3 shows the frequencies of risk factors and motives and the impact of risk factors, motives and relative degree of extrinsic motivation on women's intention to seek preconception care.

In model I the most important factor was living in a deprived neighbourhood, which raised the intention to seek preconception care with 53% (p=0.04). The other individual risk factors were not significantly associated with the intention to seek preconception counselling.

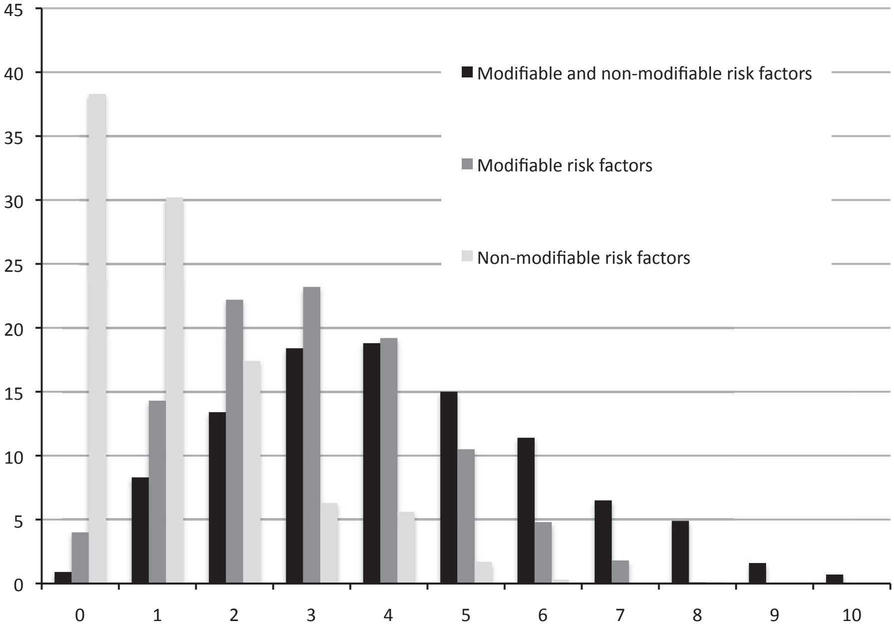

Figure 2: Number of risk factors per woman

Table 3: Frequencies of risk factors and motives and impact of risk factors, motives and relative degree of extrinsic motivation on women's intention to seek preconception care (*n*=1974). Significant results are marked in bold.

	Frequencies		Model I		Model II		Model III		Model IV	
	n	%	OR	Sig	OR	Sig	OR	Sig	OR	Sig
Constant			0,62	<0,01	0,55	<0,01	0,80	0,24	0,99	0,95
Pre-existent individual characteristics										
Age >36	186	9,4	1,18	0,30	1,23	0,23	1,12	0,53	1,04	0,87
Multi parity	673	34,1	0,99	0,92	1,02	0,91	0,98	0,89	1,01	0,96
Pregnant	311	15,8	1,08	0,57	1,13	0,38	1,08	0,62	0,95	0,80
Country of origin other than the Netherlands	185	9,4	0,77	0,11	0,78	0,15	**0,66**	**0,03**	0,64	0,08
Deprived neighbourhood	98	5,0	**1,53**	**0,04**	**1,54**	**0,04**	1,48	0,09	1,29	0,40
Non-modifiable risk factors										
(History of) bulimia nervosa	57	2,9			1,09	0,78	1,09	0,79	1,36	0,46
(History of) anorexia nervosa	34	1,7			0,81	0,59	0,86	0,72	0,74	0,58
Sexually transmitted disease	42	2,1			1,12	0,75	1,08	0,84	1,05	0,92
Risk factors for HIV or Hepatitis B	193	9,8			1,09	0,62	1,13	0,49	1,24	0,34
Non-immunity to rubella	92	4,7			0,91	0,68	0,87	0,56	1,15	0,67
Chronic diseases	432	21,9			1,09	0,52	1,14	0,35	1,13	0,49
Use of prescription drugs	319	16,2			**0,74**	**0,03**	0,75	0,06	0,75	0,12
Problematic reproductive history	287	14,5			0,97	0,87	1,01	0,96	0,99	0,97
Gestational diabetes. preeclampsia and/or HELLP syndrome in previous pregnancy	90	4,6			0,90	0,66	0,80	0,40	0,75	0,40
Uterine or cervical anomaly	62	3,1			0,90	0,72	0,86	0,63	0,85	0,68
Previous gynaecologic surgery	240	12,2			0,89	0,46	0,94	0,73	1,05	0,83
Use of DES by mother or grandmother during her pregnancy	10	0,5			1,04	0,96	1,44	0,60	1,57	0,59
Woman's family history. hereditable diseases	244	12,4			1,01	0,96	1,07	0,67	1,11	0,61
Modifiable Risk factors										
Chemical use at home/work	98	5,0			1,08	0,72	1,22	0,39	1,28	0,40
Exposure to radiation at home/work	77	3,9			0,75	0,29	0,83	0,53	0,70	0,31
Clean the litter box or work in the garden	916	46,4			1,04	0,66	1,03	0,81	1,08	0,57
Tobacco use	450	22,8			1,14	0,29	1,10	0,46	0,94	0,71
Alcohol use	758	38,4			1,14	0,22	1,09	0,42	1,01	0,94
Soft drugs use	70	3,5			1,36	0,24	1,62	0,08	1,31	0,42
Hard drugs use	25	1,3			0,60	0,27	0,68	0,44	0,95	0,93
Special eating habits	184	9,3			1,05	0,77	1,06	0,75	1,15	0,54

Table 3 (continued)

	Frequencies		Model I		Model II		Model III		Model IV	
	n	%	OR	Sig	OR	Sig	OR	Sig	OR	Sig
Unbalanced diet	110	5,6			1,41	0,10	1,46	0,09	1,66	0,09
No folic acid use	691	35,0			0,90	0,30	0,91	0,39	0,87	0,34
Do you ever you eat any of the following products (unpasteurized milk. cheese prepared with unpasteurized milk. raw fish. meat or seafood. raw vegetables)	1367	69,3			1,09	0,42	1,09	0,45	1,03	0,83
Do you ever eat foods rich in vitamin A	513	26,0			1,11	0,37	1,16	0,20	1,07	0,65
Use of over-the-counter drugs	319	16,2			0,96	0,66	0,95	0,62	1,09	0,53
Motives										
Timing of pregnancy	463	23,5					**3,21**	**<0,01**	**1,37**	**0,05**
General knowledge	1141	57,8					**3,57**	**<0,01**	**3,43**	**<0,01**
Risk-specific knowledge	586	29,7					**0,71**	**0,01**	**1,61**	**<0,01**
Usefulness	1525	77,3					**0,18**	**<0,01**	**0,08**	**<0,01**
Personality traits										
Extrinsically motivated									**0,18**	**<0,01**

The presence of specified non-modifiable and modifiable factors showed little effect. Only 'using prescription drugs' appeared of significant interest in model II. The total number of non-modifiable and modifiable risk factors was unassociated with the intention to seek preconception counselling (OR: 1.01, p= 0.561).

Model III clearly shows that women's motives had a significant impact on the intention to seek preconception counselling. Women who reported motives related to 'the timing of pregnancy' or 'perceived general knowledge' were respectively 3.21 ($p<0.01$) and 3.57 times ($p<0.01$) more likely to seek preconception counselling. Women who reported motives related to 'risk-specific knowledge' or to 'perceived usefulness' were less likely, 0.71 ($p=0.01$) and 0.18 times ($p<0.01$) respectively, to intend to seek preconception counselling. The added motives influenced the role of factors already included. Deprived neighbourhood and use of drugs on prescription were no longer significant while being of non-Dutch descent emerged as significant factor (OR: 0.66, $p=0.03$).

In the most extended model IV the addition of the relative degree of extrinsic motivation revealed that women who more frequently reported extrinsic motivations were less inclined to seek preconception counselling (OR: 0.18, $p<0.01$). Addition of the extrinsic motivation variable did not affect the strong impact of motives related to perceived general knowledge on intention to seek preconception counselling. Risk-specific knowledge, however, was positively associated with the intention. Motives indicating the usefulness of preconception care were strongly negatively associated with the intention to seek preconception counselling.

Discussion

We found that almost all women have at least one risk factor for an adverse pregnancy outcome. This finding confirms those in a study on the prevalence of risk factors among couples that wish to become pregnant.[16]

About 30% of women reported that they intended to seek preconception counselling after filling out the web-based questionnaire. This is much lower than reported by De Jong-Potjer et al.[17] who found that 57% of the respondents were interested should they decide to have children. Poppelaars et al.[18] found that 60% of couples planning a pregnancy would visit a pre-conception care clinic if such a clinic would exist. There are several reasons why our study found lower percentages. Firstly, in our study, women were asked what they 'actually' would do given the available risk profile, whereas the other studies inquire women's opinions imagining a 'hypothetical' situation. De Jong-Potjer et al.[17] asked women whether they were interested in preconception counselling 'should they decide to have children'. Poppelaars et al.[18] investigated their intention to seek preconception counselling 'if it would exist'. Moreover, with respect to the actual situation, in Poppelaar's study only 22% of the women planning a pregnancy agreed to the statement "I will visit my GP before I am pregnant to get information about risk factors and test possibilities before and during."[18] Intended behaviour in a hypothetical context clearly differs from intended behaviour when actual decisions have to be taken, which in turn differs from actual behaviour.

Another reason for the low percentage of women intending to seek individual preconception counselling is that this web-based risk assessment also provides general information on the risks detected. Couples may perceive this information as sufficient at that moment in the process of becoming pregnant. This was also concluded from a pilot study in 2007 on general preconception care using Preparing For Pregnancy in Rotterdam, the Netherlands. Parents-to-be were encouraged by a public campaign to fill out the Preparing For Pregnancy risk assessment, and send the risk profile to a caregiver to seek preconception consultation. While the Preparing For Pregnancy website use increased during the campaign, the actual number of preconception consultations did not.[6,19] Women's need for information may be satisfied after identification and information on their personal risks and on how to reduce them, and they may no longer perceive a need for additional consultation by caregivers.

Surprisingly, we found no association between the risk profile or risk load and the intention to seek preconception counselling, even hardly when women's motives were disregarded. Chuang, Velot and Weisman[20] found a similar result when exploring attitudes related to preconception health among women having a chronic disease (diabetes, hypertension or obesity). Neither the chronic condition nor the perceived risk guaranteed intention to engage in preconception health promotion.[20] One reason for this minimal influence of the risk profile could be that preconception care counselling requires that a woman contemplating pregnancy recognizes the impact of risks on the future baby's health and that when she does not, she will not be an easy target for preconception counselling. Weisman et al.[21] also examined non-pregnant women's beliefs about whether or not they can influence their future birth outcomes. They found that the more risk factors were identified the less likely it was that women has a high internal locus of control and therefore that it would be less likely they would seek preconception counselling.

Our finding that extrinsic motivation lowers the likelihood that a woman intends to seek preconception counselling is closely connected to the previous finding and theory that an internal locus of control is needed before one could expect preconception care to succeed. The study by Henneman et al.[22] confirms this as well: individuals with a higher internal locus of control tended to better accept CF carrier testing than those with less sense of control over their own health.

The motives related to perceived (non)usefulness of preconception care counselling are negatively associated with the intention to seek counselling. This may be attributed to a lack of awareness of the importance of preconception health and the existence of preconception care. A sample of US women showed that 65% knew nothing about preconception care.[23]

Our study also has limitations. Firstly, only one third of the visitors of Preparing For Pregnancy filled out the additional survey. One reason is that when visitors declined consent for usage of their data for research purposes, the risk profile is deleted and the invitational question to fill out the survey is not presented. Another likely reason is that the risk assessment questionnaire is rather long (it takes approximately 15 minutes to fill it out) and that women therefore did not want to complete the additional survey. A second limitation is that use of an anonymous web-based questionnaire precludes unambiguous identification of individuals. Although we carefully selected the participants, it could be possible that several cases come from one individual, or that people were in fact not intending to get pregnant.

Benefits of using a web-based questionnaire, on the other hand, are that this study succeeded very well in reaching women intending a pregnancy, while they are usually very hard to reach, because getting pregnant is an intimate process. Another advantage is the anonymity of a web-based tool; bias occurring by socially desirable answers is minimal.

Conclusion

To our surprise, women's intention to seek preconception counselling is to a large degree unrelated to their characteristics and risk profiles. Women's motives, in contrast, were strongly associated with the intention. Particularly general knowledge and, to a lesser extent, motives related to the timing of pregnancy, perceived usefulness and risk-specific knowledge were positively associated with the intention. Extrinsic motivation was negatively associated with the intention to seek preconception counselling.

The findings suggest that use of preconception care may be promoted by creating awareness of the benefits of preconception care and by strengthening women's intrinsic motivations.

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Chapter 7

Perceptions of preconception counselling among women planning a pregnancy: a qualitative study

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* Changes in the chapters that have previously been published as articles have been made for stylistic reasons only

Abstract

Background

Preconception care is a promising new approach to improve the health of future children through primary intervention. Although most women have a positive attitude towards preconception care, women often do not seek preconception care for themselves.

Objective

To explore women's hesitancy to seek preconception counselling.

Methods

An empirical-analytic approach was used to explore women's hesitation to seek preconception counselling. In-depth, semi-structured, face-to-face interviews (n = 16) of women desiring to conceive were conducted, and responses were analysed using the determinants 'attitude' and 'subjective norms' of the Theory of Planned Behaviour of Ajzen.

Results

The interviewed women expressed a positive attitude towards preconception care in general, but were hesitant about seeking preconception care themselves. Women seemed to regard themselves as not being in the target group for preconception care. Additionally, we identified the following four sub-themes of subjective norms around the process of becoming pregnant: planning, publicity, information on fertility and artificiality.

Conclusions

Women do not consider themselves to be part of the target group for preconception care. In some aspects, subjective norms around the process of becoming pregnant may conflict with the current practice of preconception care. Recommendations are provided.

Background

Preconception care is a promising new approach to improve the health of future children through primary intervention. Antenatal care generally starts after the 12th week of pregnancy; this practice does not account for the importance of the preconception health of prospective parents and it neglects the initial gestational weeks, during which key embryonic growth and development occur and may be associated with adverse effects on the future child.[1–3] Preconception care is the best way to ensure appropriate action and avoid risks in early pregnancy. General preconception care is directed at all prospective parents and takes place in primary care (general practitioner or midwife level). It entails risk assessment, health promotion, counselling, and if indicated, referral to a specialist (specialized preconception care). Although the primary goal is to promote better reproductive outcomes during this window of opportunity, the changes induced by preconception care are also usually beneficial to the woman's health. Furthermore, preconception care aims to improve couples' informed decision-making by providing information on reproductive options.

The Health Council of the Netherlands[4] advised the integration of general preconception care into the primary health care system, emphasizing the importance of providing preconception care in a single package to guarantee that no component is neglected. In 2007, the city of Rotterdam conducted a pilot study; through public campaigns, future parents were encouraged to complete a pre-pregnancy checklist on the Internet (www.zwangerwijzer.nl) and to send the results to a care provider.[5,6] These trained professionals perform additional risk assessment to verify certain items and to further explore identified risk factors, if needed, and the caregiver (usually the midwife or general practitioner) then uses this information to provide preconception advice and other health promotion information. During the public campaign in Rotterdam, use of the Zwangerwijzer website increased by 250%. However, the number of preconception care consultations did not increase.[7,8] It seems that couples are interested in preconception information but are reluctant to take the follow-up step to consult a professional.

Two other studies found similar hesitance to engage in preconception care consultation. Delissaint and McKyer[9] systematically reviewed literature, focusing on factors related to preconception health behaviours; they found that knowledge, awareness and belief in the benefits of preconception care do not lead to preconception health practice. Frey and Files[10] investigated women's attitudes regarding preconception care and concluded that the majority of women understood the importance of preconception care but did not discuss these issues with their physician. A study of a low-income Mexican American female population found that although almost all study participants acknowledged the importance of optimizing the health of the mother prior to pregnancy, approximately 60% never consulted a physician before conception.[11]

We identified one qualitative study that investigated why women do not participate in preconception counselling. Three main determinants were distinguished, which explain why women did not accept the invitation for preconception counselling: perceived sufficient knowledge, perceived lack of risk and misunderstanding of the aim of preconception care.[12] However, this study only included women who rejected an invitation from their general practitioner. It remains unclear what women think of preconception care in general and how they envisage preconception care in their personal situation; there seems to be a contradiction between these perspectives. In the present study, we aimed to explain this contradiction by analysing women's attitudes and norms with respect to the preconception period and preconception consultation. Because preconception care may improve the health of future children as well as the prospective parents' informed decision-making, it is important that couples wishing to conceive seek consultation. Recommendations for implementation of preconception care consultations in primary health care are provided.

Methods

Population

In total, 16 women considering a pregnancy were interviewed. As it is difficult to reach women who are planning a pregnancy, we used a variety of methods to recruit women for this explorative study: we recruited through the Internet [www.zwangerwijzer.nl; (Z1–Z11)], via a network of ethnic minority women (D1–D3), and by use of snowball recruitment (T1, T2). Women were not approached individually—they responded to a general invitation. We strived to include an ethnically and socio-economically diverse group of women of various ages, for purposes of exploration, not comparison. The 16 interviewees were between 22– and 39 years of age (mean = 32.8 years). Education was classified as follows: low (3 women), elementary school or lower vocational education; medium (3 women), secondary and medium vocational education; and high (10 women), higher secondary or vocational education. Women's ethnicities were determined by the country of birth of their parents: Dutch (12 women), Moroccan (2 women), and Surinamese (2 women). All personal identifiers were removed or disguised, such that the persons described are not identifiable and cannot be identified through the details of this report.

Interviews

Information about the research project and interview procedure was provided over the telephone and again face-to-face before the interview. All women agreed to participate.

One interviewer (BZ, medical ethicist and experienced interviewer) conducted in-depth, semi-structured, face-to-face interviews with women planning a pregnancy, to explore their perceptions towards preconception care consultation. The interviews were structured around two key questions:

- Could you please elaborate on your wish for pregnancy?
- What are your thoughts about pre-pregnancy consultation?

The interview duration varied from 45 to 90 minutes. All interviews were recorded and transcribed verbatim.

Data analysis

A thematic approach was used to analyse the data. After becoming familiar with the data by reading and rereading them, researchers BZ and SD (experienced researcher) coded the data separately, by applying and continuously adjusting brief verbal descriptions to small chunks of data. Coding was open and thus not driven by a pre-existing framework. Codings were compared, and together, BZ and SD identified themes that integrated sets of these codings; ultimately, data were divided into categories of 'attitude' and 'subjective norms'. The identification of themes was driven by the Theory of Planned Behaviour, a model that predicts the intention for behavioural change—defined in this study as 'seeking preconception care consultation'. Behaviour is determined by actual behaviour control and intention. The intention is determined by the attitude towards the behaviour, subjective norms, and perceived behaviour control (Figure 1). Because preconception consultation in the Netherlands is still in an experimental phase, we focused on attitude and subjective norms to explain women's hesitation to make a preconception care visit. Data were coded as 'attitudes' when they related to women's perceptions of whether and why they thought preconception care to be useful, in general or for themselves.

The original model specifies the determinant 'subjective norms' as 'norms of important others' and the motivation to comply with those norms. It is suggested that 'in certain contexts, we need to consider not only social pressures but also personal feelings of moral

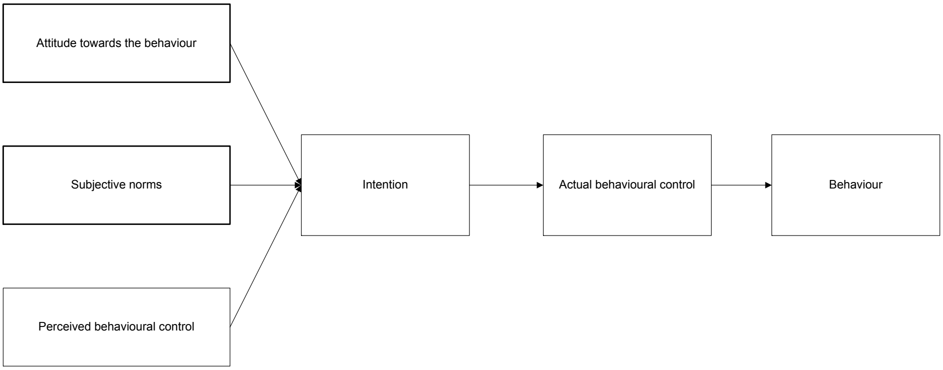

Figure 1: Theory of planned behaviour

obligation or responsibility to perform, or refuse to perform, a certain behaviour'.[13] The process of conception undoubtedly represents such context; women have strong personal norms about how the process of getting pregnant should be. Therefore, we categorised the data as 'subjective norms' when they were related to women's personal norms. We did not investigate subjective norms of important others.

After categorization of the data into 'attitude' and 'subjective norms', four sub-themes were identified relating to women's perceptions of becoming pregnant in relation to preconception care: planning, publicity, information on fertility and artificiality.

Representative quotations were chosen to demonstrate the (sub-)themes identified; these are presented in the results section, each followed by a participant number.

Results

Attitude

Attitudes towards preconception care consultation were overall positive. However, the attitude changed when women envisaged preconception care in their personal situation, with a majority responding negatively regarding whether they would consider seeking preconception care consultation.

> *Respondent: It seems to me that such a counselling is a very good initiative.*
> *Interviewer: And would you yourself consider a visit?*
> *Respondent: Well… no. (D1)*

For several reasons, the women in this study seem to regard themselves as not belonging to the target group for preconception care. They mentioned that they had already found the relevant information in books or on the Internet and that they had conducted their own risk analysis and concluded that they were 'safe' or that they could handle the risks. For some, it was not their first child and they perceived themselves as experienced mothers, not needing any further advice.

> *On the one hand, I think that I know enough about potential risks. On the other hand, I think that we don't run a risk; there are, for example, no strange diseases in our family. … It is kind of being arrogant: I just think that there are no things that I need to ask about, that I know what I need to know. (Z5)*

Another belief that determined this attitude was the frequently mentioned misunderstanding that preconception care consultation is directed at couples with fertility problems instead of all couples with a pregnancy wish.

> *I think that it is useful that there exists something like a pre-pregnancy consultation. I used to believe, however, that it is meant for people who tried to, but did not succeed in becoming pregnant. When I read about it, I thought about mentioning it to two friends who are trying to get pregnant with IVF. (Z5)*

Subjective norms

Planning

An important requirement for preconception consultation is a planned pregnancy, which is made possible by contraceptive use. Women acknowledged that planning is an important benefit of contraception; however, they also recognized it as a drawback because it is hard to decide when to stop using it and start trying to get pregnant.

> *Nowadays, we need to plan everything. Actually, the first charm fades away. On the other side, I am so glad that we have the opportunity to plan. You must plan; everyone is using contraceptives. If pregnancy overcomes you, you don't have a choice. But I must decide. I kept postponing that decision: not right now. (T1)*

That decision appears to be very difficult. Most women expressed that they had always wished to get pregnant at some point in time but had difficulties in deciding when the right time had come. The majority of respondents referred to their age when explaining the moment they chose to start trying to get pregnant.

> *When my pregnancy wish started? It started with the idea: I can't wait any longer, then I'll be too old, it's now or never. (Z11)*

Preconception counselling was perceived as having two-sided effects on this ambivalence regarding pregnancy planning. On the one hand, preconception care confirms the planned character of the pregnancy. On the other hand, preconception care could be considered a moment of reflection: women (and their partners) could discuss their decisions regarding whether and when to attempt a pregnancy with a health care expert.

> *I think that many women doubt for years: shall I or shall I not? I think that many of them would need some guidance. (Z2)*

Publicity

Respondents reported that they wanted to keep it a secret when they decided to try to get pregnant, out of fear that they may not become pregnant and that it then will be painful and annoying if others inquire about it. Some women reported that they do not want to create expectations they will not be able to meet. Another reason women stated for keeping it a secret is that they, as a couple, prefer to have a 'pact of intimacy'.

> *I want to protect my husband and myself: we might not become pregnant. I don't want my friends to call me monthly to inquire about my monthlies. In the process of getting pregnant I don't want too much fuss, to prevent disappointments. Please, leave us alone. I don't want to feel any pressure. We want to be together in the cocoon of getting pregnant. (T2)*

> *I think it is nice to keep it a secret, because it is our secret, of the two of us. (Z8)*

Preconception care was sometimes assumed to be a barrier, because it could endanger the secret. In this regard, not all locations were considered appropriate for preconception care consultation. For example, one woman felt positively about visiting a health care professional but was afraid of meeting an acquaintance by chance when entering or leaving the midwives clinic.

> *When you visit a getting-pregnant clinic, you want to have some privacy. Imagine a woman leaving the midwives clinic and then meeting a neighbour. That neighbour asks: "Oh? Are you pregnant?" And that woman has to reply: "No… I visited a clinic for people who wish to get pregnant." I would not like that very much. (Z1)*

For some women, another threat to the intimate pact is a lifestyle change that could 'betray' the wish to become pregnant or an actual pregnancy. Some reported feeling social pressure to consume alcohol because, when they don't, they immediately are 'caught'.

> *Obviously, it is very hard when you want to live according to the 'rules' while not being pregnant yet. When you usually drink a glass of wine with your friends and suddenly you stop doing so… that makes you at least suspected. (Z3)*

However, most women expected that the secret would be kept, 'despite' seeking preconception care consultation, because the medical expert is bound to professional confidentiality. Many women appreciated information and advice from a health care professional because it is perceived as reliable and desirable.

> *There is so much information on the Internet, what can I trust? Some sites are reliable. But I prefer getting that information from a professio[nal and face-to-face. (Z6)*

In some cases, women were disappointed or upset when a general practitioner did not further inquire when they visited him to remove the coil or that a gynaecologist did not mention being overweight as a cause of infertility.

Information on fertility

Of course, women strive for healthy pregnancies and healthy children; but for many, their foremost concern was about their fertility.

> *I would like to be told how incredibly fertile I am. Many of my female friends fear for infertility. They are afraid that they won't be able to get any children. (T2)*

Some women stated that they would have liked information on their menstrual cycle and fertility.

> *I remember that I decided to get pregnant and that I was convinced that I would hit the mark immediately. Later on, I learned that there are only a couple of days in which having intercourse could actually lead to a pregnancy. (D3)*

One woman even considered information on fertility as the most important component of preconception care.

> *One doesn't need a letter from the lottery on 'how to spend a million'. One needs to be informed on 'how to become a millionaire'. (T2)*

Artificiality

Many respondents mentioned that their pregnancy and the process of getting pregnant should be 'romantic' or 'natural'. However, when probing somewhat further, most respondents reported using a variety of ovulation tests.

> *It sounds ridiculous, but I have been using these tests to check whether I ovulate or not. I bought loads of ovulation tests. Well, my cycle is fine. (Z9)*

Still, they perceive 'natural' and 'romantic' as important values that preferably should accompany the process of getting pregnant.

> *I think that a pre-pregnancy clinic takes away the intimate and magic sphere, by visiting a doctor and saying: "Hi, we want to get pregnant." I think that it constitutes a huge barrier. (Z3)*

Although some women expressed concern that visiting a preconception clinic could endanger the 'natural' and 'romantic' aspects of getting pregnant, a preconception care clinic was not necessarily perceived as unnatural or unromantic.

> *The clinic is still natural; they just provide information. One is, so to speak, not having intercourse on the doctor's desk. (D3)*

One woman even considered preconception care as a way to avoid entering into the medical realm.

> *If I want to know something, I want to get the information right from the expert, without having to go into the medical merry-go-around. I consider that as an important benefit. (Z8)*

Discussion

We analysed data relating to women's perceptions of preconception care and of the process of becoming pregnant. Our findings affirm those of previous studies, that women are hesitant to seek preconception care themselves even if they have a positive attitude towards preconception care in general.[9–11] Although they were considering a pregnancy and hence were members of the target group, the women in the present study did not regard themselves as belonging to the target group for preconception care. Like Hosli *et al.*,[12] we found three reasons for this: perceived sufficient knowledge, perceived lack of risk and misunderstanding of the aim of preconception care. Furthermore, our study analysed women's personal norms relating to the process of becoming pregnant in relation to preconception care, which provided additional insight into women's hesitance to seek preconception care. We identified four themes as being important to women when considering the process of becoming pregnant in relation to preconception care: planning, publicity, information on fertility, and artificiality. Our results suggest that women's perceptions of how the process of becoming pregnant should be are sometimes in conflict with the current organisation and delivery of preconception care.

Strengths and limitations

The studied population was small but diverse with regard to ethnicity, education, and age; thus, we believe that this in-depth investigation provides relevant new insights. All interviews took place in the Netherlands and some perceptions explored (e.g. 'artificiality') could be typically Dutch. Furthermore, the situation in the Netherlands is different from that in many other countries, e.g. with respect to the percentage of planned pregnancies (85% in the Netherlands compared to less than 50% in the USA).[1,14] This should be taken into account when comparing findings among countries. Another limitation of this study is that the subjective norms of important others are not explored, only women's personal norms; the subjective norms of partners should also be included. In this study and in many others, the men's role has not been investigated, although preconception care provides the opportunity to include prospective fathers. We are currently performing a study to investigate men's perceptions on fatherhood and preconception care.

Conclusions

Summary and recommendations

This study provides insight into Dutch women's hesitance to seek preconception care consultation even if their general attitude towards preconception care is positive. First, women seem to consider themselves to not be part of the target group for preconception care. Furthermore, women's perceptions on how the process of becoming pregnant should be are sometimes in conflict with the current practice of preconception care.

We provide some recommendations based on our analysis:

- Awareness should be created of the target groups for preconception care consultation: all couples may benefit from it, not just couples who are known to be at increased risk or who are having fertility problems, as women tend to think.
- Preconception care should be offered in neutral locations, e.g. at the general practitioner or health care centre. Organized home visits could be an alternative and additional approach.
- It should be considered that the content of preconception care be extended to include the opportunity to discuss the choice of pregnancy and how to decide when to start trying to get pregnant.
- It should be considered that preconception care be extended to include information on fertility, for example, information about the menstrual cycle and fertile days.
- Practitioners should be aware of the values and ideas of 'naturalness' and 'romance' that women consider to be important in the process of becoming pregnant.

Personal identifiers

We confirm that all personal identifiers have been removed or disguised so that the persons described are not identifiable and cannot be identified through the details of the story.

Details of ethics approval

According to Dutch law, no IRB review is needed for this type of study. All respondents were adequately informed on the study before participating, and all agreed to participate.

Acknowledgements

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Chapter 8

Informing on prenatal screening for Down syndrome prior to conception. An empirical and ethical perspective

Based on*: Boukje van der Zee, Marleen Schoonen, Hajo Wildschut, Inez de Beaufort, Guido de Wert, Harry de Koning, Marie-Louise Essink-Bot, Eric Steegers. American Journal of Medical Genetics A 2012;158A(3):485-97.

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* Changes in the chapters that have previously been published as articles have been made for stylistic reasons only

Abstract

In most Western countries, information on prenatal screening for Down syndrome is provided in the first-trimester of pregnancy. The purpose of this study was to examine whether this information should additionally be provided before pregnancy to improve the informed decision-making process. In an empirical study, we obtained data from pregnant women with respect to their preferences regarding information on prenatal screening preconceptionally. Questionnaire data (n=510) showed that 55.7% of responding women considered participating in prenatal screening for Down syndrome before pregnancy. 28.0% of women possessed information on prenatal screening preconceptionally. 84.6% preferred not to receive information preconceptionally in retrospect. In an ethical analysis, we elaborated on these preferences by weighing pros and cons. We considered two arguments against the provision of information on prenatal screening preconceptionally: women's preference to receive information in a step-by-step manner, and the risk of providing a directive message. We identified three reasons supporting its provision preconceptionally: the likelihood of making an informed decision could, firstly, be increased by ''unchaining'' the initial information from possible subsequent decisions, and, secondly, by providing women sufficient time to deliberate. Thirdly, the probability of equal access to prenatal screening may increase. To conclude with, we propose to incorporate an information offer on prenatal screening for Down syndrome in preconception care consultations. By offering information, instead of providing information, prospective parents are enabled to either accept or decline the information, which respects both their right to know and their right not-to-know.

Introduction

Preconception care is a set of primary interventions that identify and modify biomedical, behavioural, and social risks to a woman's health and future pregnancies[1] Preconception care aims to optimize the health of the future child and to improve maternal health.[2] Information on prenatal screening for Down syndrome is commonly provided after conception, during the first-trimester of pregnancy. Many Western countries have policies or recommendations for prenatal screening for Down syndrome, in which either women of advanced age are offered invasive diagnostic testing (chorionic villus sampling or amniocentesis), or in which women, irrespective of their age, are offered non-invasive risk-assessment tests in the first- trimester of pregnancy (nuchal scan, often combined with maternal serum evaluation).[3,4] The latter screening tests provide an individual risk estimate of carrying a child with Down syndrome, and may be followed by diagnostic testing to confirm whether or not the foetus is affected.

Practice of Prenatal Screening in the United States

In the United States, no national screening program for Down syndrome exists. Professional guidelines recommend that, ideally, all women regardless of maternal age should be offered screening for foetal chromosomal abnormalities before 20 weeks' gestation.[5-8] According to these guidelines, the decision to screen or test for Down syndrome in a pregnancy is a personal one, and patients should have the option to have a diagnostic test regardless of maternal age after being informed on the risks, benefits, and limitations of both screening and diagnostic tests.[6] In practice, the majority of prenatal health care professionals offer first-trimester screening for Down syndrome by the combined test nuchal translucency and serum markers plasma protein-A; PAPP- A, and b-human chorionic gonadotrophin (hCG).[9] However, since there is no national screening program, also other approaches are used, both in the first- and second trimester of pregnancy. Offering the integrated test is also a common procedure; with this test, the results from first-trimester screening tests are not analyzed until the results from second trimester tests are evaluated, when both sets are assessed together.[10] It happens as well, that women who began prenatal screening in the first trimester, but were not counselled on first trimester screening, are referred to a gynaecologist with an abnormal quadruple test at 17 weeks. They typically will not seek a termination in the current United States environment (C.P. Weiner, personal communication, September 10, 2011).

Concerning the provision of information on prenatal screening, some obstetric practices in the United States have a healthcare assistant, such as a nurse, that hands out a standard brochure, with little to no discussion about its contents (C.P. Weiner, personal communication, September 10, 2011). In Figures 1 and 2, we describe respectively the decisional steps on prenatal screening for Down syndrome in the United States and in the Netherlands. With respect to the last decisional step when Down syndrome is diagnosed, continuing pregnancy is bifurcated into two options; raising the child or planning to place the child for adoption. In the Netherlands however, the latter is not a common option, and it is therefore not discussed during counselling.

Practice of Prenatal Screening in the Netherlands

In the Netherlands, a national screening program for Down syndrome exists as of January 1, 2007.[11] In this program, all pregnant women (regardless of age) are offered information on the possibility of having a screening test for Down syndrome, with the first-trimester combined test as the test of choice. Before 2007, only women aged 36 years or above, or women with a medical indication, were offered prenatal screening for Down syndrome.[12]

An important aspect of the Dutch national screening program is the distinction between the information offer, and the actual provision of information. In the Netherlands, prenatal screening falls under specifications of the Dutch medical treatment agreement (WGBO), laid down in the civil code. The ''right not-to-know'' is one of the concepts formulated in the WGBO (art 7:449; Civil code of the Netherlands). In this context, the right not-to-know implicates that women are allowed to refuse receiving information about prenatal screening. However, in order to be able to refuse something, it should be offered first. When information is provided (instead of offered), which currently is the standard procedure in the United States (Figure 1), women are faced with the information, without having received the opportunity to reject. Therefore, in the Netherlands, women are first offered to receive information. Then, only if a woman indicates she is interested in receiving this information, the actual provision of information takes place (Figure 2).

To the best of our knowledge, this ''Dutch distinction'' (between offering and providing), as an embodiment of the right not-to- know, is unique from an international perspective; in the United States and anywhere else, the right not-to-know has not been applied in order to make it possible to reject an information offer on prenatal screening. In the United States, the concept is mainly used (and criticized) in debates in the context of genetic screening.[13] In this paper, we consider the right not-to-know as an essential element of the framework of informed decision-making. This is why we started our study from the international situation in which information is provided instead of offered.

Informed Decision-Making

Facilitating informed choice on participation in prenatal screening is a fundamental part of international guidelines.[14-19,6,11]

An informed choice is based on relevant knowledge. In addition, actual behavior (in this case, participating or non-participating in prenatal screening for Down syndrome) should be consistent with the decision-maker's attitudes.[20]

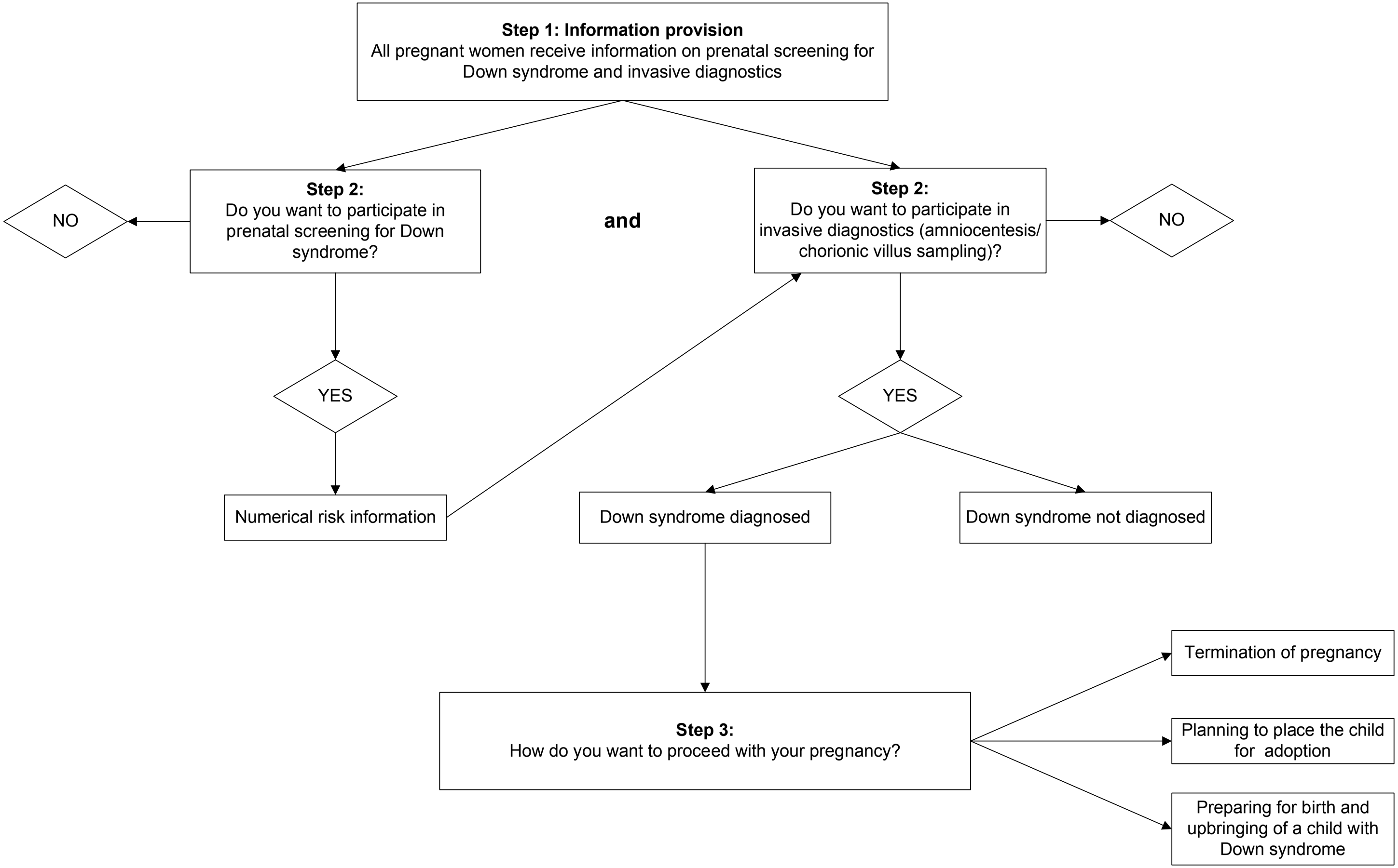

Figure 1 Decisional steps on prenatal screening for Down syndrome in the United States

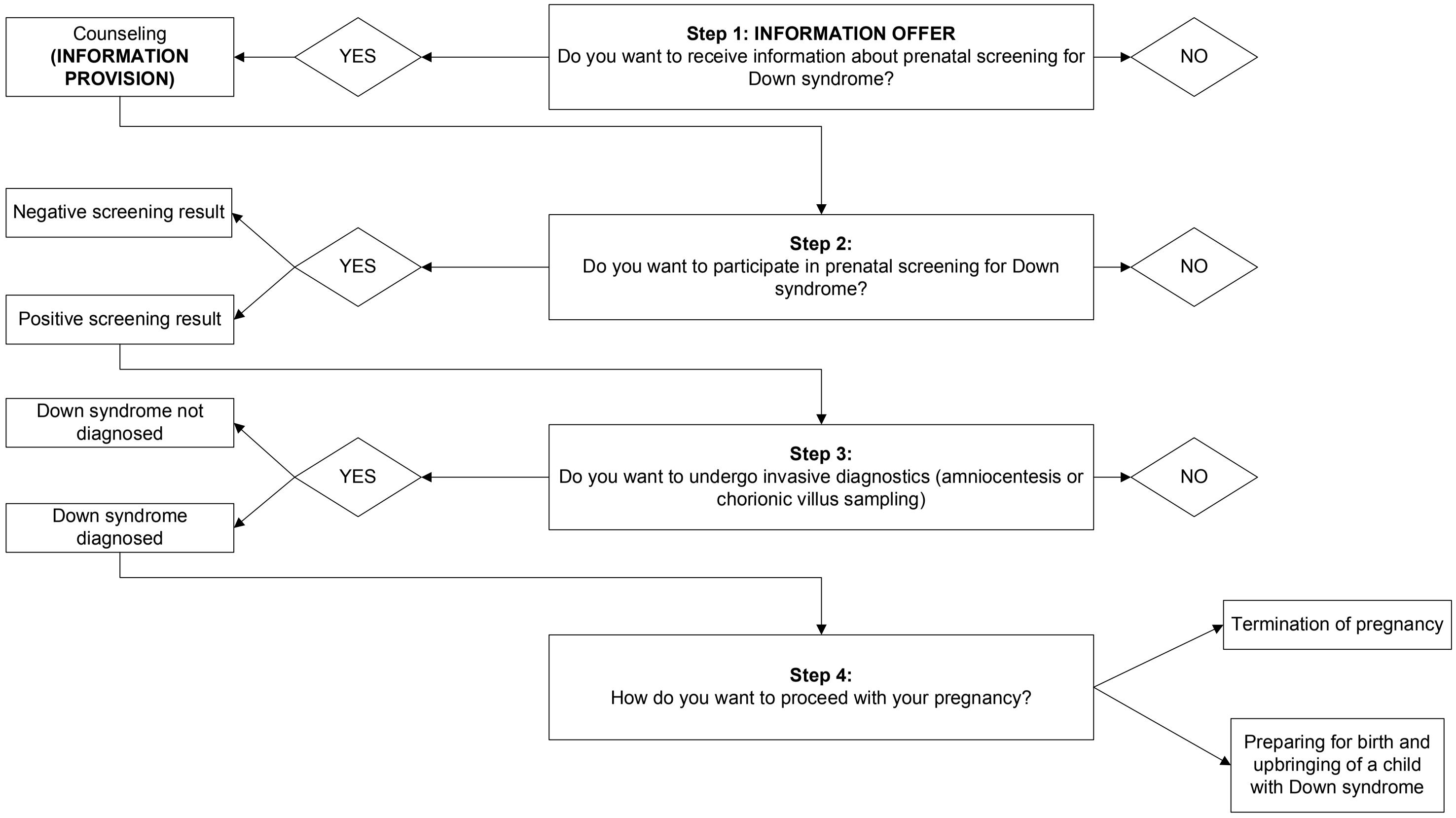

Figure 2 Decisional steps on prenatal screening for Down syndrome in the Netherlands

The optimal screening window, in terms of test performance, for first trimester screening on Down syndrome is from 11 to 14 weeks gestation.[21] Recently, it was reported that improvement in the first-trimester combined test performance might be reached through collection of the serum at two different time points in pregnancy, one before 11 weeks gestation.[22] Thus, the time that pregnant women have to make a decision about participating in prenatal screening is limited. This time window will become even shorter when new prenatal screening programs are introduced that can be performed as early as 5 weeks gestation.[23-26] Some women indicate wishing more time to consider their decision, stating that information is needed earlier in pregnancy. As the information about screening is usually given at the booking visit, it is difficult to provide it earlier in pregnancy. Therefore, there may be a need for information about prenatal screening tests before pregnancy.[27]

Information Provision on Prenatal Screening for Down Syndrome Prior to Conception?

The objective of this paper is to investigate whether information on prenatal screening for Down syndrome should be provided prior to conception, in addition to the prenatal information provision, in order to increase the likelihood of informed decision-making about participation in the screening. First, we performed an empirical study of women's preferences regarding receiving information about prenatal screening for Down syndrome prior to conception. We used the results of this empirical study as a starting point for an ethical analysis, presented in the second part of this paper. In the ethical analysis, we considered the pros and cons of providing information preconceptionally in addition to the provision during the initial prenatal visit. Using the results of our empirical study and ethical analysis, we conclude with an advice on information about prenatal screening for Down syndrome prior to conception.

Material and Methods

Empirical Study

We used a self-completion questionnaire to investigate whether pregnant women wished to receive information on prenatal screening prior to conception. Questions were part of a larger instrument to measure informed decision-making on prenatal screening for Down syndrome. Schoonen et al.[28] previously described the evaluation of the information provision procedure by using informed decision-making as a quality indicator. One questionnaire was developed to serve both these papers. Although the study population was the same, the results of the separate questions were only used once.

Data collection

Twenty community midwifery practices in the Southwest region of the Netherlands agreed to participate in this study. In the period May 2008 to May 2009, midwives provided questionnaires to pregnant women during the initial prenatal visit, after being offered and possibly having received information about prenatal screening for Down syndrome, but prior to possible participation in the screening. Hence, the participants in this study consisted of women who wished and received information on prenatal screening for Down syndrome during their pregnancy, as well as women who did not wish and therefore did not receive the information during their pregnancy.

Questionnaire

A translated version of the questions used for this study is represented in an appendix to this journal article (Appendix 1). Pregnant women were asked the following: (1) whether they had considered participating in prenatal screening for Down syndrome before pregnancy, (2) whether they possessed any information on prenatal screening prior to conception, (3) whether they wished and received information on prenatal screening during their current pregnancy and (4) whether and why they would (not) have liked to receive such information preconceptionally.

Analyses

Data were analyzed for frequency distribution tables and percentages, using SPSS 15.0.

Ethical approval

The Ethical Committee of the Erasmus University Medical Centre (Rotterdam, The Netherlands) approved the empirical part of this study (MEC-2007-166).

Results

Empirical Study

Table I provides background characteristics of the study participants (n = 510). The response rate from pregnant women on the questionnaires that were distributed was estimated to be 30–35%. We had to rely on estimates regarding the response rate because of the anonymous nature of the questionnaires.

Table II reports results of the questionnaire. Overall, 55.7% of respondent women considered prenatal screening for Down syndrome before pregnancy. Of all respondents, 28.0% reported possessing any information (not necessarily provided by a health care professional) on prenatal screening for Down syndrome prior to conception. Of all women in this study,

Table I: Background characteristics of women participating in the questionnaire study (N=510)

Characteristic	Mean (SD)	N	%	% of overall Dutch population
Age (years)	30.8 (4.2)			
Low (<36)		433	87.7	
High (≥36)		61	12.3	
Educational attainment level				
Low		223	44.1	72.2
High		283	55.9	27.8
Ethnic origin				
Non-Dutch		40	7.8	26.3
Dutch		470	92.2	73.7
Residence				
Suburban		230	46.3	
Urban		267	53.7	
Religious affiliation				
Religious		205	40.8	
Not religious		297	59.2	
Religious activity				
Often		65	13.3	
Seldom/never		423	86.7	

84.6% would not have liked receive information on prenatal screening for Down syndrome before pregnancy. During pregnancy, the information offer was declined by 33.3% of women. Of these women, 89.6% did not wish to receive information (in retrospect) before pregnancy.

The most important reason for women to desire information prior to conception was an appreciation of being timely informed of what they could expect. The most common reasons for not wishing information prior to pregnancy were ''not have been giving any thought to prenatal screening for Down syndrome'' and the opinion that ''it is better not to know everything beforehand''.

Ethical Analysis

We investigate whether information on prenatal screening for Down syndrome should be provided prior to conception, in addition to the prenatal information provision, in order to increase the likelihood of informed decision-making about participation in the screening. In the empirical study, we investigated women's preferences and concluded that the majority preferred not to receive information on prenatal screening for Down syndrome preconceptionally. Although women's preferences play an important role in our analysis, we will show

Table II: Results of questionnaire measuring interest in receiving information about prenatal screening for Down syndrome, before pregnancy

Question	Yes (%)	No (%)	Do not know (%)	Total (N)	Missing (N)
Considered partcipating in prenatal screening for Down syndrome before pregnancy?	55.7	41.7	2.6	508	2
Possessed any information on prenatal screening before pregnancy?	28.0	68.7	3.3	508	2
Accepted information offering during pregnancy (initial prenatal visit)?	65.3	33.3	1.5	475	35
Received information during pregnancy?	83.5	15.5	1.0	510	
Looking back, would have liked to receive information before pregnancy?	9.8	84.6	5.6	500	10
... of the women that considered participating in prenatal screening before pregnancy	13.8	80.0	6.2	275	8
... of the women that possessed any information before pregnancy	21.6	68.7	9.7	134	8
... of the women that accepted information offer during pregnancy (initial prenatal visit)	11.8	82.0	6.2	306	4
... of the women that did not accept the information offer during pregnancy (initial prenatal visit)	6.5	89.6	3.9	154	4
... of the women that received information during pregnancy	10.1	83.9	6.0	417	9
... of the women that considered information before pregnancy but did not possess any information before pregnancy	6.1	91.2	2.7	147	
Wanted information before conception because:			510		
... would have been easier to make a decision	1.4	98.6			
... would have made a better decision	0.4	99.6			
... not having to worry during my pregnancy	1.6	98.4			
... more time to discuss my choice with others	3.1	96.9			
... appreciated being timely informed about what to expect	7.1	92.9			
Other	1.2	98.8			
Did not want information before conception because:			510		
... had not given any thought to prenatal screening for Down syndrome	45.9	54.1			
... did not know that prenatal screening for Down syndrome was possible	4.9	95.1			
... did not want to be informed because I wanted to become pregnant first	14.7	85.3			
... would have been concerned for no reason	4.7	95.3			
... don’t think I would have understood it well enough, because I was not concerned about it	2.9	97.1			
... I would have received too much information	2.0	98.0			
... think it’s better not to know everything beforehand	20.6	79.4			
... just want to concentrate on my pregnancy without having to think about what could go wrong	15.9	84.1			
Other	11.2	88.8			

that there is more to say with regard to the question whether it is desirable to provide this information before conception. In the ethical analysis, we elaborate on the reasons mentioned by the women for preferring not to receive this information before pregnancy.

In the ethical analysis, we explicitly chose to focus only on the arguments concerning the proposed timing of the information provision. We did not consider the pros and cons of (providing information on) prenatal screening for Down syndrome in general, as previous studies have done,[29-41] nor did we elaborate on the ethical aspects related to preconception care.

The concept of informed decision-making as framework

There is consensus in ethical guidelines published in Europe and the United States that health professionals providing prenatal screening services should give prospective parents the information and support they need to make autonomous, informed decisions.[5-8] We will use the concept of informed decision-making as a framework for our study.

A process of informed decision-making results in informed decisions, also termed informed choices. To define informed decision-making, many different terms are used, often interchangeably.[42-46,20] However, there is an emerging consensus that an informed decision has two core characteristics. First, it is based on relevant, high quality information, resulting in adequate knowledge. Second, the actual choice should reflect the decision-maker's attitudes.[47,20] Following this definition, an informed choice to participate in screening occurs when relevant knowledge about the test is accompanied with a positive attitude towards participating. An informed choice to decline a test, on the other hand, occurs when relevant knowledge about the test is accompanied with a negative attitude towards participating in the screening.[20] Relevant knowledge includes information on different screening domains, e.g., the purpose of screening, the meaning of a positive or negative test result and the condition being screened for.[48]

Sometimes an additional element is included in the definition: ''deliberation'', the process of evaluating the alternatives and weighing their pros and cons.[49-50,46] We consider this third element as part of the decision-making process. In the context of screening for Down syndrome it is essential to be aware of alternatives, especially with regard to the final decision. For example, a couple considering any child to be welcome, regardless of its disabilities, might not want to participate in screening. Many couples, however, did not yet reflect on the possibility of having a child with Down syndrome. In our view, deliberation on the aspects and possible subsequent steps of a decision is necessary.

The concept of informed decision-making is embedded in the principle of respect for autonomy.[51] To respect a person as autonomous is ''first, to recognize a person's capacities and perspectives, including his or her right to hold views, to make choices, and to take actions based on personal values and beliefs. But respect involves more than taking this attitude. It involves treating agents so as to allow or to enable them to act autonomously''.[52] Respecting one's autonomy most of the time means that a patient should be informed thoroughly.

However, debate exists on whether provision of information is a prerequisite for autonomy, or that the principle of respect for autonomy sometimes prescribes to protect people from unwarranted disclosures of information.[53] The latter is conceptualized in the patient's ''right not-to-know''.[54] In this paper we consider the right not-to-know as an essential element of the framework of informed decision-making.

Despite the relevance ascribed to the concept of informed decision-making in the field of prenatal screening, it can be disputed whether informed decision-making is something every individual is willing to reach. Recently, it was argued that, because the perceived importance of parental choice and of the significant other's views with regard to prenatal screening differs among nations, the concept of informed choice is more meaningful to practices in societies that are individualistically oriented than those that are more collectively oriented.[55] Hence, people vary in their preferred degree of involvement in health decisions.[56] Finally, more information does not always lead to better, more informed decisions, and increased autonomy. It can be difficult for individuals to deal systematically with large amounts of information, often resulting in decisions being made from the context rather than from the content of the information.[44]

We are aware of these limitations in the concept of informed decision-making. However, as this concept, in its current form, is dominant in most Western countries, and as both prenatal screening and preconception care are, until now Western developments, we accept the concept of informed decision-making as a framework for this study. In the next section, we will consider pros and cons with regard to informing on prenatal screening for Down syndrome prior to conception, in addition to the prenatal information provision.

Con: step by step approach

In the empirical study, the majority of respondents preferred not to receive information on prenatal screening prior to conception. The reasons mentioned most often were ''not yet being engaged in this topic'' and ''not wishing to know everything beforehand''. This means that these women wish to approach their pregnancy in a step-by-step manner: they first wish information on getting pregnant, and once being pregnant they wish to receive the information on prenatal screening (among other things).

If information on prenatal screening was provided prior to conception, irrespective of women's preferences, a large number of women would have received information against their will (in our sample, 84.6% of women reported –retrospectively- not wish to receive this information before pregnancy). In fact, these women would not even have been able to express their reluctance. This means that, by a standard information provision before pregnancy, the right not-to-know would have been disregarded. In addition, focusing on the possibility of becoming pregnant with a child having Down syndrome, the risk appears that this unwanted information spoils the (unconcerned) process of getting pregnant.[57]

Con: a perceived directive

In addition to individual preferences, informed decision-making is dependent upon the availability and accessibility of choices and alternatives.[58-59] It is important that the decision to participate or not is made autonomously, without undue manipulation by others.[60] Repeating the provision of information on prenatal screening (i.e., providing it not only during the initial prenatal visit but also preconceptionally) may conflict with the core principle of genetic counselling; non-directiveness. Caregivers may communicate, unintentionally, a perceived directive; prospective parents may regard the choice for prenatal screening as the right thing to do and may perceive choosing against prenatal screening as imprudent. Some women seem to accept testing during pregnancy, just because these tests are offered.[61,62] As a consequence, although people are in fact free to choose one of both options, the prospective parents may not feel free to choose against participation in prenatal screening. In terms of the framework of informed decision-making, repeating the provision of information will fulfil the condition of providing adequate knowledge, but if pregnant women feel pressure to participate, choosing against participation is no longer an equivalent alternative. Hence, women may feel that their choice would no longer be voluntary.[52] Based on these perceptions, repeatedly providing information on prenatal screening increases the possibility of communicating a perceived directive.

Careful, non-directive counselling is essential in providing information about prenatal screening and it can prevent the message from being perceived as directive. However, the non-directive content of the information provided might acquire a directive character due solely to the fact that it is provided more than once. This would hinder the informed decision-making process and therefore argues against the provision of information before pregnancy.

In conclusion, women's lack of interest and the risk of spreading a perceived directive are reasons not to provide information on prenatal screening prior to conception. In the following, we will present three possible benefits of the provision of information on prenatal screening before pregnancy, in addition to during the initial prenatal visit.

Pro: preventing a gradual trap

Based on several international evaluations, a large proportion of pregnant women appear to not make informed decisions about prenatal screening[63-67,20,45] and is unaware of the decisive implications of participation in screening.[68,69] Making the decision to participate or not in prenatal screening is difficult; the decisions to be made and the chain of reasoning behind them are complex and can produce emotional burden. Prospective parents should receive information and should decide whether to participate in screening; if an increased risk of Down syndrome is detected, they must choose whether to receive invasive testing; and, if an abnormality is diagnosed, the parents must decide whether to terminate or continue pregnancy. In the United States, continuing pregnancy is bifurcated into two options; raising the child or planning to place the child for adoption.

Women may perceive the first step, the provision of information, as innocent. Having accepted the first step, it may seem rational to accept the second step as well. The same is true for the following steps, and, as a result, one can feel trapped. With regard to the last step in the chain of events, this may be most unfortunate: ''I have accepted the information, the participation in screening, the invasive testing, and now the foetus appears to have Down syndrome, I need to terminate pregnancy''. The Dutch Health Council explicitly warns against participation in screening without considering the consequences of this decision, and refers to this process as a ''gradual trap''.[70] With regard to the final step, the American College of Obstetricians and Gynaecologists (ACOG) recognizes the difficulty and recommends: ''non-directive counselling before prenatal diagnostic testing does not require a patient to commit to pregnancy termination if the result is abnormal''.[7]

The non-directive, step-by-step procedure should make it clear for women that they are not required to choose ''b'' because of choosing ''a'', and so further. In the meanwhile they should be aware of the final decision they may ultimately have to make if the foetus is diagnosed with Down syndrome: prepare for the birth and upbringing of this child with special needs, planning to place the child for adoption, or deciding to terminate the pregnancy.

Also in the United States, non-directive counselling is an important prerequisite of prenatal screening. In the American National Society of Genetic Counselors Code of Ethics genetic counsellors are recommended to ''enable clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences''.[71] In the United States all women are offered screening and all women may opt for diagnostic testing, regardless of their personal risk estimation retrieved from screening. The ACOG regards this as a decision that is based on personal values and therefore patients should be provided with their numerical risk rather than a positive versus negative screening result using an arbitrary cut-off[6,72] as is common practice in the Netherlands. The ACOG recommends that all women should be counselled about the risks and benefits of invasive testing compared with screening tests.[6]

Providing information on screening for Down syndrome preconceptionally may be helpful to ''unchain'' the choice for prenatal screening. Because prospective parents are not confronted immediately with the subsequent decisions to be confronted, they would have time to understand the complexity of the screening process and to think, discuss, and rethink about their decision when confronted with subsequent steps in the testing process.

Pro: time is pressing

Time is limited in the current procedure for presenting and performing prenatal screening. It is common practice that the prospective parents are informed about the options for prenatal screening for the first time during the initial prenatal visit. In that case, there is on average only 1 week remaining during which they have to decide on participating in the screening program. The healthcare professional informs the couple about the screening and needs an immediate response concerning their choice, because the test must be performed in a diagnostic center within a short time frame. When prospective parents are undecided, the healthcare professional attempts to keep all possibilities open—as a good antenatal care professional should do—by making an appointment for the test. The prospective parents are told to cancel the appointment in case of deciding not to participate in the screening. This way, an ''opt-in'' screening procedure changed to an ''opt-out'' screening. In fact, such cases do not conform to the model of informed decision-making. There is not enough time to process the information and the choice is not free: since an appointment has already been made, participating may appear to women ''the thing one just has to do''. Deciding to opt out may result in a woman feeling like a ''bad'' patient.

In the United States, the existence of quadruple screening makes it possible to start screening in the second trimester, which provides pregnant women with additional time to make a decision. However, quadruple screening is not an equal alternative for integrated-, sequential- or contingent-screening that all three start in the first trimester. First, performance of quadruple screening, in terms of the detection of Down syndrome, is considered less optimal when compared to screening that combines first-and second trimester testing.[6,73] Therefore, to guarantee optimal and timely screening test results, women should decide in the first trimester about prenatal testing and therefore the time frame continues to be ''short''.

Another disadvantage of suspending screening for Down syndrome until the second trimester of pregnancy is that results are available as late as the second trimester, which could create undue anxiety. In addition, choosing to terminate the pregnancy may be even more intrusive in the second trimester. The fact that waiting for a quad screen is still common in the United States may well reflect the opinion of those who do not favour early diagnosis and termination.

By providing the information on screening additionally before pregnancy, prospective parents would have more time to deliberate their choice, increasing the likelihood of making an informed decision about participating in screening.

Pro: Equal Access

One of the benefits of initiating antenatal care during early pregnancy is the possibility of a timely provision of information on prenatal screening for Down syndrome. However, Alderliesten et al.[74] found a disturbing delay in the timing of the initial prenatal visit among women from several ethnic groups in the Netherlands: more than 10% of these women had their initial visit at 18 weeks of gestation or later. This excludes them from the possibility of participating in prenatal screening for Down syndrome. In the United States in 2007, 18% of all mothers did not have prenatal care in the first-trimester. These percentages are even higher for most ethnic minorities, on the upper side of the scale 31.7% for American Indian or Alaska.[76] These women are excluded from first- trimester screening as well.

Participation rates for prenatal screening are lower in minority ethnic groups and in socially underserved groups, as compared with white and socioeconomically advantaged women with a higher socio-economic status.[65] In another study, lower participation rates did not reflect more negative attitudes toward screening, but rather low rates of informed choice.[67] In addition, women of Turkish and South Asian or Afro-Caribbean origin more often reported difficulties in understanding the information, and had less knowledge about Down syndrome, prenatal screening, and amniocentesis.[76]

What exactly causes the delay in the initial prenatal visit and the low rate of participation in prenatal screening is unknown. One possibility could be that women's knowledge is inadequate; this could be improved by providing information about prenatal screening not only during the initial prenatal visit, but also before pregnancy. In addition, women's awareness of the importance of a timely initial prenatal visit and hence equal access to the opportunity of prenatal screening for Down syndrome could be improved. We realize that it might be ''wishful thinking'' to assume that women arriving too late for prenatal care, will be in time for preconception care. We acknowledge that reaching these women is a challenge, but we want to emphasize that there is no reason not to accept this challenge. Past experiences and practices to adequately reach these groups[78-81] should be implemented and research should continue.

Preventing a ''gradual trap of choices'', providing sufficient time to make an informed decision and increasing the probability of equal access to prenatal screening are three arguments in favour of the provision of information about prenatal screening for Down syndrome before pregnancy.

Discussion

We empirically investigated women's preferences and identified arguments against and in favour of providing information about prenatal screening for Down syndrome preconceptionally. In our view, providing this information additionally before pregnancy has serious drawbacks including acting against many women's wishes and an increased possibility of communicating a directive message. Improving the informed decision-making process by unchaining the initial information offer and by providing sufficient time together with increased probability of equal access, however, constitute important benefits.

In our opinion, these drawbacks and benefits of preconceptional information provision on prenatal screening are valid and should be considered seriously. Regarding the drawbacks, we consider providing information on prenatal screening before conception not to be a desirable option. However, we showed that informing women on prenatal screening before conception does also bring forward important benefits. We believe that these benefits should not be ignored, but instead be acted upon. To bypass the drawbacks and maintain the benefits as considered in this paper, we suggest a different approach based on the Dutch information procedure about prenatal screening for Down syndrome: offering information instead of providing.

Strengths and Limitations- Empirical Study

The results of the empirical study were obtained from an unselected group of women; all women presenting for their initial prenatal visit at 20 midwifery practices in the Southwest region of the Netherlands were asked to fill out the questionnaire. This group consisted of both participants and non-participants in prenatal screening for Down syndrome. This is a major strength of the study.

The retrospective character of the questions on women's preferences could be considered a limitation. However, we also consider this as an important strength; at the moment of filling out the questionnaires, women were deciding to participate, or not, in prenatal screening and therefore this was a good moment to reflect on when (before or during pregnancy) they would most prefer to receive the information.

A limitation of our empirical study is that it only focuses on women's preferences; despite their role as important actors in the decision-making process, partners were not included in our questionnaire study. In future studies, we would highly recommend including perspectives of the partners as well.

Another limitation is that we do not know precisely how the participants understood ''information on prenatal screening for Down syndrome''. They might have understood it as information on the screening program solely (e.g., combined test, invasive diagnostics) or as information on the screening program and on the condition Down syndrome itself. In future studies we recommend to distinguish and explicate these two interpretations.

We cannot exclude the possibility of selection bias occurring in our study; women completing the questionnaires might have been more motivated to do so because they were willing to participate in prenatal screening for Down syndrome or because they were more opinionated due to worse previous experiences.

We pretested the items used in this study in a small sample, and concluded that these were comprehensible. In future studies, psychometric testing of items on validity and reliability needs to be performed and if necessary, items need to be adapted. For now, these items, although not extensively tested on validity and reliability, provide us a first insight in pregnant women's preferences regarding receiving information about prenatal screening for Down syndrome before conception.

Offering Information on Prenatal Screening Before Conception

Our proposal is to copy the first step of the Dutch information process on prenatal screening (The information offer; see Fig. 2) to the period before pregnancy. This means that, before pregnancy, the information on prenatal screening for Down syndrome should be *offered* instead of *provided*. By offering information, instead of providing information, the prospective parents are free to accept or decline the offer. In this procedure, women are given the opportunity to express their right not-to-know. Regardless of women's (non-) acceptance of the offer, the information offer should be repeated during the initial prenatal visit.

An Information Offer; Will it Work?

In our view, offering information instead of directly providing it, partly bypasses the drawbacks considered in this paper. The finding of our empirical analysis, that most women prefer not to receive information on prenatal screening before pregnancy, is an important argument against the provision of information before pregnancy. However, in that analysis, we asked women whether they would have preferred the provision of information before pregnancy. We did not ask whether they would have preferred to receive an *offer* to hear the information. The essential difference between these two questions is that if information is offered, women could choose to decline the offer when they did not wish to receive information.

Unfortunately, we cannot deduce these differences from the questionnaire. We can, however, compare our proposal to the current procedure of offering information about prenatal screening in the Netherlands. In the research population of our empirical study, all women were offered information and a substantial group (33.3%) declined the offer. Of these women, 89.6% reported not wishing information on screening before pregnancy. Based on the fact that one-third of the women were able to refuse the information offer on prenatal screening during pregnancy, we assume that women will understand the difference between offering and providing information and we believe that they will be also be able to refuse the offer before pregnancy.

Given new non-invasive prenatal diagnostic tests that become available, biotechnology companies may advertise for laboratory- developed prenatal tests for example on the Internet, in commercials on television, or in magazines. If pregnant women are casually picking up a magazine, or turning on their television, and are confronted with prenatal testing about Down syndrome, this may violate their right not to know: they may receive information unwillingly, information that they might have rejected if their physician offered the option of receiving it. On the other hand, keeping women ignorant by poor information provision by gynaecologists and by not providing information in public domains may violate women's ''right to know''. In either case, it is important that information is provided in a non-directive way, and that women are by no means pressured to undergo screening. In case of providing information by companies, it is the question while being commercially driven, the information presented is balanced enough to make an informed choice.[81] It may be hard to regulate all information provision ''in the open'' and to check on reliability and non-directiveness. A thorough discussion of pros and cons on this issue is needed, however, that falls beyond the scope of this manuscript.

With regard to the increased likelihood of communicating a perceived directive, we acknowledge that this likelihood is still increased in our proposal, because of the repeated offer for testing. However, women need not to receive the information twice. With our proposal, we give women the opportunity to decide whether they wish to receive information on prenatal screening before conception, *in addition* to the current prenatal information offer (in the Netherlands) or provision (internationally). Since women are allowed to decline the offer, this limits the risk of communicating a perceived directive. It is important to emphasize that the information on prenatal screening should be offered explicitly as an *option* and should not be perceived as an unwanted offer of excessive or unnecessary information. Therefore, health care professionals offering information on prenatal screening should be trained in non-directiveness, and in communication skills required for counselling on this topic, including an awareness of women's diverging values.[82]

The benefits discussed in this paper of providing information on prenatal screening prior to pregnancy are still valid when the information is offered instead of provided. Offering the information before pregnancy may unchain the first decisional step from the numerous decisions that may follow, thereby preventing a gradual trap of choices. Furthermore, the offer of information before pregnancy provides prospective parents who accept the offer a sufficient time window to accept or decline participation in prenatal screening. Additionally, equal access to antenatal care may be improved, at least among women accepting the preconceptional information offer, because many women currently present for their initial prenatal visit too late for the opportunity to participate in prenatal screening for Down syndrome.

Implications for Practice

In this study, we propose to give women the opportunity to decide whether to receive information on prenatal screening for Down syndrome to prospective parents before pregnancy, in addition to the current prenatal information offer (in the Netherlands) or provision (internationally). This proposal is based on an empirical study and ethical analysis. We believe that giving women the opportunity to decide whether to receive information on prenatal screening for Down syndrome prior to conception (by introducing the information *offer* at that time) would increase the likelihood of making an informed decision, with minimal disadvantages.

The *offer* of information concerning prenatal screening could be incorporated in a preconception care consultation, which is part of general preconception care that is increasingly regarded as an approach to improve reproductive health.[80] In the Netherlands, the Health Council advised to provide preconception care in a single-package consultation. In the United States the general view is that preconception care should be placed in a continuum of women's healthcare strategies, with the aim to ''catch'' women with reproductive potential at any time they meet with a healthcare provider. To enhance awareness and health promotion, it might be possible to extend the target population and provide information to high school students.[80]

Awareness among health care providers should be increased as well. In the United States the Centers for Disease Control and Prevention (CDC), the March of Dimes, the American College of Obstetricians and Gynecologists and an Expert Panel convened by the CDC published recommendations on preconception care. These recommendations are designed to promote optimal health throughout the lifespan for women, children, and families by using both clinical care and population-focused public health strategies. They are a starting point to make comprehensive preconception care a standard of care in the United States and to provide a more universal, comprehensive, evidence-based model of preconception care. The recommendations will promote the development and practice of preconception care that will be flexible to meet persons' changing reproductive care needs and address risks throughout their lifespan.[83-87]

An offer of information that is not in accordance with the goals of preconception care could result in reduced public support. The goals of preconception care are to optimize the health of the future child and mother through primary intervention and to increase reproductive autonomy by providing information on reproductive options;[87,2] Health Council of the Netherlands,[11] The offer of prenatal screening information during this counselling could be regarded as a reproductive option, thereby serving the second goal. In our view, the information offer would therefore fit appropriately in a preconception care consultation.

Also, the expert panel convened by the CDC recommended that everyone should be encouraged to have a reproductive life plan and that educational and health promotion counselling should be provided to all women of childbearing age, including information regarding the importance of early prenatal care.[83-87] Although not mentioned explicitly by the committee, these recommendations seem to be not inconsistent with our viewpoint that the information on prenatal screening for Down syndrome should be incorporated in preconception care. By extending the content of preconception care consultations, there is a risk of ''information overload''. This may lead to wrongly prioritizing the information on prenatal screening for Down syndrome in lieu of on the other important preconception information. Therefore, appropriate prioritizing by the counsellors is required. We recommend elaboration on this and other practical aspects of incorporating the information offer in preconception care consultations, prior to its implementation in clinical practice.

Recommendations for Practice and Further Research

Preconception care consultations should be carefully monitored and process evaluations should be performed regularly. Monitors and evaluations should contain at least the various aspects that were pointed at in this paper: women's preferences regarding the offer of information on prenatal screening, the fear of communicating a perceived directive by repeatedly offering/providing information, adequate prioritization, and the risk of information overload. Furthermore, monitoring and evaluation should be performed to determine if the provision of this information prior to pregnancy would indeed increase the likelihood of informed decision-making by lengthening time for contemplation and by unchaining the offer from the other decisional steps with regard to prenatal screening. Finally, it should be monitored and evaluated whether this offer would improve equal access to opportunities to participate in prenatal screening for Down syndrome.

Practices of preconception care are developing rapidly and new methodologies for prenatal screening will be introduced allowing testing very early in pregnancy. These developments require a rapid but careful implementation of information about prenatal screening for Down syndrome in preconception care consultations.

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Appendix: Self-completion questionnaire[1]

1. Before you became pregnant, did you consider participating in prenatal screening for Down syndrome for this particular pregnancy?

☐ Yes
☐ No
☐ I don't remember

2. Were you given any information about prenatal screening for Down syndrome before you became pregnant?

☐ Yes
☐ No
☐ I don't remember

3. How did you respond when your midwife or obstetrician asked you, during this particular pregnancy, if you wanted to be informed about prenatal screening for Down syndrome? (1 answer only)

☐ Yes, I wanted information about prenatal screening for Down Syndrome
☐ No, I did not want any information about prenatal screening for Down Syndrome
☐ I don't remember

4. Did you receive information about prenatal screening for Down syndrome from your midwife or obstetrician, during this particular pregnancy? (1 answer only)

☐ Yes, I received information about prenatal screening from my midwife / obstetrician
☐ No, I did not receive information about prenatal screening from my midwife / obstetrician
☐ I don't remember

5. Looking back in retrospect, do you wish you had received information about prenatal screening for Down syndrome before you became pregnant?

☐ Yes
☐ No (continue to question 7)
☐ I don't remember (>end questionnaire)

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[1] As this study has been performed in the Netherlands, the original self-completion questionnaire was formulated in Dutch. The authors indicate that the version translated to American English, as represented in this Appendix, is not suitable for use as a questionnaire for the United States population. This is mainly due to the fact that this translated version has not been tested on feasibility and psychometric properties in an American-English population.

6. You indicated that you wish you had received information about prenatal screening for Down syndrome before you became pregnant. What are the most important reasons for this? (multiple answers allowed)

☐ I think it would have made it easier for me to make a decision
☐ I think I would have made a better decision
☐ I would not have had to worry about this during my pregnancy
☐ I would have had more time to discuss my choice with other people
☐ I appreciate being timely informed about what to expect
☐ Other
>End questionnaire

7. You indicated that you did not want to receive information about prenatal screening for Down syndrome before you became pregnant. What are the most important reasons for this? (multiple answers allowed)

☐ I had not given any thought to prenatal screening for Down Syndrome before I became pregnant
☐ I did not know that prenatal screening for Down Syndrome was possible
☐ I did not want to receive information about prenatal screening for Down's Syndrome because I wanted to become pregnant first
☐ I would have been concerned for no reason
☐ I don't think I would have understood it well enough, because I was not concerned about it.
☐ I would have received too much information
☐ I think it's better not to know everything beforehand
☐ I just want to concentrate on my pregnancy without having to think about what could go wrong
☐ Other

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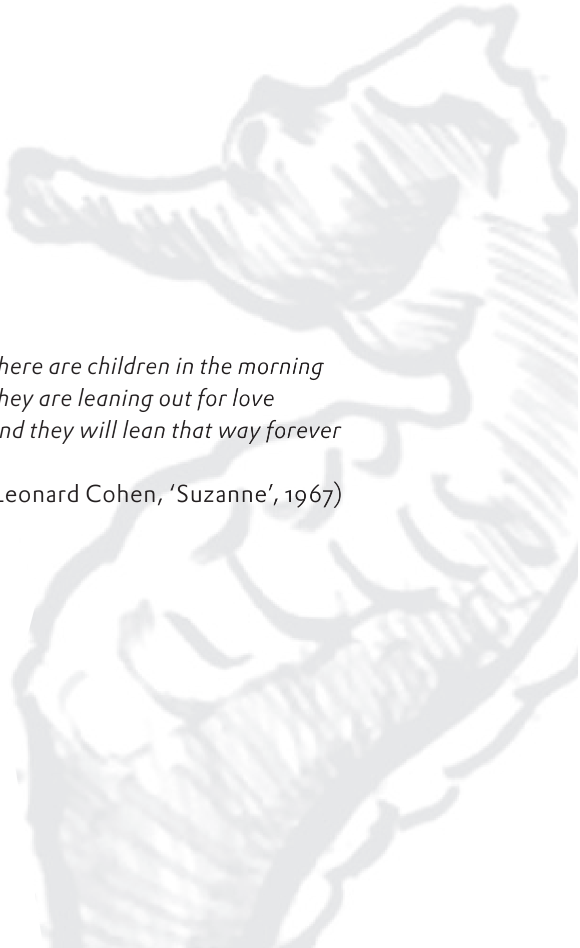
Chapter 9

General Discussion



There are children in the morning
They are leaning out for love
And they will lean that way forever

(Leonard Cohen, 'Suzanne', 1967)

Humankind depends on our continued desire to have babies. As such, care for reproductive health can be regarded as fundamental in each and every health care system. However, the span of reproductive health care is subject to debate.[1-3] This thesis has focused on the most controversial entry point for taking reproductive health issues into consideration: the period before a child is even conceived. It provides an analysis of important ethical issues regarding preconception care.

In this concluding chapter, we will present the main conclusions by answering the research questions. In order to further the debate on the implementation of preconception care on a wide scale we will discuss these main findings. We will conclude by providing recommendations for policy, practice, research and for intended parenthood.

Main conclusions

1. What parties carry moral responsibilities with respect to preconception care? And what efforts may be reasonably expected of these parties?

Moral responsibilities regarding preconception care arise because it can prevent harm to future children, improve women's health and to a lesser extent prospective fathers' health, improve public health and it can improve informed decision-making. Three key parties can be distinguished each of them having their own set of responsibilities and related efforts to undertake: prospective parents, caregivers, and governments. A fourth party that could be distinguished are 'employers'. Employers should collaborate with prospective parents as much as possible, by modifying the working conditions. They should, for example, offer prospective parents the opportunity to avoid exposure to chemicals and to avoid working night shifts. However, there are some drawbacks associated with the employers' responsibility, such as the feasibility, and whether it is fair to other employees. A thorough discussion of the employers' responsibility falls beyond the scope of this thesis. In the following, we will discuss the responsibilities of Prospective parents, caregivers and governments.

Prospective parents

Prospective parents have moral responsibilities towards their future children to prevent them from harm. They can do so by diminishing or eliminating risk factors in their own life and thereby diminishing the chance for adverse effects on the health of their future child even before pregnancy is a fact. Although the child is (still) non-existent, prospective parents are morally responsible already because the future child that may come into existence will be their own child. There are still many uncertainties, however, the future relationship is crystal clear and unchangeable: the most intimate relationship possible, that between a parent and her or his child. It would be excessive to judge all fertile people irresponsible when consuming alcohol, smoking or not taking folic acid supplements when they engage in sexual activities while taking all reasonable precautions not to get pregnant. We proposed therefore to draw a line using the concept of intention: when people procreate intentionally and would usually prefer begetting a healthy child, the moral pressure to minimize risks is increased.

With respect to future fatherhood, if based on evidence, preconception care for men may contribute to early responsible fatherhood. The current distinction may disappear between the father-as-progenitor and the father-as-carer, in which only the latter is considered to be a moral state, because of the effort that need to be made: both types of fatherhood will have a moral dimension. This is the case because men must do an effort to reach that state, for example by modifying their lifestyle to prevent their future children from harm. Thus, from an ethical point of view, paternal responsibilities will already start before conception. So far, however, the evidence for paternal preconception lifestyle risk factors for adverse effects on the child's health remains scarce.

To determine how much effort can be expected of prospective parents to prevent harm inflicted upon the future child, we introduced the so-called Evidence-Modifiability-Effort-Severity-Probability(EMESP)-ratio. The EMESP-ratio covers five aspects of a particular risk factor: the strength of the Evidence on which the risk factor is based, the Modifiability of the risk, the Efforts necessary to eliminate or diminish the risk factor, the Severity of harm, and the Probability that harm will occur. It is reasonable to expect from prospective parents to modify a risk factor when it meets a certain threshold of the EMESP-ratio. Although it is difficult to calculate the exact ratio and to determine where the threshold lies, some tentative conclusions can be drawn. For example, we argued that prospective mothers are morally responsible for reducing the risks for neural tube defects by taking folic acid supplements, because there is good evidence that the chance of having a child with a neural tube defect could be reduced (modified) by two-thirds by taking supplements. We qualified the efforts of taking supplements as low and the harm that could be prevented as severe. The probability, however, is relatively low, when not using folic acid supplements the risk of neural tube defects is still less than 0,1 percent. Taking these aspects together, it can be concluded that folic acid deficiency meets the threshold of the EMESP-ratio.

When calculating the EMESP-ratio for the risk factor preconception paternal smoking, it appeared to be important to distinguish direct and indirect harm. Direct harm of the child and the mother is caused by the smoking behaviour of the prospective father. Indirect harm of the child and the mother is caused by the prospective father's lack of support towards the prospective mother to stop smoking, as the smoking behaviour of the prospective father influences the smoking behaviour of the prospective mother. When a prospective father smokes, chances are smaller that a prospective mother wants and succeeds to stop smoking. When both prospective parents smoke, the direct and indirect harm of the fathers continued smoking behaviour is more severe and likelier to occur. Therefore, more effort may be expected of prospective fathers to quit smoking. If the prospective mother does not smoke, we argued that it would be good enough when the prospective father would reduce the number of cigarettes and that he would smoke them outside.

Caregivers

Responsibilities rest also on caregivers and on organisations of caregivers. Caregivers should be alert and aware of preconception health issues when they generally treat patients in the reproductive age (women and men alike). Providing them, for example, with medication that is teratogenic (that can cause malformations or functional damage to an embryo), needs to ring a bell, as it is potentially harmful for the future offspring. In such cases, caregivers may ask their patients whether they have an immediate child wish and inform them about the potential risks for future offspring as well as provide them with possible alternative medication.

Caregivers have an added responsibility to provide preconception care in an ethically sound manner, which implies providing prospective parents with relevant information, without burdening them with facts that are trivial for their individual case. Furthermore, if the threshold of the EMESP-ratio is met, caregivers should recommend lifestyle modification. If a prospective parent is not willing to make an effort to modify his or her lifestyle, the caregiver may well encourage him or her to do so. If the prospective parent does not succeed in lifestyle modification, caregivers should offer advice and help. Regarding the risk factor 'paternal preconception smoking', for example, the caregiver needs to emphasize that it is of the utmost importance that a prospective father modifies his smoking behaviour. He should preferably stop, but in any case he should reduce the numbers of cigarettes and smoke outside so as to prevent direct harm. In the case that the prospective mother smokes, indirect harm both to his future child and the prospective mother needs to be prevented by smoking cessation. In that case, the caregiver should additionally encourage the prospective father to participate in a program to quit smoking.

Organisations of caregivers should develop protocols for providing ethically sound preconception care based on the EMESP-ratio.

Governments

Governments should create a climate in which it is attractive to live healthily by providing incentives to choose the healthy option instead of unhealthy alternatives. Governments are responsible for organising preconception care to guarantee that all women have an equal opportunity to receive adequate preconception care, taking into account the situation in their countries. Two characteristics of preconception care in particular favour a top-down approach initiated by governments, in addition to the bottom-up initiatives organised by caregivers. First, general preconception care is a rather new concept, requiring a new mindset, for which governments should create awareness. Second, preconception care is multifaceted. It should be part of an interlinked chain that creates connections in the course of life – from preconception care through prenatal, neonatal, child, and youth care. And it entails the need for many healthcare disciplines to cooperate – general practitioners, midwives, obstetricians, clinical geneticists, and other maternal and child health professionals. To avoid bureaucratic barriers and to guarantee a continuum of optimal care these links are crucial. These characteristics may complicate and slow down the bottom-up organisation of preconception care because many disciplines must reach consensus. Comprehensive national policies can facilitate bottom-up initiatives – by creating conditions to make initiatives work. Policy, for example, might instruct insurance companies to financially cover preconception visits. Governments can take up responsibility by, for example, organising continuing mass campaigns to promote preconception health and preconception health care.

II Is the argument of medicalisation a valid argument against the widespread implementation of preconception care and for not seeking preconception care?

The medicalisation argument is regularly brought forward as an argument against preventive medicine. We identified and analysed the underlying moral considerations that appear to determine the argument of medicalisation in this context: first, preconception can be seen as a first or a last step on a slippery slope of a continuum of care; second, preconception care may lead to alienation because of 'health' being the central value of preconception care; third, prospective parents may not feel free to choose against advice given; fourth, preconception care unequally affects women in particular, thereby putting too much responsibility for a successful pregnancy outcome on their shoulders; fifth, preconception care may lead to blaming oneself or blaming by others anticipating an adverse pregnancy outcome; and finally, preconception care could be at odds with the mystery surrounding the process of becoming pregnant.

Although there is some validity in all the above-mentioned moral concerns, when counterbalancing them with moral obligations towards the future child, the overall argument of medicalisation cannot be regarded as a convincing argument for refusing to seek out preconception care. In addition, we regard not implementing preconception care to be an inappropriate measure for avoiding the presumed moral problems related to preconception care and often voiced in the medicalisation argument, because that would be like throwing the baby out with the bath water. Contrary, we argue that the only possible way to go about preconception care in a sound ethical manner is by consciously weighing its moral implications and address them in the course of implementation.[1]

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[1] Some moral lessons that can be learned from the medicalisation critique will appear as recommendations in the last section of this chapter.

III To what extent are prospective parents willing to engage in preconception care and what determines their intention?

Women's intentions for engaging in preconception care were explored in a web-based questionnaire. Women were recruited after filling out the Zwangerwijzer (Preparing For Pregnancy, an Internet tool for preconception risk assessment). Only one third of the respondents (*n*=1974), reported to intend to seek individual preconception counselling by a caregiver. Almost all of them (99%) reported at least one risk factor for adverse effects on the future child's health. However, none of the individual's characteristics or risk profiles was specifically associated with the intention to seek preconception counselling. Nevertheless, the types of motives women mentioned were positively associated with their intentions. This was in particularly true for 'general knowledge', 'intrinsic motivation' and, to a lesser extent, 'motives related to the timing of pregnancy', 'perceived usefulness' and 'knowledge on risks'. Extrinsic motivation (a party other than the woman herself was mentioned as motivator) was, in contrary, negatively associated with the intention to seek preconception counselling. Creation of awareness of the benefits of preconception care and development of intrinsic motivations to seek preconception care counselling may promote the use of preconception care.

Our complementary interview study provided insight into women's hesitance to seek preconception consultation even if their general attitude towards preconception care is positive. First, women seem not to consider themselves as part of the target group for preconception care. We found three reasons for this: first, they think they know enough, second, they think they do not run a risk, and third, they misunderstand the aim of preconception care. Furthermore, our study included women's perceptions relating to the process of becoming pregnant in relation to preconception care, which provided additional insight into women's hesitance to seek preconception care. We identified four themes that appear to be important to women when considering the process of becoming pregnant in relation to preconception care: (1) Planning: preconception care works optimally when pregnancies are planned. On the one hand, women consider pregnancy planning to be important. On the other hand, they see it as a drawback: it is hard to decide when to stop using it and start trying to get pregnant. (2) Publicity: preconception care may endanger the 'pact of intimacy', the secret wish for a child of the prospective parents. However, most women expect that the secret will be kept, despite seeking preconception care consultation, because the medical expert is bound to professional confidentiality. (3) Information on fertility: of course, women strive for healthy pregnancies and healthy children; but for many, their foremost concern appeared to be about their fertility. And finally (4) Artificiality: many respondents mention that their pregnancy and the process of getting pregnant should be 'romantic' or 'natural'. In these four domains, women's ideals sometimes conflict with the current organisation and delivery of preconception care.

In a small explorative study we looked into men's perceptions of preconception care. The results suggested that men perceived birth or the prenatal period as the start of paternal responsibilities. However, when potential benefits of preconception lifestyle modification for their future children's health were pointed out to them, almost all acknowledged that paternal responsibilities could already start before pregnancy.

Furthermore, this exploration indicated that prospective fathers demand strong evidence of the effects of lifestyle and lifestyle modification in order to consider lifestyle modification before pregnancy. They were in principle not unwilling to modify their lifestyle, but they needed to be convinced of the benefits with evidence-based facts. When evidence is lacking or weak, this is apparently a barrier. We showed, however, that these men were right in requiring evidence, but that they were too demanding: we argued that *fair* evidence would be *good enough*.

IV Would it be morally justifiable to include information about screening for Down syndrome in preconception care consultation and why (not)?

Information on prenatal screening for Down syndrome is commonly provided after conception, during the first trimester of pregnancy. In an ethical analysis we argued that providing information on prenatal screening for Down syndrome additionally before pregnancy has serious drawbacks. It goes against many women's wishes and entails an increased risk of communicating a directive message. However, it also constitutes important benefits: improving the informed decision-making process by unchaining the initial information offer and by providing sufficient time; and an increased probability of equal access to prenatal screening, as currently some women arrive too late in pregnancy for their initial visit to participate in screening. To bypass the drawbacks and maintain the benefits as considered in this chapter, we favour a different approach. This approach is based on the Dutch information procedure about prenatal screening for Down syndrome: offering information instead of providing. The first step of the Dutch information process on prenatal screening can be copied to the period before pregnancy. This means that the information on prenatal screening for Down syndrome should be offered –instead of provided– before pregnancy. By offering information, the prospective parents are free to accept or decline the offer and they are given the opportunity to express both their right to-know as their right not-to-know. Regardless of women's (non-) acceptance of the offer, the information offer should be repeated during the initial prenatal visit.

Summary of the main conclusions

To summarize, there are many ethical angles to preconception care, which all merit careful consideration. First of all, the key parties involved in preconception care, notably the prospective parents, caregivers, and governments, all have a unique set of responsibilities and actions to undertake. Moral obligations to take up these responsibilities and contribute to the health of a future child outweigh arguments of medicalisation for disregarding such obligations, ranging from the slippery-slope argument to concerns about the loss of the mystery accompanying the process of becoming pregnant. When looking more in detail into the motivations of the prospective parents, it appears that attitudes regarding preconception care are not necessarily in line with their intentions for actually engaging in it and taking up the responsibilities linked to it. Women's ideals of the process of becoming pregnant sometimes conflict with the current organisation and delivery of preconception care. Finally, from an ethical point of view, it appears that preconceptionally providing information about screening for Down syndrome is controversial. As such, these types of information deserve an alternative approach within the framework of preconception care, which respects the right-not-to-know of future parents.

Discussion

To further the debate on preconception care it is important to address two main crosscutting points. First, the type of counselling (non-directive versus directive) depends on how the different aims of preconception care are prioritised. Second, the duration of the preconception period which obviously varies between individuals, which poses challenges for designing preconception care strategies.

Non-directive versus directive counselling

Directive counselling has long been the standard approach in health care. In using a directive counselling approach the counsellor tries to direct a person at a particular decision or behaviour (in this thesis: modifying preconception risk factors). However, in the context of clinical genetics and especially in reproductive clinical genetics a new approach was considered to be more appropriate: non-directive counselling.[4] The principle of respect for autonomy is central in a non-directive counselling approach and prescribes that people should make their own reproductive decisions, and counsellors need to support them to do so in a non-directive way. To determine which approach is appropriate in preconception care, a discussion about a potential hierarchy in the aims of preconception care is needed.

Preconception care aims (1) to prevent harm to future children, (2) to enable and improve informed decision making and (3) to improve prospective parents' health, mainly women's health. A fourth aim is the improvement of health and cost saving at the public health level, which plays a role in discussing *facilitating* preconception care, but is in our opinion less relevant when discussing approaches to *provide* preconception care and is therefore left outside this reflection on how to provide preconception care.

It is not clear yet whether the three aims can be regarded of equal importance or if there is a certain hierarchy amongst them. The aim of 'improving informed decision making' is best achieved by using a non-directive approach. An example of using a non-directive approach to improve informed decision making is the offer of preconceptional information on prenatal screening for Down syndrome: we argued that the information should be offered in stead of provided to respect both the right to-know as well as the right not-to-know.

How to achieve the objective of 'improving prospective parents' health' is less clear and may confront the caregiver with a moral dilemma. Providing directive advise, e.g. to quit smoking, may be justified because the prospective parents' health is at stake. However, by pressuring them to stop, their autonomy to live as they want to, may be constrained. Bringing in the third aim may dissolve this dilemma: smoking is not only harmful to the prospective parents themselves, but may cause harm to the future child as well. The aim to 'prevent harm to future children' often requires a directive approach, because of the moral responsibility of the prospective parents and the vulnerability and dependence of the future child.[5] We would like to emphasise that a directive approach does not necessarily constrain prospective parents' autonomy; it may even be considered as an expression of respecting one's autonomy. Pointing at the prospective parents' responsibility to prevent harm to their future children is to take them seriously in their role of future parents.[6] Furthermore, where addiction plays a role, e.g. in case of smoking, decisional competence may well be compromised. If so, insisting on efforts to stop smoking or drinking (and referring them to professional help) may be regarded as aimed at restoring rather than limiting prospective parents' autonomy, because it enables them to make better informed reproductive decisions and thus to take them seriously as autonomous authors of their own lives.[6]

To achieve the three preconception care objectives, we conclude, that a mixed approach is needed, merging directive and non-directive strategies. To decide what information directive and what non-directive, the Dutch Health Council suggested that information about non-modifiable risk factors should be provided in a non-directive way (as is common in reproductive clinical genetics) whereas information about risk factors that can be modified should be provided in a directive way. However, we argued that there are more aspects of a risk factor that have moral relevance than only its modifiability. We regard the EMESP-ratio key in deciding on which approach to take. Although it is difficult to calculate the exact ratio and to determine where the threshold lies, some tentative conclusions with respect to the EMESP-ratio and EMESP-threshold can be drawn. In cases where the EMESP-ratio meets a certain threshold, a directive approach is justified, whilst a lower score would favour a non-directive approach. When, for example, there is sufficient evidence that a modifiable risk factor would require considerable effort to reduce it, the harm is qualified as not severe and the probability of the harm to occur is small, a non-directive approach would be appropriate. However, if a risk factor meets the EMESP-threshold and there is, for example, sufficient evidence that a relatively small effort is required to modify the risk factor to prevent likely and severe harm, the aim of harm-prevention should prevail over the aim of informed decision making, and therefore a directive approach would be justified.

This implies also that genetic risk factors do not necessarily require a non-directive approach: if there is fair evidence that a genetic risk factor that is likely to cause severe harm to the future child and that it can be modified for example by preimplantation genetic diagnosis and IVF preventing the harm to occur, we may expect a prospective parent to do that effort and a directive counselling approach can then be justified. Still, prospective parents remain free to choose against the advice given.

In the context of genetic risk factors, the concept of the right not-to-know is also relevant, e.g. we showed that it plays a central role in the discussion about informing about prenatal screening for Down syndrome. Acting upon the right not-to-know is very difficult because there is a tension between the right to-know and the right not-to-know. The right not-to-know prescribes that prospective parents should be offered the possibility to refuse receiving information. However, in order to make an informed decision about refusing information, they must have at least some information. Moreover, it may be demanding for caregivers to explore prospective parents' preferences with respect to all these risk factors and they need to be very careful in deciding not to provide information. Not providing information that is available would mean to limit prospective parents' autonomy, as being adequately informed is a condition for making informed decisions. Illustrative is a woman's personal experience with both a gynaecologist and a midwife withholding information about the potential relation between her overweight on her miscarriage and its implication for future pregnancies. "It would be easier to loose weight, if the gynaecologist I visited last week for a follow-up visit, would have said: 'Madam, I am very sorry about your miscarriage and of course we cannot prevent all miscarriages to happen, and so on, but may I, as an aside, inform you about the potential relation between overweight and miscarriages… Of course it is not the only risk factor and loosing weight does not guarantee a healthy pregnancy, however, if there is anything you would like to do yourself, losing weight can be useful in reducing the chance for a miscarriage.' I would have appreciated that honesty, instead of this, kind of, keeping it quiet. No one mentioned it to me, neither the gynaecologist, nor the midwife."[II] Also, in retrospect, when parents have a child with a disease or condition that could have been prevented by doing something different before or during pregnancy, they may feel misinformed and treated wrongly.

We would like to emphasise that, even if the choice of prospective parents is not morally indifferent and counselling about risk factors meeting the EMESP-threshold should be directive in the sense that future parents should be persuaded to behave responsibly, they should not

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[II] Fragment from an unpublished interview be forced to do so. It is important that people remain legally free to choose against the advice given. In other words, there should be no legal directives for prospective parents.[III]

Duration of the preconception period

Lifestyle advice before pregnancy may be compared to advice during pregnancy. However, among other differences, the duration of the preconception period clearly differs from the nine months period of pregnancy. In theory, the preconception period is as long as the fertile period lasts. However, we argued in chapter 3 to draw a line using the concept of intention. When people intend to conceive children, then these want-to-be parents may be held morally responsible for preventing their children from harm. This concept is more than a practical concept to limit the group of people that could be held responsible for future offspring: it is morally relevant as well. The moral concept of preventing harm is the same, but because want-to-be parents procreate intentionally and would usually prefer begetting a healthy child, the moral appeal to minimize risks is increased.

Still, however, the duration of the preconception period that starts with the intention to become pregnant, and ends with pregnancy may vary between one month and several years, and for some, pregnancy may never be reached. This uncertainty may form a motivational barrier for prospective parents to act upon the advice given. Moreover, if time passes by, the EMESP-ratio may change, as the effort may increase to continue acting upon the advice given, for example, not consuming alcohol for one month would be much easier then to continue the healthy behaviour for two years, and thus, if time passes by, what we may expect of prospective parents may change as well. That the EMESP-ratio changes because of the increased efforts, does not automatically imply that prospective parents are no longer expected to maintain the healthy behaviour, this depends upon the relative position of the EMESP-threshold.

Implication for practice

The suggestion that a dual approach is needed that merges directive and non-directive strategies and the observation that the duration of the preconception period differs between individuals, pose major challenges for the development of preconception care strategies. Moreover, to do justice to the individual's situation, tailored care to the individual is needed, which will require much of the judgment of caregivers.

[III] In cases in which a child may be severely harmed by the behaviour of (mostly drug addicted) prospective parents, a legal directive may be justified, such as forced contraception use. A discussion of this issue falls beyond the scope of this thesis. See for example: Under what conditions is it ethical to offer incentives to encourage drug-using women to use long-acting forms of contraception? Lucke JC, Hall WD

Strengths and limitations of this thesis

This study crossed boundaries between the theory and the practice of both the fields of medical ethics and obstetrics, which can be regarded both its strength as well as its limitation. Crossing boundaries between disciplines makes it possible to consider an issue from various perspectives and thereby provide valuable insights and it usefully combines the theoretical and the practical.

The reverse side of this interdisciplinary character is that specialists on both sides of the academic spectrum may point at disciplinary gaps. Physicians might, for example, miss a detailed report of the medical aspects of preconception care or they might underestimate the value of ethical analysis is for the practice. Ethicists, on the other hand, may wonder how an empirical study into the perspectives of women and men contributes to an ethical analysis about moral justifications for choices regarding preconception care or they may hold that by discussing the wide variety of topics related to the subject matter, the thesis might loose some of its ethical depth.

Concerns of both sides have partly been accommodated in the research. To the ethicist critics we would like to respond that we *considered* women's and men's perspectives on preconception care, as opposed to automatically copying the prospective parents' opinions as the new norm. To the physician critics we would like to underline that we applied theory to practice by taking into view women's and men's perceptions: their perceptions have enabled us to understand some arguments against the implementation of preconception care and to draw more carefully balanced conclusions. Not including an extensive report on the medical aspects of preconception care and not further debating ethically interesting issues have been deliberate choices. Ultimately, we had to make choices and could not cover all interesting aspects related to both ethics and medicine applied to preconception care.

Recommendations

In order to implement and provide preconception care in an ethically sound manner, the outcome of this study points at the following recommendations for policymakers, caregivers, researchers and prospective parents:

Recommendations for policymakers of the Dutch Ministry of Health

From an ethical perspective it is critical that governments widely implement general individual preconception care, thereby facilitating prospective parents and caregivers in taking up their respective responsibilities. We firmly oppose the current Dutch policy that has reversed the intention of a former minister to integrate general preconception care in the Dutch health care system.[7] The current policy is to not widely implement preconception care, but to leave the initiative to the professionals in the field.[8] We agree with the advice to conduct further research on how preconception care can be directed at difficult-to-reach target groups.[8]

Efforts should be undertaken to make preconception care part of standard care. This includes the following:

- It is important that governments promote measures to facilitate preconception care for all, by organising preconception consultations in low threshold locations and by ensuring that the costs of these consultations are covered by health insurances.
- Governments should aim for a change in public opinion towards preconception care, by initiating public campaigns that raise awareness of the importance and existence of preconception care consultation for everyone.
- In raising awareness, governments should frame preconception care in positive terms, focusing on opportunities instead of risks and rights instead of obligations.
- In raising awareness, high schools may be a useful entry for educating all about the importance of preconception health and about the use of timely seeking out preconception care.

Recommendations for caregivers

- In order to lower the threshold for seeking out preconception consultation, it should be offered in neutral locations, such as general health facilities (e.g. general practitioner, health care centre) or organized home visits by midwifes.
- A targeted effort is required to include men in preconception care.
- Special effort is required to reach the most vulnerable subpopulations such as immigrants and those of low socio-economic status. This may call for non-conventional methods, like the Rotterdam preconception project engaging social peer group networks and community social workers as a means of connecting to specific groups.
- Organisations of caregivers should develop protocols for providing ethically sound preconception care based on the EMESP-ratio, merging directive and non-directive strategies.
- Preconception care requires a tailor-made approach to account for individual differences in risk profile and needs or preferences.
- Caregivers need to realise that the length of the preconception period differs between couples, and thus that the prospective parents' efforts to continue lifestyle changes may increase.
- The focus of preconception care should be broadened to include consultation on the choice for and timing of pregnancy, as it appears that prospective parents are unsure about if and when to begin trying to conceive. This requires a real dialogue between caregiver and prospective parents. Caregivers should also include information on fertility and on the menstrual cycle and fertile days.

- Furthermore, preconception care consultations should include the offer of information about prenatal screening for Down syndrome.
- Caregivers should communicate in common language, and they should thus avoid using alienating academic terms such as ‘pregnancy outcome’.
- Although preconception care does not necessarily make the process of getting pregnant artificial, practitioners should be aware of the values and ideas of ‘naturalness’ and ‘romance’ that prospective parents consider as important.
- Although prospective parents should be pointed to their moral responsibility to modify risks, in order to prevent blaming, caregivers should nuance their message by mentioning that the parents’ potential influence is limited and that no guarantees can be given

Recommendations for researchers

- Preconception care consultations should be carefully monitored, including the study of the effects of preconception interventions on pregnancy outcome, and process evaluations should be performed regularly.
- The effectiveness of e-health tools in preconception care needs to be studied.
- Research should be increased into the effects on (modification of) preconception risk factors for men as well on their willingness to engage in preconception care.
- Studies are needed to explore the possible adverse effects of psychosocial risk factors, such as housing and a social network, on the health of the future child. Furthermore, an ethical debate about including these risk factors in preconception care is necessary.
- Ethical aspects with respect to preconception care and cultural diversity should be investigated.
- An ethical and empirical study is needed into the employers’ moral responsibility and the feasibility to collaborate with prospective parents to prevent harm to their future children.

Recommendations for prospective parents

- All people should make a pregnancy plan or they should carefully use contraceptives.
- Prospective parents should engage in preconception consultation.
- Starting with the intention to become pregnant, prospective parents should act upon their responsibilities towards their future children by modifying potential risk factors for the health of their future children.
- A prospective father should support the prospective mother to take up her responsibilities by modifying her behaviour before pregnancy and continue it throughout the pregnancy.
- Prospective parents’ efforts to prevent harm to their future children need not to be considered as sacrifices but as acts of love.

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Appendix: List of participants expert meetings in alphabetic order

Mw. I. Aalhuizen
Prof. Dr. I. de Beaufort
Drs. J. Boonekamp
Dr. P. Borry
Prof. dr. M. Cornel
Dr. S. Denktas
Dr. L. de Jong
Drs. K. Jongsma
Prof. dr. L. ten Kate
Dr. P. Lakeman
Dr. M. Lambregtse-van den Berg
Prof. dr. P. Mastroiacovo
Prof. dr. G. Pennings
Dr. K. Prinsen
Mw. J. Derksen
Dr. V. Ruiz van Haperen
Prof. dr. E. Steegers
Dr. A. Struijs
Prof. dr. P. Verloove-Vanhorick
Drs. E. van Vliet-Lachotzki
Dr. T. Voorham
Prof. dr. G. de Wert

Summary

This thesis deals with ethical issues of preconception care. It will be argued that preconception care needs to be facilitated by governments, provided by caregivers and sought by prospective parents.

Part I Concepts

In Chapter 1 we argue that, as general individual preconception care is a new preventive strategy to improve the health of future children, and as ethical issues will in all likelihood influence the uptake and the success of preconception care, a careful ethical analysis is needed. A timely ethical analysis may make it possible to influence the development of preconception care. We introduce the objectives of the thesis. Generally, this thesis aims to provide an overview of the important ethical issues regarding preconception care and to systematically analyse those issues in order to further the debate on the implementation of preconception care on a wide scale. To answer these questions, this study relies both on ethical theory as well as on the practice of preconception care by using the method of the reflective equilibrium. In this method, several elements are considered, such as relevant background theories, moral judgements and empirical data; and is searched for coherence, the 'equilibrium', between these elements. This relation between practice and ethical theory gives the thesis an interdisciplinary character involving the fields of general practice, midwifery and obstetrics as well as the domain of medical ethics.

Chapter 2 introduces preconception care: the benefits, the situation in the Netherlands and worldwide, several potential approaches and challenges. We discuss how preconception care offers new strategies for improving reproductive health. Reproductive health has improved little in the last few decades. The Netherlands, particularly in large cities, has relatively high perinatal death rates compared with other European countries. Lack of improvement in reproductive outcomes despite improved quality of and better access to prenatal care strongly suggests that prenatal care alone is insufficient. Preconception care usefully connects the life course of future children, from preconception through prenatal to childhood and connects many health-care disciplines. We argue that combining a top-down policy structure and bottom-up organisation around caregivers would be a promising approach. Given the likely benefits and cost savings calculated for the Netherlands, we conclude that failing to facilitate preconception care would reflect a breakdown of both professional and governmental responsibilities.

In chapter 3, we argue that prospective parents have moral responsibilities towards their future children to prevent them from harm. They can do so by diminishing or eliminating risk factors in their own life and thereby diminishing the chance for adverse effects on the health of their future child even before pregnancy is a fact. Although the child is still non-existent, prospective parents are morally responsible because the future child will be their own child. Even if there are still many uncertainties, the future relationship is crystal clear and unchangeable: the most intimate relationship possible, that between a parent and his or her child. It would be excessive to judge all fertile people irresponsible when consuming alcohol, smoking or not taking folic acid supplements when they engage in sexual activities while taking all reasonable precautions not to get pregnant. We propose therefore to draw a line using the concept of intention: when people procreate intentionally, the moral pressure to minimize risks is increased. In the second part of this chapter we translate the want- to-be parents' responsibilities into practice. We distinguish four components of risk factors: modifiability, chance, severity and effort. We examine some evidence- based risk factors using these variables determining moral responsibilities, including folic acid deficiency. The chance of having a child a neural tube defect could be reduced (modified) by two-thirds by taking supplements. Although the chances are small (less than 0,1 percent), the severity of the harm that could be prevented is immense and the efforts are low. Therefore, we think that prospective mothers are morally responsible for reducing the risks for neural tube defects by taking folic acid supplements. Informal protocols could be developed on the basis of an extended and thoroughly debated risk-responsibility analysis.

Chapter 4 focuses on paternal responsibility and the role of evidence. We point to a potential conflict between the view that preconception care should be also directed at men and the scarcity of evidence on (modification of) paternal preconception risk factors for adverse pregnancy outcomes. We argue that from an ethical perspective, responsible fatherhood starts already before conception, as long as evidence increases. Our explorative interview study suggests that the strength of the evidence for paternal preconception lifestyle modification is also important for men. However, it seems that men require *good* evidence in order to be willing to change their preconception lifestyle, while we argue that *fair* evidence would be good enough. We elaborate on the risk-responsibility analysis of chapter 3 and introduce the EMESP-ratio to determine the moral responsibility of prospective fathers to modify their behavior: the strength of the Evidence on which the risk factor is based, the Modifiability of the risk, the Efforts necessary to eliminate or diminish the risk factor, the Severity of harm, and the Probability that harm will occur and that it will be prevented by modifying the risk factor. Furthermore, we argue that one may expect prospective fathers to modify a risk factor when it meets a certain threshold of the EMESP-ratio. Also, caregivers may be expected to provide information about the risk factors that meet that threshold in a directive way, which means that they should encourage prospective fathers to modify their risk factors.

Chapter 5 discusses the argument of medicalisation regarding preconception care. The argument of medicalisation is sometimes used to prevent preconception care from being part of general health care. The argument also functions as a barrier for women to seek preconception care. We identify six underlying moral concerns: preconception care can be seen as a first or a last step on a slippery slope of a continuum of health care; preconception care may lead to alienation because of ‘health’ being the central value of preconception care; prospective parents may not feel free to choose against advice given; preconception care affects women in particular; preconception care may lead to blaming oneself or blaming by others; preconception care could be at odds with the mystery surrounding the process of becoming pregnant. Although there is some validity in these moral concerns, for example the focus on ‘health’, when counterbalancing them with moral obligations towards the future child, the overall argument of medicalisation cannot be regarded as a convincing argument for refusing to seek preconception care. In addition, we regard not implementing preconception care to be an inappropriate measure for avoiding the presumed moral concerns related to preconception care and often voiced in the medicalisation argument. Contrary, we argue that the only possible way to go about preconception care in a sound ethical manner is by consciously weighing its moral implications and address them in the course of implementation

Part II Perceptions

Chapter 6 quantitatively investigates women’s intentions to seek preconception counselling by using a web based questionnaire related to a national preconception risk assessment website, ‘ZwangerWijzer.nl’ (‘Preparing For Pregnancy’). Only one-third of the responding women (n =1974) intend to seek counselling. Women’s intention to seek preconception counselling appears to be unrelated to their characteristics and risk profiles. The types of women’s motives, in contrast, are strongly associated with the intention to seek preconception counselling. Particularly ‘general knowledge’ and, to a lesser extent, ‘motives related to the timing of pregnancy’, ‘perceived usefulness’ and ‘risk-specific knowledge’ are positively associated with the intention. Extrinsic motivation is negatively associated with the intention to seek preconception counselling, which means that when she points to a party other than the woman herself to explain her intention, she will be less likely to intend to seek preconception counselling. The findings suggest that use of preconception care may be promoted by creating awareness of the benefits of preconception care and by strengthening women’s intrinsic motivations.

Chapter 7 qualitatively investigates women’s perceptions with regard to the process of becoming pregnant and regarding preconception care. The interviews show that women’s attitude towards preconception care in general is overall positive, but when asking about seeking preconception care themselves, respondents are hesitant. It thus seems that women do not consider themselves to be part of the target group for preconception care. We provide three reasons for this: first, perceived sufficient knowledge, second, perceived lack of risk, and third, misunderstanding of the aim of preconception care. Furthermore, our study includes women's perceptions of the process of becoming pregnant in relation to preconception care, which provides additional insight into women's hesitance to seek preconception care. We identify four themes that appear to be important to women when considering the process of becoming pregnant in relation to preconception care: (1) planning, (2) a secret and intimate process of becoming pregnant, (3) information on fertility, and (4) a 'natural' process of becoming pregnant. In these four domains, women's ideals are sometimes in conflict with the current organisation and delivery of preconception care.

In chapter 8 we identify arguments against and in favor of providing information about prenatal screening for Down syndrome preconceptionally, in addition to the common information provision during the first trimester of pregnancy. We argue that providing information on prenatal screening for Down syndrome additionally before pregnancy has serious drawbacks. It goes against many women's wishes and entails an increased risk of communicating a directive message. However, it also constitutes important benefits: improving the informed decision-making process by unchaining the initial information offer and by providing sufficient time; and an increased probability of equal access to prenatal screening, as currently some women arrive too late in pregnancy for their initial visit to participate in screening. To bypass the drawbacks and maintain the benefits, we favour a different approach. This approach is based on the Dutch information procedure about prenatal screening for Down syndrome: *offering* information instead of *providing*. The first step of the Dutch information process on prenatal screening can be copied to the period before pregnancy. This means that the information on prenatal screening for Down syndrome should be offered –instead of provided– before pregnancy. By offering information, the prospective parents are free to accept or decline the offer and they are given the opportunity to express both their right to-know and their right not-to-know. Regardless of women's (non-) acceptance of the offer, the information offer should be repeated during the initial prenatal visit.

Finally, in Chapter 9, we summarize and discuss the main findings of the thesis, as well as the strength and limitations of the study. The key parties involved in preconception care, notably the prospective parents, caregivers, and governments, all have a unique set of responsibilities and actions to undertake. Moral obligations to take up these responsibilities and contribute to the health of a future child outweigh arguments of medicalisation for disregarding such obligations, ranging from the slippery-slope argument to concerns about the loss of the mystery accompanying the process of becoming pregnant. We suggest that to achieve the various aims of preconception care, a mixed approach for preconception consultations is needed, merging directive and non-directive strategies. A directive approach is needed to prevent harm to future children, and a non-directive approach to improve informed decision making. We regard

the EMESP-ratio key in deciding on which approach to take. In cases where the EMESP-ratio meets a certain threshold, a directive approach is justified, whilst a lower score would favour a non-directive approach. The common distinction between genetic and non-genetic risk factors is thus no longer used. This ‘mixed approach’ poses a challenge for caregivers. The fact that the duration of the preconception period differs between individuals and that some will never become pregnant poses another challenge for the provision of preconception care. We argue that to do justice to the individual’s situation, tailored care to the individual is needed. We conclude by providing recommendations for policymakers, caregivers, researchers and prospective parents. Among the most important recommendations, is that, from an ethical perspective, it is critical that governments widely implement general individual preconception care as part of general health care, thereby facilitating prospective parents and caregivers in taking up their respective responsibilities.

Samenvatting

Dit proefschrift gaat over ethische vragen rond preconceptiezorg. Er zal worden verdedigd dat preconceptiezorg moet worden gefaciliteerd door overheden, worden verleend door zorgverleners en worden bezocht door toekomstige ouders.

Deel I Concepten

In Hoofdstuk 1 beargumenteren we dat een ethische analyse van het concept preconceptiezorg nodig is. Preconceptiezorg is een nieuwe preventieve strategie om de gezondheid van toekomstige kinderen te verbeteren en het is waarschijnlijk dat ethische argumenten het succes ervan zullen beïnvloeden. Omdat de ethische analyse gelijk opgaat met de ontwikkeling van preconceptiezorg is het mogelijk die ontwikkeling te sturen. Ook presenteren we in dit hoofdstuk de doelstellingen van dit proefschrift. In het algemeen richt dit proefschrift zich op het geven van een overzicht van de belangrijkste ethische overwegingen ten aanzien van preconceptiezorg en op het systematisch analyseren van die overwegingen om het debat ten aanzien van de brede implementatie van preconceptiezorg verder te brengen. Om deze vragen te beantwoorden baseert de studie zich op zowel ethische theorieën als op de praktijk van preconceptiezorg door gebruik te maken van de methode van het reflectief evenwicht. In deze methode worden verschillende elementen gecombineerd, zoals relevante achtergrond theorieën, morele oordelen en empirische data; en wordt er gezocht naar de samenhang, het ‘evenwicht’, tussen die elementen. Deze relatie tussen praktijk en theorie geeft het proefschrift een interdisciplinair karakter, waarin zowel de velden van de huisartsenpraktijk, de verloskunde en de obstetrie en het domein van de medische ethiek worden betrokken.

Hoofdstuk 2 introduceert het concept van preconceptiezorg. We bespreken de voordelen van preconceptiezorg, de ontwikkelingen in Nederland en wereldwijd en uitdagingen voor de implementatie van preconceptiezorg. We bespreken hoe preconceptiezorg kan bijdragen aan de verbetering van de reproductieve gezondheid. De reproductieve gezondheid is in de laatste decennia nauwelijks verbeterd. Nederland heeft, met name in de grote steden, een relatief hoge perinatale sterfte in vergelijking met andere Europese steden. Het uitblijven van verbetering, ondanks verbeterde kwaliteit en verbeterde toegang tot prenatale zorg, suggereert dat prenatale zorg alleen niet voldoende is. Preconceptiezorg verbindt verschillende fases in de levensloop van het toekomstige kind, van preconceptioneel via prenataal naar kindertijd, en legt verbindingen tussen verschillende zorgdisciplines. We beargumenteren dat een *top-down* beleid nodig is om een *bottum-up* aanpak succesvol te maken. Ten slotte concluderen we dat het niet aanbieden van preconceptiezorg betekent dat overheden en professionals hun verantwoordelijkheden niet nakomen.

In hoofdstuk 3 beargumenteren we dat toekomstige ouders morele verantwoordelijkheden hebben ten aanzien van hun toekomstige kinderen om te voorkomen dat hen schade wordt aangedaan. Dat kunnen ze doen door al voor de zwangerschap risicofactoren voor negatieve effecten op de gezondheid van het toekomstige kind te minimaliseren. Ook al bestaat het kind nog niet, toch zijn zij er al verantwoordelijk voor omdat het kind in de toekomt hun *eigen* kind wordt. Er zijn nog veel onzekerheden, maar de toekomstige relatie is helder en onveranderlijk: de meest intieme relatie mogelijk, die tussen een ouder en zijn of haar kind. Het zou overdreven zijn om alle vruchtbare mensen die seksueel actief zijn te beoordelen als onverantwoordelijk wanneer zij alcohol drinken, roken of geen foliumzuur supplementen slikken, als zij tegelijkertijd alle voorzorgsmaatregelen nemen om niet zwanger te raken. Daarom stellen wij voor om een grens te trekken met behulp van het concept ‘intentie’: er is extra morele druk om risico’s te verminderen als mensen de *intentie* hebben om kinderen te krijgen. In het tweede deel van dit hoofdstuk worden de verantwoordelijkheden van toekomstige ouders vertaald naar de praktijk. We onderscheiden vier componenten van risicofactoren: beïnvloedbaarheid, kans, ernst en moeite. Voor enkele risicofactoren waarvoor voldoende bewijs beschikbaar is worden op basis van deze vier componenten morele verantwoordelijkheden voor de toekomstige ouders afgeleid, waaronder het niet slikken van foliumzuur supplementen. De kans dat een kind wordt geboren met een neurale buisdefect kan door het slikken van supplementen worden teruggedrongen met tweederde. Ook al zijn de kansen klein (minder dan 0,1 procent), de mogelijke schade die voorkomen kan worden is heel groot en de moeite daarvoor heel klein. Daarom achten wij toekomstige moeders moreel verantwoordelijk voor het verminderen van het risico op neurale buisdefecten door het slikken van foliumzuur supplementen. Informele protocollen kunnen worden ontwikkeld op basis van een uitgebreide en intensief bediscussieerde risico-verantwoordelijkheidsanalyse.

Hoofdstuk 4 richt zich op de morele verantwoordelijkheid van toekomstige vaders en de rol van bewijs voor het bepalen van morele verantwoordelijkheden. We wijzen op een mogelijk conflict tussen het idee dat preconceptiezorg zich ook op mannen zou moeten richten én het schaarse bewijs voor het bestaan van leefstijlrisicofactoren (en de beïnvloeding daarvan) van toekomstige vaders voor de gezondheid van hun toekomstige kinderen. We beargumenteren vanuit een ethisch perspectief dat verantwoord vaderschap al begint voor de conceptie, ten minste, als het bewijs toeneemt. Ook uit ons verkennende empirisch onderzoek lijkt naar voren te komen dat mannen belang hechten aan bewijs. Het lijkt erop dat de mannen *sterk* bewijs als voorwaarde stellen voor hun eventuele leefstijlwijziging, terwijl wij beargumenteren dat *redelijk* bewijs goed genoeg zou zijn. Voortbouwend op de risico-verantwoordeijkheid analyse uit hoofdstuk 3, introduceren we de EMESP-ratio om morele verantwoordelijkheid van toekomstige vaders voor het aanpassen van hun leefstijl te kunnen bepalen. De EMESP-ratio brengt vijf componenten van risico’s samen: de mate van bewijs (Evidence), de beïnvloedbaarheid van het risico (Modifiability), de moeite die moet worden gedaan om het risico te beïnvloeden (Effort), de ernst van de schade (Severity) en de kans dat de schade optreedt en dat de schade zal worden voorkomen door de beïnvloeding van het risico (Probability). We laten zien dat van toekomstige vaders verwacht mag worden dat zij die risicofactoren minimaliseren die een bepaalde grens van de EMESP-ratio bereiken. Ook voor zorgverleners gelden er bepaalde morele verantwoordelijkheden. Van hen mag worden verwacht dat zij op een *directieve* manier informatie aanbieden over de risicofactoren die deze grens bereiken, wat wil zeggen dat zij toekomstige vaders zouden moeten aanmoedigen de risicofactoren te minimaliseren.

Hoofdstuk 5 bespreekt het argument van medicalisering in de context van preconceptiezorg. Het argument wordt soms gebruikt om te voorkomen dat preconceptiezorg deel gaat uitmaken van de algemene gezondheidszorg. Het functioneert ook als een drempel voor vrouwen om een preconceptieconsult te bezoeken. We identificeren zes onderliggende morele problemen: preconceptiezorg kan worden gezien als de eerste of juist de laatste stap van een hellend vlak naar een continue gezondheidszorg; preconceptiezorg kan leiden tot vervreemding omdat 'gezondheid' de centrale waarde is; toekomstige ouders kunnen zich mogelijk niet vrij voelen om tegen een advies in te kiezen; preconceptiezorg treft met name vrouwen; preconceptiezorg kan leiden tot het zich schuldig voelen of tot het aanwijzen van schuldigen; preconceptiezorg kan haaks staan op het mysterie dat het proces van zwanger worden omgeeft. Sommige van deze morele problemen, die deel uitmaken van het bezwaar van medicalisering, zijn inderdaad te beschouwen als mogelijk problematisch, zoals de nadruk die preconceptiezorg legt op de waarde 'gezondheid'. Die problemen wegen we af tegen de morele verplichtingen ten aanzien toekomstige kinderen. We beargumenteren dat de bezwaren die worden uitgedrukt met medicalisering geen rechtvaardiging zijn voor toekomstige ouders om niet deel te nemen aan preconceptiezorg, noch voor overheden om preconceptiezorg niet te implementeren. In plaats daarvan moeten de morele implicaties van preconceptiezorg worden onderkend en moet er rekening mee worden gehouden in het implementatieproces van preconceptiezorg.

Deel II Percepties

Hoofdstuk 6 betreft een kwantitatief onderzoek. Door middel van een vragenlijst verbonden aan de website ZwangerWijzer.nl, waarmee preconceptionele risico's kunnen worden geïdentificeerd, onderzoeken we de intentie van vrouwen om een preconceptieconsult te bezoeken. Slecht één derde van de ondervraagde vrouwen (*n* =1974) is van plan om een consult te bezoeken. Hun intentie is ongerelateerd aan hun persoonlijkheidskenmerken en risicoprofiel. De typen motieven van de vrouwen zijn daarentegen sterk gerelateerd aan hun intentie om een preconceptiezorg consult te bezoeken. Vooral 'algemene kennis' en in mindere mate 'motieven gerelateerd aan de timing van de zwangerschap', 'vermeend nut' en 'risicospecifieke kennis' zijn typen motieven die positief gerelateerd zijn aan de intentie. Een extrinsieke motivatie van vrouwen is negatief gerelateerd aan de intentie, wat wil zeggen dat als een vrouw buiten zichzelf kijkt voor een reden, zij minder geneigd zal zijn om een consult te bezoeken. Deze resultaten suggereren dat het gebruik van preconceptiezorg kan worden aangemoedigd door het creëren van bewustzijn van de voordelen van preconceptiezorg en door de intrinsieke motivatie van vrouwen te versterken.

Hoofdstuk 7 beschrijft een kwalitatieve studie naar de percepties van vrouwen ten aanzien van het proces van zwanger worden en ten aanzien van preconceptiezorg. De interviews laten zien dat hun attitude ten aanzien van preconceptiezorg in het algemeen positief is, maar dat, wanneer gevraagd wordt naar hun eigen voornemen om een consult te bezoeken, zij afhoudend zijn. Het lijkt erop dat vrouwen zichzelf dus niet als deel van de doelgroep beschouwen. Hier worden drie mogelijke redenen voor genoemd: ten eerste denken vrouwen al genoeg te weten; ten tweede denken zij geen risico te lopen; en ten derde begrijpen zij het doel van preconceptiezorg vaak verkeerd. Deze studie richt zich verder op hun percepties van het proces van zwanger worden en preconceptiezorg en biedt meer inzicht in de aarzeling van vrouwen om een consult te bezoeken. We identificeren vier thema's die voor hen belangrijk lijken te zijn: (1) planning; (2) een geheim en intiem proces van zwanger worden; (3) informatie over vruchtbaarheid; en (4) een 'natuurlijk' proces van zwanger worden. Op deze vier domeinen conflicteren de idealen van vrouwen soms met de huidige organisatie en aanbieding van preconceptiezorg.

In hoofdstuk 8 identificeren we argumenten voor en tegen de preconceptionele aanbieding van informatie over prenatale screening op Down Syndroom in aanvulling op de gebruikelijke informatieverstrekking in het eerste trimester van de zwangerschap. In een ethische analyse laten we zien dat het ook vóór de zwangerschap verstrekken van deze informatie nadelen heeft: het gaat in tegen de voorkeur van veel vrouwen en vergroot het risico op het communiceren van een directieve boodschap. De preconceptionele informatieverstrekking biedt echter ook belangrijke voordelen: ten eerste een verbeterde geïnformeerde besluitvorming door het loskoppelen van de informatie en de screening zelf en het voldoende tijd te geven voor de beslissing; en ten tweede een vergrote kans op gelijke toegang tot prenatale screening, aangezien sommige vrouwen nu pas zo laat in de zwangerschap hun eerste afspraak hebben bij een zorgverlener dat het te laat is voor deelname aan prenatale screening. Om de nadelen te pareren en de voordelen te behouden, geven wij de voorkeur aan een andere aanpak. Deze aanpak is gebaseerd op de Nederlandse informatieprocedure voor prenatale screening: het *aanbieden* van informatie in plaats van het *verstrekken* van informatie. Die eerste aanbiedingsstap wordt in ons voorstel gekopieerd naar de periode voor de zwangerschap. Dit betekent dat de informatie over prenatale screening op Down Syndroom moet worden aangeboden (en dus niet verstrekt) vóór de zwangerschap. Door de aanbieding hebben toekomstige ouders de mogelijkheid om het aanbod te accepteren of af te slaan en wordt hun zo de mogelijkheid geboden om uitdrukking te geven aan zowel hun recht om te weten als hun recht om niet te weten. Onafhankelijk van de acceptatie van het aanbod, moet het informatieaanbod worden herhaald tijdens het eerste bezoek bij de verloskundige in de zwangerschap.

Tenslotte vatten we in hoofdstuk 9 de belangrijkste resultaten van dit proefschrift samen en bespreken we de sterke en zwakke punten van de studie. We onderscheiden drie centrale verantwoordelijke partijen die betrokken zijn bij preconceptiezorg: toekomstige ouders, zorgverleners en overheden. De morele verantwoordelijkheden van deze partijen ten aanzien van de gezondheid van het toekomstige kind wegen zwaarder dan de morele problemen die vallen onder het argument van medicalisering, zoals het hellend vlak argument het verlies van het 'mysterie'. Preconceptiezorg moet dus worden gefaciliteerd door overheden, worden verleend door zorgverleners en worden bezocht door toekomstige ouders. Verder beargumenteren we dat, om de verschillende doelen van preconceptiezorg te dienen, zorgverleners twee strategieën moeten hanteren: een directieve aanpak gericht op gedragsverandering gecombineerd met non-directieve aanpak gericht op verbetering van geïnformeerde besluitvorming. De EMESP-ratio kan helpen om te bepalen welke informatie directief en welke non-directief moet worden aangeboden. Tot een bepaalde grens van de EMESP-ratio moet informatie non-directief worden aangeboden, en vanaf die grens is directieve informatieverstrekking gewenst. Het reguliere onderscheid tussen genetische en niet-genetische risicofactoren wordt hier dus losgelaten. Deze 'gemixte aanpak' stelt zorgverleners voor een grote uitdaging. Wat het verlenen van preconceptiezorg verder lastig maakt, is dat de duur van de preconceptionele periode steeds anders is en dat sommige wensouders uiteindelijk nooit zwanger zullen worden. We stellen dat, om recht te doen aan de individuele situatie, preconceptiezorg op het individu moet worden afgestemd. We concluderen met aanbevelingen aan het adres van beleidsmakers, zorgverleners, onderzoekers en toekomstige ouders. Eén van de belangrijkste aanbevelingen is dat vanuit ethisch perspectief het van het grootste belang is dat overheden bijdragen aan de invoering van algemene individuele preconceptiezorg als deel van de reguliere zorg. Dit maakt het ook voor zorgverleners en toekomstige ouders mogelijk hun verantwoordelijkheden te nemen.

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Een wijze ethicus maakte eens een treffende vergelijking tussen promoveren en het beklimmen van een berg: mooie beloften leiden ertoe dat iemand zich begeeft in een activiteit waarbij op een gegeven moment de vraag kan rijzen, waarom men er toch ooit aan is begonnen. Boven op de berg zou het leed snel vergeten zijn.*

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* de Beaufort, ID. Promotiebegeleiding is een soort van wetenschappelijke adoptie. Nieuwsbrief van de Nederlandse Vereniging voor Bio-ethiek 2011;5:42.

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About the author

Curriculum Vitae

Boukje van der Zee was born on Augustus 9th 1982, in Nijmegen, the Netherlands. In 2000 she graduated from secondary school, the Stedelijk Gymnasium Nijmegen. She achieved her 'propedeuse' in Psychology at the University of Amsterdam and after that she studied Philosophy at the same university. She did a minor 'Italian language and culture' at the University of Perugia in Italy. She did an internship at the Centre for Ethics and Health. In 2005 she graduated with a master's thesis on the role of the body for the construction of personal identity. Then she worked as a freelancer and, among other things, she performed a study for the Centre for Ethics and Health to the use of the concept 'normal care' in allocating professional health care. In February 2007 she started as a PhD student at the department of Medical Ethics and Philosophy of Medicine and the department of Gynaecology and Obstetrics at the Erasmus University Medical Center in Rotterdam. She was a member of the PhD Council of the Netherlands School for Research in Practical Philosophy, which organises seminars for PhD students. During the PhD project she worked as an editor for the Journal of the Dutch Organisation for Bioethics. She combined the final stage of her PhD with teaching activities at the department of Medical Ethics and with a study for the Centre for Ethics and Health on the allocation of scarce resources at intensive care units during a pandemic. Boukje is currently employed at the Dutch Health Council.

Boukje van der Zee werd geboren op 9 augustus 1982 in Nijmegen. In 2000 behaalde zij haar gymnasium diploma aan het Stedelijk Gymnasium Nijmegen. Zij rondde haar propedeuse psychologie af aan de Universiteit van Amsterdam en studeerde vervolgens wijsbegeerte aan dezelfde universiteit. Zij deed een minor 'Italiaanse Taal en Cultuur' aan de Universiteit van Perugia in Italië. Daarna liep zij stage bij het Centrum voor Ethiek en Gezondheid (CEG). Zij studeerde in 2005 af op haar doctoraalscriptie 'Buitenste-Binnen. De rol van het lichaam voor de verwerving van de persoonlijke identiteit'. Vervolgens werkte zij als freelance onderzoeker, ondermeer voor het CEG. Dit resulteerde in het signalement 'Formalisering van informele zorg. Over de rol van 'gebruikelijke zorg' in de toekenning van professionele zorg'. In februari 2007 begon zij als promovenda aan de afdeling Medische ethiek en Filosofie van de Geneeskunde en de afdeling Verloskunde en Vrouwenziekten aan het Erasmus Universitair Medisch Centrum te Rotterdam. Zij was in die periode lid van de Promovendiraad van de Onderzoeksschool Ethiek, die onder andere seminars organiseert voor promovendi. Tevens was zij redactielid bij het Podium voor Bio-ethiek (hiervoor 'NVBe Nieuwsbrief') van de Nederlandse Vereniging voor Bio-ethiek. Zij combineerde de afronding van haar proefschrift met het geven van onderwijs aan de afdeling Medische Ethiek en met het schrijven van een signalement voor het CEG over de verdeling van schaarse middelen op de intensive care ten tijde van een grieppandemie. Momenteel is Boukje werkzaam als wetenschappelijk secretaris bij de Gezondheidsraad.

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PhD Portfolio

Summary of PhD training and teaching

Name PhD student: Boukje van der Zee
Erasmus MC Department: Medical Ethics and Philosophy of Medicine and Gynaecology and Obstetrics.
Research School: Netherlands School for Research in Practical Philosophy

PhD period: 2007-2012
Promotors: Prof. dr. I.D. de Beaufort, Prof. dr. E.A.P. Steegers, Prof. dr. G.M.R. de Wert

1. PhD training

	Year	Workload (Hours/ECTS)
General courses		
• English scientific writing (VU)	2009	1
• Presenting in English (VU)	2010	1
• Mediatraining (NWO)	2007	0,5
• Dagcursus didactiek (ErasmusMC)	2008	0,5
Specific courses		
At the Netherlands School for Research in Practical Philosophy:		
• Summer school ‘Of things to come’	2007	6
• Ethical Theories and moral practice	2007	6
• Ethics of care and health	2008	6
• Summer school ‘Bioethics and ethical theory’	2009	6
At the Netherlands Institute for Health Sciences:		
• Course Maternal and child health	2007	0,9
Seminars		
• Seminars for PhD students at the Netherlands School for Research in Practical Philosophy on various ethical topics and research skills	2007-2010	3
Oral presentations		
• Second Summit Preconception Care Oakland, California ‘Preconception care on the right track’	2007	1
• Preconceptiezorg congres, Utrecht, ‘Medicalisering als argument tegen preconceptiezorg?’	2008	1
• IAB World Congress Croatia, ‘Medicalization as argument against preconception care’	2008	1
• Research meeting department of Gynaecology and Obstetrics ‘preconceptiezorg en medicalisering’	2008	1
• Preconceptiezorg congres, Utrecht, ‘Ik ga, ik ga niet’	2009	0,6
• Research meeting department of Gynaecology and Obstetrics ‘Preconceptioneel aanbieden van informatie over prenatale screening op Downsyndroom. Een empirisch onderzoek en ethische reflectie’	2010	0,6
• IAB World Congress Singapore ‘Moral responsibilites of future parents’	2010	1
• Research meeting Department of Medical Psychology ‘Ethische aspecten van preconceptiezorg’	2010	0,6
• First European Congress on Preconception health and preconception care, Brussels, Belgium, ‘Women’s perceptions on preconception care consultations’	2010	1

2. Teaching activities

· Various classes 'medical ethics' for 1st-4th year medical students	2007-2011	10
· Supervision of bachelor thesis		
· Supervision of bachelor thesis	2008	0,8
· Courses 'Ethical and legal aspects of prenatal screening' for medical professionals	2010-2011	0,8
ErasmusMC	2010	1
· Supervising a paper of two midwifery students		
· Lecture at HOVO, higher education for older people 'Medicalisering en	2009	0,4
preconceptiezorg'	2009	0,3
· Lecture at Midwifery school 'Preconception care'	2011	0,3

3. Other activities

· Member PhD Student Council, the Netherlands School for Research in Practical Philosophy	2008-2010	1,5
· Editor of 'Podium voor Bio-ethiek' of the Dutch Association of Bioethics	2009-	3