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Managing high risk at first trimester prenatal screening

Exploring how clinicians, pregnant women, and their partners manage and negotiate a high-risk screening result for chromosomal abnormality in the fetus

PhD dissertation

Stina Lou

Health
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CONTENTS

PREFACE

PREFACE

This PhD dissertation offers an anthropological perspective on prenatal screening for chromosomal abnormalities. It reflects my personal and professional interests, competences and experiences as a trained anthropologist with years of professional experience working in public health and health services research.

Back in 2005, as a newly graduated anthropologist, I was engaged by the Department of Epidemiology at Institute of Public Health, Aarhus University, to conduct a qualitative, explorative pilot study of pregnant women's knowledge of and experiences with the then newly implemented prenatal screening program (Lou 2005; Lou et al., 2007; Dahl and Lou 2007). The aim of my study was to inform a subsequent questionnaire survey investigating the importance of pregnant women's knowledge (Dahl et al., 2011a; 2011b). Back then, the interviewed pregnant women knew relatively little about the screening procedure and the complex knowledge they would face following a high-risk screening result. Instead, they expressed a profound trust in the health professionals responsible for the screening. One of the pregnant women said:

'The important thing is that the support strategies are in place [if the screening result is high-risk]. That is, I take a leap of faith [by participating in the screening] and if the result turns out to be 'high risk', then I expect someone to catch me. I definitely expect that someone will be there to catch me.' (Charlotte, 27 years old, no children) (Lou 2005: 67)

This comment intrigued me, and I wondered if these expectations were being met. It was beyond the scope of the study in question to explore how high-risk was communicated and negotiated in the ultrasound examination room. The question, however, kept lingering in my mind – even after I started to work in completely different areas of the health care system. Thus, I was never in doubt about the subject of this dissertation, nor that I wanted to investigate it from within the hospital.

Though biomedical research has traditionally revolved around natural science and quantitative methodologies, the clinical practice of biomedicine incorporates both aspects of natural science and social science, and in my experience, anthropology resonates well with some of the challenges faced in the clinic. With a social constructivist curiosity and theoretical focus on processes of interaction and knowledge production, anthropology is able to provide clinically relevant perspectives and point to new understandings. In return, everyday clinical life as well as the biomedical knowledge tradition can productively

challenge the very same constructivist and sometimes intangible approach of anthropology. I have very rarely experienced 'science wars' in my collaboration with clinicians, and I think that the traditional epistemological differences between the natural and social sciences can be very productive when addressed through dialogue and mutual recognition.

Over the years I noticed how prenatal screening is regularly addressed in the media. Newspaper headlines such as 'There are few like Elliot left' (Korsgaard & Heinskou, 2012), 'A fetus is guilty till proven innocent' (Cramon, 2014) and 'Children with Down's syndrome are widely deselected' (Ritzau, 2009) reveal the strong public emotions that prenatal screening has potential to generate. These public debates reveal unresolved, societal dilemmas regarding life and non-life, health and sickness, rights and responsibilities that prenatal screening raises. Newspapers, the Danish Council of Ethics and patient organisations all express legitimate concerns about the ways in which the ever-advancing biomedical technologies push boundaries and change the information, understandings and options available to the individual; including making decisions about fetuses. However, there is a gap between the high-flown headlines of the media and the ways in which the pregnant women in my previous and present research speak of and experience prenatal screening. With the studies in this dissertation, I hope to push the debates forward by adding a scientific perspective.

The dissertation approaches biomedicine – its technologies, understandings and practices – as an object of study. However, it also reflects my engagement with biomedicine as field of practice. The papers that form the core of this dissertation display my ambition to not only do anthropology of biomedicine, but also to be an anthropologist within biomedicine. Consequently, while paper 1 is written with a social science audience in mind, the remaining two papers (and the additional paper in appendix 1 (Lou et al., 2014b)) were driven by the ambition to get involved and add to the field of biomedicine. Thus, this PhD dissertation is theoretically and methodologically positioned in the intersection between anthropology and medicine, research and practice. I hope it will be approached with this in mind.

CHAPTER 1

INTRODUCTION

INTRODUCTION

In this introductory chapter, I provide background information on prenatal screening in Denmark and outline the main debates that initially served to frame the research questions and the aim of the PhD dissertation. I do so to set the scene and to argue for the relevance of my study and to situate it in relation to the current discussions within the field of first trimester screening (FTS). I describe the process from the initial research questions to the focused research aims, which the studies in this dissertation address. The chapter concludes with an outline of the structure of the dissertation.

SCREENING IN A FEW WORDS

Within health care systems, *screening* refers to all kinds of testing of a healthy population in order to identify groups or individuals at higher risk for potential, future disease (Kamper-Jørgensen et al., 2009). Screening provides information and consequently allows for prevention or early treatment of the condition or disease in question. The concept of screening fits well with the new public health ideals in which citizens are increasingly made responsible for their own future health. In order to act as good and moral citizens, people are expected to seek information about their health status and act accordingly and responsibly (Lupton, 2013a; Petersen and Lupton, 1996). Consequently, screening is a subject of growing importance on the political agenda and is in increasing demand, not only by health planners and the public health sector, but also within the medical specialties, patient organisations and the general public (Kamper-Jørgensen et al., 2009).

Screening tests provide a risk assessment and are generally not diagnostic. Thus, screening results are uncertain and demand further diagnostic testing, which turns attention to some of the inadequacies or adverse outcomes of screening programmes. Depending on the sensitivity and specificity of the test, there will always be *false* test results; some people who test positive will turn out not to have the disease (a false-positive result) while some people who test negative will in fact have the disease (a false-negative result). As such, screening can cause both unnecessary worry but also a deceiving reassurance, which was also pointed out in a report by the Danish Council of Ethics (1999) on ethical problems connected with screening. The counsel continues to question if the offer of screening as well as participating in screening will induce worry or reassurance, but concludes that more research is needed (The Danish Council of Ethics, 1999; 2009).

However, the existence of false results continues to be an inescapable part of screening per se, but can be ameliorated on two levels. First, advances in screening technologies and more sensitive tests can limit the number of false positive and false negative results. Secondly, continuous improvements in the communication, information and professional support offered may alleviate some of the worry and uncertainty following a positive screening result. This dissertation addresses the latter issue.

PRENATAL SCREENING IN DENMARK

Denmark has a tax-financed, free-for-all health care system through which all pregnant women are offered prenatal care. In 2004, the Danish National Board of Health introduced new prenatal care guidelines (Danish National Board of Health, 2004), and since 2006 a combined first trimester screening (FTS) for Down's syndrome and other chromosomal abnormalities in the fetus has been available to all pregnant women (Ekelund et al., 2008; Nicolaides, 2005). The FTS is a risk assessment based on maternal age, nuchal translucency measurement[1] and maternal blood test[2]. The blood tests are taken prior to the first trimester ultrasound scan at 11 to 13+6 weeks gestation. During the ultrasound scan, the nuchal translucency is measured and the FTS result is subsequently calculated. The ultrasound examination, the measurement of nuchal translucency and the ensuing communication of FTS results are performed by sonographers and doctors certified by the Fetal Medicine Foundation in the United Kingdom. The procedure takes approximately 30 minutes and by the end the woman/couple receives the statistical FTS result in shape of a numerical risk figure.

In 2012, an estimated 93% of all pregnant women in Denmark participated in FTS (National database of Fetal Medicine, 2012), and studies have shown how Danish women generally have a high degree of knowledge of the test concept and a positive attitude towards the FTS (Dahl et al., 2011a; Bangsgaard & Tabor, 2012). It has also been found that many pregnant women consider the FTS to be recommended by the health care system and to be a routine part of the prenatal care programme (Lou et al., 2007; Gottfredsdottir et al., 2009).

[1] The Nuchal translucency is an area of tissue at the back of the fetal neck. It is measured at the first trimester ultrasound scan, where the first trimester screening (FTS) result is also calculated.

[2] A biochemical test for pregnancy-associated plasma protein A (PAPP-A) and β-human chorionic gonadotropin (β-hcG), called the double test. It is taken prior to the first trimester ultrasound scan.

The vast majority of the screened women receives a normal risk result (risk lower than 1:300) and proceeds in the standard prenatal care programme. However, for approximately 5% of the screened pregnant women, this 'routine' first trimester ultrasound scan ends with a high-risk FTS result. Based on the woman's (and her partner's) evaluation of their specific risk figure, they can either proceed in the standard prenatal care programme or they can have invasive diagnostic testing, most often chorionic villus sampling (CVS). The diagnostic testing provides a definitive answer regarding Down's syndrome and other chromosomal abnormalities, but also involves a ½ -1% risk of miscarriage due to the procedure (Tabor & Alfirevic, 2010). Consequently, the woman/couple cannot get a conclusive result without putting the fetus at risk. Thus, in order to come to a decision, they have to negotiate the tension between fear of miscarriage and worries about the health of the fetus.

In Denmark, approximately 85% of women with a high risk screening result decide to have diagnostic testing (Petersen et al., 2014), but the processes through which they arrive at their decision to accept or decline remain to be investigated. Less than 10% of the women accepting invasive testing receive an abnormal test result and must make the difficult decision regarding continuation or termination of the pregnancy. The remaining 90% receive a normal chromosomal result and continue in the standard prenatal care programme. Though the final outcome is normal, there are ongoing debates about the unnecessary worry that these couples may go through and how it may affect their subsequent pregnancy (Harris et al., 2012; Fisher, 2011; Öhman et al., 2006; Baillie et al., 2000; Rapp, 1999).

MAIN DEBATES IN RESEARCH ON PRENATAL SCREENING

There is an abundance of both biomedical and social science literature on prenatal screening. Here I introduce primarily social studies in order to outline the main areas of research within this field.

Informed choice as clinical ideal

The FTS strongly resembles a screening programme and encompasses all the advantages and challenges of screening procedures, and in the remainder of the dissertation I will consequently refer to it as a screening technology. However, in the 2004 guidelines, the Danish National Board of Health emphasised that the offer of FTS is *not* screening. This distinction relates to the fact that prenatal screening does *not* allow for prevention or early

treatment of chromosomal abnormality. Abnormal chromosomes cannot be biomedically treated or fixed, and therefore the only option available to pregnant women/couples is to continue or to terminate the pregnancy. Consequently, it is clearly stated in the guidelines that the aim is to assist pregnant women who express an interest in such assistance in making her personal reproductive decisions. Participations as well as non-participation should be based on informed decision-making. Consequently, it is argued that this cannot take place if the FTS is considered standard or routine. The explicit premises of the guidelines are that pregnant women must make active, informed, autonomous decisions.

Informed choice and non-directiveness are integral to the increasing focus on patient autonomy in modern health care and reflect an influential, neo-liberal emphasis on the patient as citizen and consumer where autonomy and choice is by definition what is best for the patient (Mol, 2008; Petersen, 1999; Petersen & Lupton, 1996). Elements considered necessary for making an informed choice are the presence of alternatives, sufficient and value-free information, and the absence of constraints (Beauchamp & Childress, 2001). In modern administration of health care, the concept of informed choice serves as a paradigm for the doctor-patient relationship where the doctor's role is to provide sufficient, non-directive information, free of professional and moral judgement. On the basis of this, the patient must make his/her individual and autonomous decision, free of influence from the potentially authoritative and paternalistic doctor. This paradigm frames the way the FTS is implemented in Denmark. For example, contrary to other screening programmes (e.g. pap-smear or mammography), the pregnant woman is not automatically invited to the FTS, nor does she receive a reminder if she fails to show up. Instead, she accesses the FTS through her general practitioner, who is responsible for providing neutral and sufficient information in order for the woman to make an informed decision regarding participation. Prior to the first trimester ultrasound scan, the sonographer also provides brief information about the FTS and asks the woman to confirm her participation/non-participation. The decisions following a high-risk screening result should also be autonomous and based on non-directive information.

The dominant, clinical ideal of informed choice has been the topic of much research within prenatal screening (Green et al., 2004; Dahl et al., 2006a; 2006b; Reid et al., 2009). One line of research implicitly or explicitly accepts informed choice as the golden standard for clinical interaction and consequently has information and decision-making as focus. Studies investigate if women have sufficient knowledge to make informed choices (McCoyd, 2013; Gourounti & Sandall, 2008; Potter et al., 2008; Siegristet al., 2008), and what types of information techniques may support informed choice (Legare et al., 2011; Nagle et al., 2008a;

Beattie et al., 2013; Hall et al., 2007). Several studies show that prenatal screening decisions are not always well-informed. There are considerable national differences (Favre et al., 2008; van den Berg et al., 2005; Jaques et al., 2005), but the Danish pregnant population generally has a high degree of knowledge and positive attitude towards the FTS (Bangsgaard & Tabor, 2012). Within this line of research there are also a few studies investigating if counsellors and health professionals are providing non-directive information and living up to ideals about informed choice (Favre et al., 2009; Nagle et al., 2008b; van den Berg el al., 2007; Farsides et al., 2004; Williams et al., 2002). A considerable amount of the literature points to the difficulties of implementing informed choice in practice and consequently leads the authors to suggest that more or different types of information and education are needed in order to successfully reach the informed choice golden standard.

However, some studies use their findings to question the general applicability of informed choice to fit the complex clinical interactions between health professionals and pregnant women (Schwennesen & Koch, 2012; Pilnick, 2008; Garcia et al., 2008). These studies reflect a more general and growing critique of the pervasiveness of informed choice in modern health care. From this perspective it is contended that the paradigm of informed choice is based on the largely unquestioned assumption that knowledge is value-neutral and that people are independent, rational individuals (Høyer, 2006; Petersen, 1999). It is argued, first, that knowledge is always embedded in interaction and the product of interpretation and contextualisation; and second, that people (health professionals and patients alike) are always making decisions in relation to their social and personal worlds. Consequently this perspective questions the very foundation of informed choice as a guiding principle for clinical interaction. From this perspective, when health professionals and patients do not strictly live up to the principle of non-directiveness and autonomous choice, it is not because they are failing, it is because the principle is misapplied. Nevertheless, informed choice remains a guiding clinical ideal for FTS in Denmark as well as other Euro-American countries (Gammeltoft, 2007; Hall et al., 2007).

Women's reasons for participating in prenatal screening

Another central theme in the research on prenatal screening is women's reasons for participating in FTS (Reid et al. 2008). When the prenatal guidelines were first implemented in Denmark, I was part of a research team investigating pregnant women's knowledge and experiences with FTS (Lou et al., 2005; Dahl & Lou, 2007; Dahl et al., 2011a; 2011b). Part of the investigation was an explorative, qualitative study in which 26 pregnant women were interviewed before and after participating in FTS (Lou et al., 2007). The results resonated

with international findings with motivation for participation falling into three overlapping and interwoven categories.

First, women participate in FTS out of concern for the health of the fetus: A motivation commonly reported in the literature is to get a general affirmation that the fetus and the pregnancy is developing as expected at the time (Aune & Moller, 2012; Williams et al., 2005; Pilnick et al. 2004). Second, as previously mentioned, women consider prenatal screening to be integral to the standard prenatal care and even as recommended by the health care system (Gottfredsdottir et al., 2009; Lou et al., 2007). As reported by Markens et al. (1999), many women think that if the technology is available, why not use it? This attitude suggests that some women may be less aware of the potential negative consequences of screening technologies. And third, the ultrasound technology is considered attractive. Several studies have shown how pregnant women are motivated by the opportunity to see the baby and share the experience with their partner (Ekelin et al., 2004; Harris et al., 2004). Ultrasound imagery of the fetus generates a strong sense of joy in prospective parents (Lupton, 2013b; Draper, 2002; Georges, 1996), and studies suggest that ultrasound examinations reduce anxiety (Da Silva et al., 2012; Ekelin et al., 2009) and increase fetal-maternal bonding (Kleinveld et al., 2007; Öhman & Waldenstrøm, 2010). In her study of men's role in prenatal ultrasound examinations, Draper (2005) argues that the ultrasound examination is a 'social event' with potential to transform the social status of the fetus (our child) as well the pregnant woman/couple (prospective parents), making ultrasound highly attractive to pregnant women/couples.

Overall, these studies illustrate how the decision-making process does not depend on information alone, and that clinical interaction is much more than the exchange of non-directive information. Women enter the screening programme for multiple reasons, and they actively appropriate the biomedical technologies to fit their own needs. Awareness of this intersecting and juxtaposing nature of women's decision-making (Reid et al., 2008) often leads to concern that women are not necessarily aware of or prepared for the complex information and burdensome choices they may face following a high-risk screening result (Baillie et al., 2000; Ahman et al., 2010; Williams, 2005).

A high-risk screening result

For the vast majority of women who participate in screening the first trimester ultrasound scan ends with a normal screening result. These women and their partners leave the ultrasound examination with a printed photo of their baby, a due date in their medical file and a biomedical confirmation of a normally developing fetus. Their recollection of the scan

and of 'baby's first picture' (Mitchell & Georges, 1998) will feed into the discourses shaping the first trimester scan (including the FTS) as an 'amazing experience'. Opponents of screening sometimes assert that these women have been given a 'false' sense of certainty that they will have a normal child. I will not venture into these debates here, only point out that studies have also found that women view prenatal screening as a 'so far so good' rather than a guarantee (Heyman et al., 2006; Rapp, 1999)

However, for approximately 5% of women who participate in FTS the outcome of the scan is that the sonographer delivers news of a high-risk screening result. Quantitative studies have shown a significant increase in anxiety following a high risk screening result (Cheng et al., 2008; Chueh et al., 2007; Kleinveld et al., 2006). Qualitative studies have shown how women struggle to understand 'high risk,' and that they feel confused or frustrated about how to respond to a high risk result (Markens et al., 2010; Heyman et al., 2006; Öhman et al., 2006). A respondent in the study by Baillie et al. (2000) reported: '*I didn't know what to do, cos it was all just swimming around in my head*' (p. 383). It is integral to the FTS that risks can be calculated and communicated as objective facts, leading women to assess the information and act accordingly (Reid et al., 2009). Some studies have investigated how best to communicate risks and how different types of framing support different decisions (e.g. Pilnick & Zayts, 2014; Sarangi et al., 2003). These studies highlight that there is no one-to-one correspondence between expression and reception in risk communication. The statistical FTS risk figure does not necessarily make sense in itself, but must be re-interpreted, made meaningful and be responded to by the pregnant woman and her partner whose imagined future as parents and family is unexpectedly at stake. As indicated above, the high-risk result demands further clarification – the form of information, dialogue and possible invasive testing and/or more ultrasound examinations – and as such it is highly dependable on the context in which health professionals and pregnant women/couples collectively negotiate its meanings and implications. From this perspective, high-risk must be understood and investigated as a socially and culturally constructed process in which meanings and outcomes are not predetermined, but unstable and constantly negotiated.

Decision-making following a high-risk FTS result

A high-risk screening result is an uncertain situation of which most women have no prior experience (Boholm, 2003) and thus, they are dependent on the information and understandings presented to them by the health professional. Studies have investigated how women employ biomedical knowledge as well as personal experiences and interpretations as they try to come to terms with a high-risk result, its meanings and possible implications (Burton-Jeangros et al., 2013; Markens et al., 2010). However, less is known about how

pregnant women interpret and manage the health professionals' information and guidance as it unfolds in concrete, clinical interactions following a high risk screening result.

Women with a high-risk screening result must navigate the tension between fear of procedure-related miscarriages and worries about the health of the fetus in order to come to a decision. Several qualitative studies have found that women accept diagnostic testing because they want to stop worrying (Ahman et al., 2010; Kenen et al., 2000) and want to know the health status of their fetus (Kobelka et al., 2009; Öhman et al., 2006). Women's reasons for declining diagnostic testing include concerns about procedure-related miscarriage, rejection of the high risk status, and faith in a healthy child (Markens et al., 2010; Lippman, 1999). Interestingly, acceptance of a handicapped child is mentioned as a reason for both acceptance and decline of invasive diagnostics (Markens et al., 2010; Lippman, 1999; Rapp, 1999). However, the actual decision-making process through which women arrive at this decision has not been sufficiently addressed.

As indicated above, a screening result is ambiguous and has no unequivocal solution - it is diffuse, uncertain and subjective in character and studies indicate that health professionals may find it difficult to convey this complexity in a non-directive manner (Zayts & Schnurr, 2014; Williams et al., 2002; Getz & Kirkengen, 2003). Health professionals will often actively interpret the situation and approach the information and interactions in ways they deem relevant and appropriate for the specific patient (Pilnick & Zayts, 2014; Schwennesen & Koch, 2012). However, there is a lack of knowledge of how health professionals assess, adapt and communicate information about a high-risk screening result, and how they experience and negotiate the clinical interaction following a high risk screening result.

AIM AND RESEARCH QUESTIONS

Based on this overview of the current scientific literature – and 10 years after the introduction of the prenatal screening programme in Denmark – we still lack knowledge about how a high risk screening result is managed, made meaningful and decided upon in the clinical interaction. Women's experiences with a high-risk screening result have been previously addressed in research. However this research has largely been based on retrospective interviews and has almost exclusively left out the considerations and experiences of the health professionals with whom the pregnant women interact.

Addressing this gap in the research, the aim of this dissertation is to provide an anthropological analysis of the clinical interactions following a high-risk screening result for Down's syndrome or other chromosomal abnormalities, with a view to the production of meaning and knowledge. The initial research questions were:

- Which actors (people, objects, categories, etc.) are significant in the FTS and in the negotiation of a high-risk result?
- How do health professionals position themselves and engage in the interactions?
- How do high-risk women/couples position themselves and engage in the interactions?
- Which significant discourses structure the actors' understandings and interactions?

These interactions may be under-researched due to the practical difficulties in accessing high-risk FTSs – which are relatively small in number and their occurrence cannot be predicted. Furthermore, there is the emotional character of the woman's/couples' circumstances that requires a sensitive and flexible approach. Consequently, long-term anthropological fieldwork at an obstetric ultrasound unit seemed an appropriate methodological solution.

In line with the anthropological research tradition, research questions are initially broad allowing for continual development and refinement in focus during the research process. As I started fieldwork and continued my practical and theoretical exploration of prenatal screening, the initial research questions were challenged, further developed and sharpened by new empirical and theoretical insights. For example, I quickly realised that trying to analyse clinical interaction as the meeting of two different positions (medical and lay) did not do justice to the complex and creative interactions I observed. Therefore research questions were reformulated to promote a more dynamic approach. Another important insight which challenged the initial research questions was the importance of the partner. With a few notable exceptions (Dheensa et al., 2013; Locock & Alexander, 2006; Draper, 2002), the perspective of partners, husbands, boyfriends and fathers-to-be are left unaddressed in research on prenatal screening. However, in the ultrasound examination room they were not to be overlooked – physically or interpretively - and I specified the research accordingly. Finally, 'worry' emerged as a central concern in the research – to the health professionals concerned with causing unnecessary worry and to the couples for whom coming to a decision was not the end of worry and uncertainty. Consequently, the specific research questions addressed in this dissertation are:

- How is 'high risk' understood, negotiated and decided upon in clinical interactions between pregnant women, their partners and sonographers?
- How do high-risk women/couples who choose invasive testing manage worry while waiting for diagnostic results?
- Does prenatal screening cause anxiety in women with a false positive screening result?

The first two research questions were investigated through fieldwork and anthropological inquiry while the final research question was addressed by a systematic review of scientific literature. As Maxwell notes:

> 'Qualitative research design, to a much greater extent than quantitative research, is a 'do-it-yourself' rather than a 'off-the-shelf' process, one that involves the 'tacking' back and forth between the different components of design, assessing their implications for one another. It does not begin from a predetermined starting point or proceed through a fixed sequence of steps, but involves the interconnection and interaction among the different design components' (Maxwell, 2013:3)

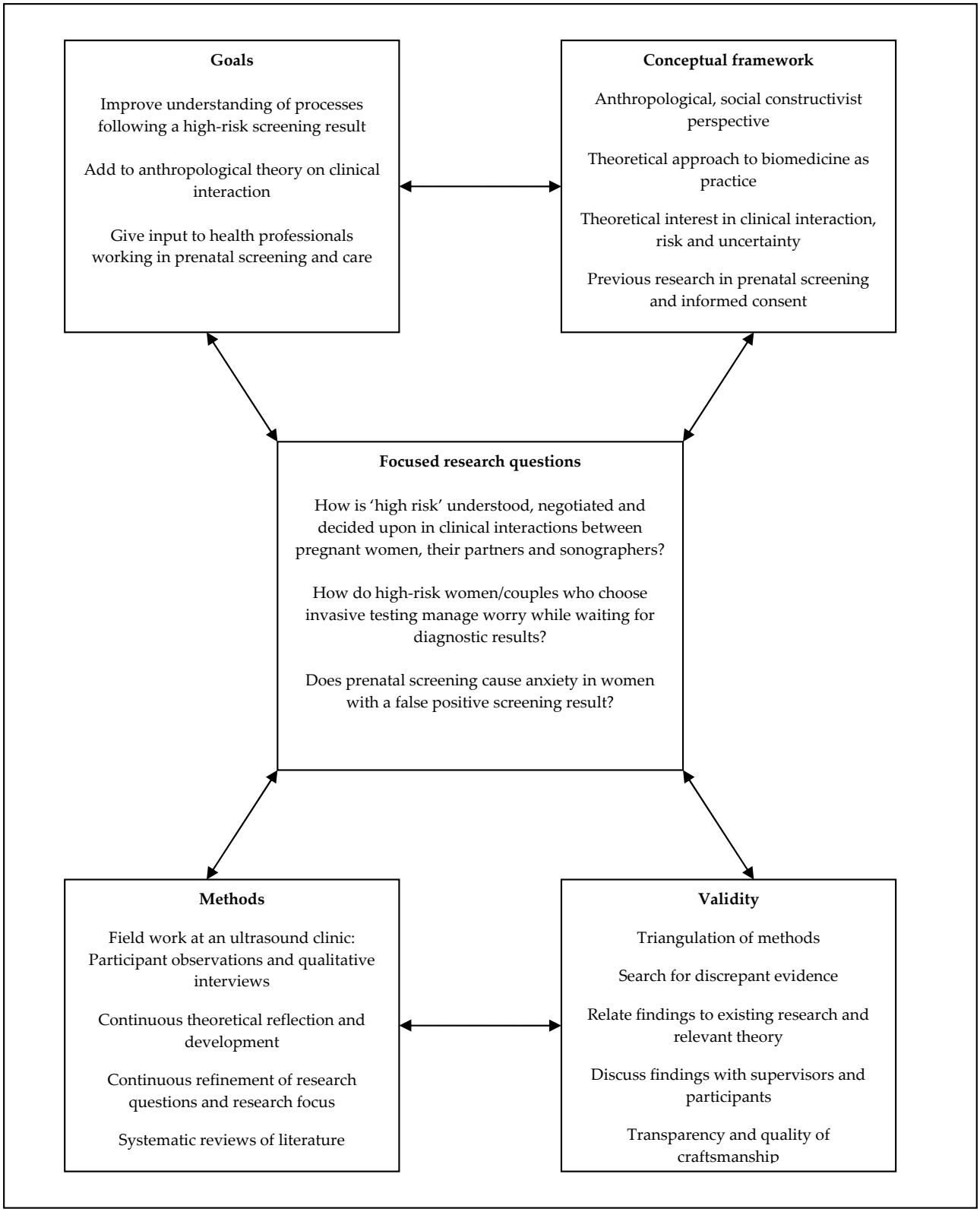
The different components that Maxwell refers to that guided the development of the research questions and research strategy are shown in figure 1. Thus, the research was guided by a tentative theory of the object of study (Maxwell, 2013; Hansen, 1996), a preliminary conceptual framework that guided the development of the research protocol – research questions and methods. In the following chapters, I will further address my methods and the theoretical approaches that shaped the process in which the focused research questions were formulated.

OUTLINE OF THE DISSERTATION

In addition to this introductory chapter, the dissertation is composed of five chapters. In Chapter 2, I present the design and methods. I introduce the ultrasound clinic, and demonstrate and discuss the events and decisions that shaped the process of generating data through fieldwork. I also present the methods applied for the literature review addressing the last research question. In Chapter 3, the theoretical approaches that framed the analysis of data are introduced. Chapter 4 features the three papers that form the core of the

dissertation, and in Chapter 5 the papers are shortly summarised and discussed. This chapter also includes a critical reflection on the strengths and weaknesses of the chosen design and methods as well as suggestions for the potential implications of the findings – for future research and for clinical practice.

Figure 1: Research design map



CHAPTER 2

DESIGN AND METHODS

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In this chapter I elaborate on the methods used to generate data for this dissertation. First, I briefly touch on the ontological differences between quantitative and qualitative scientific approaches as an introduction to fieldwork as a research strategy. I then present the process of fieldwork in which the qualitative data was gathered, and I discuss the different strategic considerations and decisions made during this process. The aim is to allow readers to critically reflect on and be able to assess the substance and strength of the material. As I consider ethical concerns to be embedded in all aspects of qualitative research (see AAA guidelines, 2012), ethical considerations are discussed continuously rather than in a separate section. The chapter concludes with a presentation of material and methods used in the systematic literature review also included in this dissertation.

THE QUALITATIVE APPROACH

Anthropology studies social life as an ongoing fluid process (Emerson et al., 1995). By comparison, the natural sciences rest on a 'stable' ontology (Hoyer, 2007) where the world is understood as objectively real and subject to causal laws. Therefore, the aim of science is to continuously develop measuring devises and discover connections without changing the objective, true essence of the phenomenon under investigation. At the other side of the ontological spectrum, the humanities and social sciences often take as their starting point a more or less 'fluid' ontology where study objects are understood as mutable and inter-dependent. From this perspective there is no objective, privileged position from which knowledge can be obtained, and the process of investigation will always in some way or another affect the world. Thus, the purpose of investigation is not to determine essential truths, but to reveal the multiple truths apparent in our lives (Emerson et al., 1995). Qualitative research is based on the ontological assumption that knowledge is the product of interaction between people. Thus, in order to get to know, the anthropologist must interact (Jutel, 2011).

Fieldwork as research strategy

Fieldwork is '*a form of inquiry in which one immerses oneself personally in the ongoing social activities of some group for the purpose of research*' (Wolcott 2005: 4). The fieldwork researcher steps into a social world and investigates it by engaging in social relations (Hastrup 2003). Immersion precludes being a passive, objective observer, in order to learn what is required to

become a member of the world under study the anthropologist interact and impact as a source of learning (Emerson et al., 1995; Wind 2008). As noted by Agar:

> When you stand on the edge of a village and watch the noise and motion, you wonder, 'Who are the people and what are they doing? […] Hypotheses, measurements, samples, and instruments are the wrong guidelines. Instead, you need to learn about a world you understand by encountering it firsthand and making some sense out of it. (Agar 1886: 12)

Fieldwork is often presented as a specific method used by anthropologists in particular. However, most anthropologists would argue that fieldwork is not just a method, but a distinctive research strategy where the methods used and the methodological decisions made are always linked to specific analytical understandings and theoretical reflections. Anthropologist Helle Plough Hansen (1996) employs the concepts of 'method space' (*metoderummet*) and 'thought space' (*tankerummet*) to illustrate the two intermingling positions that the researcher employs in the process of fieldwork (Hansen, 1996:118). 'Method space' encompasses the anthropological research traditions such as participant observation and qualitative interviews, and 'thought space' contains epistemological understandings, anthropological theories and traditions of reason and analysis. I find this distinction very useful in describing the dialectics and dynamics of fieldwork as a research strategy. Similarly, Cecilie Rubow (2004) identifies the different identities that the researcher put into play during fieldwork: The anthropologist (with interest in cultural-theoretical questions) and the fieldworker (engaged in a specific cultural field). Rubow then adds the identity of the (semi-) native (with a personal history and identity), which I find an important addition as it explicitly points to the lived reality of being in the field, the physicality of being present and using oneself to gain insight into unknown territory.

Fieldwork is characterised by being 'analytical along the way' in the sense that the methodologies are not only guided by theoretical interest, the specific analysis of empirical experience is also always underway. Hastrup identifies three constitutive 'pieces' in anthropological research: experience, ordering and ending (Hastrup, 2003:402). Experience is the way anthropology generate material – from the inside of someone's culture. It is a source of both insight and puzzlement that drives the inquiry. The second piece is 'ordering', an analytical management and ordering of experiences and material; e.g. a focusing of initial research questions and the interpretive processes. Finally, 'ending' is the theoretical ambition to see new connections or meanings in the material and to shape these into results and conclusions. These pieces interconnect in time and space, they happen interchangeably and

simultaneously, but in this chapter I will try to disconnect them and disclose them, even if writing them up as neatly successive stages is somewhat misleading. Because the object of anthropological inquiry is fluid, changing and with no clear-cut boundaries, the investigation of it – through fieldwork – is not a linear process that can be guided by standardised procedures (Maxwell, 2013; Hammersley & Atkinson, 2007; Wolcott, 2005). It is a strategy, guided by intention, consideration and decision and moulded by methodology, theory and the specific social context.

Quality in ethnographic research

Within positivistic sciences, verification of knowledge is usually discussed in terms of reliability and validity. Reliability depends on repeatability; that other scientists performing the same experiment will get the same results. Validity concerns the degree to which the scientist actually records or measures what she claims to measure (Kvale & Brinkmann, 2009; Sanjek, 1990). Unlike the lab experiment, fieldwork cannot be reproduced in a controlled environment, and consequently there has been an ongoing debate about how to acquire and claim reliability and validity in anthropological research.

Some researchers, like Wolcott, dismiss the concepts of reliability and validity in qualitative research altogether, arguing that it is futile to reinterpret concepts of quality based on quantitative assumptions (Wolcott, 2005:159). Consequently, a number of other concepts for evaluating qualitative research, such as trustworthiness, transferability and authenticity, have been proposed (Maxwell, 2013; Guba & Lincoln, 2005; Selmer 1998). Nevertheless, several researchers stick to the term 'validity' and use it in a straightforward, non-positivistic sense to address the accuracy or credibility of a piece of qualitative research. What seems to be consistent across different arguments is the value of researcher reflexivity (Hammersley & Atkinson, 2007), and the importance of documentation and transparency in all parts of the research process; from research questions to final results (Kvale & Brinkmann, 2009; Wolcott 2005; Sanjek, 1990). This kind of transparency allows for an imaginary repetition of the research process and unfolds the methodological and theoretical decisions made during research and analysis to scientific scrutiny and debate. Furthermore, documentation and transparency also allow readers to assess the '*quality of craftmanship*' (Kvale & Brinkmann, 2009), the researcher's competence to generate meaningful and relevant material of high quality.

In this method section, I aim to render transparent the most important events and decisions that shaped the fieldwork process and the material generated through it.

FOLLOWING THE SONOGRAPHERS

As previously suggested, one reason that clinical interactions following a high risk screening result remain under-investigated is the difficulty in accessing them. I knew that in order to obtain an adequate sample size I would have to observe several hundred FTS scans. Consequently, I approached the university hospital with the largest fetal medicine unit in the region performing more than 4,600 FTSs every year. Fortunately, the chief consultant and charge nurse as well as the sonographers at the clinic were very interested in my research proposal and supported fieldwork as an appropriate method. With their formal acceptance and articulated interest I consequently spent a total of 5 ½ months – between June 2011 and May 2013 – participating in everyday routines and dramas at the ultrasound clinic. The first four consecutive months, I observed a total of 405 FTSs and recruited 20 high-risk women/couples for the study. Later, I returned for three rounds of two weeks where I tested, challenged and further investigated initial findings and theoretical approaches.

Tagging along

During fieldwork I followed the daily work of the sonographers and got to observe and participate in the otherwise inaccessible routines and dramas, conflicts and joys that shaped everyday life at the clinic. I worked out a schedule to fit in as many FTSs as possible – I usually observed between six and eight a day. The half hour slots allowed me to shift location from one examination room to another in between examinations, and I thus got to observe all the sonographers in action many times. During time slots with no FTSs I either tagged along for other types of scans, dropped by the reception desk to see if something interesting was happening or went to the staff kitchen to write additional notes or maybe to clean the tables and brew a fresh pot of coffee for the sonographers. I also participated in invasive procedures, genetic counselling, coffee breaks, peer supervision and other ultrasound examinations. This approach allowed the identification of practices and understandings that are at risk of being missed in research based solely on interviews, because informants are unaware, unwilling or unable to put them into words (Patton, 2002).

By tagging along I slowly became familiar with the daily production, interpretation, negotiation and mediation of biomedical knowledge and practices at the ultrasound clinic. I followed the sonographers in their everyday work in dark ultrasound examination rooms; navigating ultrasound probes across pregnant bellies to produce a blurry, black and white, two-dimensional image on a computer screen. They meticulously scrutinised the fetus and interpreted the shades of grey to assess the health of the fetus and the state of the pregnancy.

I observed as they calmed down nervous couples, changed due dates, identified heartbeats and smiled over images of a fetus with the hiccups. I stood in the corner while sonographers delivered dreadful news – news of high-risk, of malformations and dead fetuses. News that made people cry and sometimes made them angry. And I tried to keep up with the sonographers as they rushed to find a doctor or dropped in on a colleague to provide a second opinion on uncertain findings. Throughout the day, I witnessed - and participated in – a constant flow of occupational talk, sharing images, discussing cases, asking about patients and a constant re-organisation of schedules and tasks to make ends meet.

Tagging along provided not only opportunities to observe but also an abundance of opportunities for informal conversations every day. Sometimes with me as the initiator, sometimes as participant or simply overhearing the conversations of others. What makes these conversations useful for research purposes was my theoretical intent and focus: '*They are never **simply** conversations, because the ethnographer has a research agenda'* (Hammersley & Atkinson, 2007:117). These conversations were an invaluable source of information in the process of understanding the knowledge and practices guiding everyday life at the clinic. Through informal conversations I casually shared my thoughts and questions with sonographers which provided me with deeper insight, challenged my own understandings and preliminary interpretations and thus added to the quality of the material.

A position as quasi-sonographer

During fieldwork the researcher is the research instrument (Wind, 2008; Bernard, 2006), which highlights the importance of position. The role taken by – or assigned to – the ethnographer in the field may define the activities and the different types of knowledge that the researcher can access. In my case, the charge nurse insisted that I should wear a sonographer's uniform - for hygienic reasons. The hospital uniform is such a powerful symbol, imbued with significance, expectations and responsibilities, and wearing it gave me instant and unquestioned access to the physical space and social community of the hospital. Wearing my blue shirt and pants, clogs and a name tag firmly positioned me as a 'professional.' It allowed me to feel like a sonographer and visually be part of the group. The uniform was a potential cloak of invisibility with all of its advantages. Anthropologists aim to make the people we study feel so comfortable around us that they behave in a free and unhindered manner (Spradley, 1980). However as anthropologists we are also ethically obliged to let people know (and not let them forget) that they are being studied (Kvale & Brinkmann, 2009). As Hastrup observes; *'The anthropologist in the field engages the world as a 'double agent', being both a trained researcher and a character in to local drama'* (Hastrup, 2004:465). With the uniform I took the position of a 'quasi'-sonographer in the local drama.

The uniform allowed not only for me to be a 'double agent', but also potentially to be 'under-cover agent' – deceiving or tricking staff and patients into thinking I was something that I was not. At times, visiting interns, doctors and midwives would ask me about lab results, patient's journals or the whereabouts of the attending fetal medicine specialist. Thus, I was always careful to be explicit about my research and reasons for being present – for example when new medical interns came to the clinic for training or when doctors from other departments participated in examinations. In all honesty, this constant reminding people that I was an anthropologist-turned-quasi-sonographer also served to make the various people I met during fieldwork interested in the research, sympathetic to my incompetence and prone to share their views with me.

Fieldnotes

Writing fieldnotes is central to the anthropological fieldwork. It is the way anthropologists have traditionally recorded events and transformed observed interaction into a written, running log that can later be revisited, reorganised and analysed (Emerson et al., 1995; Sanjek, 1990). At first, I did not take notes while observing in the examination rooms. Inspired by Schwennesen and Koch (2011) I refrained from taking notes during ultrasound examinations because I worried that it would inappropriately position the woman and the sonographers as study objects. However, I realised that note taking *after* an FTS did not sufficiently capture the complex and multi-layered interactions that I was observing. Thus, after a few weeks of fieldwork, I started to write fieldnotes during observations. Neither patients nor professionals objected to my new practice, and throughout fieldwork this experience reminded me that it is unwise to let one's strategies be guided entirely by ones presuppositions about what is and is not acceptable (Hammersley & Atkinson, 2007). Sometimes, considerations for informants' privacy are reflections of the researcher's own self-consciousness. When using yourself as a research tool, it is necessary to cross boundaries – to deliberately sit in the chief obstetricians' chair or to stay in the waiting area with a sobbing couple, even if it feels uncomfortable. It is necessary to test the boundaries of which methods, practices and interpretations are acceptable and which are unacceptable. Apart from this methodological reminder, I also found that publicly taking notes was an honest expression of my reasons for being present – I did not try to pass as an intern or a sonographer. A few women/couples commented on my notes after the scan, and I simply and briefly described what I had jotted down. The sonographers never asked about my notes, but sometimes joked that *'when people start to cry, then Stina starts to write'* (which was actually not true. I always wrote, even when seemingly nothing was happening). Being able to write 'in medias res' allowed for much more detail in the accounts. I was able to shorthand almost word for word the communication between sonographer and couples, which greatly

improved the quality of my notes and the subsequent analysis of them. After particularly interesting observations, I would rush to the staff kitchen to go over my fieldnotes, add observations and fill out gaps in the jottings. On a separate page I added personal reflections and analytical considerations. I used up four and a half A5-sized notebooks during the first four months of fieldwork.

Focused observations

When I first started fieldwork at the ultrasound clinic I was absolutely unknowing and incompetent (Bernard, 2006; Rabinow, 1977). The ultrasound images were a black and white blur, the practices of the sonographers a mystery, and the communication a constant source of curious intrigue for me. As the daily conundrums became more routine (I could identify nuchal folds and knew the sonographers' introduction by heart), I used focused observation (Wolcott, 2005) as a very useful tool to stay curious and alert. For example, I would listen for specific themes in the communication – 'socialising the fetus', 'inclusion of couples' previous experiences', 'worry'. Or I would be particularly attentive to specific elements in the interactions – the role of the partner, the ritual of printing photos, the way supervisors entered an examination room. A continuous and deliberate shifting of foci is an example of fieldwork's dual 'thought space' and 'method space', where empirically as well as theoretically driven interests focused the data gathering. I was both testing insights from the field as well as testing theoretical understandings from the scientific literature on my own data material.

Semi-structured interviews with sonographers

Following the initial four months of fieldwork, I did formal interviews with seven sonographers whom I purposefully sampled considering their educational background, age and years in sonography (see table 1). By then, I had become an insider – I knew a lot about high-risk, communication, local standards and ethics, concerns and controversies. With the formal interviews I was not only looking forward to having coherent and uninterrupted time, but also to explore more personal matters of motivation, responsibilities and insecurities in depth. I was curious to find out what was at stake for sonographers in their production of knowledge about the fetus and in their communication with pregnant women/couples. The interview themes covered the challenges and rewards of sonography, communication of high risk, and interactions with pregnant women/couples. The semi-structured interview guide is enclosed (appendix 3). All interviews lasted 60-90 minutes, six took place at the ultrasound clinic, and one sonographer was interviewed in her home. All interviews were transcribed ad verbatim and analysed. My theoretical and methodological

considerations when doing formal, semi-structured interviews are further addressed in the section presenting my interviews with women/couples with a high-risk screening result.

Table 1: Participant characteristics, interviewed sonographers

Name*	**Education**	**Age**	**Years as sonographer**
Emma	Midwife	38	4
Fiona	Nurse	40	6
Alicia	Nurse	46	6
Chelsea	Nurse	40	7
Meredith	Nurse	39	11
Rose	Midwife	44	12
Ingrid	Nurse	58	22

*Names are changed for anonymity

ENCOUNTERS WITH THE PARTICIPATING WOMEN/COUPLES

Fieldwork allowed me to observe the interactions between sonographer and women/couples following a high-risk screening result. These observations also provided an opportunity to establish contact with high-risk women/couples. They became participants in the research through a string of encounters – at the ultrasound clinic and in the women/couples homes. Here, I describe these meetings to make transparent the ways in which data material on the women/couples were generated.

Considering the sampling strategy

The participating sonographers and women/couples in this study were recruited through fieldwork. While it was possible to strategically and purposively sample the sonographers, the women/couples recruited were those who happened to get a high-risk FTS result while I was coincidentally observing their first trimester scan. Often, this type of sampling is – somewhat misleadingly – labelled 'convenience' sampling (Bernard, 2006). There is nothing convenient about observing more than 400 scans in order to get 20 samples of clinical interactions following a high-risk screening result. However, in order to achieve the specific type of samples (interactions and participants), it was necessary. Thus, the sampling strategy was definitely purposive in achieving a typicality of setting and practices, allowing comparison across settings and between individuals (Creswell, 2007). Furthermore, the

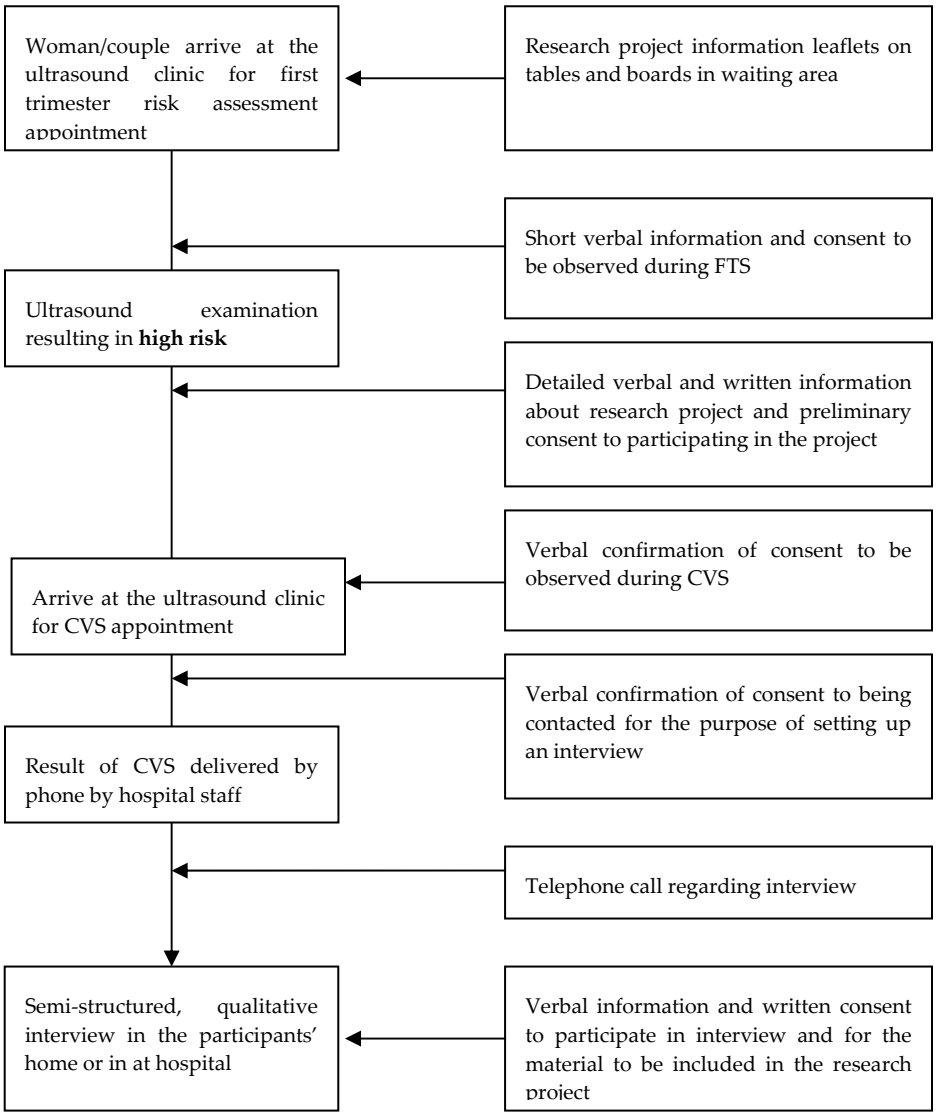
sampling strategy allowed me to observe and include a range of different women/couples – including women/couples who would possibly not respond to a subsequent written invitation from an unknown researcher.

A potential meeting: Some thoughts on consent

I first met the couples in the ultrasound examination room. I refer to these initial meetings as 'potential meetings' because of the observed 384 first trimester scans that ended in a normal-risk FTS result and therefore did not involve any further interaction between me and the pregnant woman and her partner. In the ultrasound examination room, the sonographer informed the pregnant women/couples that I was 'following her today,' and I introduced myself as an anthropologist doing research on FTS and on sonographers' communication. I subsequently asked if I could observe their scan.

During fieldwork, I had ongoing ethical deliberations over who, when and how much to inform about the research. Ethnographers rarely tell all the people we study everything about the research, because fully informed consent from all is both practically unattainable and could be experienced as intrusive – or simply annoying (Kvale & Brinkmann, 2009; Hammersley & Atkinson, 2007). Of course, the concern is not to 'trick' someone to be part of research against their will. At the ultrasound clinic, the research project was first presented to women/couples by pamphlets in the waiting area, and subsequently by my introduction. The women's/couples' consent was based on a very brief outline, and my intentions of further research in case of a high-risk screening result were deliberately toned down, because I did not want to cause unnecessary worry or disturbance to the situation. My concern was that emphasising the 'true' research agenda at this point might prompt some women/couples to think that they were more likely to be high-risk since I had 'chosen' their scan for observation. Furthermore, pregnant women/couples look forward to the FTS with excitement and some nervousness; I did not want to rob them of that special moment by insisting on thorough information which could be experienced as intrusive (Hammersley & Atkinson, 2007:211). I decided that withholding some information would benefit the majority (normal risk) and not harm the minority (high risk). These considerations guided the processes of information and consent during the research.

Figure 2: Information and consent



During fieldwork my request to observe was not once refused. First, I considered if it was my uniform that made people accept, and for a few days I wore my own clothes to test that assumption. It made no difference (apart from the sonographers complimenting my clothes and me feeling like an outsider in the staff kitchen). In a study of Swedish patients consenting to donating blood samples for scientific research, Hoyer and Lynöe (2006) similarly found that patients often did not read the information material, but spontaneously consented upon the nurse's mentioning of the research. Hoyer and Lynöe argue that there is a basic relation of trust within the Swedish healthcare system and a cultural expectation that health care personnel can be trusted. Thus, patients' responses to scientific requests *'should be*

analysed in its social and historical context rather than as a response to rational assessment of information of research purposes' (Høyer and Lynöe, 2006:229). Similarly, pregnant women/couples may have consented to my presence because they trusted the Danish health care system in general, and the particular university hospital and the sonographer in front of them. As patients we are used to a number of unidentified personnel tagging along the doctor / nurse / midwife and we trust that they are there for a reason. I capitalised on that trust which gave me a special obligation to handle it with care.

During the first trimester scan, I most often sat behind the sonographer where I could see the couple and the ultrasound monitor. A duplicate screen was mounted on the wall by the foot of the bed allowing the couple to visually follow the scan. I always had mixed emotions observing those scans, one part of me hoping for a high-risk result, the other keeping fingers crossed that everything was ok. Mostly, everything was completely normal, and the pregnant woman/couples who left the FTS with smiling faces and relieved sighs also left the ultrasound clinic without having to deal with me and my research.

Observing these FTSs gave me a unique insight into the agendas, concerns and questions that are brought into play during a scan – regardless of the end result. They allowed me to investigate how sonographers produce and communicate information and to become familiar with the joys and concerns that pregnant couples bring with them into the ultrasound examination room. I discovered how scans are simultaneously unique and very similar, and I documented the many ways in which sonographers and women/couples negotiated the content of the scan (e.g. how biomedical and social agendas merged, as described in Paper 1). My understanding and analysis of the high-risk interactions are intrinsically linked to the material gathered and insights made during *all* the scans I observed.

First meeting: High-risk result

When an observed FTS ended with a high-risk result, I simply continued to observe and take notes during the subsequent dialogue and decision-making. I jotted down the conversation in the greatest detail possible and made shorthand signs to be filled out later. I noted body language, changes in tone, I wrote like a madman. As the dialogue drew to a close (and on the sonographer's discreet indication), I asked for the couples' attention. This was a pivotal moment in my research, and I never stopped feeling nervous and humble as I asked these women and couples, often still visibly shaky and sad from the high-risk result, to please consider participating in my research project. I shortly described my research interests, stressing that high-risk happened to people every day at the clinic and that we needed to

know more about their experiences. I handed them a more detailed, written information (appendix 2) and requested permission to meet them at the CVS. If the women/couple declined the CVS, I requested permission to call them later in order to potentially set up an interview. Thus there was a continuous negotiation of consent as demonstrated in figure 2. Of the 21 high-risk cases I observed, 20 women/couples gave positive response.

Second meeting: The CVS

17 couples decided to have invasive diagnostics. I met with them in the waiting room prior to the procedure. The purpose for this was twofold. First, I needed their consent to my observations of the CVS (all consented) and second, it was an opportunity to strategically small-talk about their thoughts and concerns following the FTS. These conversations set off my interest in the women/couples management of waiting time. Generally the couples were more calm and collected at this encounter; some had prepared questions for the doctors while others were very concerned with the size of the needle. During the CVS, I noted the couples' questions, their reactions to seeing the fetus on the screen, the interaction between women/couple and professionals and professionals' ways of framing the situation. The whole procedure took about 15 minutes and afterwards I walked with the women/couple to the recovery room for a small chat and for their permission to call them after the diagnostic result to potentially set up an interview.

Third meeting: The interview

Three to four weeks after the FTS, I contacted the participating women by phone in order to set up an interview. All 20 agreed and background information is presented in table 2. 16 women/ couples were interviewed at home, while four women/couples preferred being interviewed at the hospital. When the interviews were set up, I strongly encouraged the woman's partner to participate, and in 15 cases he did. Much research in pregnancy, prenatal care and birth include only women's perspectives. My observations of the FTSs made apparent that this part of prenatal screening was a collective experience – the initial joys of 'seeing the baby' and the subsequent negotiation of the high-risk result were very much a collaborative and joint process. It has been suggested that joint interviewing reduces gender differences and enhances women's perspectives (Seale et al. 2008). In my research, the joint interviews allowed me to capitalise on the gender differences and added a new level of dialogue to the interview as couples challenged, supported and elaborated on each others' statements. Their recollection of the high-risk result and the subsequent events were collectively re-enacted during the interview and thus allowed a more comprehensive understanding of how couples manage a high-risk screening result. Of course, this perspective enhances the collaborative aspects. In solo interviews, the women spontaneously

referred to their partner and the ways in which they had managed the situation, which to me established the situation as something that was managed jointly by the couple.

Interviewing is another way of gaining insight into the experiences, interpretations and concerns of those we study. Rubow (2004) argues that in connection with 'typical' participant observation, interviews are a supplementary form of participant observation where the researcher experiences social situations alongside the informant. *'Interviewing gives us access to the observations of others. Through interviewing we can learn about places we have not been and could not go and about settings in which we have not lived'* (Weiss, 1994 in Maxwell, 2013:103). Interviews allowed me to imaginatively enter the couples' homes and conversations as they were waiting for diagnostic results and let me eavesdrop on telephone conversations with consoling mothers. Collectively, we explored their experiences, interpretations and concerns regarding the high-risk situation.

The contextualised interview

The interviews were performed at 15-28 gestational weeks when the result of the diagnostic test was known for those undergoing diagnostic testing. The formal interviews were based on a semi-structured, qualitative interview guide with open-ended questions (Kvale & Brinkmann, 2009; Bernard, 2006). The interview themes included experiences with the FTS and feelings about the high risk status. The questions also explored decision-making, management of waiting time and the potential impact of the screening result on the pregnancy. Interview guides can be found in appendix 4 and 5. Prior to a formal interview, I reread all fieldnotes involving the woman/couple and revised the interview guide accordingly – adding questions and areas of specific interest. I used this contextualised, customised interview guide as a tool to further my understanding of the observations and to deepen the interview by reflecting on concrete occurrences.

As previously mentioned, anthropology understands knowledge as socially produced and re-produced, and knowledge gained through interviews is no exception. Interviews are a co-production between interviewer and interviewee (Kvale & Brinkmann, 2009; Kvale 2006), and thus, the quality of the interview depends on both interlocutors. However, there is an essential, relational asymmetry in qualitative interviews which grants the researcher more authority over the situation and the dialogue. It is the researcher who initiates the situation, defines the area of interest and decides which questions to explore and which to ignore. As Kvale (2006) points out, this asymmetry should not (and cannot) be eliminated but should be reflected upon. However, I think it equally important to consider the authority of the interviewee. The aim of the interview is to provide new insights, challenge previous

interpretations and stretch or deepen our understandings. To that end the researcher is completely dependent on the participants' willingness to share intimate details about their thoughts and experiences. Interview participants can very easily withhold information and choose not to share their thoughts leading to misunderstandings and poorer quality of the data material. A successful interview that leads to good, thick descriptions and new, significant and trustworthy knowledge is based on a trusting relationship between interviewer and interviewee.

Within anthropology this relationship sometimes referred to as 'building rapport' (Spradley, 1979), meaning that the anthropologist aims to create relations to participants characterised by a basic sense of trust that allows for open, unprejudiced conversation (Hammersley & Atkinson, 2007; Spradley, 1979). I had several meetings with the women/couples (and the sonographers) before interviewing them, which not only meant that we got acquainted, but also that we shared very distinctive experiences and had a collective frame of reference. This gave the interviews a unique starting point since trust had already been established (they had several opportunities to get rid of me before the actual interview, see figure 2). In the initial framing of the interview, I emphasised the interview as a collective process where my understanding was dependent on the interviewees. In my experience, this framing is very important for the participants' subsequent engagement and commitment to producing a good interview. Thus, prior to the interview, I repeated my aim of getting to know the woman/couples unique experiences, concerns and actions following the high-risk result. Sometimes, interviewees withhold things that they think the researcher might find irrelevant. In order to avoid this I explicitly encouraged participants to go 'off track' and share all bits and pieces with me. Participants were encouraged to correct me, oppose my interpretations and to point out my blind spots during the interview. The aim of the briefing was to position the women/couples as authoritative and responsible and thus initiate a more dialogue-style interview with the woman/couple as the experts. Authority was not eliminated, but 'played' back and forth between me and the woman/couple (or the sonographer), and in my estimation the result was indeed good, thick descriptions and trustworthy knowledge.

Table 2: Participant characteristics, interviewed women and partners

Participants	FTS result	Woman age	Mothers occupation	Partner age	Fathers occupation	GA at interview	Children	CVS
Cristina & Frank	1:30	42	Teacher	44	Teacher	20	1	+
Caroline & Oliver	1:116	30	Doctor	29	Doctor	20	0	+
Anita & Hugh	1:37	40	Office assistant (unempl.)	43	HR consultant	21	1	+
Katie & William	1:297	39	Management-coach	39	Teachers training	17	1	+
Jennifer* & Robert	1:150	40	Healthcare assistant	42	Car painter (unempl)	20	1	+
Kimberly & Jerome	1:113[3]	27	Kindergarden teacher	-	Graduate student	19	0	+
Anna & Jacob	1:222	34	Social worker	28	Graduate student	20	0	+
Monica & Jack	1:47	31	Dentist	32	Carpenter	14	0	+
Lilly & Stephen	1:244	37	Administrator	35	Sales representative	18	1	+
Isabella* & Brad	-[4]	30	Kindergarden teacher	40	Sales representative	-	1	+
Fay & Simon	1:71[5]	35	Geophysicist	36	Geophysicist	15	0	+
Zoe & Leonard	1:435[6]	40	Pharmaconomist	38	Engineering student	19	1	+
Uma & Josh	1:67	21	Pharmaconomist student	25	Bookseller	15	0	+
Sofia & Matt	1:223	30	Graduate student	30	Prof. soccerplayer	16	0	+
Jessie & Simon	1:121	35	Self-empl., administration	36	it-consultant	15	0	+
Rachel & Nicolas	1:274	28	Graduate student	30	Business developer	17	0	-
Emily & Daniel	1:292	38	Social worker	37	sales and marketing	29	1	-
Andrea	1:26	44	Light technician, coach	-	-	22	0	-
Helen* & Gordon	1:33	38	Nurse	42	Self-empl, roofing	21	1	+
Eve* & Ben	1:48	38	Self-empl., interior design	42	Self-empl., contractor	17	0	+

Women marked * were interviewed alone. All others were jointly interviewed.
All names have been changed for anonymity.

[3] Trisomy 18

[4] This couple was never informed about their exact risk figure

[5] Trisomy 13

[6] Following a normal FTS result, this couple was offered invasive diagnostics due to previous, terminated pregnancy with diagnosed chromosomal abnormality in the fetus

The never-ending study object, or, when is enough enough?

After four months of fieldwork, I had observed 21 FTS with a high-risk screening result and recruited 20 women/couples for interviews. In qualitative research, it is often a challenge to estimate how much data material – time in the field, number of interviews - is needed (Maxwell, 2013). In hypothetico-deductive quantitative research, researchers have finite ideas of the aim and scope prior to the research, and calculating an adequate sample size based on preselected parameters and objectives is generally straight forward. In qualitative research, researchers work in a more open-ended context where emergent empirical and conceptual findings shape the course of the research. Thus, it can be difficult to estimate in advance how much material is needed to answer the research question which is itself changing as the process of inquiry narrows in on particular themes and topics. The privilege of the research for this dissertation was the absence of financial and/or time constraints often defining sample sizes in qualitative research. Thus, I was free to continue fieldwork and recruit participants until I 'had enough', what some qualitative researchers refer to as data 'saturation'.

'Saturation' is a concept originally developed within the grounded theory approach to describe the theoretical saturation, where categories are fully accounted for and a theory can emerge (O'Reilly and Parker, 2013). The concept has disseminated more broadly into qualitative research and is more generally used to address 'data adequacy' (Morse, 1995) i.e. the point in data collection when new information produces little or no change in the empirical and theoretical understandings of the study field (Guest et al., 2006). The concept of 'saturation' has been widely debated within qualitative research. The main objection to the concept is that due to our fluid object of study, new perspectives and understandings can always be found (O'Reilly and Parker 2013), and consequently the decision to stop gathering data is a theoretical and methodological decision, not something that emerges from the data itself. I will not go into these debates here, but note that after 20 interviews, I did experience 'saturation' in the sense that the participants' overall answers rarely surprised me. As I was transcribing and open-coding interviews concurrently, I noted how I added fewer new codes, when analysing new interviews, suggesting saturation or data adequacy. On the basis of this, I decided not to include any more high-risk women/couple in the study.

However, to expand my understanding of both the couples' experiences with the FTS and their management of waiting for diagnostic results, I conducted six postnatal, follow-up interviews in order to explore whether the women/couples had changed their views. I strategically selected women/couples who had expressed the most and the least doubt/concerns during the observations and interviews. When interviewed five to nine

months after delivery, the women/couples concurrently reported having good pregnancies and that the high-risk was just part of their history now. These interviews did not challenge or modify my initial findings and conclusions, and thus I decided to stop this line of inquiry after six interviews.

As all of 'my' participants received a normal chromosomal result, I needed some insight into the experiences and interpretations of women/couples with an abnormal diagnostic result. I thus began to observe CVSs where the woman/couple had a risk higher than 1:50. Procedure for consent was similar to the recruitment process described above. I observed more than 40 CVSs for this purpose and five women/couples received an abnormal chromosomal result. They all agreed to be interviewed. However, the interviews revealed considerable differences in the women's/couples' experiences, interpretations and concerns, and thus I estimated that I needed an additional eight to ten interviews to compile a data material adequate for a valid analysis. Consequently, I had to forego this line of inquiry, but I still genuinely hope to be able to pursue it in future research.

Thus I ended the 'experience' part of fieldwork (Hastrup, 2004), content with the size and quality of the material, but also humbly aware of all the experiences, perspectives and practices that I had to leave behind.

MANAGING THE MATERIAL

As this chapter has hopefully reflected, the process of analysis – of 'ordering' and 'ending' the material and the results (Hastrup, 2004) – was an ongoing process during fieldwork, referred to by Wadel (2002) as a *circular dance* between theory, method and data. The processes of analysis included on-going reading and re-reading of written material, tentative development of codes and searching for relevant theoretical literature.

Having completed first all of the interviews with high-risk couples and later with sonographers, I formally coded the two sets of interviews separately. The process of coding interviews had three steps. The first round consisted of an open coding, using inductive (bottom-up) and deductive (top-down) codes (Braun & Clarke, 2006; Emerson et al., 1995). I simply read the transcripts and wrote notes, thoughts and preliminary codes in the margins and on a separate piece of paper. This was followed by critical consideration and an initial grouping and ordering of these preliminary codes. Second round consisted of a more

focused coding where the specific definitions and content (including when to use and when not to use) of each code was further developed in order to secure a consistent, final coding. A common description when reading qualitative accounts is that themes 'emerge' from the data as if '*themes 'reside' in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from thinking about our data and creating links as we understand them'* (Ely et al., 1997 in Braun & Clarke, 2006:80). Codes and themes do not magically emerge in the qualitative data-material, but are crafted in a process of decision-making where some concepts, meanings and connections were high-lighted and further investigated, while others were dismissed. On the basis of this, and after discussions with the team of supervisors, the final codes were settled ('ended'), and I performed a final coding of interviews using Nvivo 9.0 software (QSR International, Doncaster, Australia).

Next step in the analysis was working with the codes – investigating connections, overlaps and contradictions. Often this meant re-consulting original interviews and fieldnotes, continuously relating data extracts to their context. By investigating repeated patterns across the dataset and relations between codes, candidate themes were generated and explored in relation to the full data set. The theoretical perspectives guiding the analysis are presented in chapter 3. The final stage was writing up the papers where the interplay between empirical data and theoretical approach was further developed within the scope of the targeted journals. In this process of writing, the relation between material, analysis and the overall contribution of the papers were strengthened even further in collaboration with the co-authors.

This process from ultrasound examination room to final article is a process of ordering and editing, where the material and analysis is under constant scrutiny: Am I getting it right?

> 'In writing, anthropologists make connections and sort out hierarchies of significance that cannot bypass local social knowledge even while transcending it. The ethical demand is to 'get it right', not in any ontological sense, but in being true to the world under study and to the epistemological premises of anthropology' (Hastrup, 2004: 469).

With this detailed description of the process from clinical observation to final manuscript, I have aimed to render transparent the events and decisions that shaped the research process. The descriptions provide insight into my efforts to do thorough, valid and reflexive qualitative research characterised with a high quality of craftsmanship, and the aim to be

true to the world under study. The strengths and limitations of my approach will be discussed further in Chapters 2 and 5.

THE SYSTEMATIC LITERATURE REVIEW

The idea to do a systematic literature review grew from my observations in the ultrasound clinic. I noticed how the on-going discussions in media, in academia and in health administration about the pros and cons of screening were debated with some concerns amongst sonographers and obstetricians. One day I got a phone call from an obstetrician, on his way to a conference panel discussion on prenatal screening. Preparing himself for attack, he asked me: 'Am I in the worry industry?' and thus, performing a literature review on screening and anxiety was motivated by my interaction with the 'world under study'. Consequently, what was initially a purely qualitative research became a mixed-method project.

The aim of the review was to summarize existing research points to whether screening for Down's syndrome causes anxiety in pregnant women, specifically 1) Differences in anxiety between women who accept screening and women who either decline screening / are not offered screening, and 2) Differences in anxiety before and after screening in women who accept screening.

We used the PRISMA guidelines (Moher et al., 2012) to structure the review process' and methods are thoroughly described in Paper 3. We decided to only include studies that used quantifiable measures of anxiety on validated scales. Based on an initial scoping of the literature, search terms were formulated, and test searches were performed to develop the final search strategy. The search terms agreed on included ("pregnancy" or "pregnant women") and ("mass screening" or "prenatal diagnosis") and ("behavior"). In April and May 2013, we performed a systematic search in five databases (PubMed, Embase, Cinahl, PsychInfo, and Cochrane) which identified 383 candidate publications. After removal of duplicates and initial screening for eligibility by title, abstract, and full-text, 40 publications were identified for potential inclusion. All studies were read in full by Stina Lou and research assistant Line Mikkelsen, and assessed for eligibility according to PICOS and exclusion criteria. Searching the reference lists and Science Citation Index did not identify additional studies.

Criteria for excluding publications were:

- Studies that used non-validated scales
- Studies on fetal anomalies other than chromosomal abnormalities
- Studies on parental knowledge and decision-making regarding screening
- Studies on anxiety during invasive testing

Consequently, another 33 publications were excluded. Study relevance and validity, including risk of bias, was assessed independently by Stina Lou and supervisor Camilla Palmhøj Nielsen, using checklists developed by the Danish National Board of Health (Danish National Board of Health, 2014), and assessments were compared and discussed between the authors.

Studies were subsequently ranked according to the Oxford Centre for Evidence-based Medicine (CEBM) guidelines (University of Oxford, 2009). Based on the assessment of the individual study, grades of recommendation (A-D) of the overall evidence on relevant outcomes were given according to the CEBM guidelines. For the evidence to be graded with recommendation A, consistent level 1 studies (RCT and cohorts) are required and recommendation A thus indicates high level of evidence, whereas a recommendation D reflects level 5 studies (e.g. expert opinion) or troubling inconsistent studies of any level, and thus poor level of evidence. Due to the heterogeneity of aims and designs of the included studies, we decided to do a narrative review and thus no meta-analysis was performed.

In November 2014, I was invited to co-author a 'Status article' for a thematic special issue on screening in the Danish medical journal, Ugeskrift for Læger (see appendix 1). In order to write the article, relevant databases (PubMed, Embase, Cinahl, PsychInfo and SweMed) were searched using search terms ("Decision-making" or "Behavior") and ("prenatal ultrasonography"). The search identified 1301 candidate publications. After removal of duplicates and initial screening by title, 119 publications remained. They were screened by abstract and full-text, and a total of 30 studies were identified as potentially relevant for the article. A 'Status article' is a small review article, which describes the latest developments, scientific status and practical perspectives. It is peer-reviewed, but does not require full documentation and systematic critical review of the entire literature of the field, and it has more of a commentary status. Therefore the article is not included for assessment in this dissertation.

CHAPTER 3

THEORETICAL APPROACHES

THEORETICAL APPROACHES: FRAMING THE ANALYSIS

Having established the background, aim and methods of the present dissertation, this chapter serves to present the conceptual framework that guided the analysis. I start by outlining relevant developments in anthropological approaches to biomedicine as a study object; biomedicine as nature, as culture and as practice. The reason for this is twofold; first, I wish to position this study within the medical anthropology tradition; and second, these different approaches have served as comparative perspectives that I have used to discuss and reflect on my material during the development of the conceptual framework. I then present different theoretical approaches to clinical interaction and argue in favour of understanding clinical interaction as a collaborative process of knowledge production. Finally, I present three central concepts pertaining to the interaction: choice, risk and uncertainty, and discuss how I have approached them theoretically in order to push the analysis forward.

BIOMEDICINE AS THE OBJECT OF ANTHROPOLOGICAL STUDY

Medical anthropology is characterised by an empirical interest in individual health and social and cultural health institutions rather than by a specific theoretical approach (Mogensen & Whyte, 2007). Human suffering and healing have always been central to anthropology, but have traditionally been investigated as belonging within the realms of the religious and social. With the expansion of modern, Western medicine, healing and suffering have largely been reconfigured as biological problems: *'What we knew as divination now appear to be diagnosis; what we analysed as ritual is now termed therapy. The victim of supernatural forces is called the patient, and his or her relatives – the therapy management group.'* (Whyte, 1989 quoted in Paarup, 2008:8).

Biomedicine as nature

Initially, medical anthropology was primarily concerned with the cultural interpretations of suffering and healing. A well-known example of this approach is from the now classic – yet debated – dichotomy between *illness* and *disease* (Helman, 2007; Kleinman, 1988) as the first productive step towards addressing biomedicine as an object of anthropological inquiry. In this approach, *disease* refers to the 'objective' conditions of the patients; the symptoms and diagnosis as they are interpreted from the biomedical standpoint (of the doctor). *Illness* refers to symptoms as perceived and managed by patients and the social worlds in which they live.

These categories have since been subject to debates that are beyond the scope of this dissertation (see for example Risør & Ørtenblad, 2010). However, they illustrate how anthropology positioned itself 'alongside' biomedicine to investigate the cultural interpretations and implications of biomedicine. This approach reproduced the dichotomy between the world of the natural (objective, biomedical) and the social (open to cultural interpretation) and was based on an implicit acceptance that the natural world exists prior to and independent of cultural interpretation. Hence, the social sciences turned to cultural interpretation associated primarily with the lay and non-medical and left the world of disease, symptoms and biomedical knowledge unaddressed. Rhodes (1990) calls this a 'bracketing of biomedicine', where the objective nature of biomedicine was taken for granted and not questioned or investigated by anthropology as an object of study in itself.

Biomedicine as culture

Moving beyond an understanding of medicine-as-nature and patients-as-culture, it has been argued that the concept of culture must be applied ubiquitously and to all aspects of knowledge, including scientific knowledge (Lock & Ngyuen, 2010). Consequently, biomedicine can be understood and investigated as a cultural system in itself - defined by specific assumptions, values and practices (Lupton, 2003). This approach allows an anthropological analysis of biomedicine as a system of knowledge and practice that is made and moulded through specific conditions, interests and contingencies (Rhodes, 1990). Within this approach, feminist anthropology has generally been very critical of Western biomedicine as a dominant system of knowledge. Critiques concern the biomedical – and reductionist - construction of the female body, medicalisation (e.g. of pregnancy) and the relations of power between patients and medical professionals (Lupton, 2003). For example, in her seminal analysis of amniocentesis in the United States, Rayna Rapp (1999) observes the tension between the dominant, biomedical language and the personal narratives of the women in her study, causing pregnant women to doubt their own interpretations and conceptualise their pregnancy in medical terms. This critical anthropology is positioned in opposition to biomedicine and consequently defines biomedicine in terms of its authoritative and reductionist capacities. The strength of this perspective is the critical approach to modern medical knowledge, practice and institutions so powerful in shaping lives and societies (Lock and Nguyen, 2010; Rapp, 1999; Jordan, 1997; Davis-Floyd, 1992). However, these studies also tend to represent biomedicine as a culturally coherent community where health professionals are understood as authoritative and compliant representatives of this culture. Thus, this perspective holds a danger of *'seeing the discourse of biomedicine as a language without significant dialects'* (Frankenberg 1993: 225), because the complexities and diversities within biomedicine and amongst its practitioners are left unaddressed.

Biomedicine as practice

In a discussion of the medicine-as-culture perspective, Rhodes (1990) argues that the practice of biomedicine *'often differs significantly from the standard descriptions of biomedicine as a system of knowledge'* (Rhodes, 1990:172). Maintaining the idea that biomedicine is 'cultural' in the sense that it is a systematised body of knowledge and practice that has emerged and developed in modern society, Lock & Ngyuen (2010) remind us that (biomedical) culture is neither static nor homogeneous, and that culturally informed values are always subject to dispute and never distributed equally across groups or people (Lock & Nguyen, 2010:7). In recent medical anthropology there has been increased focus on the eclectic and pragmatic diversity of biomedicine and biomedical practices (Mattingly, 2010; Saunders, 2008; Atkinson, 1995; Good, 1994). For example, in his anthropological exploration of the CT scan, Barry Saunders (2008) shows how professional experience, division of labour, communicative rituals and feelings of excitement and intrigue all play a part in the constant clinical negotiations about the meaning of the CT images. Similarly, Paul Atkinson (1995) investigates the micro-sociology of medical knowledge by analysing how haematologists' clinical decision-making is based on the discussion, negotiation and dissemination of expert opinions. What these approaches have in common is an analytical approach to biomedicine as practice. Biomedicine is investigated from within the hospital, and analytical focus is on biomedical knowledge and practice as negotiated, locally accomplished and contextually embedded. This approach has framed the analysis in the present dissertation. Biomedical knowledge and practice must be investigated through '*a close reading of practice*' (Rhodes, 1990:172) in order to understand biomedical knowledge itself as culturally produced and reproduced by both health professionals and patients.

Approaches to clinical encounters

Anthropological approaches to biomedicine significantly frame how the clinical encounter, the meeting between clinician and patient, is understood and analysed. From an illness/disease perspective, clinical consultations are ultimately understood as transactions between lay and medical explanatory models (Helman, 2007). From a medicine-as-culture perspective, clinical interactions are often represented as a clash of cultures. Several studies have investigated how biomedicine, as an authoritative knowledge tradition, can powerfully define women's experiences with childbirth (Jordan, 1997), prenatal screening (Markens et al., 2010; Lippman, 1999) and lifestyle during pregnancy (Browner & Press, 1996; Root & Browner, 2001). These studies often apply concepts of 'experiential' or 'embodied' knowledge that represent the 'lay' position of women resisting or complying with the 'professional' biomedical knowledge tradition. These approaches tend to represent the clinical encounter as a competition or struggle between different positions or contrasting

cultures (disease/illness, biomedical/embodied), where the patient's problem is often reduced and appropriated by the practitioner to fit biomedical discourse and purposes.

An analytical focus on biomedicine as practice also entails increased analytical focus on doctors as both individual persons and clinical experts, and on patients as biological citizens (Rose & Novas, 2005), a *'meeting between experts'* (Tuckett et al. in Nettleton 2004: 672). Instead of approaching clinical encounters as exchange, my analytical approach has been to analyse them as processes of production. In this I am inspired by the social constructivist approach of science and technology studies. Central to this approach is a collapse of the dichotomy between knowledge that resides in the minds of people and knowledge as objective reality in the world (Latour, 1994). Dutch ethnographer and philosopher Annemarie Mol (2007) argues in favour of an analytical approach that moves beyond the dichotomy between knowing subjects (patients, doctors) and their objects of knowledge (pregnancy, statistical risk) to instead investigate knowledge as it is located in activities, in practice (Mol 2007:32). Mol uses the term 'enactment' to designate the way phenomena come into being, are made 'knowable' through practices. Consequently, instead of investigating 'high risk' as a process where information is exchanged between sonographers and women/couples, this dissertation has analytical focus on 'high-risk' as an enacted, social construction, whose meaning, implication and reality is generated in the clinical interaction through practice. Thus, knowledge production in clinical encounters is approached as a collaborate state, where meanings and interpretations are produced and displayed through interaction.

CHOICE AND CARE IN CLINICAL ENTECOUNTERS

The clinical interactions explored in this dissertation are approached theoretically as taking place in a biomedical field that is produced and reproduced through numerous intermingling, competing and contradictory discourses (Lock & Ngyuen, 2010; Lupton, 2003). Discourses are social practices through which social and cultural categories, meanings and values are created, interpreted and negotiated through language. This perspective serves to remind us that clinical interactions are part of a larger biomedical field that feed into and define the meanings and practices available to patients and clinicians in their interaction. For example, as mentioned in the introduction, the ideal of non-directiveness and patient autonomy is a dominant discourse within prenatal screening. It serves as an ideal for clinical practice and positions the health professional as a source on unbiased information, based on

which patients must make their own autonomous choices. As such, the discourse of informed choice aims to eliminate the traditional 'paternalistic' doctor telling his patients what to do and instead position health professionals and patients as equals.

However, I repeatedly observed the practical tensions between clinical ideals of patient autonomy and clinical concerns with taking good care of the sad and frustrated high-risk women/couples. In considering how to approach this tension theoretically, I turned to Mol's concept of 'logic of care' (2007). Addressing the pervasiveness of the paradigm of 'informed choice' in modern healthcare ('the logic of choice'), Mol argues that while choice was meant to give the patient authority, to free the patient from the doctor's patronage, it also places a burden of responsibility on the patient's shoulders – including responsibility for what might go wrong. The pervading paradigms of 'choice' and 'patient autonomy' are high on the health care agenda and have an almost magical power to end all discussions of doctor-patient interactions. How, asks Mol, does this correspond with everyday biomedical practices?

Mol builds her argument on the case of a chronic illness – diabetes – which demands a continuing, uncompleted and interactive collaboration between patient and health professionals. By observing the *'messiness of mundane practices'* (Mol, 2007;43) in clinical interactions, Mol identifies 'care' as a guiding rationale running parallel to, intermingling with and interfering with the logic of choice. The logic of care is not a nostalgic return to the passive patient, but an approach to biomedical problems that people *'shape invent and adapt, time and again, in everyday practice'* (Ibid:8). The logic of care incorporates a collaborative, practical figuring out of what to do, based not only on the available evidence but also on the patient's lived experiences and the professional's knowledge – Moll calls it 'shared doctoring'.

Whereas the logic of choice positions doctors as robots delivering treatment in accordance with the available evidence and consumers' preferences, practitioners of care accept that sometimes what patients need or want is obscure, sometimes the evidence or the medical justification is missing; and sometimes facts and values (e.g. of a high risk screening result) cannot easily be separated. Within the logic of care, the aim of the interaction is – in collaboration with the patient – to figure out ways to live with and deal with reality. What is important is to test and fail until a satisfactory result is reached. Thus, the logic of care is an attuned approach where the professional is more than a neutral and objective fact provider, and where the patient is not the only one who interprets the facts and makes choices. By

identifying logic of care, the clinical encounter is investigated not as transaction, but as interaction (Mol, 2007: 20).

The intermingling logics of choice and care offer a perceptive, a theoretical lens that is able to encompass the mundane messiness of the interactions I observed at the ultrasound clinic. It convincingly repositions health professionals as people and patients as knowledgeable, and it allows for a much more complex and meticulous analysis of interaction, as demonstrated in Paper 1.

THEORETICAL APPROACHES TO RISK

Risk in society

Through prenatal screening it is possible to calculate a woman's statistical risk of carrying a baby with chromosomal abnormality. This knowledge is made available by the scientific tradition of epidemiology.Epidemiology is the study of patterns of diseases and their causes in populations. Through large population studies, risks are identified by linking specific diseases with their causal variables in order to predict future health outcomes. Epidemiology relies on the principle of 'web of causation' (Krieger, 1994), where diseases are understood as the result of complex interactions of several risks and protective factors. Thus, it relates specific groups (e.g. pregnant women) to specific identified risks (e.g. chromosomal abnormality) through the language of statistics. Consequently, it is possible to calculate individual risk of disease based on standardised estimates derived from population studies. Though epidemiologists as a scientific community may recognise the limits and '*fuzziness'* of their practice (Petersen & Lupton, 1996:33), the knowledge they produce is usually presented as facts, departing from an objective knowledge base supported by the scientific principle of unbiased observation, testing and calculation. Epidemiological knowledge has been highly influential in public health and modern health care administration due to its predictive – and thus potentially preventive – potential. It constitutes a major source of knowledge and supports decision-making in public health (Petersen & Lupton, 1996), and both its language and results have diffused into the general public, mainly through the media (Boholm, 2003).

Within the social sciences, the knowledge tradition of epidemiology and its language of risk-as-objective-fact have been subject of investigation and criticism. I will shortly mention two critiques. First, Michel Foucault has critically addressed the role of modern surveillance techniques – epidemiological, demographic and biomedical – in investigating, monitoring

and assessing the population (Lupton, 2013a; Foucault, 1997). These surveillance techniques and the knowledge they produce have the capacity to divide a population into categories such as high risk/low risk, sick/healthy, normal/deviant, safe/in danger and form the basis for intervention and regulation. Central to this argument is that the concept of risk is a moral technology – identifying normal and high risk is not a neutral matter, but holds implicit, normative assumptions about how individuals should appropriately manage themselves in relation to certain categories. Thus, the work of Foucault offers a strong social constructivist perspective on the ways in which discourses, practices, strategies and institutions produce 'truths' about risk; bringing it into being and constructing it as a phenomenon in the social world (Steffen & Samuelsen, 2004; Caplan, 2000: Lupton, 2013a). From this perspective, risks are not seen as pre-existing in nature, but as the product of historically, socially and culturally contingent ways of seeing. Epidemiological knowledge is understood as a powerful and productive discourse, shaping societies and forming individuals as objects of risk.

Second, cultural theory has argued that epidemiological risks cannot be understood outside of their cultural context. In their work on risk as a social and cultural phenomenon, Douglas & Wildavsky (1983) investigate the processes of cultural selection and prioritising of risks. They argue that since no one can worry about all risks all the time, priority is needed. What we, as society, highlight as risks and put on the scientific and political risk agenda is neither random nor objective. On the contrary, the choice of risks is linked to our choice of social life, and the way we organise our society: Risks are not objective but serve cultural and social purposes (Douglas & Wildavsky, 1983:37). From this perspective, epidemiological risks are identified and accentuated because they have a cultural role to play.

In my work on this dissertation, the tensions between these different theoretical approaches to risk framed my understanding of prenatal screening as a socio-cultural, historical phenomenon that positions risk of chromosomal abnormality as a concern for pregnant women to deal with. The debates outlined above question the common distinction between objective and subjective risk, that has served as conceptual baseline for much research, by pointing to the subjective ways in which risks are identified and come to have social impact. However, these approaches are unable to account for how risk is actually managed in everyday life at the ultrasound clinic. In the following, I turn to risk as it translates into clinical encounters – as it shapes and is shaped through these encounters.

Situated risk

When a pregnant woman/couple receives a high risk FTS screening result, most often the sonographer presents it as a statistical risk figure; as 1:297 or 1:30 risk for Down's syndrome in the fetus. Often, the sonographer will also mention the cut-off value at 1:300, and when introducing the option of invasive diagnostic tests (CVS) she will add the 1:100 procedure-related risk of miscarriage. The interaction is swarmed with statistics and, as Boholm (2003) observes, there is no simple translation from 'risk' as it is defined by the scientific community to the 'situated risk' as it is understood and contextualised by people.

There are numerous theoretical approaches as to how people perceive risks, how they make decisions about them, and how risks are most appropriately communicated. It ranges from the maximizing actor in rational choice theory over the benefit-minus-barriers equation of the Health Belief Model (Good, 1994; Green & Tones, 2010) to discursive strategies used to frame risk in meaningful ways and promote useful, clinical communication (O'Doherty & Suthers, 2007; Sarangi et al., 2003). However, many of these approaches have prescriptive aims of describing 'good' decision-making and 'appropriate' clinical communication. As mentioned, my approach was driven by a bottom-up perspective and analytical attention to the practices in which high-risk was enacted by sonographers and women/couples. Consequently, I turned instead to a more generic framework for thinking about situated risk, as provided by Åsa Boholm (2003). With the aim to approach 'the cultural nature of risk' analytically, she defines 'risk' as: *'A situation or event where something of human value (including humans themselves) has been put at stake and where the outcome is uncertain.'* (Boholm, 2003:165).

To me, this definition has been valuable to think with – during field work and when analysing the material. It accentuates how 'risk' is situated in both time and space: In people's lives of future, presents and pasts, and in a certain location (of the hospital, the home, Denmark). It also highlights that what is at stake is not given. This definition disconnects from the narrow outcome of epidemiology and opens up for an exploration of the values at stake for the individual woman/couple (and sonographer, for that matter). Furthermore, risk does not exist independently. If nothing of human value is threatened then risk is non-existent: To a couple who is accepting of a child with Down's syndrome, the risk figure poses no risk. Finally, the outcome is uncertain, implying the possibility of both a negative and a positive outcome (not only eliminating risk but also hoping for the best) as well as the uncertainty of the outcome itself (its shape, size and the consequences it may bring). These considerations, concerns and interpretations do not take place in a vacuum, but are socially embedded and shaped by *'culturally based notions about the state of the world, what the world consists of and how it works'* (Boholm, 2003:161; see also Jenkins et al., 2005). This

situated concept of risk, where risk is understood as inherently dynamic and relational, offered a valuable way of discerning individual variations as well as identifying patterns in the ways a high-risk FTS result was understood and managed – in the clinic and while waiting for diagnostic results.

MANAGING UNCERTAINTY

Risk is 'calculated uncertainty' (Boholm, 2003), and as such it produces both knowledge and new uncertainties. Knowing about high risk entails uncertainties about the health status of the fetus and the concerns regarding risk of procedure-related miscarriage, which can induce worry and anxiety in the woman/couple. In the comprehensive NHS review of prenatal screening literature, Green et al. (2004) notes, that much of the included literature is based on the implicit assumption that worry and anxiety are adverse effects: unwanted and abnormal responses that should be eliminated or alleviated. However, as the authors go on to suggest, worry and anxiety can also be approached as productive, since increased emotional responses are associated with both more effective decision strategies (Green et al., 2004; Bekker et al., 2003). Of course, very high levels of anxiety may impair appropriate understanding and decision-making, but some arousal may be a completely appropriate and enabling response to a situation of existential uncertainty. With this in mind, uncertainty and concomitant worry are approached theoretically without preconception and with attention instead to the processes in which they are enacted - in clinical interactions and in the women's/couples' subsequent management of waiting.

My approach to uncertainty as a social process is inspired by anthropologist Susan Whyte (1997). In her work from Uganda, she identifies three aspects of dealing with uncertainty and misfortune. First, inquiry about what is happening; second, probing responses and attempts to alleviate the situation and limit uncertainty; and third, uncertainty and response is linked to broader social and moral concerns. Fundamental to this theoretical approach is that uncertainty is understood as a generic feature of human life. Humans are never merely victims of fate (or uncertain biomedical knowledge). Despite the impossibility of complete certainty, we actively attempt to create meaning, reasons and degrees of security (Jenkins et al., 2005). In this dissertation, uncertainty is approached analytically as an on-going process of knowing and not knowing, and it is dealt with through everyday practice.

I draw on insights from pragmatic philosophy (Dewey, 1960; Brinkmann, 2006) and ethnomethodology (Risør 2003; Silverman 2010), where practice is understood as the basis of knowledge production: To know and to gain knowledge is a process of relating to the world, engaging with it and doing things with it and to it (Risør, 2003). From this perspective, uncertainties are addressed not by intellectualised thinking and analysing until arriving at a definitive answer (what Dewey (1960) calls 'the spectator theory'), but through involvement, experiment and probing responses in order to gain the kind of understanding that is necessary to deal with problems as they arise.

In order to address the link between cultural context and individual response to uncertainty and worry, I draw on Bourdieu (Bourdieu & Wacquant, 2009; Samuelsen & Steffen, 2004; Bourdieu, 1994) whose concept of *habitus* is able to embrace the way in which people are independent individuals as well as cultural beings. Bourdieu investigated the complex relations between the individual and society, and defined the habitus as the generative and durable dispositions that individuals acquire through socialisation. In their argument for the continued relevance of Bourdieu in anthropological research, Steffen & Samuelsen highlight the habitus as *'an organising principle of action; it is a basis for regular modes of behaviour, without being determining of specific practices. Habitus constitutes a practical logic rather than a conscious reasoning.'* (Steffen & Samuelsen, 2004:5). My point is that dealing with uncertainty is both a cultural and an individual practice. The habitus embodies both dispositions for culturally relevant probing responses and the capacity for creative and unusual individual responses, because it is exactly social reality's existence in individuals that allows them to creatively act in their social worlds. The habitus is not fixed, but formed through experience and consequently subject to change and transformation (Bourdieu & Wacquant, 2009). The value of habitus as theoretical approach is the attention to the simultaneously cultural and individual resources and strategies which both sonographers and women/couples employ when dealing with the uncertainties generated by a high risk FTS results.

This does not mean that a high-risk FTS result is 'routine uncertainty' to either sonographer or pregnant woman/couples, and in order to grasp this I have turned to the concept of 'disruption'. Drawing on his work with infertile couples, Gay Becker (1994), identifies how people's lives are structured by cultural expectations about each phase of life, and within this frame infertility is experiences as a 'disruption'; highlighting the disparity between '*cultural ideals about how things are supposed to be and how they actually are'* (Becker, 1994:410). Such disruptions represent a loss of future that high-risk couples also experience. The health of their child and their future as parents are no longer given, which opens up a new sense of uncertainty. The disruption leads towards a reflexive uncovering of the fragility of our lives

(Becker, 1998) and is thus a moment of existential uncertainty where a sense of continuity must be recreated by reworking understandings of the self and the world. The concept of disruption served as a tool to approach the existential uncertainties that I expected a high-risk screening result and subsequent waiting for diagnostic results to generate.

The uncertainties generated by a high-risk screening result causes increased anxiety. It is a disruption, a period of liminality that causes out-of-the-ordinary worry and makes it imperative to consider the taken-for-grantedness of everyday life. However, uncertainty is also a human condition that we deal with (in some form or another) all the time. Throughout the work on the present dissertation, I have approached uncertainty theoretically with an aim to encompass both the extraordinary and the routine in the management of a high risk screening result.

CHAPTER 4

RESULTS

PAPER 1

Lou S, Nielsen CP, Hvidman L, Petersen OBP, Risør MB. *'What do* you *think?' The intermingling of choice and care in a Danish obstetric ultrasound unit*. Submitted to Anthropology & Medicine

ABSTRACT

Prenatal screening for chromosomal abnormality potentially puts pregnant women and their partners in a difficult situation: the health of their baby is questioned and decisions must be made. Although prenatal screening has received much attention within the qualitative sciences, the actual interactions between health professionals and women/couples following a high-risk screening result have not been substantially explored. Based on extensive ethnographic fieldwork at an obstetric ultrasound unit in Denmark, this article analyses these ongoing, complex interactions. Drawing on the *logic of choice* and *the logic of care*, the results show how sonographers caringly engage with the unique experiences and interpretations of women/couples who have received a high-risk screening result. The findings also highlight the situation as one of inescapable choice, namely whether to undergo diagnostic testing. As a consequence, sonographers and women/couples collectively reduce complexity by emphasising certain interpretations and future scenarios (e.g., a happy pregnancy), while leaving others unspoken (e.g., Down's syndrome). This caring practice potentially challenges the ethics of the logic of choice of providing neutral information and autonomous choice, while simultaneously being directed towards that very end, the choice regarding diagnostic testing. In the obstetric ultrasound unit, the logic of choice provides a powerful frame, with the logic of care filling in the gaps and discontinuities of the logic of choice to facilitate decisions. In sum, the logics of choice and care provide a valuable analytical lens through which to view the complex ways in which prenatal screening results are collaboratively practised, negotiated and decided upon.

Word count: 6.100

Keywords
Prenatal screening; clinical encounter; decision-making; risk

INTRODUCTION

In this article, we explore a few minutes of clinical interaction at an obstetric ultrasound unit in Denmark. The interaction takes place between sonographers and pregnant women following a high-risk screening result for Down's syndrome. It is an intense situation in which the health of the fetus is questioned and where decisions about how to respond to the risk must be made. We investigate this complex interaction by means of a close reading of practice.

Denmark has a tax-financed, free-for-all health care system through which all pregnant women are offered prenatal care, including a first-trimester risk screening (FTS) for Down's syndrome. In 2012, 93% of all Danish pregnant women had FTS (Danish national database of fetal medicine 2012) and it is widely accepted as a routine part of prenatal care (Bangsgaard and Tabor 2013). The FTS is a combined screening (Petersen et al. 2014) that is performed and calculated at the first-trimester ultrasound scan, where, by the end of the scan, the sonographer (nurse or midwife) responsible for the ultrasound examination delivers the FTS result in the form of a statistical risk figure. A risk higher than 1:300 is considered 'high risk' and generates an offer of invasive diagnostic testing (chorionic villus sample, CVS). The diagnostic testing provides a definitive answer regarding chromosomal abnormalities, but also involves a 1% risk of miscarriage due to the invasive procedure. Thus, the unsuspecting, anxious woman/couple must weigh up concerns about the health of their baby against the risk of miscarriage and decide for or against diagnostic testing.

Prenatal screening has been the subject of much attention within the qualitative sciences, and both women's reasons for participating in screening (Gottfredsdottir et al. 2009; Reid et al. 2009) and their experiences with screening and ultrasound examinations (Williams et al. 2005; Aune and Möller 2012), as well as their reasons for accepting or declining invasive diagnostics (Lippman 1999; Markens et al. 2010;) have been well investigated. However, many of these studies are based on retrospective interviews and consequently do not address these issues as they unfold in actual clinical interactions; nor do they include the perspectives of partners and professionals. Despite some insightful exceptions (e.g., Pilnick and Zayts 2012, 2014; Zayts and Schnuur 2014), actual interactions between health professionals and women/couples following a high-risk screening result remain to be substantially investigated.

In Denmark, as in many other countries, participation in prenatal screening is based on informed choice (Beauchamp and Childress 1994; Danish Board of Health 2004), reflecting the dominant values of patient autonomy and informed decision-making through value-free information. The dominance of informed choice is also manifested in research where numerous studies have investigated women's level of informed consent prior to screening (van den Berg et al. 2006; Dahl et al. 2011;), and their interpretation of the high-risk status (Baillie et al. 2000; Heyman et al. 2006). Fewer studies have investigated the experiences (and frustrations) of professionals delivering value-free information (Williams et al. 2002; Getz and Kirkengen 2003; Schwennesen and Koch 2012).

In modern health care, informed choice serves as a model for the doctor–patient relationship, allowing patients to make their own choices, unbiased by the medical professional's personal views (Beauchamp and Childress 1994; Petersen and Lupton 1996). This powerful discourse is identified by Mol (2008) as *the logic of choice*. However, by observing the 'messiness of mundane practices' (Mol 2008, 43)in clinical interactions, Mol identifies 'care' as a guiding rationale running parallel to, intermingling with and interfering with the logic of choice. *The logic of care* incorporates a collaborative, practical figuring out of what to do, based not only on the available evidence but also on the patient's lived experiences and the professional's knowledge – 'shared doctoring'. The logic of care is an attuned approach, where the professional is not an objective and neutral fact provider, and where the patient is not the only one who interprets the facts and makes choices.

Care practices have been investigated in a number of settings (e.g., Mol et al. 2010; Henwood et al. 2011), including in prenatal care (Schwennesen and Koch 2012). However, in this analysis, we go beyond identifying 'care' practices in order to address the intermingling and overlapping of both care and choice in clinical interactions. Our aim is to explore how high-risk screening results are practised, negotiated and decided upon in a context defined by the clinical ideals of informed choice and by the mundane messiness of everyday clinical interactions.

METHODS

The analysis draws upon a total of 5½ months of ethnographic fieldwork conducted between 2011 and 2013 at an obstetric ultrasound unit at a university hospital in Denmark. The research explored the interactions and communication between pregnant women/couples

and sonographers following a high-risk screening result. Data were primarily generated through participant observation, that is, by following the daily work of sonographers at the unit and participating in examinations, invasive procedures, genetic counselling and coffee-breaks. Central to the fieldwork was the opportunity to observe more than 400 FTSs of which 21 resulted in a high-risk result. SL followed 20 of these women/couples in their subsequent appointments at the ultrasound unit. The consent of the women/couples was renegotiated at each encounter. All 20 women/couples had participated in in-depth, qualitative interviews by mid-pregnancy and six of them were also interviewed after delivery. Furthermore, seven sonographers were interviewed. During interviews, having a common ground of shared experience from the ultrasound unit provided a valuable opportunity to discuss and reflect on specific situations and interactions. Insights from the formal interviews continuously informed the ongoing participant observations – and vice versa. Interviews were recorded and transcribed verbatim. Both interview transcripts and field notes were coded, and themes, patterns and connections between codes were identified, investigated and settled. The present analysis draws primarily on the field notes, and throughout the article, field note excerpts allow glimpses into the ultrasound examination room.

RESULTS

Merged agendas at the FTS

> As the pregnant woman takes off her coat, Helen (the sonographer) explains the purpose of the examination and adds: 'I can see that your GP has indicated in the file that you want a risk assessment for Down's syndrome, is that correct?' The woman nods yes, and as she lies down on the bed, Helen explains that the outcome is a statistical number, not a definitive answer, and introduces the difference between normal risk and high risk saying: 'If you get a normal result, then it's just "good-bye and see you later".' The couple chuckle. 'And if it's a high risk, well, then we will discuss the options available to you. We'll deal with that, if it becomes relevant, OK?'

This is the standard introduction used in various forms by all sonographers at the ultrasound unit because, as sonographer Ingrid explained, '*I have to make sure that this is what they (the couple) want. Once I've given them the risk assessment, I can't take back that knowledge*'. With the introduction, sonographers intentionally frame the situation in a logic

of choice by repeating the couple's consent and by pointing to the potential future options in case of a high risk.

During the ultrasound examination, the sonographer guides the couple through the blurry black-and-white ultrasound images on the monitor: *'There's the little heart beating'*, she says, while the couple smile and squeeze each other's hands. Several studies have documented how the fetal image on the screen generates a strong sense of pleasure and joy and has the potential to 'accelerate the pregnancy' (Lupton 2013; Mitchell and Georges 1998; Rapp 1999). The playful comments made by couples during the scan, such as *'honey, I think we have a future soccer player'* or *'look, it's gonna have your nose'* reveal how the ultrasound images of the fetus are infused with meanings of an imagined future as parents and as family (Mattingly 1998). In her analysis of men's empirical accounts of the prenatal ultrasound, Draper (2002) identifies a potential 'clashing of world views' (p. 787) between the pregnant couple's expectation of the ultrasound as a social event and the expert paradigm of the ultrasound as a diagnostic event. However, at the ultrasound unit, we see these 'views' merging rather than clashing. As sonographer Emma explained during a coffee-break, *'Yes, it's a fetus and we are here to examine it. But it is also their child. In a few months, it'll be living with them in their house. So the scan is also about creating that bond and recognising that it's a precious moment.'* Similarly, the FTS is not merely a social event for the couples; they too have a biomedical agenda. While adoring the future soccer player, they actively question, investigate and interact with the biomedical information produced by sonographers in order to obtain knowledge about the health of their baby. Thus, rather than clashing, sonographers and pregnant women/couples collaborate to mix biomedical purpose with social and personal concerns. The ultrasound scan is not only an exchange of information, but also a sharing of doctoring (Mol 2008) in which the standard expert/lay positions are reconfigured and the logics of choice (presenting knowledge in order to advance reproductive choice) and care (imagining future parenthood) are enacted by both sonographers and women/couples.

The turning point

> OK, what I've seen today looks fine (smiles), but I'm just gonna calculate those numbers for you, says Meredith and turns to the computer in the corner of the room. Anna gets dressed, quietly whispering something to Jacob. Both are smiling. Anna sits down on the end of the bed, while Jacob gathers their bags and coats. Then, almost in slow motion, Meredith turns on her chair and rolls it close to the couple. Jacob sits down next to Anna. Meredith stretches her arm out to turn on the lights and then says in a quiet, serious voice: *'Well, Anna and*

> *Jacob, we need to have a little talk. Unfortunately, when I punch in the numbers you end up in "high risk" for Down's syndrome'*.

This last sentence marks a boundary as the situation is dramatically reshaped by the high-risk category and new agendas are brought into play. Meredith gently strokes Anna's arm and asks, '*What do you think? Have you considered that this might happen*?' Evidently, sonographers have extensive experience with high-risk screening results and of the different responses of women/couples to them. They have a repertoire of communications, interpretations and options at hand, and in order to decide which ones to bring into play in this particular interaction, the sonographers engage in a constant involvement with and adaptation to the couple, inviting them to share their perspectives and ask 'what are your feelings right now?', and 'have you thought about this?' This allows the sonographer to guide the interaction in accordance with the specific couple and walk down the paths to which they point. Meredith's question in the quote above enacts a logic of care, where she positions Anna and Jacob as knowledgeable interlocutors. Sonographers invite the women/couples to be the first to define this specific situation and thus initiate a situation of involvement and collaboration, where answers are not necessarily definitive or certain. This is a caring practice in which the unique history of the woman/couple is acknowledged as important; however, it is also a practice of choice in which the woman/couple can and should autonomously evaluate the risk presented to them. At this point, most women/couples are visibly confused and saddened, and their first concern is to understand the numbers. Consequently, the conversation swarms with statistics, for example, '1:213 risk figure, 1:300 cut-off, 1:100 risk of miscarriage, 1:625 age-related risk'. Often, both the sonographer and the woman/couple suggest different ways to contextualise the statistics; for example, the partner converts the risk figure to a percentage, the sonographer brings forth the image of tickets in a lottery, or the couple will compare 'their number' to the cut-off of 1:300.

> Lilly: '1:244, I don't know… we just haven't…'
> Stephen (partner) interrupts: 'so, 1:300, that's normal risk? Is there a 1:100?'
> Helen (sonographer): 'Yes, and there is also 1:2 – that's a tough one. 1:244 – that's not so tough. The odds are good… 243 healthy children.'

On the one hand, Lilly and Stephen relates to the cut-off that officially categorises 1:244 as high risk, which results in the offer of invasive diagnostics. On the other hand, they are invited to interpret the risk assessment: '*is 1:244 a high risk for you*?' (Helen, sonographer). So, women/couples have the choice to (and are invited to) override the cut-off and decide that 1:244 is not a high risk and that invasive diagnostics are needless. However, they cannot

avoid the high-risk result as such or avoid making a decision about what to do. The high-risk result makes a situation of choice inescapable.

Along with the efforts to deal with the statistics, another question often arises: Why? Why did we end up as high risk? To answer this question, sonographers usually invoke the components in the risk algorithm: '*The blood test is a bit skewed, so that's what tips the scale*' (Meredith), or '*Your ultrasound and blood test are fine, so it's really your age that is the "villain" here*' (Rebecca). These are compelling and authoritative answers, pointing to the complicated biochemical lab results and the complex algorithm behind the risk figure. Most women/couples accept these explanations as sonographers chain the elusive statistics to something tangible, and convincingly link the uncertainty to unruly hormone levels and aged egg cells. However, some women continue to question whether the high-risk result could have been avoided if they had done something differently. Sonographers often terminate these inquiries by calling the result 'unfortunate' or even 'bad luck'. While 'bad luck' is virtually empty of explanatory content (Ramløv 1986), its contextual value lies in the framing of high risk as an unfortunate and unexplainable random event that the woman could not have prevented or adverted. 'Bad luck' serves to alleviate women from feeling guilty or responsible for the high-risk outcome.

In these exchanges, although the responsibilities and potential feelings of guilt that come with parenthood are acknowledged, invoking 'bad luck' also effectively shuts down other attempts to discuss or question the statistics. They can be interpreted and explained, but they cannot be eliminated, thus reinforcing the situation of choice. Somatic explanations and fatalistic practical reasoning do not radically attune to the uncertainties of the women/couple but rather to their position as decision-makers.

Reducing complexity through collaboration

Decision-making is inescapable, but when weighing up the risk of miscarriage against the worries about the condition of the fetus, statistics do not provide the answer. The numbers do not address in any satisfactory way what is at stake in this situation and/or give any directions for how to manage it.

In a logic of choice, the sonographers position the woman/couple as knowing subjects and autonomous decision-makers, however, being in charge in the unknown territory of risk figures and jeopardised future, parenthood can be lonely and difficult (Mol 2008). Consequently, several of the women/couples turn to the sonographer and ask, '*What do you think? What is your advice?*' These questions challenge the logic of choice, in which giving

direct advice is inappropriate, and concurrently demonstrate acknowledgement by the woman/couple of the sonographer's extensive professional knowledge and experience. Schwennesen and Koch (2012) find that 'authority is trustingly delegated' to the sonographer. Similarly, we find that the woman's/couple's request for guidance addressed the very knowledge differences that the logic of choice is intended to eliminate. However, we understand these requests as an *invitation to collaborate* rather than as a delegation of authority. Asking for advice shows how the logic of care is not only something health professionals use to engage with patients; it is also something patients enact and promote in their interactions with professionals, for example, when they position decision-making as a collaborative practice. In subsequent interviews, several women/couples explained that they did not want the sonographers to make choices *for* them, but to consider the situation *with* them. This highlights that patients also engage in both logic of care and logic of choice; they expect and appreciate making their own decisions, but do not expect to make them in the vacuum sometimes implied by a strict logic-of-choice paradigm.

In responding to their invitation, sonographers walk a tight-rope in balancing the logics of care and choice: promoting autonomy and choice, while not leaving the woman/couple alone in unknown territory. By attuning to the cues of the woman/couple, sonographers emphasise certain meanings and interpretations while underplaying or silencing others. This is a process of reducing and transforming a complex situation into manageable platforms of meaning from which a decision can subsequently be made.

> Following Lilly and Stephen's quiet discussion of the 1:244 risk figure, silence falls. When sonographer Helen asks for their thoughts, Lilly shrugs her shoulders and Stephen mentions that he actually thinks 1:300 (the cut-off) is a high risk. Helen offers an interpretation: 'I think, what you need to consider is the seed of uncertainty that we have planted with this risk figure, OK'.

Stephen mentions the cut-off and Helen shifts the attention to the category of high risk rather than the specific (abstract and debatable) risk figure. Similarly, in a subsequent interview, Nicolas (partner) recalled, '*What mattered most was that they pointed us out as high risk. We ended up in the bad group.*' Sonographers and women/couples collectively reproduce the high-risk category as authoritative and powerful, regardless of the specific statistical probability. This consequently reduces the complexity of the situation and condenses it to the main issue, namely that what needs to be dealt with by the couples is not necessarily the individual risk, but the fact of being 'pointed out' and the 'seed of worry' planted by the categorisation.

Another example of reducing complexity is to focus on the immediate future of the pregnancy. For example, when Anna and Jacob expressed uncertainty about what to do, the sonographer (Meredith) responded, *'The most important thing is that you can reconcile to whatever decision you make. And that you can feel happy and safe throughout the pregnancy. That's the most important.'* Similar reflections are often initiated by the women/couples:

> Katie is sitting on the hospital bed, 'what do you think?' she asks her husband, Ruben. 'It's pretty close…' Ruben responds and both of them look up at the sonographer, Ingrid. 'Maybe you should go home and digest this whole thing', she says, 'think it over. 1:297. We're not in a hurry'. Katie hesitates and Ingrid starts to explain the options of additional ultrasound, and maybe amniocentesis, if the couples should change their mind later. Katie interrupts: 'No, let's have it done. I just know I won't be able to leave this alone (Ruben: 'I know, you won't'). I'll spend all of this pregnancy thinking and worrying. I'll go crazy (Ruben: 'You'll drive me crazy!')'.

By accentuating the importance of having a happy and safe pregnancy (whether undergoing invasive diagnostics or not), sonographers and women/couples relate to the latters' immediate lived experiences. The immediate future of the pregnancy is given primary concern, whereas more distant and uncertain futures, such as having a child with Down's syndrome, are only rarely and briefly addressed at this point. Sonographers and women/couples collectively negotiate the complex high-risk situation by simplifying and ascribing certain meanings (e.g., categorisation is powerful, uncertainty causes worry) while ignoring others (e.g., risk of miscarriage, disability).

As Pilnick and Zayts (2014) observe, the uncertainty of the risk figure allows for two simultaneous interpretations and two different rationales; it can be interpreted as a rationale for further testing (uncertain results must be confirmed) or for no further testing (uncertain results can be discounted). The examples above all speak in favour of further testing and implicitly work to legitimise invasive diagnostics. Engaging a logic of care, the women/couples use feedback from the sonographer to test their personal reasons and the social acceptability of being willing to risk the pregnancy for a 1:297 risk of chromosomal abnormality.

The risk of miscarriage is the paramount concern for high-risk women/couples. To Anna and Jacob, the sonographer (Meredith) said, *'Yes, there is a risk. We are obliged to say that it's a half to one per cent. It's there. But our doctors are very good. They do this every day.'* First, by using

'obliged to say', Meredith points to some obscure authority beyond this particular examination room, and even beyond the ultrasound unit. This authority is challenged by reference to the sonographer's professional, everyday experiences of invasive diagnostics – discreetly suggesting an actual lower risk of procedure-related miscarriages. Second, she challenges the statistics by emphasising a local expertise that may (or may not) influence the risk of miscarriage: competent doctors who do this every day. With these comments, she localises the statistics and engages the trust of the woman/couple in the hospital in order to downplay the risk of miscarriage. This can be interpreted as nudging women towards the CVS, thereby neglecting non-directive information; however, it may also be construed as the logic of care, as sharing the burden and inducing hope without making promises.

In summary, sonographers and women/couples collectively attend to values and reduce complexity by emphasising certain interpretations and future scenarios, leaving others unspoken. This can potentially be construed as violating the ethics of autonomy and value-free information. However, in line with Schwennesen and Koch (2012), we found that these interpretations are exactly what make the random and meaningless situation of high risk meaningful and manageable. We add to this that the whole situation is directed towards a certain end, namely, taking a decision. From the standpoint of the sonographer and the woman/couple, they need to come to terms with the uncertain situation in a way that will allow them to make a decision to which they can commit.

Coming to a decision

> Sonographer Julie has only just mentioned the 1:223 screening result when Sofia turns to her and says 'yeah, we want the CVS', then turns back to exchange a searching look with Matt to confirm. 'Don't we, babe?'. Julie smiles and says, 'that's fine, but let me just talk you through this, OK. So you know what you are getting into and what your options are'.

Observing the interactions at the ultrasound unit, it was apparent that decision-making does not necessarily follow from information; sometimes it is the other way round, and women/couples voice a decision only seconds after – or even before – the sonographer has fully explained the risk figure. Even though the high-risk situation is an unequalled situation in which most women/couples have no prior experience or established management strategies (Boholm 2003), and even if they initially need feedback to make the high-risk status meaningful and manageable, most still have a gut feeling, a spontaneous concern and/or a more or less explicit personal conviction about what to do in this situation, all of which results in 'prompt' decisions. Interestingly, these prompt (or 'default') responses are

generally not supported by the sonographers, who often remind the woman/couple that this is a serious situation requiring contemplation of the understandings and alternatives at hand. Sonographers thereby enact the logic of choice by which decision-making requires more than spontaneous gut feelings and rather a weighing up of the evidence to arrive at an informed choice. Consequently, they initiate a short dialogue about the risk assessment and the options available, of which some examples have been mentioned above. Only then, is the final decision established.

Of the 20 women/couples followed in this study, 17 decided to have invasive diagnostics and 12 of these requested to have it done immediately. Sonographers will often advocate for an appointment the following day; having time to 'digest' and 'talk it over' serves as their argument for this. In so doing, the sonographers enact the decision as an important one requiring contemplation. Furthermore, they invoke the limits of the hospital setting and position 'home' and 'everyday life' as important factors when making important decisions. Finally, a night at home is introduced to the women/couples as an opportunity to 'calm down' and 'feel certain', resulting in a less stressful invasive procedure (for both professionals and women/couples).

Coming to a decision is the pinnacle of the interaction and represents an intermingling of both choice and care rationales. On the one hand, women/couples are given space to connect to lived experiences of everyday life – even if that is not their initial desire (they want to get it over with) – enacting a logic of care where the professional sometimes does know what is best for the patient. On the other hand, the sonographer's insistence on time to digest the information also enacts a logic of choice as a way to secure patient autonomy and reduce hospital influence on the woman's/couple's final decision. Going home serves both ends. In this example, care is not so easily distinguishable from choice, or vice versa.

In subsequent interviews, the women/couples generally express a high degree of satisfaction with the sonographers and the way the dialogue around high risk was conducted. They all felt that they had made their own decision and that alternatives were made available to them. They appreciated that the decision was theirs to make – even if a difficult one – and valued the opportunity to think the situation through with the sonographer. Both sonographers and women/couples reproduce the logic of choice, but it is not in any simple way disconnected from or in opposition to the logic of care that also flows through the clinical interactions that follow a high-risk screening result.

CONCLUDING DISCUSSION

In this article, we have drawn on the logics of choice and care as analytical tools for illuminating the interactions between sonographers and pregnant women/couples following a high-risk screening result. This perspective brings to the fore some key points.

First, it is noteworthy how the logics of choice and care merge at the initial ultrasound scan, as the woman/couple and sonographer engage in enacting the fetus as a biomedical object and a social being. Some scholars have convincingly argued for the authoritative ways in which ultrasound imagery has the potential to produce powerful and normalising knowledge about both the fetus and parents (Mitchell and Georges 1998; Lupton 2013). This potential should certainly be acknowledged; however, what the logics of choice and care allow us to see in this specific context are the collaborative, joint perspectives of sonographers and women/couples, not just the production of only one knowledge position. This may be explained in part by the specific Danish context in which FTS has been part of prenatal care for the past 10 years, and studies show very high levels of information and positive attitudes towards the FTS among Danish women and their partners (Bangsgaard and Tabor 2013). Further, in a non-problematic FTS ultrasound scan, there are no major discrepancies between the expectations of sonographers and women/couples, that is, a biomedical confirmation of a healthy fetus and of future parenthood.

Second, after a high-risk result, both sonographers and women/couples engage in a logic of care to reduce complexity and make risk meaningful and manageable. In a logic of choice, the doctor provides the facts, while patients add values and personal interpretations (Mol 2004). However, at the ultrasound unit, facts and values intermingle as the interpretations of the high-risk situation are tested and shared, thereby incorporating both lived and professional experience. In the logic of choice, this may be construed as paternalistic authority, as a failure to live up to clinical ideals of neutral information and distanced professionals. However, in line with Schwennesen and Koch (2012), our study simultaneously draws attention to the ways in which high-risk knowledge is produced rather than simply consumed; patients are not *tabula rasa*, but bring with them experiences and expectations when interacting with professionals and the information provided by them. The logic of care, enacted by both parties, embraces these differences in knowledge and experience to establish an understanding that is meaningful and manageable for the woman/couple.

Third, in the collaborative production of knowledge about the high risk, authority shifts back and forth between sonographers and women/couples. The sonographer manages her institutional authority by delegating it to the woman/couple and asking for their opinion and thoughts. This is an example of the logics of choice and care intertwined as women/couples are recognised as knowing, responsible experts. When the women play this responsibility back to the sonographer by asking 'why', the sonographer takes it upon herself to demarcate the inescapability of the situation by referring to hormone levels and bad luck. When women/couples subsequently invite the sonographer to reach a joint interpretation of the high risk, an interesting difference in the professional's and the woman's/couple's management of the logics of choice and care emerges. For the sonographer, who is steeped in the logic of choice and the clinical ideals of neutral information and patient autonomy, the logic of care is a potentially sensitive/delicate matter. It is potentially precarious because allegations (e.g., from patients, colleagues, management or the media) of coaxing patients towards certain (eugenic) decisions are always lurking. From a professional's perspective, engaging in values and sharing responsibilities with patients must be carried out with great consideration. However, patients have fewer reservations and concerns – they actively promote feedback and involvement of experience (their own and others') (Garcial et al. 2008; Carrol et al. 2012) – because that is how most of us reason and navigate in everyday life. To the women/couples in our study, the involvement of professionals' experiences does not contrast or preclude autonomous decision-making. Thus, the logic of choice is less precarious and consequently enacted less dogmatically by the women/couples, who are not subjected to clinical guidelines of informed consent and non-directive information. This discrepancy allows and promotes the shifting of authority throughout the interaction.

Finally, the logic of choice offers a powerful frame. We have investigated the use of the logics of choice and care as analytical tools for opening up clinical interaction to scrutiny. Although we have identified care as continually running through the interaction between the sonographer and the woman/couple, it is also evident that in this whole situation, a logic of choice is heavily scripted; the mere availability of the FTS points to knowing about the fetus and making reproductive choices. Like other screening technologies, prenatal screening is based on an assumption that knowledge provides opportunities to act and control. Several studies have shown how the mere availability of risk information links to a moral imperative to prevent adverse outcomes and make choices towards control and elimination of risk (Petersen 1999; Svendsen 2005). This is also the case in the ultrasound examination room. Regardless of whether couples wish to eliminate the risk of miscarriage (by not having the CVS) or risk of Down's syndrome (by having the CVS), the choice is inescapable, and thus the logic of choice is ever-present in the interactions and interpretations reached.

Overall, our findings show how the sonographer and the woman/couple organise their interactions and interpretations around and towards the logic of choice. It is possible to identify caring practices, and they are not in opposition to the logic of choice but support and fill in the gaps that allow choice to be practised. This is an important difference with the work of Mol (2008). For patients with chronic illness and the professionals working with them, the logic of care offers an approach in its own right: it provides an alternative to the logic of choice. On the other hand, in prenatal screening, the logic of care is limited to a supporting role. However, the logics of choice and care provide a valuable analytical lens through which to view the complex ways in which prenatal screening results are collaboratively practised, negotiated and decided upon by knowing sonographers, women and partners.

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PAPER 2

Lou S, Nielsen CP, Hvidman L, Petersen OBP, Risør MB. *Coping with worry and uncertainty while waiting for diagnostic results: A qualitative study of the experience of pregnant women and their partners following a high-risk screening for chromosomal abnormality*. Submitted to BJOG: An International Journal of Obstetrics and Gynaecology

ABSTRACT

Objective This study investigated the experiences of pregnant couples that underwent diagnostic testing following a high-risk screening result for fetal chromosomal abnormality. The aim was to identify strategies employed to cope with worry and uncertainty while waiting for diagnostic results.

Design Qualitative study.

Setting Denmark.

Population Pregnant women and their partners with a high-risk first trimester screening result (≥1:300) who underwent diagnostic testing.

Methods A total of 17 qualitative, semi-structured interviews, 13 joint interviews with couples and four solo interviews with women. The participants were recruited as part of an anthropological study at a university hospital fetal medicine unit. Data were analysed using thematic analysis.

Main outcome measures Coping.

Results When couples received the high-risk screening results, all of them reported feeling worried and sad. While waiting for the diagnostic results, they continually attempted to manage worry by alternately focusing on and seeking distractions from their uncertain situation. In addition, couples used intentional, reassuring reasoning as a way to control worry and maintain their hopes for a good outcome.

Conclusion Clinical information may support couples' understanding and decision-making, but it cannot eliminate the existential worries following a high-risk result. The interviewed couples did not put the pregnancy on 'stand-by'; they worked hard to keep faith that they would have a healthy baby and a normal pregnancy. Clinicians are encouraged to support women/couples' development of coping strategies.

Keywords Pregnancy, first trimester screening, worry, coping, Denmark.

Word count 3,933

INTRODUCTION

The ever-advancing technologies in prenatal screening continue to provide more detailed and complex information about the fetus. This allows for early interventions and individualised care, but it also has the potential to generate acute worry in pregnant women and couples concerned about the health of their baby. Often, parents must wait for further tests and examinations, which increases the potential for worry and confusion.[1] How best to support these women/couples continues to be a clinical challenge.[2,3]

A high-risk screening result for chromosomal abnormalities is one example of prenatal information that requires testing and waiting for clarification. Quantitative studies have found a significant increase in anxiety following a positive screening result,[4-7] and qualitative studies have investigated the complex information and burdensome decision-making that high-risk women face.[1,8-11] Invasive diagnostics (chorionic villus sampling (CVS) or amniocentesis) will provide a definite answer, but carry a small procedure-related risk of miscarriage.[12]

Women choose diagnostic testing because they want to know the health status of their fetus[1,13,14] and because they want to stop worrying.[10,15] However, coming to a decision regarding invasive diagnostics does not eliminate uncertainty. What follows is a period in which the fear of miscarriage, worry about the health of the fetus and concerns about what to do in case of an abnormal result are waiting to be resolved.[10] Not enough is known about pregnant women and their partners' experience of this waiting time and the coping strategies they use to deal with uncertainty and worry.

Coping theory concerns the thoughts or actions engaged to manage stressful situations, such as avoidance, planning, seeking support or turning to religion.[16,17] Coping theory essentially discerns between problem- and emotion-focused coping. The former is aimed at actively resolving the source of the stress, while the latter is aimed at managing the emotional distress. Though there are some studies of women's coping following a diagnosis of fetal anomaly,[18-20] less is known about pregnant women's coping during the preceding diagnostic process. An understanding of this period is particularly important, because the majority of screen-positive women receive a normal diagnostic result. Thus, the unnecessary worry is the major psychosocial cost of screening for most women.[21] Improvements in the professional support offered during this process may contribute to an appropriate management of uncertainty and worry.

Our objective was to investigate how high-risk women and their partners experience waiting for diagnostic results and to identify strategies employed to cope with worry and uncertainty.

METHODS

The material presented in this article is part of a larger anthropological study of clinical communication and prenatal screening at a university hospital fetal medicine unit in Denmark.

Setting

In Denmark, a combined first-trimester risk screening (cFTS) for chromosomal abnormality is available to all pregnant women as part of the standard, tax-financed prenatal care programme. In 2012, 93% of all pregnant women in Denmark underwent cFTS,[22,23] and generally, Danish women know a great deal about and are favourably disposed towards the cFTS.[24,25]

At the fetal medicine unit where this study was conducted, more than 4600 cFTSs are performed every year.[23] The cFTSs are performed by sonographers (midwives and nurses certified by the Fetal Medicine Foundation, London) who do the ultrasound examination, calculate the screening result and inform women/couples about the results and the options available to them. The women at high risk (>1:300) are also counselled by the sonographers and given the option to have an additional consultation with a fetal medicine expert. We estimate that less than 5% of women/couples at high risk choose the additional expert consultation. The majority of screen-positive Danish women (85%) choose to undergo invasive testing,[26] which is normally booked the day after the cFTS. The results for trisomy 13, 18 and 21 are generally available within a week or less.

Participants

As a part of the overall anthropological study, SL observed more than 400 cFTSs in which 21 women/couples received a high-risk result. Seventeen couples decided to undergo diagnostic testing and consented to SL observing the procedures. All had normal diagnostic results. SL subsequently contacted the women by phone to set up an interview with them and (preferably) their partners. Seventeen women/couples agreed to participate and were interviewed 2–6 weeks after the diagnostic result (see Figure 1). Participant characteristics

are shown in Table 1. Informed, written consent was obtained in accordance with the American Anthropology Association's code of ethics.[27]

Data collection

Between July 2011 and January 2012, SL conducted open-ended interviews in participants' homes or at the hospital. Interviews lasted 45–90 minutes and a semi-structured interview guide was used.[28,29] The interview explored the woman/couple's expectations, experiences and considerations regarding the cFTS, the high-risk result and the CVS. Interview themes also covered woman/couple's feelings and experiences while waiting for the final diagnostic result and concluded with summary questions, asking the woman/couple to reflect on the experience as a whole and on the potential impact of the high-risk experience on the pregnancy and future parenthood. Through participant observation, SL became familiar with the couples and their high-risk trajectory, which allowed specific situations and events to be explored in interviews.

Data analysis

The interviews were transcribed verbatim by SL and a research assistant, and the data were analysed by SL. Upon a thorough reading of all transcripts, initial codes were generated in line with thematic analysis as formulated by Braun and Clarke.[30] Both inductive (bottom-up) and deductive (top-down) codes were identified and discussed between the authors. All interviews were coded using Nvivo 9.0 software (QSR International, Doncaster, Australia). By investigating repeated patterns across the dataset and relationships between the codes, candidate themes were generated and explored in relation to the full data set. The data were scrutinized for 'negative cases' and disconfirming evidence to the check candidate themes and preliminary analytical understandings. Throughout the analytical process, MBR acted as supervisor and discussant. This iterative process of defining and validating the themes continued until both researchers were satisfied that there was substantial theoretical basis for explaining how women/couples at high risk cope with worry while they are waiting.

RESULTS

In general, the couples were very satisfied with the information they received at the cFTS. Sonographers were described as professional, empathetic and attentive in conveying the information about the high-risk result and the options available. All couples said that the decision to have CVS was their own and that they were content with their decision.

When asked about their feelings as they left the ultrasound clinic, many reported feeling empty, disappointed and sad:

> '*I felt that…. That carefree happiness was wiped out by… I wouldn't call it grief, but it was definitely some sort of worry. Yeah… worry….*' (Cristina, 42 years old, one child)

> '*All of a sudden… The future we saw for ourselves was shaky.*' (Stephen, 35 years old, no children)

The high-risk result interrupted the couples' hopes of a normal, happy pregnancy and positioned them in an intermediate state of uncertainty. When asked about their management of this period, many couples' initially responded that there was really nothing they could do but wait. However, the subsequent dialogue revealed a range of different strategies they employed to deal with waiting and worrying.

Managing worry by focus and distraction

An initial strategy of many of the interviewed couples was withdrawal from social relations and everyday activities. Being '*just us*' was described as a safe place in difficult times. All couples stressed the importance and value of taking time to jointly attend to the uncertain situation by seeking advice, gathering information and talking it through and through.

> '*That evening, we went online to find out what a "bad" nuchal translucency looks like. You know…. Just to check that ours was OK. Sort of to confirm our own understandings that the baby was normal and digest what we had been told at the hospital.*' (Simon, 36 years old, no children)

Though the situation was widely felt to be out of their hands, the interviewed couples took control of the situation through a process of coming to their own understanding and responses.

While staying at home, couples also reported that they spent time watching TV, working or reading magazines as a deliberate strategy to mentally disengage and to '*take a break*' from worry. Another, somewhat contrasting, strategy that couples placed importance on was engaging in everyday social activities, such as having a birthday party, going to lectures, or attending a music festival:

> '*We considered not going (to a niece's birthday), but in the end it was a nice distraction. Sitting at home wouldn't have done us any good.*' (Oliver, 29 years old, no children)

Thus, deliberately shifting between focusing attention and seeking distraction were described as strategies to pass time and manage worry. Maintaining everyday plans and routines was experienced as valuable in shifting focus away from worry. Several couples described periods of feeling unfit or disinterested in '*facing the world*', but nevertheless, they prioritised participating in '*normal life*' as a strategy to prevent worry from escalating. Some couples chose not to disclose their uncertain situation as they carried on with everyday activities because this allowed them to feel normal and not be the centre of concerned attention. Others sought emotional support and advice from family and friends. In these couples' accounts, sharing experiences and concerns with family and friends helped them to re-think the situation, keep things in perspective and make them feel loved and cared for. Thus, sharing was a valuable strategy for relieving worry and doubt, though sometimes it was also a source of frustration:

> '*Oh, people are so full of encouraging comments and home-spun advice, and honestly, that is the last thing you want to hear. The last thing.*' (Anna, 34 years old, no children)

When they sought emotional support, the couples were clearly vulnerable to responses they perceived to be too empathetic, too light-hearted or otherwise misunderstood. Several couples reported becoming more strategically selective in whom to turn to for support and advice.

In summary, these women/couples coped with worry in very concrete ways using contrasting practical strategies: social withdrawal versus social engagement combined with strategies of focusing on and actively seeking distraction from uncertainty and worry. All couples employed some combination of these strategies, alternately and sometimes even simultaneously, as when a dinner party provided a convenient distraction for a couple as well as an opportunity to talk about their worries and concerns with selected friends.

Managing worry through reassuring reasoning

To remain hopeful and not let worry get out of control was a main concern for the couples throughout their wait for diagnostic results. One consistent strategy was a selective recollection of the clinical communication and interactions following the high-risk screening result:

> '*I just kept thinking to myself: She [the sonographer] told us the baby looked fine. And I know it's not rational and you can't see the chromosomes on an ultrasound, but it was just so comforting to me and something I clung onto in those horrible days.*' (Caroline, 30 years old, no children)

> '*At the CVS, they told us that the procedure went really well and it was a good sample. I kept thinking that that was good. A good sign.*' (Matt, 30 years old, no children)

Thus, the couples actively chose to focus on clinical comments and encouragements that could be re-interpreted as hopeful and positive reassurance. Although factual information was also appreciated, reassuring comments from health professionals were considered valuable emotional leverage in coping with worry and uncertainty.

Another strategy was to reinterpret the uncertain situation in terms of the couples' personal understandings of their pregnancy, good health and trust in a good outcome.

> '*I just got pregnant so easily. Like it was destiny or something? We kept telling ourselves that this [child] was meant to be.*' (Eve, 38 years old, no children [solo interview])

> '*I mean, look at us! (smiles). How could we make anything but an amazing child. We said that to each other a lot.*' *(Sofia, 30 years old, no children)*

In these personal narratives, the couples coped with worry by pragmatically emphasising positive pregnancy experiences, such as an uncomplicated pregnancy or simply 'feeling good'. Common to these personal narratives was the tendency to support the likelihood of a good outcome; they promoted the idea that, because of their specific circumstances, the specific couples' actual risk was in fact lower than the statistical risk. Couples reported that being nauseous or having stomach pains made worry more difficult to control, but this did not exclude a simultaneous use of positive personal narrative strategies. Sometimes couples referred to these interpretations as 'irrational' and contrary to 'rational' or biomedical information, and they were quick to add, '*this is going to sound a little crazy….*' In these conversations, some of the participants mentioned having reassuring inner conversations with the fetus or with a departed mother. Others reported looking for good signs in rays of sunlight or bellyaches. These examples illustrate how the couples engaged in practises and understandings that went beyond rational logic, but nevertheless, they regarded them as reassuring and comforting in dealing with worry and waiting.

Many couples also described how they turned to home and everyday life as a meaningful counterbalance to their high-risk status, expressing a renewed and humble awareness of all the good things that they already had in their lives: amazing children, fulfilling lifestyles and loving relationships:

> '*I tried to focus on my daughter and how blessed we are to have her.*' (Cristina, 42 years old, one child)

Turning focus away from statistics and uncertainty towards the blessings of everyday life foregrounded everything that was *not* at risk and would persist beyond an abnormal test result. Choosing this perspective allowed the couples to create situated meaning and certainty in the midst of uncertainty and thus to create a positive counterbalance to worry.

Discussions about what to do in case of an abnormal test result were notably absent in the majority of the couples' accounts of waiting. When asked about this during interviews, they provided two main reasons: First, the majority of couples were certain that they would terminate the pregnancy in case of an abnormal result. Second, those who expressed uncertainty about termination preferred to postpone the final decision until the final result was available. This bracketing of the potential abnormal result allowed the couples to continue and to hold on to a 'normal' pregnancy. Many couples described how they consciously decided to use—and continually re-employ—an innocent-till-proven-guilty approach to deal with their worries about the fetus's health.

In summary, the couples coped with worry by using reassuring interpretations of the uncertain situation in accordance with their everyday lives and experiences. The strategies they employed included a selective memory of clinical comments, belief in good health combined with specific personal circumstances and a humble awareness of everyday life. Consequently, biomedical information, bodily sensations and pragmatic everyday reasoning were interlaced in the couples' attempts to control worry and to keep up hope. Thus, drawing on the different strategies described here, each couple pieced together their own, personal puzzle of strategies to manage worry while waiting for results.

When asked to reflect on the experience of a high-risk result, the invasive testing and receiving results as a whole, the interviewed couples generally framed the situation in positive terms, highlighting the empathetic, professional approach of professionals, the speedy procedure and response, as well as the security of now knowing that the

chromosomes were normal. None of the interviewed couples regretted having the cFTS and all of them expected to have cFTS in a future pregnancy.

DISCUSSION

Overall, our study showed that the participants coped with the worries generated by a high-risk screening result through a range of practical and emotional management strategies. Drawing on these strategies, the interviewed couples continuously and creatively managed uncertainty and the lurking worry while waiting for diagnostic results.

Obviously, when faced with the possibility of something being wrong with the fetus, pregnant women become worried and perceive a loss of control because of their uncertainty about the future.[1,20,31] However, our results showed that the interviewed couples did not passively accept this worry or sit on their hands while waiting for clarification.

First, by withdrawing from activities to attend to the situation, gathering information and seeking support, the couples sought to manage worry by actively defining their own understandings and management strategies. Thus, our results showed that, even in a situation in which couples could not change or alter the final outcome, they still engaged in problem-solving coping strategies (aimed at removing or altering the stressor).[16,17] This process of active coping allowed them to regain some control and sense of agency in a situation in which the future was unpredictable. Our results resonate with other studies that have found that pregnant women also use problem-solving coping strategies following the prenatal diagnosis of fetal anomaly. Consequently, the authors of these studies suggest that parents need opportunities for active coping following such diagnoses.[18,19,32] We suggest that this is also the case for parents *waiting* for diagnosis.

Second, by positive re-interpretations of clinical information and a thankful focus on the good in their lives (including gut-feelings and life experiences), the couples sought to infuse the uncertain situation with positive, reassuring interpretations. These responses are all types of emotion-focused coping (aimed at managing emotional distress), and Carver et al.[17] suggest that construing a stressful situation in positive terms encourages continuous, active coping. Folkman and Moskovitch[33] suggest that people under stress turn to positive, social events not only as an escape or distraction, but also as an active strategy to counterbalance the negative, emotional consequences of a stressful event.

Being at high risk is an unwelcome disruption in a pregnancy that leads to worry and concern, but as sociologist Becker reminds us, "*Disruption to life is a constant human experience.*"[34,p.180] Thus, we argue that the coping with worry that people do while waiting for diagnostic results should be understood within a framework in which uncertainty is a generic and definitive feature of the human condition in general.[34-37] For example, Brisch et al.[38] showed how the coping strategies of women at high risk for fetal malformation were similar to those at normal risk, which indicates that strategies for managing worry are something that people bring with them rather than something they establish anew with every new stressful situation. Our results showed that couples were initially shocked and sad, but they were not unprepared to deal with worry and uncertainty in general. These everyday resources and strategies were crucial to the couples' coping with waiting.

Interestingly, our findings diverge from some previous research, which found that a high-risk screening result made women put the pregnancy on stand-by.[14,39-41] For example, Öhman et al. found that a high-risk screening result made pregnant women 'withhold the pregnancy' as they tried to live as if they were not pregnant.[14] Similarly, Aune and Möller suggest that high-risk women created a distance to the pregnancy as a defence mechanism to be able to handle a high-risk screening result.[39] The difference in findings may be explained by the relatively small sample sizes (of the current and the previous studies) and the different contexts (Sweden and Denmark). For example, stress reactions have been shown to increase during waiting time,[42,43] and consequently the short turnaround time between the screening test and the diagnostic result (often less than a week) in the current study might bolster positive coping and explain the differences in results. However, understanding the wait for diagnostic results following a high-risk screening result as a period when women can and will selectively ignore or '*withhold*' the pregnancy does not resonate with our findings. Although we do not deny that some women may employ this strategy (some of the time), we suggest a more complex approach in which worry is understood as being managed through a diverse range of practical and emotional strategies that change and repeat in the process of waiting for diagnostic results.

Methodological strengths and limitations

A key strength of the present work is the inclusion of partners in the interviews. In the present analysis, we focused on joint strategies rather than gender differences[44,45] (e.g., men generally being more number oriented and more optimistic).[46,47] This approach is consistent with other studies showing that couples experience pregnancy as a collaborative project.[48-50] A second strength is the anthropological approach, which allowed SL to observe the couples at both the cFTS and at the CVS and added to the richness of the individual interviews and

the analyses. Furthermore, this sampling strategy resulted in a high response rate (20 out of 21) and thus low selection bias.

To evaluate the results of this study, some considerations must be taken into account. First, the couples were given the result of the cFTS immediately after the ultrasound scan. Several studies have documented the positive effect of ultrasound on maternal anxiety[51,52] and fetal–maternal attachment.[52,53] Ekelin et al. found that the ultrasound examination made prospective parents feel closer to the baby and to each other.[54] In our study, the couples we interviewed all had normal ultrasound examinations, which may have increased their ability to control worry and nurture positive thinking. Second, by the time they were interviewed, all of the participants had received a normal diagnostic result, which may have influenced their memory. Because interviews were conducted 3–13 weeks after the CVS procedure, some recall bias is possible. However, in interviews the couples seemed to remember the situation vividly, which is consistent with research showing that the recall of emotional, pregnancy-related events is highly consistent over time.[55,56] Third, we speculate that a short turnaround time is essential to allow the couples to keep up active coping and positive re-interpretations.

Also, we must keep the Danish context in mind. Denmark was the first country to offer free, tax-financed prenatal screening to all pregnant women based on informed decision-making. Thus, pregnant women are very familiar with the availability of the cFTS, and the knowledge about the procedure is relatively high, which correlates with lower decisional conflict.[24,25,57] Moreover, the study was conducted in the fetal medicine unit of a university hospital that routinely conveys such information and has the appropriate expertise to communicate sensitively with high-risk couples. Consequently, the couples in this sample may have felt more involved, informed and empowered, and thus less worried than high-risk couples in other settings.

Finally, the results are based on a smaller, exploratory study intended to provide an in-depth understanding of waiting and worrying from the viewpoint of high-risk couples in a fetal medicine clinic in Denmark. Thus, the results may not be generalizable in the traditional quantitative research sense; instead, these results provide an explanatory theory for the experiences of other high-risk couples in comparable situations. We hope that our results will encourage further qualitative research on this matter.

CONCLUSIONS

Our study shows that high-risk screening results generated both worry and uncertainty, but the strategies for dealing with the results were already ingrained in the couples' everyday lives. The couples actively pieced together personal coping strategies that helped them stay positive and counterbalance worry. None of the couples we interviewed reported putting the pregnancy 'on stand-by', and all of them expected to have cFTS in a future pregnancy.

Clinicians can effectively support high-risk women and their partners not only by helping them understand information and make decisions, but also by helping them prepare for waiting for results. By addressing different coping strategies, clinicians can encourage couples to seek their own personal understandings and management strategies as a way to gain some control in an uncertain situation. Furthermore, by adopting a reassuring attitude and sharing the positive aspects of the ultrasound examination and test procedure, clinicians may support an appropriate way of coping with worry and waiting.

Figure 1 Recruitment flow chart

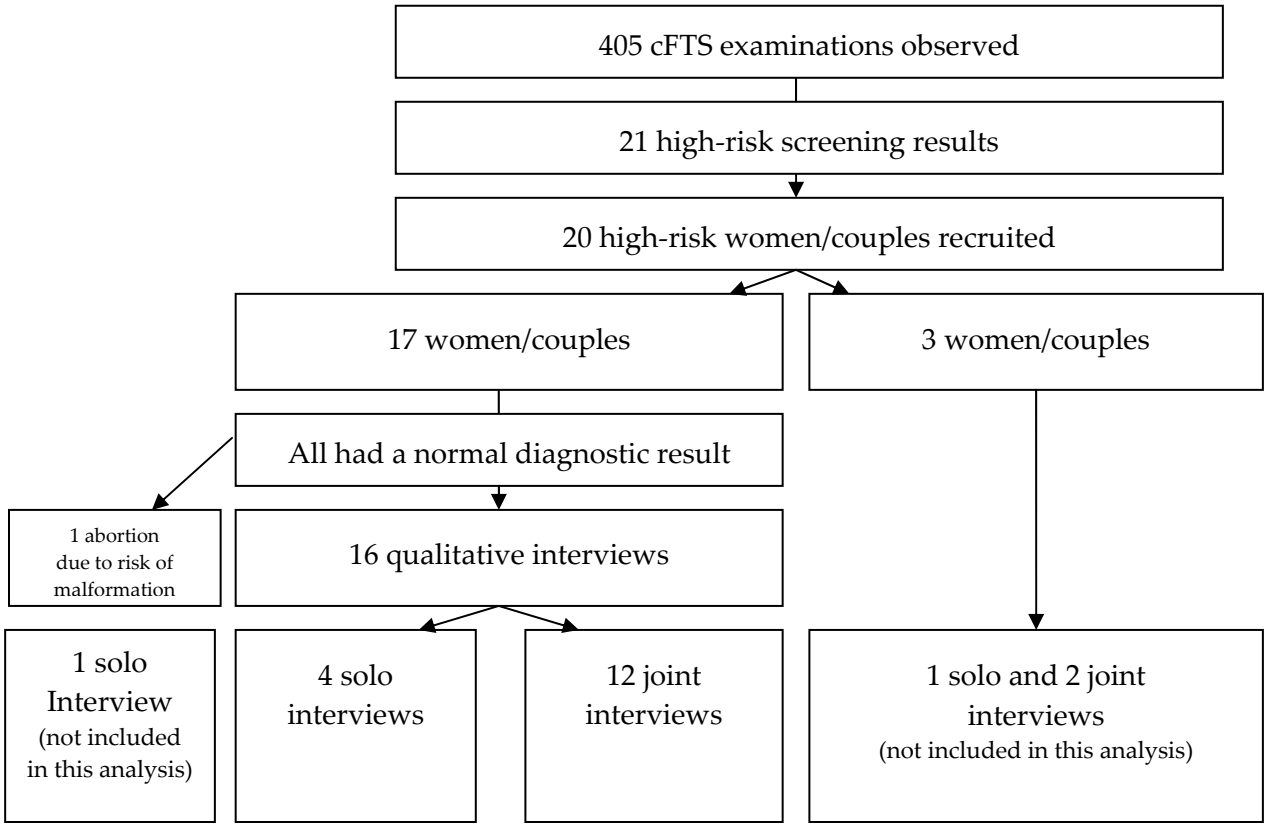

Table 1 Characteristics of the sample

Average age, pregnant woman (n=17)	35 years (range 21–42)
Average age, partner (n=17)	36 years (range 25–44)
Parity	0=9 (53%)
	1=8 (47%)
Gestational age at interview (weeks)	Mean 18 (range 14–26)
Risk assessment	Mean 1:122 (range 1:30–1:297)
CVS	17 (100%)
Maternal educational level*	
Low	2 (12%)
Medium	7 (41%)
High	8 (47%)
Employed	12 (71%)
Students	4 (23%)
Unemployed	1 (6%)

* Using the education nomenclature (ISCED) from Statistics Denmark, educational level was grouped into three categories; low (1-10 years), medium (11-14 years of education), and high (>15 years). Students are categorised by their next educational level.

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PAPER 3

Lou S, Mikkelsen S, Hvidman L, Petersen OBP, Nielsen CP. *Does screening for Down's syndrome cause anxiety in pregnant women? A systematic review*. Acta Obstet Gynecol Scand 2015; 94: 15-27

AOGS
ACTA Obstetricia et Gynecologica Scandinavica

AOGS REVIEW ARTICLE

Does screening for Down's syndrome cause anxiety in pregnant women? A systematic review

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Key words
Pregnancy, antenatal care and diagnosis, screening, down's syndrome, anxiety

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Conflict of interest
All authors have explicitly stated that there are no conflicts of interests in connection with this article.

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Abstract

Background. Prenatal screening for Down's syndrome and other chromosomal abnormalities is included in prenatal care programs in many countries. However, the potential association between prenatal screening and maternal anxiety remains an issue of debate. *Objective.* To systematically review and summarize the current scientific evidence on whether screening for Down's syndrome might cause anxiety in pregnant women with a negative or a false-positive screening result. *Methods.* Five databases (PubMed, Embase, Cinahl, PsychInfo and Cochrane) were systematically searched for randomized controlled trials or cohort studies comparing screening and no screening, or comparing different types of screening for Down's syndrome. The search was limited to studies published between September 2001 and April 2013. In all, 316 studies were identified through search of databases and 40 were included for full-text assessment. Two observers independently screened the articles and seven studies satisfied the inclusion criteria. They were subsequently assessed for risk of bias and level of evidence. *Main outcome measures.* Quantitative measurements of maternal anxiety or worry. *Results.* Two studies compared anxiety in pregnant women who accepted or declined screening and showed no difference between groups. All studies described a decrease in anxiety following a screen-negative result. Four studies reported that women's anxiety levels increased significantly upon receiving a screen-positive result. However, after a normal diagnostic result, anxiety levels declined to the same level as for screen-negative women. *Conclusion.* Studies using quantitative, validated measures to estimate anxiety showed no association between screening and residual anxiety.

Abbreviations: CEBM, Oxford Centre for Evidence-based Medicine
HADS, Hospital Anxiety and Depression Scale; NTM, nuchal translucency measurement; PRAQ-R, Pregnancy Related Anxiety Questionnaire-Revised; STAI, Spielberger's State-Trait Anxiety Inventory.

Introduction

In many countries, pregnant women are offered prenatal screening for Down's syndrome and other chromosomal abnormalities. However, the advantages and shortcomings of screening for Down's syndrome remain issues of debate in the media, in academia, and among clinicians.

Key Message

There does not appear to be any evidence to suggest that screening for Down's syndrome causes anxiety in screen-negative women. Screen-positive results increase anxiety but the anxiety returns to normal levels following a normal diagnostic result.

Proponents stress the right of pregnant women to have access to information about their fetus and to make reproductive choices (1,2). Opponents are concerned with the ethical implications of screening for a condition that cannot be prevented or cured (3–5). Often, it is asserted that screening causes unnecessary worry or anxiety in women because it introduces or underscores the possibility that there might be something wrong with the fetus (6–8). It is argued that this anxiety may linger throughout the pregnancy, even after a normal screening and/or diagnostic result has been obtained (9,10).

Since the late 1980s, extensive research has been conducted on the potential emotional consequences of prenatal testing. In 2004, the NHS Research and Development, Health Technology Assessment program published a systematic review by Green et al. (11) on the psychosocial aspects of genetic screening in pregnant women and newborns. That review presented a thorough, robust assessment and discussion of the published literature on screening for Down's syndrome and the associated anxiety. Based on 24 qualitative and quantitative studies, the review concluded that there was no evidence of increased anxiety among screen-negative women (11, p. 26). The authors also found some evidence that anxiety was raised in women that received a positive screening result, but anxiety decreased when subsequent diagnostic testing showed a normal result (11, p. 28). They found insufficient evidence to determine whether residual anxiety remained. However, the authors expressed substantial methodological concerns regarding many of the publications; thus, their ability to make robust conclusions was limited. Consequently, further research was recommended.

Currently, a decade later, it may be relevant to ask whether the recommendations of Green et al. have been addressed with further research. What is the current scientific evidence on psychosocial aspects of prenatal screening for Down's syndrome? In the continuously expanding and advancing field of prenatal screening, we chose to narrow our focus to a core area of debate among clinicians, administrators and ethical commentators – the association between prenatal screening and anxiety. Since the majority of women who undergo screening receive either a negative or a false-positive screening result, we decided to limit the investigation to these two groups. Anxiety is a complex concept and we decided to focus solely on studies using quantifiable measures of anxiety. Accordingly, the aim of this review was to summarize the scientific, quantitative evidence that points to whether screening for Down's syndrome causes anxiety in pregnant women, and we address specifically (i) differences in anxiety between women who accept screening and women who either decline screening or are not offered screening, and (ii) differences in anxiety before and after screening in women who accept screening.

Material and methods

Search strategy

We used the PRISMA guidelines (12) to structure our review process. In an initial scoping of the literature, we specified the search strategy accordingly, based on PICOS:

- **P**opulation: Pregnant women.
- **I**ntervention: Maternal serum, nuchal translucency or combined screening for Down's syndrome.
- **C**omparison: screening vs. no screening, or pre-screening vs. post-screening.
- **O**utcome: Maternal anxiety.
- **S**tudy design: Quantitative studies: randomized controlled trials and cohorts.

To investigate current practices and technologies in screening for Down's syndrome, the search was limited to studies published after Green et al. (11) completed their literature search. Thus, this review includes only studies published between 1 August 2001 and 1 April 2013.

Based on the PICOS, search terms were formulated, and test searches were performed to develop the final search strategy. The search terms agreed on are presented in Table 1. In April and May 2013, we performed a systematic search in five databases (PubMed, Embase, Cinahl, PsychInfo, and Cochrane). When possible, we used thesaurus terms (such as terms included in the Medical Subject Headings index, MeSH). Because each database uses slightly different thesaurus terms, the terms were adapted accordingly, without changing the meaning of the search terms in the search protocol. The full search strategy can be obtained from the authors on request.

Study selection

The systematic search identified 383 candidate publications (Figure 1). After removal of duplicates, two of the authors (S.L. and L.M.) independently screened the

Table 1. MeSH terms used in PubMed search.

Patient		Intervention		Outcome
Pregnancy or Pregnant women	AND	(Mass Screening or Prenatal diagnosis) and (Chromosomal disorders or Down Syndrome)	AND	Behavior or Emotions

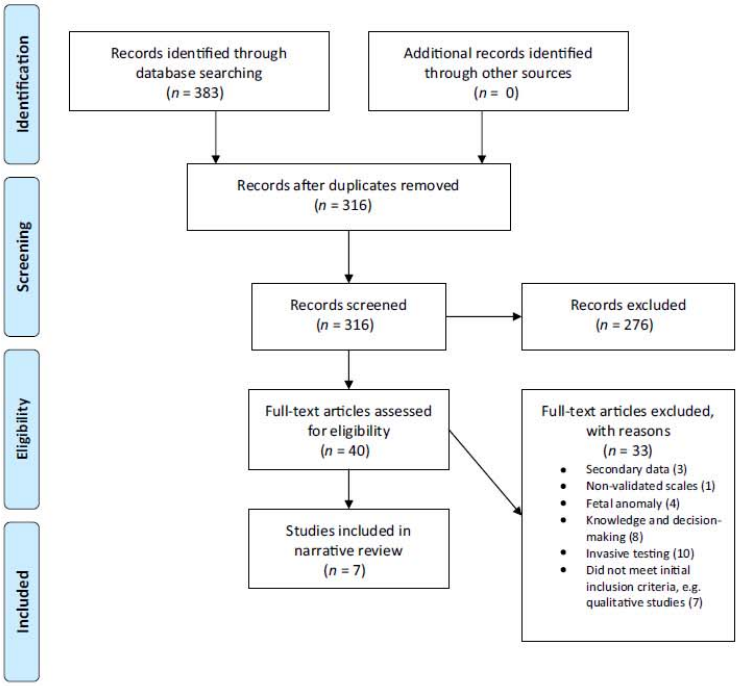

Figure 1. PRISMA 2009 flow diagram.

remaining 316 publications for eligibility by title, abstract and full-text, when necessary. Criteria for inclusion at this point were quantitative studies that investigated screening for Down's syndrome and emotional responses from pregnant women.

As a result, 40 publications were identified for potential inclusion. All studies were read in full by authors S.L. and L.M. independently, and assessed for eligibility according to PICOS and exclusion criteria. A search of reference lists and Science Citation Index did not identify additional studies.

Criteria for excluding publications were:

- Studies that presented only secondary data, such as reviews.
- Studies that used non-validated scales developed specifically for the study in question.
- Studies on fetal anomalies detected during the screening process.
- Studies on parental knowledge and decision-making regarding screening.
- Studies on anxiety during invasive testing.

Consequently, another 33 publications were excluded. The seven eligible publications are listed in Table 2. Study relevance and validity, including risk of bias, was assessed independently by authors S.L. and C.P.N. using checklists developed by the Danish National Board of Health (13), and assessments were compared and discussed between the authors.

Studies were subsequently ranked according to the Oxford Centre for Evidence-based Medicine (CEBM) guidelines (14). Based on the assessment of the individual study, grades of recommendation (A–D) of the overall evidence on relevant outcomes were given according to the CEBM guidelines (14). For the evidence to be graded with recommendation A, consistent level 1 studies (randomized controlled trials and cohorts) are required: recommendation A thus indicates high level of evidence, whereas a recommendation D reflects level 5 studies (such as expert opinion) or troubling inconsistent studies of any level, and thus poor level of evidence.

Due to the heterogeneity of aims and designs of the included studies, we decided to present a narrative review and thus no meta-analysis was done.

Results

Characteristics of included studies

Table 2 displays the main characteristics of the studies included. The studies were ranked as 1b to 2b level of evidence according to CEMB guidelines. The studies

Table 2. Description of included studies (in order of year of publishing).

Reference	Intervention	Study	*n*	Stated aim of the article	Design	Outcome measures	Study group(s)	Results	Level of evidence
(21)	Maternal serum test	Lai et al. (2004) Singapore	109	To assess anxiety levels in mothers with low-risk pregnancies before and after offering routine serum screening	Cohort	Anxiety – Spielberger's STAI • T1: Before serum counseling • T2: After counseling but before screening • T3: On day of 20-week scan (screening results known) • T4: 4–6 weeks after scan	Routine maternal serum screening at 15–20 gws	No difference between pregnant women and reference population at baseline Significant decrease in S-anxiety from T1 to T4	2b
(17)	Nuchal translucency measurement	Öhman et al. (2004) Sweden	2026	To evaluate the effect of ultrasound screening for Down's syndrome on women's anxiety in mid- pregnancy and 2 months after delivery	Randomized controlled trial	Anxiety – Spielberger's STAI Cambridge Worry Scale Edinburgh Postnatal depression scale • T1: Early pregnancy (at inclusion, before randomization) • T2: At 24 gws • T3: 2 months postpartum	Intervention: Offered NTM at 12–14 gws (n = 1030) Control: Standard care, no screening offered (n = 996)	No statistically difference between groups. In both groups, women's worries decreased from baseline over mid-pregnancy to 2 months after delivery	1b
(15)	Nuchal translucency measurement or maternal serum test	Kleinveld et al. (2006) The Netherlands	2879	(i) Does offering prenatal screening increase anxiety? (ii) Does receiving a negative screening result make women less anxious and does a positive screening result make women more anxious? (iii) What are the long-term consequences for anxiety of offering screening and receiving a screening result?	Randomized controlled trial	Anxiety – STAI-form Y Child-related anxiety – PRAQ-R • T1: Before information about screening • T2: After information • T3: After test result was known • T4: At 24 gws • T5: Postpartum (not included in this study)	Intervention 1: Offered NTM screening (n = 686) Intervention 2: Offered MST screening (n = 648) Control: Standard care, no screening offered (n = 512)	Generally, offering screening and receiving test result do not adversely affect anxiety. Women who screened positively had the highest general anxiety, however, at T4 this had returned to normal	1b
(16)	Nuchal translucency measurement	Müller et al. (2006) The Netherlands	687	(i) To compare anxiety and depression during pregnancy and puerperium between woman who are offered NTM and women who are not, and (ii) to compare levels between women	Cohort	Anxiety – Hospital anxiety and depression scale (HADS) • T1: Intervention group: After information, but before screening (11–14 gws)/Control group: 12 gws	Intervention: Information and offer to undergo NTM screening (n = 527) Control: Standard care, no screening offered (n = 160)	Offering screening does not increase anxiety or depression levels. Women who were offered screening (accepting/declining) had significantly lower HADS-levels at T2 and T3	2b

Table 2. Continued

Reference	Intervention	Study	*n*	Stated aim of the article	Design	Outcome measures	Study group(s)	Results	Level of evidence
				accepting and declining screening.		• T2: Both groups: 20 gws • T3: Both groups: 6 weeks postpartum			
(19)	Nuchal translucency measurement	Chueh et al. (2007) Taiwan	352	To assess pre- and post-procedural maternal anxiety when screening for Down's syndrome, and the psychological impact of a positive screening result.	Cohort	Anxiety – Spielberger's STAI • T1: Before screening • T2: 1 week after screening • T3: At 22 gws (invasive testing complete and • T4: 6 weeks postpartum	Intervention: NTM screen-positive result (n = 172) Control: Normal screening result (n = 180)	Women with positive screening result did not have sustained increase in anxiety.	2b
(20)	Maternal serum test	Cheng et al. (2008) Taiwan	2782	To study the effect of fast reporting by mobile phone SMS on anxiety levels in women undergoing prenatal biochemical screening for Down's syndrome.	Randomized controlled trial	Anxiety – Spielberger 's STAI • T1: At inclusion, before screening • T2: Before appointment at clinic (when SMS had already been given to intervention group) • T3: 3 days after appointment.	Intervention: Fast reporting by SMS (n = 1422) Control: No mobile phone reporting (n = 1360)	Fast reporting by SMS significantly alleviates anxiety for screen-negative women while waiting for appointed clinical visit	1b
(18)	Nuchal translucency measurement	Öhman et al. (2009) Sweden	620[a]	To explore how information about being at risk for Down's syndrome was understood and whether the actual risk and the woman's perception of risk was associated with worry or depressive symptoms during and after pregnancy.	Cohort	Worry – Cambridge Worry Scale Edinburgh postnatal depression scale • T1: Early pregnancy (at inclusion, before randomization) • T2: At 24 gws • T3: 2 months postpartum	Women undergoing risk assessment for Down's syndrome 26 women were high-risk (all false-positive) 582 women were low risk	No significant relation between high risk and worry/depressive symptoms during or after pregnancy. Women perceiving as being at high-risk were slightly more worried in mid-pregnancy, but this abated to the same levels 2 months postpartum.	2b

CEBM, Oxford Centre for Evidence-based Medicine; gws, gestational weeks; HADS, Hospital Anxiety and Depression Scale; NTM, nuchal translucency measurement; PRAQ-R, Pregnancy Related Anxiety Questionnaire-Revised; STAI, Spielberger's State-Trait Anxiety Inventory.
[a]Öhman et al. (18) included 620 women in their study but only reported results from 608 women.

Table 3. Timepoints and anxiety scores (with standard deviations).

Reference	Study	Scales	Baseline	Screening	Late pregnancy	Postpartum
(21)	Lai et al. (2004) Singapore	STAI[a]	15–20 gws Before counseling: S-Anxiety: 36.73 (±6.99) T-Anxiety: 39.73 (±6.53) After counseling (same day): S-Anxiety: 35.50 (±7.78) T-Anxiety: 39.25 (±6.84)	On day of screening, before screening (20 gws) S-Anxiety: 35.46 (±7.34) T-Anxiety: 38.96 (±6.57)	24–26 gws S-anxiety: 30.61 (±5.66) T-anxiety: 38.55 (±6.55)	
(17)	Ohman et al. (2004) Sweden	STAI EPDS[b]			24 gws Screening: S-Anxiety: 32.8 (±8.7) T-anxiety: 34 (±8.6) EPDS: 11.8 No screening (control): S-Anxiety: 32.9 (±8.8) T-anxiety: 34 (±8.5) EDPS: 13.3	2 months postpartum Screening: S-Anxiety: 30.2 (±8.4) T-anxiety: 32 (±8.8) EPDS: 8.2 No screening: S-Anxiety: 31 (±8.2) T-anxiety: 32.1 (±8.4) EDPS: 9.0
(15)	Kleinveld et al. (2006)[c] The Netherlands	STAI PRAQ-R[d]	<16 gws STAI (S-anxiety) Before/after information Screening accepted: 37/36 Screening declined: 37/35 No screening (control): 37/36 PRAQ-R After information Screening accepted: 2.5 Screening declined: 2.4 No screening (control): 2.4	After test result (or comparable time) STAI (S-anxiety) High risk: 42 Normal risk: 33 Screening declined: 33 No screening: 35 PRAQ-R High risk: 2.8 Normal risk: 2.2 Screening declined: 2.3 No screening: 2.3	28 gws STAI (S-anxiety) High risk (false-positive): 37 Normal risk: 35 Screening declined: 34 No screening: 36 PRAQ-R High risk (false-positive): 2.7 Normal risk: 2.2 Screening declined: 2.3 No screening: 2.2	
(16)	Muller et al. (2006) The Netherlands	HADS[e]	<11 gws Screening: 7.55 (±5.18) No screening (control): 8.63 (±4.07)		20 gws Screening: 5.66 (±4.07) No screening: 7.50 (±5.69)	6 weeks postpartum Screening: 6.97 (±6.08) No screening: 8.91 (±6.05)
(19)	Chueh et al. (2007) Taiwan	STAI	11–14 gws High-risk screening result S-anxiety: 39.2 (±9.8) T-anxiety: 40.1 (±17.2) Control S-anxiety: 41.2 (±11.3) T-anxiety: 41.7 (±13.9)	1 week after NTM result High-risk screening result S-anxiety: 44.3 (±14.4) T-anxiety: 42.6 (±9.2) Control S-anxiety: 37.3 (±10.8) T-anxiety: 40.9 (±11.3)	22 gws False-positive screening result S-anxiety: 36.9 (±8.8) T-anxiety: 39.7 (±11.7) Control S-anxiety: 37.1 (±12.1) T-anxiety: 41.5 (±8.9)	6 weeks postpartum False-positive screening result S-anxiety: 38.5 (±9.9) T-anxiety: 39.6 (±10.2) Control S-anxiety: 37.1 (±12.1) T-anxiety: 41.5 (±8.9)

Table 3. Continued

Reference	Study	Scales	Baseline	Screening	Late pregnancy	Postpartum
(20)	Cheng et al. (2008) Taiwan	STAI	<14–18 gws	At day of clinical follow-up[f]	3 days after clinical follow-up	
			Normal risk screening result	Normal screening result	Normal screening result	
			Intervention	Intervention	Intervention	
			S-anxiety: 38.9 (±9.9)	S-anxiety: 33.8 (±7.9)	S-anxiety: 35.3 (±12.5)	
			T-anxiety: 39.8 (±11.2)	Control	Control	
			Control	S-anxiety: 39.1 (±10.1)	S-anxiety: 34.9 (±10.1)	
			S-anxiety: 37.8 (±11.3)	High-risk screening result	High-risk screening result	
			T-anxiety: 38.4 (±10.9)	Intervention	Intervention	
			High-risk screening result	S-anxiety: 44.1 (±13.4)	S-anxiety: 43.4 (±9.6)	
			Intervention	Control	Control	
			S-anxiety: 39.2 (±11.4)	S-anxiety: 42.9 (±11.5)	S-anxiety: 43.1 (±10.6)	
			T-anxiety: 38.7 (±8.8)			
			Controligh-risk			
			S-anxiety: 39.9 (±9.4)			
			T-anxiety: 40.1 (±13.2)			
(18)	Öhman et al. (2009)[g] Sweden	EPDS SCWS[h]	11–14 gws		24 gws	2 months postpartum
			High-risk screening result		High-risk screening result (false-positive)	High-risk screening result (false positive)
			EDPS: 5.6		EDPS: 7.2	EDPS: 5.6
			SCWS: 3.2		SCWS: 2.7	SCWS: 1.5
			Normal risk screening result		Normal risk screening result	Normal risk screening result
			EDPS: 5.8		EDPS: 5.4	EDPS: 4.9
			SCWS: 3.1		SCWS: 2.6	SCWS: 1.1

gws, gestational weeks.

[a]The State Trait Anxiety Inventory (STAI) scores respondents on a scale of 20–80. Scores of 35 are considered normal anxiety and scores of 50–61 are considered an acute anxiety response (11,24).

[b]The Edinburgh Postnatal Depression Scale (EDPS) scores respondents on a scale of 0–30. Scores of ≥13 indicate probable minor depression in the antenatal period (49).

[c]Kleinveld et al. (15) did not supply T-anxiety scores or information on standard deviations.

[d]The Pregnancy-related Anxiety Questionnaire-Revised (PRAQ-R) consists of three subscales, but only "fear of bearing a physically or mentally handicapped child" is included in the present study. Scores range from 1 (low anxiety) to 5 (high anxiety) (15).

[e]The Hospital Anxiety and Depression Scale (HADS) scores respondents on a scale of 0–56, where values of 8–11 define possible and values of 11 or more definite probable cases of anxiety or depression (16).

[f]Results of screening known by intervention group and high-risk group.

[g]Öhman et al. (18) did not provide information on standard deviations.

[h]The Swedish version of the Cambridge Worry Scale (SCWS) only include one item ("worry about the possibility of something being wrong with the baby") scoring on a 0–5 scale. Values of 4–5 are defined as "major worry" (18).

include a total of 8835 participants. Two studies were conducted in the Netherlands (15,16), two in Sweden (17,18), two in Taiwan (19,20) and one in Singapore (21). All studies had a stated aim to assess anxiety or worry in pregnant women undergoing screening for Down's syndrome, but the study designs varied considerably. Three studies were randomized controlled trials and four were cohort studies. The studies included 109–2782 participants. The screening tests investigated were maternal serum test (20,21), nuchal translucency measurement (NTM) (16–19), or both (15). Three studies compared a group of women who were offered screening with a control group of pregnant women who were not offered screening (15–17). Three studies compared interventions in a cohort where both the intervention and control groups underwent screening (18–20). One study did not include a control group (21).

All studies used self-administered questionnaires to measure respondents' anxiety levels at several points during pregnancy. All studies included a baseline anxiety measurement and a mid-pregnancy, post-screening measurement at approximately 20–28 gestational weeks, thus allowing for comparisons across studies. Four studies also included anxiety measurements at 6–8 weeks postpartum (16–19). Table 3 displays numerical results and standard deviations (where available) of the individual measurements in the included studies. Statistical significance is reported under Results where relevant.

Five studies, including the three randomized controlled trials, used Spielberger's State-Trait Anxiety Inventory (STAI). STAI is a validated (22), 40-item scale that differentiates between the temporary condition of "state anxiety" (S-anxiety) and the more general, long-standing quality of "trait anxiety" (T-anxiety) (23). Thus, S-anxiety fluctuates over time, whereas T-anxiety is more stable. Respondents are scored on a scale of 20–80, where the higher scores are positively correlated to higher levels of anxiety. A STAI score of 35 is considered normal anxiety, and STAI scores of 50–61 are considered acute anxiety responses (11,24). The widespread use of STAI facilitates comparisons across studies. The remaining studies also used validated scales; for example the Cambridge Worry Scale (25) and the Hospital Anxiety and Depression Scale (HADS) (26).

In the following presentation of results, the Green et al. (11) review is used as frame of reference to compare previous and current scientific evidence on screening and anxiety. We emphasize that the results of the present review are autonomous and can be read independently of Green et al (11).

Anxiety before screening

Green et al. (11) reported mean anxiety scores of 33–36 (27) and 38 (28) on the STAI for pregnant women that chose screening. Green et al. considered a STAI score of 34 as "normal", and they suggested that pregnant women had slightly increased anxiety levels compared with a non-pregnant population (11). Due to significant drop-out in the included studies, the authors recommended that those scores should be interpreted with caution.

In the present review, all studies included anxiety measures in early pregnancy prior to any randomization and/or intervention (at 8–16 gws). For the five studies using the STAI, the mean scores ranged from 36.7 (21) to 41.7 (19). We found moderate to good evidence (CEBM recommendation B) that the mean anxiety scores for women in early pregnancy were within this range; however, these studies did not report a comparable anxiety score for the background population or a matched non-pregnant group.

Müller et al. (16) included a reference to a Dutch validation study of the HADS-scale providing a mean score for the general population (29). The authors concluded that there was no significant difference between Dutch subjects and pregnant women. However, on the basis of the present review, we could not conclude whether pregnant women were more or less anxious at baseline than the general population.

Anxiety in women who are offered screening compared with women who are not

Green et al. (11) did not address the issue of anxiety in women who are offered screening compared with women who are not. In the present review, two randomized controlled trials (15,17) and one cohort study (16) addressed this question. In the Swedish randomized controlled trial by Öhman et al. (17), 2026 pregnant women were randomized to either a 12–14 gestational weeks (gws) ultrasound examination including screening for Down's syndrome or to standard prenatal care (routine scan at 15–20 gestational weeks with no screening for Down's syndrome). The results showed no statistical difference between the intervention and the control group regarding anxiety or depressive symptoms during pregnancy or postpartum.

In the study by Kleinveld et al. (15), pregnant women were randomized to three groups: one was offered a maternal serum test, the second was offered NTM, and the third received standard care (no screening). In the two groups randomized to screening ($n = 1471$), the pregnant women received information and decided for or against screening; 694 declined the offer. The results showed that S-anxiety levels in women who declined screening were lower than in women who were not offered screening at all. This led the authors to conclude that allowing women to have a choice regarding prenatal

screening may have a small favorable effect on general feelings of anxiety. This result was supported by the findings of Müller et al. (16) who showed that women who were offered screening (acceptors as well as decliners) had significantly lower HADS scores at 20 gestational weeks and postpartum than women who had not been offered screening at all.

Thus, with one study showing no difference between groups, and two studies showing lower anxiety levels in women who were offered screening compared with women who were not, we found low to moderate evidence (CEMB recommendation C) that allowing women to have a choice regarding prenatal screening had a positive effect on general feelings of anxiety.

Anxiety among pregnant women who decline screening

Green et al. (11) found three studies that compared women who accepted screening with women who were offered, but subsequently declined, a maternal serum test or NTM screening (30–32). However, the drop-out rates were 47–78% among women who declined screening. Therefore, the authors could not conclude whether anxiety differed between women who chose and those who declined screening.

In the present review, the two Dutch studies included pregnant women who declined an offer of prenatal screening. Müller et al. (16) found no statistically significant difference in anxiety between women who accepted or declined screening, at 12 gestational weeks, 20 gestational weeks or at six weeks after birth. Kleinveld et al. (15) found that after having received information about the offer of prenatal screening, women who declined screening had lower child-related anxiety [Pregnancy Related Anxiety Questionnaire-Revised ((PRAQ-R)] than women who accepted; however, the authors found no significant difference in STAI scores between women accepting and women declining screening. This lack of difference between groups continued throughout the pregnancy, both immediately after screening (or at a comparable time for decliners), and in the last trimester of pregnancy. Based on the Müller et al. and the Kleinveld et al. studies, we found low to moderate evidence (CEBM recommendation C) that anxiety levels did not differ between pregnant women who accepted and pregnant women who declined the offer of screening for Down's syndrome.

Anxiety after a screen-negative result

Green et al. (11) found that anxiety before a screening test was slightly elevated compared with STAI norms, but anxiety returned to normal levels after a negative result had been obtained.

The studies in the present review show similar results. Three studies reported mean S-anxiety scores between 33 and 37.3 for screen-negative women (15,19,20). Two studies showed that post-result anxiety scores were significantly lower than pre-screening anxiety scores (15,20). Two other studies reported a numerical decrease in scores, but this was not statistically significant (19,21). All studies found that, in screen-negative women, anxiety continually decreased over time, from pre-screening to mid- and late pregnancy (20–28 gestational weeks) where mean STAI scores ranging from 30.6 to 37.1 were reported (16,17,19–21). Kleinveld et al. (15) reported HADS anxiety and depression scores of screen-negative women to be 35 after screening, compared with 37 at baseline. Furthermore, after test results were known, screen-negative women had significantly lower PRAQ-R scores than women who declined screening. Three studies measured anxiety postpartum, and all reported the lowest anxiety levels at this point (16,17,19). Thus, we found no evidence (CEBM recommendation B) to support an assumption of residual anxiety in screen-negative women.

Anxiety after a screen-positive result

Green et al. (11) found that women experienced an acute response when they received a positive screening result. STAI scores rose to about 55 points upon receiving a positive screening result (30,33,34). Nevertheless, the findings also suggested that anxiety scores returned to normal levels after diagnostic testing showed normal results (33,35).

In the present review, three studies included screen-positive women. All three reported significantly higher levels of anxiety compared with screen-negative women. The S-anxiety scores reported were 42 (15), 42.9–44.1 (20) and 44.3 (19); thus, these scores were numerically much lower than those reported in the studies reviewed by Green et al. (11).

For example, Chueh et al. (19) compared two groups of pregnant women; one was a group with positive screening results (NTM screening, $n = 172$) and the other was an age-matched control group with negative screening results ($n = 180$). One week after screening, women with positive screening results scored significantly higher than controls for S-anxiety. However, at 22 weeks' gestation and at six weeks after delivery, STAI scores did not differ between the groups. Chueh et al. concluded that screening does not induce a sustained increase in anxiety. Though much smaller in sample size, the findings by Kleinveld et al. (15), and Müller et al. (16) ($n = 20$ and $n = 8$, respectively) supported this conclusion. By 28

gestational weeks, Kleinveld et al. (15) found a numerical difference in PRAQ-R Child-related anxiety between women with a normal screening result (2.2) and women with a false-positive screening result (2.7). However, this difference was not statistically significant.

Öhman et al. (18) found that a woman's perception of being at high-risk for Down's syndrome (regardless of the actual risk score) was associated with worry and depression. In contrast, the actual risk score was not associated with worry or depression. However, two months after delivery, Öhman et al. found no association between the level of worry and either the actual or perceived risk.

Based on the included studies, we found moderate to good evidence (CEBM recommendation B) that anxiety levels increased upon receipt of a screen-positive result. However, upon receipt of a normal diagnostic result, in the third trimester, and after delivery, we found no significant difference in anxiety levels between women with negative and positive screening results. Therefore, the present review did not support the hypothesis of residual anxiety. On the contrary, we found moderate to good evidence (CEBM recommendation B) that anxiety levels declined to normal levels after receiving a normal diagnostic result.

Discussion

In this article, we reviewed and summarized very different studies in different countries with different traditions regarding prenatal care and screening. Interestingly, across all studies, anxiety in screen-negative women consistently decreased from baseline to the third trimester and postpartum. All four studies measuring screen-positive women's anxiety after screening found a statistically significant increase in anxiety (15,16,19,20). However, by the third trimester, anxiety levels in false-positive women returned to the same level as for screen-negative women (15,16,19). Thus, our results contribute to the current base of evidence for understanding anxiety in relation to screening for Downs' syndrome in pregnant women.

There are some methodological challenges pertaining to most of the study designs which may limit the generalizability of the results. First, there is risk of selection bias in the inclusion of pregnant women in the studies. For example, in the Swedish study by Öhman et al. (17) the inclusion rate was only 23%, and compared with the background population, the sample population included fewer women of non-Swedish decent and larger proportions of older women, nulliparous women, women who were married/cohabiting, and women with a relatively higher level of education. The only other study providing demographic statistics, Kleinveld et al. (15), similarly reported women in the study population to be of higher education than the general population of pregnant women. Studies have shown a positive correlation between educational level and knowledge about prenatal screening (36,37), and making an informed decision regarding prenatal screening has been shown to decrease decisional conflict (38) and increase satisfaction later in pregnancy (39). Consequently, the included women might be better at coping with screen-associated anxiety, and thus, the anxiety levels in these studies could be biased towards lower values of anxiety.

Secondly, the drop-out rates must be taken into consideration. Only Müller et al. (16) analyzed data according to intention-to-treat and thus included scores for all participants in the analysis – including the drop-outs. All the other studies selectively analyzed only data from participants who completed all the questionnaires. Because dropping out of a study is known to be proportionally larger in sections of the population with relatively low resources, these attrition rates potentially added to the selection bias already present at inclusion. Öhman et al. (17) reported that drop-outs did not skew the socio-demographic distribution of women in their final study group. Similarly, Müller et al. (16) reported no significant difference in socio-demographic or obstetric background between completers and drop-outs. However, drop-out levels in the other studies might potentially influence the validity of the results in the present review. Similar to the selection bias, we hypothesize that drop-out might lead to an underestimation of the anxiety levels.

Despite these limitations, we argue that our findings address important aspects of prenatal screening. The pros and the cons of prenatal screening have been an ongoing debate; currently, there remain professionals, academics and decision-makers who question the benefits of prenatal screening, primarily due to the assumption that it induces harmful anxiety (3). One concern is the general anxiety and medicalization of pregnancy that prenatal screening might increase by making pregnant women aware of the risk that something might be wrong with the fetus. Green et al. (11) referred to a few studies that indicated that prenatal screening could result in residual anxiety lingering throughout the pregnancy and postpartum period (10,40,41); however, they concluded that this relation was yet to be confirmed. In the present review, we did not find any evidence to support the hypothesis of residual anxiety. On the contrary, there was a continual decrease in anxiety throughout the pregnancy for women participating in screening.

We have limited the present review to quantitative studies using validated scales to address anxiety at the epidemiological level. Thus, it is important to acknowledge that for the individual woman, participation in prenatal screening might be stressful and raise anxiety and

concerns. For example, a qualitative study by Aune & Möller (42) show the complex feelings, sense of responsibility, social pressure and moral issues that women engage with when processing risk information about pregnancy and the fetus. However, that study also finds that a low-risk result increased reassurance and relief. These findings are in line with several other studies that demonstrate a reassuring affect (43,44) and increased fetal-maternal attachment (45,46) following a normal screening result.

Another often-voiced concern regarding prenatal screening is the problem of false-positive screening results, and the immediate worry and potential residual anxiety it may lead to. In all screening procedures, the risk of false-positive results is an unfortunate, but inherent, shortcoming. The studies in this review collectively stress the significant increase in anxiety following a high-risk result. Qualitative studies have described the complex information, moral dilemmas, and difficult decisions that pregnant women and their partners must deal with following a screen-positive result (7,47,48). Thus, a continual development of screening technologies to raise the level of specificity is necessary to reduce the number of false-positive women who endure emotional turmoil and risk miscarriage of a healthy fetus due to the invasive diagnostic procedures. However, a very important result of this review is that false-positive pregnant women can bounce back. We find that once a false-positive screen result is rectified by a normal diagnostic result, there is no significant difference in anxiety between women with false-positive and those with negative screening results; thus, at the epidemiological level, a false-positive screening result does not result in lingering anxiety. This finding suggests that a conclusive diagnostic result can restore the pregnant woman's faith in a healthy fetus and normal pregnancy. These findings also speak in favor of a continual optimizing of clinical practices, particularly regarding a smooth running of the diagnostic process and a fast diagnostic response to minimize undue anxiety.

This review of quantitative studies, which used validated scales, represents one perspective on prenatal screening and anxiety. Our results are consistent with the present information and refine existing knowledge. However, there are important aspects to pregnancy, screening and anxiety that are difficult to capture in randomized controlled trials and cohort studies. First, we need a better understanding of (and an ability to identify) why some women experience extremely high anxiety levels that impede effective, contemplative decision-making. Secondly, we need to investigate further the complex feelings of anxiety, excitement, nervousness and joy that inform the pregnant women's experiences with pregnancy and prenatal care. To address these complex issues, we suggest future combined studies of both epidemiological and experiential perspectives on screening.

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CHAPTER 5

CONCLUDING DISCUSSION OF RESULTS AND METHODS

CONCLUDING DISCUSSION OF RESULTS AND METHOD

In this concluding chapter, the scientific papers presented in Chapter 4 are briefly summarised. Subsequently five overall analytic inferences from the studies are discussed in relation to the larger field of research on prenatal screening and related issues. Next, the strengths and limitations of the chosen design are shortly addressed, and the validity and transferability of the qualitative studies are discussed. The strengths and limitations of the literature review are also addressed. I round of the dissertation by discussing future perspectives, first with regard to futures studies and then regarding the potential clinical implications of this dissertation.

SUMMARY OF RESULTS

A central focus in the present dissertation has been on how a high-risk screening result is managed and negotiated; first, in clinical encounters, and second, while waiting for diagnostic results. By using an explorative approach and carrying out fieldwork I have been able to first observe clinical interactions and subsequently discuss the experience with high risk women/couples. This allows detailed insight into the understandings, negotiations and management of high risk results and the subsequent waiting time. In the analysis and presentation of results I have aimed to give a nuanced and comprehensive insight into what is at stake for both sonographers and pregnant women/couples, and the strategies used for dealing with the uncertain situation. The qualitative studies are accompanied by a systematic literature review. Often, literature reviews are used to 'set the scene' prior to subsequent studies, but in this case the review answered a question that emerged during the research process: What is the relation between prenatal screening and anxiety? Together, the studies offer a comprehensive and composite perspective on prenatal screening in Denmark.

In Paper 1, it is investigated how high-risk is understood, negotiated and decided upon in clinical interaction following a high risk screening result. Using the concepts of 'logic of choice' and 'logic of care' as theoretical approach, the collaborative efforts of sonographers and women/couples are identified. Together, they transform the statistical FTS risk figure into a contextualised and manageable platform of understanding from which a decision regarding invasive testing can be made. This process involves reducing complexities by focusing in values instead of numbers, and by shifting authority back and forth between sonographers and women/couples. Central to the analysis is that both sonographers and

women/couples engage in the same range of biomedical, social and local discourses when negotiating a meaningful understanding of the risk situation. The caring practices involved in this process potentially challenge the paradigm of informed choice that serves as a strong clinical ideal in prenatal screening. The analysis shows how 'care' is guided towards good decision-making and thus not in opposition to the 'logic of choice'. The analysis identifies the logics of 'choice' and 'care' as not only intermingling, but interdependent in clinical interaction.

In Paper 2, it is investigated how high-risk couples who choose invasive testing manage waiting for results. Using coping theory as an explanatory framework, the findings show that the couples actively piece together their own personal coping strategies using both practical strategies, such as withdrawing from and participating in everyday activities, as well as different forms of reassuring reasoning. The strategies are directed towards controlling worry and keeping up hope for a good outcome. Thus, the results do not resonate with studies which find that women mentally put their pregnancy 'on hold' following a high-risk screening result. Consequently, a more complex approach is suggested, where worry and uncertainty are understood as managed through a diverse range of practical and emotional strategies that change and repeat while the women/couples are waiting for the results. Based on the findings, clinicians are encouraged to also address coping strategies in clinical encounters following a high-risk screening result and/or invasive diagnostics.

In Paper 3, it is investigated if screening for Down's syndrome causes anxiety in pregnant women who receive a negative or false-positive screening result. PRISMA guidelines were followed in order to systematically review and summarise the current scientific literature. Including only studies using quantitative outcome measures of anxiety or worry, we found no evidence to suggest that prenatal screening for Down's syndrome causes anxiety in women with a negative screening result. A positive screening result causes significantly increased anxiety, but anxiety returns to normal levels following a normal diagnostic result. Concerns about unnecessary and/or residual anxiety and worry following a negative or false-positive FTS result are among the main objections against prenatal screening. This review offers an overview and an evaluation of the current scientific evidence indicating that invasive testing can restore high-risk pregnant women's trust that they will have a healthy fetus and a normal pregnancy.

DISCUSSION OF RESULTS AND PERSPECTIVES

The findings of the individual papers are discussed within each paper and therefore in this section, I instead take the opportunity to elaborate on five overall analytic inferences and discuss how they relate to the larger field of research.

First, the findings of this dissertation demonstrate the complex ways in which biomedical knowledge interlaces with other types of knowledge. This process takes place in the clinical encounters, where risk is negotiated, and while waiting for diagnostic results. The women/couples actively engage in the re-production of biomedical knowledge and the interpretations of it, which can be understood within the frame of the 'e-scaped' medicine as suggested by Nettleton (2004). Nettleton argues that a consequence of the pervasive and constantly growing information technologies is that biomedical knowledge is no longer exclusive to the medical academy. Instead it has *'escaped into the networks of contemporary info-scapes where it can be accessed, assessed and re-appropriated'* (Nettleton, 2004: 674). Thus, people engage with biomedical knowledge outside of the clinic and enter the clinic knowledgeable and prepared. The results of this dissertation show that the women/couples may not be prepared for the high-risk result as such, but they are prepared to enter a biomedical discourse about the meaning and implications of the result. In line with Lash (2002), Nettleton also argues that the pervasiveness of mass information leads to less evident hierarchies of knowledge: *'Logical and ontological knowledge no longer have a separate status from trivial everyday or empirical knowledge'* (Lash, 2002 in Nettleton 2994:674). This is evident in the way in which the couples deal with waiting time. Here biomedical information does not hold a privileged status as 'correct' but interweaves with a myriad of experiential, social and spiritual types of knowledge and practice that contest the statistics in order to keep up hope.

Biomedical knowledge is thus appropriated to fit local needs and situated practices. Similarly, Lippmann (1999) and others (see for example Root & Browner, 2001; Rapp, 1999) have shown how women 'reconcile' various sources of information to create their own knowledge, where statistical knowledge, personal experiences and gut feelings are not competing sources of information, but different strands in the complex fabric that makes up women's responses to prenatal screening (Lippman 1999: 269). The results of this dissertation add to these findings by showing that this process of reconciliation starts within the clinical encounter, and also includes the sonographer. The sonographer's presentation of biomedical knowledge similarly interlaces with her personal and professional experience, social concerns and hopes for the future pregnancy of the woman/couple. Thus, women/couples and sonographers are positioned not as representatives of two different knowledge

traditions, but as simultaneously engaged in a range of ways of knowing in the process of appropriating the risk figure to make it meaningful and manageable.

Second, Paper 1 and Paper 2 show how a 'high risk' FTS result is a powerful category that transforms the opaque uncertainties in pregnancy into one identified risk that puts the health of the fetus and the future pregnancy at stake. However, the FTS is only one of many potential risk scenarios being investigated at the first trimester ultrasound scan; one of many parameters in which the fetus and the pregnancy are measured and monitored: anatomical features, amniotic fluid, blood flow in the fetal heart or the umbilical cord; these features all provide detailed information on the basis of which the fetus can succeed or fail, be categorised as normal or at risk. The FTS must be understood within this larger process of producing potential diagnosis.

This dynamic process of generating biomedical knowledge is theoretically approached within the growing sociology of diagnosis (Jutel, 2011; Timmermans & Haas, 2008), where diagnosis is investigated as a social process that is located and distributed within a social and technical division of labour, and where skills, knowledge and authority are distributed and contested (Atkinson, 1995). This approach does not dismiss the 'realness' of biomedical findings (e.g. the FTS risk figure or an enlarged nuchal translucency), but investigates the processes of categorisations and the ambiguities and uncertainties inherent in producing biomedical knowledge, as well as the complexities that clinicians face and manage in everyday diagnostic processes (see for example Saunders, 2008).

The point I wish to make is that it is not only the women/couples who have something at stake at the first trimester ultrasound scan. Clinicians – sonographers *and* obstetricians - similarly have stakes in the categorisation of fetuses; in the production and management of risk scenarios. Sonographers must navigate the womb and overcome limited visibility, retroverted uteruses and belly fat to produce accountable images and measurements. Obstetricians must estimate the significance of a large nuchal translucency, the meaning of a suspicious dot, and decide if the identification of a nasal bone is really necessary in this particular case. Obstetric ultrasound is not an exact science but a process in which the competence of the clinician is at stake as she must estimate if the ultrasound images can be trusted to represent the 'real' (e.g. fetus in the womb), and what the consequences may be. Thus, sonographers and obstetricians (from now on referred to collectively as 'clinicians') have to navigate what Saunders has called '*the perils of poor seeing (…) in a performative milieu in which the veracity of the viewer is not so much presumed as it is at stake'* (Saunders, 2008:17).

At the first trimester ultrasound scan, clinicians are responsible for producing risk scenarios and identifying potential diagnosis. Their expertise and experience define the quality and trustworthiness of these scenarios on the basis of which the women/couples must decide what to do next. The process of diagnosis brings lay and professional together '*in a curiously intimate and consequential way*' (Jutel, 2011:75), as the decisions made by the women/couples then define new tasks and options for sonographers and obstetricians. Thus, I argue that the processes in which the fetus is examined and categorised powerfully positions clinicians and pregnant women/couples as interdependently responsible for the health of the fetus and a good outcome.

Third, the results show how talk of Down's syndrome is largely absent in the clinical encounter and is also generally postponed while waiting for diagnostic results. Thus, the moral and ethical dilemmas so often addressed as closely intertwined with prenatal screening are not as visible in the present studies as could have been expected. In her seminal work, Rayna Rapp (1999) explores the use and meanings of amniocentesis in the United States. Her definition of pregnant women as 'moral pioneers' has been widely influential, and she points out that pregnant women undergoing prenatal testing are being situated in the research frontier of the expanding capacity for prenatal genetic diagnosis, and as such they are *'forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standards of entry into the human community*' (Rapp, 1999: 131). Similarly, Williams et al. (2005) argue that prenatal screening potentially introduces new and novel ethical dilemmas for pregnant women, obligating them to act as moral pioneers in increasingly complex settings.

The findings in this dissertation add to these understandings in two important ways. First, the results show how the moral concerns regarding life/death, normal/disabled, good quality/poor quality are postponed in favour of more pragmatic concerns, such as having a happy pregnancy, being grateful for ones family and placing importance on certainty. Second, the analysis also include the perspectives of the clinicians who are positioned right alongside the women/couples on the 'research frontier', and who deal with the ambivalences, dilemmas and conflicts of prenatal screening and diagnosis as part of their everyday work. Thus, the results point to the value of addressing morality not as a set of abstract beliefs, codes or rules, but as practices and a process of becoming. In her latest work, Mattingly (2013) approaches clinical interaction as a potential moral laboratory; a setting where the potential for moral experiments is present. In this perspective, 'moral' does not refer to a golden standard of metaphysical, ethical rules but to the ability to cultivate 'the best good' in the ambiguous circumstances of everyday life, where the possibility of mistakes

and unintended consequences always lure. The strength of this perspective is that it allows us to understand *both* clinician *and* women/couples as engaged in doing the 'best good' in a world where a universally, morally right act is often challenging or impossible to discern (Mattingly, 2013:307). Furthermore, the laboratory metaphor accentuates the stepwise approach revealed in the studies of this dissertation. The analysis shows that neither sonographers nor women/couples aimed to encompass all available information to arrive at a final (and morally defendable) conclusion about a potential abnormal, diagnostic result. Rather, they approached uncertainty in a stepwise manner, with probing responses in order to 'do the best good' in a situation where larger, socio-ethical questions are postponed until they receive the final diagnostic result.

Fourth, the results show how prenatal screening addresses a problem that is already defined by its solution, the invasive diagnostic testing. In their analysis of 'social technologies', Jöhncke et al. (2004) show how solutions (specific technologies, interventions) actually produce problems by providing a frame within which a specific condition can be identified and formulated as a problem. The authors point out how conditions are considered inevitable and invariable until promises of change, mending or solution reframe them as a 'problem' that demands attention and action. One could argue that it was the existence of a fit technological solution (the risk assessment and invasive diagnostics) that framed Down's syndrome as a problem to be addressed by pregnant women. This perspective offers a theoretical approach to the continuous development of new prenatal monitoring technologies; from the very advanced ones, such as non-invasive prenatal testing (NIPT), through free fetal DNA in the mother's blood, to the clinical implementation of a printed form where risk factors for restricted intra-uterine growth can be checked off. What they have in common is their capacity for 'discovery;' they carve out problems for the health professional and the pregnant women to deal with, and they offer solutions or a promise of a better future.

These are examples of the continued monitoring and medicalisation of pregnancy. Conrad (2007) identifies what he calls the '*shifting engines of medicalisation*' (Conrad, 2007:133), where the development of biomedicine to a larger and larger extent falls outside the biomedical academy and is instead driven by the pharmaceutical industry, by patients as consumers and by the health administration. Within prenatal screening one example is the financial interests of private companies in promoting NIPT technologies. Aided by the media and by pregnant women's voiced interest in such technologies, there is a strong push towards extending the potential problem of chromosomal abnormality to a wider group of women via an easy solution, an NIPT blood test. With the new technologies it is very possible that a larger

number of women will begin to consider the risk of chromosomal abnormality as a problem for which they need biomedical intervention. These processes of medicalisation are not necessarily bad, but we must be critically aware of the ways in which processes of medicalisation push and mould not only biomedicine and biomedical practices, but also social discourses and individual identities.

With technological advances almost uncontrolled, medicine is becoming 'sub-political', changing and developing practices to fit local needs and interests (Beck-Gernsheim, 1996:148). These local decisions and developments can be understood as driven by what Mary-Jo Delvecchio Good (2001) defines as '*the medical imaginary*': the enthusiasm for medicine's possibilities and the constant developments that make medicine a fun and intriguing enterprise (Good, 2001:397). Local clinical decisions to implement NIPT or to systematically measure ductus venosus flows *do* provide more detailed and better information, on the basis of which fetal health can be optimised and reproductive choices made. However, these local decisions simultaneously increase the number of potential problems and delineate new understandings, identities and choices available to pregnant women/couples (and clinicians). What these results underline is that biomedical 'problems' or conditions are social constructions embedded in specific socio-technico-historical contexts. They come into being in multiple and complex ways, driven by a number of engines – from commercial interests and media to local enthusiasm for development and providing good care. The FTS must be understood within this frame of reference.

Finally, the results in this dissertation show that women/couples can manage a high-risk result. In a situation of uncertainty, where the future is at stake, they create foothold. The high-risk FTS result is an unexpected and unwelcome disruption of the imagined future of parenthood and the taken-for-grantedness of everyday life (Becker, 1998). The studies in this dissertation document the considerable increase in worry and anxiety following a high-risk screening result.

The analysis shows that the management of a high risk FTS result is not just a matter of interpreting the statistical figure, but a continuous process of engaging with risk and uncertainty (Svendsen & Wahlberg, 2014) and managing it through actions and interpretations. The anthropological approach offers a perspective that does not judge or discriminate; its global research tradition recognises that human attempts to deal with matters of life and death may be as much an engagement with mysterious or occult possibilities as an effort to assert predictable 'rational' control (Jenkins et al., 2005: 27). The women/couples searched the internet, asked the sonographer, trusted their gut feelings and

found hope in the love for their spouse, and these responses are not due to lack of information or rationality but just a testimony to the pragmatic practices that make up everyday life (Svendsen, 2005; Risør, 2003).

The results contributes to the current debates about screening in general and prenatal screening in particular by offering a perspective from within the clinical interactions and within the couples' waiting for results. A high-risk FTS result does cause disruption, and we should always be critical of the ways in which screening practices and biomedical monitoring inflict on peoples lives and frames of reference (citizens as well as clinicians). However, the studies in this dissertation indicate that pregnant women/couples are resilient and able to piece together a meaningful understanding and an engaged response to a high risk FTS result.

STRENGTHS AND LIMITATIONS OF THE QUALITATIVE STUDIES

The primary strength of this dissertation is the use of ethnographic fieldwork as a research strategy, allowing for the opportunity to *'be with other people to see how they respond to events as they happen and experiencing for oneself these events and the circumstances they give rise to'* (Emerson et al., 1995: 3). Doing ethnographic fieldwork allowed the sampling of high-risk interactions and recruitment of high-risk women/couples. Generating data through participant observation, rather than relying on interviews alone, provided valuable information about what sonographers and women/couples actually *did* and allowed me to assess the taken-for-granted everyday routines, the self-evident rationales of clinical practice, subtleties in the communication and body language. These are all different layers that make up FTS practices and that cannot be captured in interviews alone because they are tacit, taken for granted, forgotten, deemed irrelevant or simply impossible to put into words. Using fieldwork as a method generated a rich and complex understanding of the everyday routines and dramas at the ultrasound clinic. In Chapter 2, I introduced the methodological and theoretical considerations and decisions that shaped the process of data gathering. In this section of the concluding chapter, I shortly address how these decisions impacted the data material and results.

Of course, the decision to do fieldwork in the ultrasound clinic meant that I got a deeper insight into sonographers' practices and concerns than into the everyday lives of the participating women/couples, whom I only met at the hospital and possibly once or twice in

their homes for interviews. This corresponded with the research goals and has not affected the answering of the research questions, but, as Donna Haraway reminds us, we are always investigating the social world '*from somewhere*' (Haraway, 1991). Consequently we must describe and reflect on how our position influences our seeing. It is possible that the methodological choice to follow the sonographers has made me more sympathetic to their experiences and concerns as my understanding of their everyday life, concerns and rationales is necessarily 'thicker' (Geertz, 1973) than my relation to and knowledge of the participating women/couples.

Thus, the study and the results might have benefitted from participant observation in the women's/couples' homes and everyday lives following the high-risk FTS result and throughout the pregnancy in order to get a more comprehensive understanding of each woman/couples and their management of the FTS result. Doing so was not within the scope of the research project. However, during fieldwork I did consider the possibility of visiting the women/couples as they were waiting for final diagnostic results. In the end, I felt it unethical to intrude on the participants' lives in those short, stressful days of waiting, but it is also likely that it was my own discomfort that prevented me from pursuing that line of research.

Much of the analysis is based on written fieldnotes. In line with anthropological tradition, I relied on fieldnotes in order to document my observations and reflections in the field. Taking notes in medias res allowed me to shorthand conversations and interactions in great detail, but audio recording the FTS interactions would undoubtedly have added even more detail to my material. I disregarded audio recording during the first four months of fieldwork, because that would require a longer initial introduction to the couples prior to the FTS (about anonymity and safekeeping), and in my experience people sometimes feel uncomfortable and self-conscious with an audio-recorder on the table. I did not want to influence the FTS in this way. However, when I returned for additional fieldwork, I did audio record some genetic counselling sessions. For those more structured encounters, audio recording can be a valuable tool and something I will consider in future studies.

The sampling strategy meant that I consecutively recruited 21 high-risk women/couples to participate in the research. Ideally in qualitative research, the researcher purposefully samples participants; that is, she handpicks them with a view to assembling a group of participants covering the variety of different positions in a field. In reality, this is often not possible, and consequently the researcher must reflect on the make-up of the accomplished sample and its relation to the wider field of research. In this case, my presence at the FTS and

the shared experiences of the communication of the high-risk result, as well as my personal invitation, resulted in a high uptake; only one couple declined to participate. The remaining 20 women/couples had several possibilities for opting out of the research, but none of them did, and all agreed to be interviewed. Furthermore, the consecutive sampling reduced bias in recruiting, and the participating women/couples represent a range of positions in terms of age, education, prior pregnancy experiences and life trajectories that covers the different positions in the field adequately. There is, however, one important limitation: I did not observe any women/couples with an ethnic minority background who received a high-risk FTS result, and I did not include women who did not speak Danish.

Lastly, the study and its conclusions may have benefitted from a comparative approach. A parallel fieldwork at a smaller, regional hospital could have provided a valuable source of comparison. As mentioned in Chapter 2, doing qualitative research is potentially a never-ending endavour that must be deliberately delineated by the researcher. I decided to focus on the university hospital in order to get as large a sample of high-risk interactions and women/couples as possible.

Discussion of validity of qualitative results

Validity in qualitative research concerns the relationship between conclusions and the field/world under study as well as the correctness or credibility of these descriptions, interpretations and conclusions (Maxwell, 2013). It is the extent *'to which an account accurately represents the social phenomena to which it refers'* (Hammersley, 1990:57). Approaching the social world from a fluid ontology, entails that claims to validity in terms of 'objective truth' fall short, but reflexivity offers an alternative approach. As Hammersley & Atkinson (2007) argue, by engaging reflexively and by including our own role and systematically using it and reflecting on it, we can produce accounts of the social world and justify them without relying on references to positivism and objectivism. As mentioned in Chapter 2, transparency is essential when documenting these processes and consequently essential to the credibility and validity of qualitative research. It is important to note that transparency is not in itself a sign of good quality, but rather a *tool* allowing readers to estimate the quality and credibility of the research process, the material generated and interpretations made.

The main source for validating qualitative results – for increasing the likelihood of *'getting it right'* (Hastrup, 2003) – is a continuous testing of material and interpretations by giving them the chance to prove us wrong and to resist our preliminary interpretations (Maxwell, 2013; Seeberg, 2009). My long-term involvement produced rich and differentiated data, allowing me to observe rare moments and to get a full and revealing 'picture' of life at the ultrasound

clinic. Long-term involvement serves to *'rule out spurious associations and premature theories'* (Maxwel, 2013:126) and provides time and opportunity to develop and test alternative hypotheses.

Another way of validation qualitative results is through triangulation: *'the checking of the inferences drawn from one set of data sources by collecting data from others'* (Hammersley & Atkinson, 2007:183). It is a comparison of data (and interpretations) deriving from different methods, phases, positions and individuals in the field (Ibid.). As described in Chapter 2, I used *participant* triangulation by including and comparing accounts from different participants located differently in the field (different women, partners, sonographers, doctors). The long-term involvement gave me the opportunity to test and challenge data and preliminary interpretations through triangulation, which should not be confused with 'respondent validation' (Silverman, 2010). The latter concept is much debated with some checklists for qualitative research (e.g. COREQ) suggesting that transcripts should be returned to participants for correction (Tong et al., 2007). It has rightly been argued that participants do not have to agree with the analysis in order for it to be valid – participants do not have privileged access to the truth about their world and as such they can not validate qualitative findings (Bloor, 1978 in Silverman, 2010:236). However, checking and debating data and interpretations with participants can be valuable insofar as it will test opinions and experiences of the people studied and potentially lead to new interesting paths. I also performed 'triangulation in time', as I returned to some of the participants after they had given birth in order to check if their perspectives on the FTS had changed. The triangulation of *methods* – participant observation and interviews – also allowed resistance, e.g. when I used my observations and interpretations from fieldwork in the interviews. Finally, ongoing discussions with my supervisors served as a forum of *researcher* triangulation where different positions and scientific backgrounds (medicine, anthropology, political science) challenged my understandings and conclusions. During processes of analysis, I also used *theoretical* triangulation – using alternative interpretations or *'rival hypotheses'* (Maxwell, 2013:123) - as a way of theoretically trying to prove my interpretations wrong, e.g. by asking myself how the material would be interpreted from a feminist theoretical perspective.

Through detailed description of methods, considerations and limitations of the studies in this dissertation, I have aimed to share my reflections, convey the quality of my craftsmanship (Kvale & Brinkman, 200) and to make a case for the validity of the methods, the theoretical perspectives and the final conclusions presented in this dissertation.

Generalisability and transferability

Working in a setting dominated by a positivistic research tradition, I am often – and understandably - asked about the generalisability of results derived from qualitative research. Similar to the discussions of reliability and validity in qualitative research, the discussion of generalisability is often based on quantitative standards for quality, and - in the case of generalisability - the misconception that a qualitative study can and should be treated as if it was a sample of one drawn from a wider universe of such samples (Bryman, 1988).

Even though generalisability is not a primary concern within anthropology (Hammersley & Atkinson, 2007), it is nevertheless relevant to address how the results presented in this dissertation may extend beyond the specific participants and the particular ultrasound clinic. For this, the concept of 'transferability' is relevant (Kvale & Brinkmann, 2009; Selmer, 1998); Is the knowledge produced in one setting transferable to other, similar situations? This is also sometimes referred to as 'theoretical generalisation' (Selmer, 1998). I have provided a theory of the processes operating in clinical interactions following a high-risk screening result and while couples wait for diagnostic results. I have suggested that 'care' and 'collaboration' can be appropriate theoretical lenses for investigating clinical interaction, and I have argued in favour of coping strategies as a suitable approach for understanding waiting time. Based on the long-term involvement, richness of data, careful analysis and processes of validation, I argue that these results provide a potential explanatory theory for the experiences of others in similar situations. It may work well in some cases, and produce different outcomes under different circumstances, but the point is that the analytical perspectives (on clinical interaction as collaboration, on logics of care, on coping with worry) inspire to understand and analyse other situations in similar ways.

Maxwell (2013) suggests a more pragmatic approach to the general applicability of qualitative results called 'Face generalisability': Are there obvious reasons not to believe that results apply more generally? The clinical encounters explored in this dissertation may be a best case scenario, taking place at an ultrasound clinic at a university hospital with pronounced attention to good communication and patient involvement. The communication about high-risk is performed by the same sonographer who is responsible for the ultrasound examination, which gives the sonographer and the women/couple a common ground for communicating. By letting the sonographer present the result, the high-risk is staged as something less worrisome than findings demanding the attention of a doctor. This may influence the understandings, involvement and subsequent coping of the women/couples in this study. Furthermore, the women in this study are relatively well educated and, as stated in the introduction, their knowledge about the FTS is relatively high which may decrease

worry and anxiety. With relevant reservations regarding differences in hospital practices and in pregnant women's backgrounds, the findings of the qualitative studies may be transferable to relatively similar situations. However, qualitative inquiry cannot and should not permit the kinds of precise extrapolation of results to defined populations as provided by some types of quantitative research.

STRENGTHS AND LIMITATIONS OF THE LITERATURE REVIEW

The systematic literature review was focused on creating a transparent overview of a relatively narrow topic, namely the relation between prenatal screening and levels of anxiety in women with a negative or false positive screening result. The aim was to provide an input into the debates on consequences of prenatal screening. Inclusion of qualitative studies potentially could have added other dimensions of women's experiences to the review, but since review methods for quantitative and qualitative studies differ substantially, we made the decision to focus on providing a thoroughly prepared quantitative review with a solid and well-structured overview of existing studies.

In assessing the level of evidence in the included studies, we used the National Board of Health checklists (Danish National Board of Health, 2014). We subsequently summarised and estimated the level of evidence for different outcomes (e.g. anxiety following a normal screening result) based on the quality of the studies reporting these outcomes. This is approximately the same approach as GRADE (Guyatt et al., 2011), and looking back, using GRADE to systematically assess the evidence for the different outcomes and produce a meta analysis of the data could have strengthened the review even further.

FUTURE PERSPECTIVES (I): SUGGESTIONS FOR FURTHER RESEARCH

The present dissertation offers insight into the clinical encounter between sonographers and women/couples with a high risk screening result. However, there are still many areas of research that should be explored further. Such explorations could serve to test and challenge the findings of this dissertation as well as to explore relevant areas of interest that I have been unable to address within the scope of this dissertation. I propose two areas of research in particular: People and phenomena.

There are a number of groups that are overlooked in present research that deserves scientific attention through explorative, qualitative investigation:

- *Women/couples who decline invasive testing*: Three of the participating women/couples declined invasive testing, and in subsequent interviews two of the couples reported that the high-risk result had caused them to worry during pregnancy. This stands in contrast to the women/couples in the study who accepted diagnostic testing and who – following a normal diagnostic result – reported that the high-risk did not subsequently influence their pregnancy. Approximately 15% of high-risk women/couples decline invasive diagnostics, and we need to deepen our understanding of their experiences and concerns in order to better support them in their decision.

- *Women/couples with an ethnic minority background*: The material for this dissertation does not include clinical encounters between sonographers and women/couples with an ethnic minority background. Approximately 11% of the Danish population is of an ethnic minority background (Statistics Denmark, 2014), and thus it is relevant to explore the experiences and concerns of these women/couples and investigate how clinicians provide information to and care for them. Such an investigation would provide an opportunity to test and challenge the theoretical approach of logic of 'choice' and 'care' in a different setting. A particularly interesting subgroup would be those women/couples with no or limited language proficiency in Danish who rely on family members or fragments of broken Danish to communicate.

- *Women/couples who receive an abnormal diagnostic result*: I interviewed five women/couples with an abnormal diagnostic result and first of all became aware of how sad and difficult this situation is no matter what; and second, how many different ways of responding to it there is. We need a thorough and explorative longitudinal investigation of the experiences, concerns and decisions following an abnormal diagnostic result. This study should include the women/couples participation in clinical encounters (including delivery of result to the woman/couple) and participant observation in their everyday life. The study should ideally include both women/couples who decide to terminate the pregnancy, and women/couples who decide to continue. The results would provide valuable information, not only to the clinicians responsible for these women/couples, but also to women/couples in similar situations requesting experiential information.

- *Women/couples, being continuously and routinely monitored for other risks than FTS, e.g. risk of restricted intrauterine growth*: From an analytical perspective these women are subject to considerable medical surveillance and processes of medicalisation, but how do they experience that? How are they met in the clinic, and how does it affect pregnancy to be constantly monitored? Research on these matters would be an opportunity to further investigate the intermingling of knowledge and uncertainty, of feeling safe and feeling worried during pregnancy and to call analytical attention to the more routine and mundane aspects of obstetric ultrasound and clinical interaction.

In addition to research on the experiences and actions of specific groups of women/couples, the findings of this dissertation also point to specific prenatal screening related phenomena that deserve scientific attention:

- *Processes of biomedical knowledge production and diagnosis*: Obstetric ultrasound is not an exact science, but depends on the clinicians' technical competence, personal experience, the quality of the images and the current state of available biomedical knowledge with which these images can be interpreted. Furthermore, it is performed in front of a live audience of attentive parents-to-be. Under these circumstances, how is information about the fetus produced? How do clinicians discern and determine relevant and irrelevant findings? And how are decisions about what to share (and not to share) with the pregnant woman/couple made? This could be a site for further investigation into the role of the 'logic of care' in diagnostic practices.

- *Worry*: It has been suggested that pregnant women are expected to worry and to express appropriate levels of concern (some, but not too much) about their own and the fetus' health as a part of 'doing' pregnancy (Lupton, 2013). During fieldwork I experienced clinicians' concerns with introducing 'unnecessary' worry and women's/couples' strategies for managing worry. On the basis of this, I suggest a further exploratory investigation of 'worry' as a socially constructed and legitimised/legitimising concept that shapes pregnancies and clinical interactions in specific ways.

- *Discourse*: During the work of this dissertation, I was struck by the multiple and sometimes uneasy and conflicting discourses surrounding prenatal screening. Ideas and ideals of women's reproductive autonomy, of an inclusive and multifarious society, of Down's syndrome and eugenics, of the welfare state and the quality of life; all influence the way prenatal screening can be understood, communicated and

practiced. A discourse analysis on prenatal screening (e.g. inspired by Gottfredsdottir et al., 2010) would provide useful insight into the discrepancies and discomforts that shape public debate and opinion. Standing on the brink of the implementation of non-invasive prenatal testing, it would be relevant to investigate how it has been introduced and staged discursively.

FUTURE PERSPECTIVES (II): CLINICAL IMPLICATIONS

In this final section of the dissertation, I summarise the findings which are most relevant for the development of clinical practices. They should be considered 'food for thought' rather than bulletproof recommendations, and they should be developed further and shaped in dialogue with sonographers and obstetricians.

The studies performed and questions addressed in this dissertation all relate to the expectation formulated by the pregnant woman quoted in the preface: *'I definitely expect that someone will be there to catch me.'* The studies in this dissertation suggest that this expectation is being met. First of all, there is a support system in place, and clinicians are ready to 'catch' the high-risk women/couples with empathetic information, professional procedures and fast turnaround times for diagnostic results. Second, the participating women/couples were actively 'catching themselves' by engaging with clinicians and the available information in order to piece together their own understandings and management strategies. Overall, the findings suggest that doing 'the best good' in the wake of a high-risk FTS result is a collaborative effort and turns our attention to how clinicians may best support such collaboration.

First of all, the findings demonstrate how informed choice is an inadequate model for understanding and discussing the complexities of clinical interaction in a prenatal screening setting. 'The logic of care' offers a supplementary language that is able to encompass the collaborative, caring and subjective aspects of communication about high risk results. The caring practices identified in the qualitative study are not in opposition to informed choice, but rather support and fill in the gaps that allow choice to be practiced. The findings demonstrate the importance of care – sharing responsibilities with the patients, providing possible interpretations, making reassuring comments – and show how these practices do not contrast with autonomous decision-making or preclude the women/couples from making their own decisions. I hope that these findings will promote a more nuanced

dialogue, where the complexity and flexibility of clinical interaction will be addressed as more than a matter of either living up to or failing to perform non-directiveness and autonomous decision-making.

Second, the findings demonstrate the active, knowledgeable and creative ways in which women/couples manage and negotiate a high-risk screening result. First, in collaboration with the sonographer; and second, while waiting for diagnostic result. With the clinical focus on decision-making, the subsequent gap between decision and final result has received less attention. The findings are of clinical interest for mainly two reasons. First, the results show the importance pregnant women/couples place on the positive comments from and reassuring attitudes of sonographers and obstetricians. In cases where the outcome of the diagnostic testing is most likely normal, clinicians can adopt a reassuring attitude and point to the positive aspects and normal findings of the ultrasound examination and test procedure. In this way clinicians may support an appropriate way of coping with worry and waiting. Second, the results show that mentally *putting the pregnancy on hold* is not a coping strategy used by the participating women/couples. While recognising that some women may employ this strategy (some of the time), the analysis argue in favour of a more complex understanding of worry as being managed through a diverse range of practical and emotional strategies that change and interlace during the process of waiting for diagnostic results. The findings indicate that sonographers and obstetricians can effectively support high-risk women/couples by addressing waiting time. Clinicians can encourage couples to seek their own personal understandings and management strategies as a way to gain some control in an uncertain situation.

And finally, the results can be seen as a response to the clinical concerns about inducing unnecessary worry in pregnant women/couples. The high-risk FTS result does initially generate worry and sadness. However, research indicates that worry may be an uncomfortable but appropriate response in a situation where the stakes are high, and the findings show that women/couples are not unprepared for dealing with worry and uncertainty in general. The studies in this dissertation emphasize that a normal diagnostic result alleviates the worries caused by a high-risk FTS result. In subsequent interviews, the participating women/couples accentuated the fast response time and the conclusiveness of the answer as central to their capacity for leaving behind worry and uncertainty about chromosomal abnormality. Of course, special attention should be given to those women/couples who experience inappropriately high levels of worry and anxiety, but the findings indicate that to the majority, a high-risk screening result does not generate worry beyond levels that are acceptable and manageable. None of the interviewed women/couples

regretted having the FTS, and all of them expected to have an FTS in a possible future pregnancy.

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ENGLISH SUMMARY

ENGLISH SUMMARY

In Denmark, all pregnant women are offered a first trimester prenatal screening (FTS) for Down's syndrome and other chromosomal abnormalities. The FTS is performed at the first trimester ultrasound examination, and widely accepted as an integral part of the prenatal care. Approximately 5 % of the screened women receive a 'high risk' FTS result. It is well documented that pregnant women and their partners are often unprepared for the complex information and decision-making that follows in the wake of such an outcome. The woman/couple is offered invasive diagnostic testing, which provides a definitive answer regarding chromosomal abnormalities, but also involves a ½ -1% risk of procedure-related miscarriage. Thus, the woman and her partner must consider uncertainties about the health of their baby against the procedure-related risk of miscarriage. In the end, they must decide for or against diagnostic testing. A high-risk FTS result also places much responsibility on the clinicians – sonographers and obstetricians - who must communicate the high-risk result and present the options available in a thorough and neutral manner. It has been 10 years since the FTS was nationally implemented in Denmark, however, we still lack knowledge about the clinical interactions following a high-risk FTS result. How do clinicians, pregnant women and their partners manage and negotiate a high-risk screening result for chromosomal abnormality in the fetus?

Applying an anthropological perspective, the aim of this PhD dissertation has been to explore how a high-risk FTS result is managed and negotiated; first, in clinical interactions between clinicians (sonographers) and women/couples; and second, while the women/couples are waiting for diagnostic results. A third aim of the dissertation is to investigate whether prenatal screening causes anxiety in women with a negative or a false-positive FTS result.

The dissertation is based on qualitative data material generated during a total of 5 ½-months ethnographic fieldwork in an obstetric ultrasound clinic at a university hospital in Denmark. During this period, more than 400 FTSs was observed and qualitative interviews were conducted with seven sonographers and 20 women/couples with a high-risk FTS result. To answer the third aim, a systematic literature review was performed.

The results of this dissertation show that pregnant women and their partners feel sad and worried upon receiving a high risk screening result. The analysis demonstrates the collaborative efforts of sonographers and women/couples to transform the statistical FTS risk

into a meaningful and manageable understanding. This process of interpretation creates a platform from where a decision regarding invasive testing can be made. It is central to the analysis, that the sonographer and the women/couples draw on the same agendas and discourses in their interpretations of the FTS result, and that the clinical interactions are guided towards the woman/couple making their own, thoughtful decision. The majority of the women/couples decided to have invasive testing. The analysis shows that waiting for the final diagnostic results is an intermediate period, where worries about potential miscarriage and the uncertain future linger. During this period, the couples actively piece together their personal coping strategies, aimed at controlling worry, passing time and keeping up hopes of a good result. None of the women/couples in the study regretted having FTS and all of them expected to have FTS in a future pregnancy. Lastly, a systematic review of the current scientific literature indicates that participating in FTS does not cause anxiety in women receiving a screen-negative result. Women receiving a screen-positive result experience acute increase in anxiety, however upon receiving a normal diagnostic result, these women return to same anxiety level as screen-negative women.

Overall, this PhD dissertation document the significant ways in which statistical risk and concomitant uncertainty and worry are caringly and creatively managed and negotiated following a high-risk screening result. Consequently, the results contribute to nuanced perspective on prenatal screening in Denmark.

DANSK RESUME

DANSK RESUME

I Danmark tilbydes alle gravide kvinder i første trimester en prænatal screening (FTS) for Down's syndrom og andre kromosomafvigelser hos fosteret. FTS foretages under 'nakkefoldsscanningen', ultralydsundersøgelsen i første trimester, der er bredt accepteret som en integreret del af de prænatale omsorgstilbud. For ca. 5 % af de screenede gravide viser undersøgelsen at der er 'høj risiko' for kromosomafvigelser, og resultatet præsenteres for kvinden/parret som en statistisk sandsynlighed. Flere studier viser, at gravide og deres partnere ofte er uforberedte på et sådant udfald og på den komplekse situation, det bringer dem i. Kvinden/parret tilbydes invasiv diagnostik, der kan give entydigt svar på eventuelle kromosomafvigelser, men den indebærer også en procedurerelateret risiko for abort på ½ -1 %. Kvinden/parret står således over for en potentielt vanskelig beslutning, hvor usikkerhed omkring fosterets helbred skal afvejes mod bekymringen for procedurerelateret abort. Et højrisiko resultat stiller også store krav til de sundhedsprofessionelle, som skal kommunikere screeningsresultatet og de diagnostiske muligheder på en fyldestgørende og neutral måde. I Danmark har man tilbudt gravide FTS i mere end 10 år, men vi mangler stadig viden om, hvordan sundhedsprofessionelle og gravide kvinder/par faktisk forstår og håndterer et FTS-screeningsresultat, der viser høj risiko for Downs syndrom eller andre kromosomafvigelser.

Formålet med denne ph.d.-afhandling har derfor været, fra en antropologisk vinkel, at undersøge, hvordan et højrisiko-screeningsresultat fortolkes og forhandles; først i den kliniske interaktion mellem sundhedsprofessionel (sonograf) og gravid kvinde/par; og dernæst, mens kvinden/parret venter på de diagnostiske resultater af den invasive test. Et tredje formål med afhandlingen har været at undersøge, om prænatal screening skaber angst hos gravide kvinder med et negativt eller falsk-positivt screeningsresultat.

Denne ph.d.-afhandling er baseret 5 ½ måneders etnografisk feltarbejde på en obstetrisk ultralydsafdeling på et universitetshospital i Danmark. Feltarbejdet gav mulighed for deltagerobservation – herunder observation af mere end 400 nakkefoldsscanninger. Endvidere blev der gennemført dybdegående, kvalitative interviews med syv sonografer og med 20 kvinder/par, der havde fået et højrisiko FTS-resultat under mine observationer. Til besvarelse af forskningsspørgsmål 3 blev der udført en systematisk litteraturgennemgang.

Afhandlingens resultater viser, at et højrisiko FTS-resultat gør gravide kvinder og deres partnere både triste og bekymrede. Resultaterne viser, hvordan kvinden/parret og sonografen i fællesskab afprøver forskellige forståelser og fortolkninger af den statistiske

risikovurdering. I denne proces gøres risikovurderingen meningsfuld og håndterbar for kvinden/parret og muliggør, at de kan træffe et valg angående invasiv diagnostik. Det er centralt i analysen, at sonografer og kvinder/par trækker på de samme dagsordener og diskurser i deres fortolkninger af FTS-resultatet, og at interaktionen er rettet imod, at den gravide og hendes partner skal tage et selvstændigt, velovervejet valg. De fleste kvinder/par vælger at få foretaget invasiv diagnostik. Mens de venter på det endelige resultat, oplever de en fortsat bekymring – både omkring fosterets helbred og om risikoen for spontan, procedure-relateret abort. Afhandlingens resultater viser, hvordan kvinderne/parrene håndterer ventetiden og bekymringen ved aktivt at sammenstykke deres personlige forståelser og handlestrategier. Rationalet bag disse strategier er at kontrollere bekymringen og holde fast i troen på et godt, normalt udkomme. Ingen af parrene i analysen fortryder at have fået FTS, og alle parrene forventer at ønske FTS i en eventuel fremtidig graviditet. Den sidste del af afhandlingen er en systematisk litteraturgennemgang af den aktuelle evidens for sammenhængen mellem screening og angst. Litteraturen peger på, at gravide, som tilbydes og deltager i FTS, og som får et normalt screeningsresultat, ikke oplever øget angst. Hos kvinder med et højrisiko-screeningsresultat ses en signifikant stigning i deres angstniveau, men efter et normalt diagnostisk resultat falder disse kvinders angstniveau til samme niveau, som hos kvinder med et normalt screeningsresultat.

Samlet set bidrager denne ph.d.-afhandling med et nuanceret perspektiv på prænatal screening i Danmark. Den demonstrerer de betydningsfulde måder, hvorpå statistisk risiko og den medfølgende usikkerhed og bekymring, kreativt og omsorgsfuldt forvaltes og forhandles af både gravide kvinder/par og de sonografer og obstetrikere, som de møder i klinikken.

APPENDICES

APPENDIX 1: ADDITIONAL PAPER

Lou S, Dahl K, Uldbjerg K. Screening kan give både tryghed og ængstelse – eksempelvis ved screening for Downs syndrom. Ugeskrift for Læger 2014;176:122-5.

sesarbejdet, da den ikke på samme måde indeholder direkte konfrontation med patienter, der lider af en given sygdom. Man bør dog være opmærksom på, at sundhedsøkonomisk analyse af forebyggelsestiltag næsten altid vil være baseret på modelberegninger med relativt lang tidshorisont. Disse modeller er ofte så komplekse, at selv erfarne analytikere kan have meget vanskeligt ved at gennemskue beregningerne. Derfor skal sundhedsøkonomiske beregninger udføres med samme omhu, åbenhed og uvildighed som de kliniske studier, da mulighederne for at fordreje analysens resultater er relativt stor. Endvidere er det vigtigt at være opmærksom på, at resultaterne af de økonomiske analyser meget direkte hviler på det kliniske grundlag. Hvis dette er usikkert, vil resultaterne af de sundhedsøkonomiske analyser blive mindst lige så usikkert, da forskellen i de fremtidige omkostninger også er baseret direkte på den modellerede kliniske effekt af screeningsprogrammet.

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Screening kan give både tryghed og ængstelse – eksempelvis ved screening for Downs syndrom

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Det er nu ti år siden, at Sundhedsstyrelsen udsendte nye retningslinjer for fosterdiagnostikken [1]. Dermed sikredes et landsdækkende og ensartet prænatalt tilbud til alle gravide kvinder, herunder et tilbud om førstetrimestersrisikovurdering for Downs syndrom. Tilbuddet blev modtaget godt, og i dag deltager næsten 93% af de danske gravide [2]. En nyligt publiceret undersøgelse viste endvidere, at 97% havde en positiv holdning til risikovurderingen [3].

Som med andre screeningstilbud er også tilbuddet om screening for Downs syndrom genstand for tilbagevendende debat. Der sættes i medier, i professionelle fora og fra interesseorganisationers side løbende spørgsmålstegn ved screenings individuelle og samfundsmæssige konsekvenser [4, 5]. Et centralt tema er, om tilbud om screening skaber tryghed og ro, eller om det i højere grad skaber bekymring og ængstelse ved at sætte fokus på risikoen for, at der kan være noget galt?

Et andet tema er de mulige konsekvenser af et såkaldt falsk-positivt screeningsresultat. Blandt de gravide, som bliver screenet positivt (høj risiko), er det kun hos få (ca. 5%), at der efterfølgende konstateres kromosomfejl hos fosteret [2, 6]. Det vil sige, at langt de fleste screeningspositive gravide kan nøjes med forskrækkelsen – et falsk positivt screeningsresultat. Selvom det endelige udfald altså er normalt, diskuteres det løbende, om en sådan unødig forskrækkelse giver en vedvarende øget bekymring?

Formålet med denne statusartikel er – med screening for Downs syndrom som eksempel – at sætte fokus på de individuelle konsekvenser af screening. Vi adresserer i denne artikel screeningstilbuddet, som det ser ud for størstedelen af den gravide befolkning – nemlig dem, der får et negativt eller et falsk-positivt screeningsresultat – og spørger: Hvad betyder tilbuddet om screening for Downs syndrom for gravides oplevelse af tryghed og ængstelse?

TILBUD OM SCREENING FOR DOWNS SYNDROM

Ved første svangrekonsultation hos egen læge informeres den gravide kvinde om muligheden for at få foretaget en risikovurdering (screening) for Downs syndrom hos fosteret. På baggrund af den gravides al-

der, en blodprøve (dobbelttest: *pregnancy-associated plasma protein A* og beta-humant choriongonadotropin) og en ultralydundersøgelse af fosterets nakkefold (nakkefoldsskanningen) beregnes en statistisk risiko for visse kromosomfejl hos fosteret, herunder Downs syndrom. Er risikoen større end 1:300, tilbydes der en invasiv, diagnostisk undersøgelse (moderkageprøve). Den invasive diagnostik indebærer en risiko for procedurerelateret abort (½-1%), hvilket den gravide informeres om. Der går ca. en uge fra et højrisikoscreeningsresultat, til resultatet af moderkageprøven foreligger – ofte mindre. Hvis der påvises kromosomfejl, har den gravide mulighed for at ansøge om provokeret abort (efter uge 12).

GRAVIDITET UDLØSER MANGE FØLELSER

En graviditet er en tid, der er præget af følelsesmæssige, fysiske og sociale forandringer [7]. I den tidlige graviditet kan der være både bekymringer om risikoen for spontan abort og en række individuelle og eksistentielle overvejelser i forbindelse med at bringe nyt liv til verden: Hvordan vil det gå? Hvordan vil det påvirke mig og mit liv? Er det det rigtige tidspunkt?

Karakteren af disse bekymringer og overvejelser varierer fra kvinde til kvinde og er under indflydelse af tidligere erfaringer – studier viser, at bl.a. alder, uddannelsesniveau og paritet kan have indflydelse på gravides angstniveau [8]. Fra den kliniske hverdag ved vi jo også, at der ganske enkelt er forskel på menneskers personlighedstræk [9], hvor nogle er optimistiske og fulde af tillid til fremtiden, er andre mere disponerede for bekymring og ængstelighed. Ydermere er det vigtigt at huske, at de fleste gravide oplever både glad forventning og øget bekymring i løbet af deres graviditet – de sindstilstande går hånd i hånd [7].

Forskningsmæssigt har der været stor fokus på graden og betydningen af ængstelse under graviditeten. Flere studier viser, hvordan gravides angstniveau følger en U-formet kurve, hvor ængstelsen er størst tidligt og sent i graviditeten [10]. Der kan imidlertid være en tendens – i den videnskabelige litteratur såvel som i medierne – til implicit og a priori at antage, at en øget ængstelse er unormal og uhensigtsmæssig i en graviditet. I flere studier peger man dog på, at en let øget affekt er hensigtsmæssig, når mennesker skal træffe betydningsfulde valg [11, 12]. I dette perspektiv er en grad af usikkerhed eller nervøsitet ikke nødvendigvis noget, vi som klinikere må gøre alt for at afhjælpe eller eliminere, men snarere et godt tegn på, at den gravide er i en livsforandrende situation, hvor der er meget på spil, og hvor hun er optaget af at træffe gode beslutninger for sig selv og sit ufødte barn. En af disse beslutninger vedrører deltagelse i screening for Downs syndrom.

At se det lille foster er en kilde til både glæde og bekymring hos vordende forældre.

GIVER INFORMATION OM SCREENING EN ØGET BEKYMRING?

En central del af screeningstilbuddet er, at den gravide skal informeres neutralt og fyldestgørende for på et informeret grundlag at kunne træffe beslutning om, hvorvidt det er en undersøgelse, hun ønsker. Tidligere har man forskningsmæssigt været optaget af, om information om fosterundersøgelser påvirkede den gravide og gjorde hende bekymret, men generelt har man ikke i studierne fundet nogen sammenhæng mellem viden og nervøsitet [11, 13]. Tværtimod viser studier, at velinformerede gravide er mindre i tvivl om deltagelse i screeningsprogrammer [14].

Flere danske undersøgelser viser, at langt størstedelen af de gravide deltager på et informeret grundlag [3, 14].

HVORFOR VÆLGER GRAVIDE SCREENING?

Gravide kvinder deltager i screening for Downs syndrom af mange grunde. I flere studier peger man på, at gravide kvinder oplever tilbuddet om screening som en integreret del af den prænatale omsorg. De håber og forventer, at nakkefoldsskanningen vil give dem en generel forsikring om, at fosteret ser normalt ud, og at graviditeten udvikler sig, som den skal [15, 16]. En anden vigtig motivation er, at den gravide simpelthen glæder sig til at se barnet og til at dele oplevelsen med faderen [17, 18]. Når gravide vælger screening for Downs syndrom, er bekymring for sygdom kun en del af et mere komplekst billede, hvor også glæde ved graviditeten, forestillingen om et fremtidigt familieliv og forventning om tryghed spiller ind.

GIVER NORMAL RISIKOVURDERING ØGET TRYGHED?

De gravide, som vi møder i ultralydafdelingen på vej til nakkefoldsskanning, udstråler alt fra spændt og ubekymret forventning til koncentreret og fåmælt nervøsitet. Men når de en lille halv time senere kommer ud fra ultralydundersøgelsen, er de oftest smilende og synligt lettede.

FAKTABOKS

Bekymring er en af de følelser, gravide går igennem, og det er ikke nødvendigvis dårligt.

At takke ja til screening handler om mere end angst for sygdom – det handler også om glæde og fremtiden som familie.

Screeningsundersøgelser med normalt resultat giver øget tryghed.

Angstniveauet hos gravide, der er screenet falsk positive, vender tilbage til samme niveau som hos gravide med et negativt screeningsresultat.

Der findes efterhånden talrige undersøgelser, der samstemmende dokumenterer den tidlige ultralydskannings betydning for den gravide kvinde og hendes partner. Når undersøgelsesresultatet er normalt, bidrager skanningen til at gøre graviditeten mere virkelig [19], til en øget følelse af tilknytning til foster og partner [19-21] og til at skabe vished for, at det ventede barn ser ud til at udvikle sig normalt [22, 23].

Et normalt screenings- og skanningsresultat i første trimester er jo ikke en garanti for et sundt barn, og det ved de fleste gravide godt [14]. Men det opleves som en milepæl i graviditeten, der giver tryghed i en situation fuld af forandring og uforudsigelighed.

HVILKE FØLELSER UDLØSER EN FORHØJET RISIKO?

Inden nakkefoldsskanningen er de gravide af egen læge og skanningspersonalet blevet informeret om og forberedt på risikoen for et screeningspositivt resultat. Dette forhindrer dog ikke, at langt de fleste gravide (og deres partnere) bliver både rystede, kede af det og bekymrede, når screeningen viser forhøjet risiko. Flere studier viser da også en signifikant stigning i de gravides angstniveau efter et screeningspositivt resultat [24, 25]. Andre studier viser, at gravide i denne situation kan have vanskeligt ved at forholde sig til selve det statistiske risikoestimat [26, 27], og at den oplevede risiko bl.a. afhænger af sundhedspersonalets kommunikation og af den gravides personlige resurser og erfaringer [28]. Bekymringen for, at der kan være noget i vejen med barnet, kompliceres yderligere af den lille risiko for abort, som er forbundet med moderkageprøven, hvilket for nogle gravide opleves som et vanskeligt dilemma.

KAN DIAGNOSTISK UNDERSØGELSE SKABE TRYGHED?

På trods af abortrisikoen vælger langt hovedparten af de screeningspositive gravide at få foretaget en moderkageprøve. En væsentlig årsag er, at risikoen entydigt kan afklares og erstattes med sikkerhed for, om fosteret har Downs syndrom eller ej. Det er klart, at ventetiden på det diagnostiske resultat er en tid, hvor både bekymring for fosterets sundhed og bekymring for abort kan fylde meget, og hvor nogle måske sætter graviditeten på standby [29].

Til gengæld tyder litteraturen på, at falsk positive gravide tager det gode svar om normale kromosomer til efterretning. I studier af sammenhængen mellem screening og angst har man fundet, at screeningspositive gravide efter et normalt diagnostisk resultat falder tilbage til det samme angstniveau som screeningsnegative kvinder [25, 30].

DISKUSSION

I litteraturen peges der på, at bekymring er en integreret del af de mange følelser, som gravide kvinder håndterer under en graviditet. En let øget bekymring, nervøsitet eller opmærksomhed er ikke nødvendigvis uhensigtsmæssig eller uønsket, men derimod et resultat af den særlige omstændighed, som en graviditet er. Når gravide takker ja til at blive screenet for Downs syndrom, handler det ikke blot om bekymring for sygdom, det handler også om forventningens glæde og om at få bekræftet fremtiden som forældre. Når screeningsresultatet er normalt, bidrager det til en øget tryghed og større tilknytning til fosteret. Et screeningspositivt resultat skaber øget bekymring, men resultaterne af studier indikerer, at angstniveauet hos gravide, der er skannet falsk positive, falder til samme niveau som angstniveauet hos gravide med et negativt screeningsresultat.

Som med andre screeningstilbud munder det endelige resultat af screening for Downs syndrom således ud i en afklaring for langt hovedparten af deltagerne. For alle screeningsundersøgelser gælder det imidlertid, at der vil være en lille gruppe, for hvem tilbuddet resulterer i uklare fund. I forhold til prænatal screening er f.eks. fund af en særlig tyk nakkefold problematisk. Selv hvis en opfølgende moderkageprøve viser normal kromosombesætning, er den tykke nakkefold fortsat associeret til øget risiko for f.eks. føtale hjertemisdannelser. Vi tilbyder derfor at følge den gravide i trinvis afklaring helt frem til uge 20. Og selv da er vi nogle gange i tvivl om prognosen. Det er en meget lille gruppe, men den udgør en særlig vanskelig og kompleks problemstilling – både for lægen og for den gravide, som ofte vil opleve en stor og velbegrundet angst. Med udviklingen af nye teknologier – som f.eks. måling af frit føtalt DNA – bliver vi potentielt endnu mere præcise og detaljerede i den primære opsporing af mulig sygdom. Det forventes at komme flertallet til gavn, men problematikkerne om uklare fund vil formentlig fortsat være en iboende del af screeningen.

Med denne artikel har vi påvist, at tryghed og ængstelse følges ad i en graviditet, og at deltagelse i screening kan bidrage til begge dele. Langt de fleste af de ovenfor diskuterede faktorer har ækvivalenter i andre screeningsprogrammer, hvorfor erfaringerne

fra denne meget store og ret homogene population formentligt kan bidrage til evaluering af andre screeningsprogrammer, ligesom det prænatale screeningsprogram kan høste af erfaringerne fra andre screeningsprogrammer.

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APPENDIX 2: WRITTEN INFORMATION

Du/I får denne informationsskrivelse, fordi resultatet af din nakkefoldsskanning har vist forhøjet risiko for Downs syndrom . Du/ I har fået et tilbud om yderligere undersøgelser og / eller samtaler. Med denne informationsskrivelse præsenteres et forskningsprojekt, som vi vil spørge om du/I vil deltage i.

Jeg hedder Stina Lou. Jeg er antropolog og ph.d.-studerende ved Sundhedsvidenskabeligt Fakultet, Aarhus Universitet. I samarbejde med Aarhus Universitetshospital Skejby er jeg i gang med et forskningsprojekt om, hvordan gravide og personale kommunikerer og træffer beslutninger - i forbindelse med nakkefoldsskanninger og ved opfølgende undersøgelser efter nakkefoldsskanninger, der viser forhøjet risiko for Downs Syndrom.

Jeg vil gerne bede om lov til at sidde med ved de opfølgende undersøgelser og samtaler på Skejby, som du/I vil blive tilbudt i den kommende tid. Jeg vil hverken bidrage til eller blande mig i undersøgelserne eller din/jeres dialog med sundhedspersonalet. Mit fokus er på samspil og kommunikation mellem sundhedspersonalet og dig/jer, så jeg vil blot følge jeres samtale på sidelinjen og evt. notere lidt.

På et senere tidspunkt vil jeg gerne interviewe dig/jer om, hvordan du/I har oplevet undersøgelserne/ samtalerne med sundhedspersonalet. Jeg er interesseret i, hvad der har været vigtigt for dig/jer i dette forløb. Et interview varer ca. en time og kan foregå på Skejby eller hjemme hos dig/jer. Efter interviewet vil jeg bede om lov til evt. at kontakte dig/jer senere for endnu et interview.

Notater fra observationsstudier og interviews behandles fortroligt og vil blive anonymiseret, så du/I ikke kan genkendes i de endelige forskningsresultater. Resultaterne vil blive samlet i en ph.d.-afhandling, som foreligger ultimo 2014. Allervigtigst skal forskningsresultaterne give sundhedspersonalet mere viden om, hvordan de bedst informerer, støtter og vejleder gravide og partnere i en vanskelig situation.

Hvis du/I har spørgsmål eller overvejelser i forhold til at lade mig sidde med ved din/jeres undersøgelse(r), er du/I altid velkomne til at ringe til mig (også udenfor almindelig arbejdstid). Jeg kan træffes på mobil: XXXX XXXX. Læg evt. en besked, så ringer jeg tilbage.

Jeg vil kontakte dig/jer i venteværelset inden din/jeres næste aftale på Skejby for at høre, om du/I vil deltage i forskningsprojektet.

Du/I kan til enhver tid trække et evt. tilsagn om deltagelse tilbage uden at det får indflydelse på behandlingen af dig/jer og dit/jeres barn.

Med venlig hilsen
Stina Lou
Ph.d.-studerende, antropolog.

APPENDIX 3: INTERVIEW GUIDE, SONOGRAPHERS

Intro:
Noget jeg har glædet mig til ☺
Stil endelig spørgsmål til mig og ret mig endelig, hvis der er noget jeg ikke har forstået eller ikke er opmærksom på
Interviewet indgår i datamaterialet – hvis jeg bruger citater bliver de anonymiseret.
Publicering og endelig afhandling – tilbud om at få den tilsendt

Spørgsmål inden vi går i gang?

Om at være sonograf
Hvor længe har du været sonograf?
Kan du ikke starte med at fortælle mig, hvorfor du blev sonograf?

Hvad kan du rigtig godt lide ved dit job?
Hvornår synes du at dit job er vanskeligt?

Nakkefoldsscanninger, generelt
Synes du, at det er en god ide at tilbyde gravide en nakkefoldscanning og en risikovurdering for Downs Syndrom? Hvorfor / hvorfor ikke?

Ved du noget om, hvad det vil sige at have et liv med Downs Syndrom?

Nogle par vil gerne have en scanning, men ikke en risikovurdering. Hvad siger du til den beslutning?
Hvilke udfordringer giver det dig som sonograf?

Nakkefoldsscanninger, konkret
De fleste par som kommer til nakkefoldsscanningen vil jo gerne have en risikovurdering. Nu skal vi tale om dem.

Hvordan forbereder du dig inden du skal møde parret?
- Hvorfor er det rart for dig at vide / være forberedt på?

Er der noget særligt du lægger mærke til, når du hilser på den gravide / parret?

Hvad gør du, når I er kommet ind på stuen?
Hvordan informerer eller præsenterer du scanningen og risikovurderingen for parret?
- Hvad lægger du vægt på? Hvorfor / hvorfor ikke?
- Er denne indledende information vigtig? Hvorfor / hvorfor ikke?

Oplever du, at de gravide er bekymrede for om deres foster er sygt?

Nu ligger den gravide på lejet og du sætter proben på – kan du ikke prøve at forklare mig, hvordan du arbejder? Hvad kigger du efter og hvilke overvejelser gør du dig undervejs?

- Hvad er de scanningsmæssige udfordringer ved at lave en nakkefoldsscanning
- De fleste par vil jo gerne have et billede: Hvad prøver du at få med, når du tager et billede til parret?

Hvad synes du er vigtigt i din kommunikation med den gravide?
Hvad er partnerens rolle under scanningen?

De fleste par går jo glade fra nakkefoldsscanningen med besked om, at de er i normal lav risiko – Hvad er det for en følelse du håber at de par går herfra med?

Når fosteret er synligt sygt / har tyk nakkefold
De fleste af de scanninger som jeg har været med til, der ved vi jo først at der er forhøjet risiko, når alle tallene er lagt sammen. Men ind i mellem så kan I jo på scanningsbillederne se, at alting måske ikke er helt som det skal være. Måske fordi nakkefolden er synligt 'for tyk' eller fordi der er noget andet, som fanger din opmærksomhed. Kan du ikke prøve at fortælle mig om den sidste situation du kan komme i tanke om, hvor det skete for dig.

Jeg har lagt mærke til at sonografen kan blive lidt stille, når det muligvis er noget galt. Man taler ikke så meget om, at den lille ligger og vinker og den slags. Er det noget du kan genkende? (Om at gøre rutcheturen kortere / om ikke at få sagt mere end man kan trække i land)

Ved en fortykket nakkefold, det kan der jo måske være noget og måske er der ikke noget. Hvad lægger du vægt på, når du prøver at formidle det?

Jeg har lagt mærke til at disse par ikke altid får et billede med hjem – er det noget du tænker over?

Forhøjet risiko for Downs Syndrom / kromosomsygdom
Sidder ved computeren og kan se at risikovurderingen slår ud for Downs Syndrom – hvad gør du?
Er der nogle forhold der gør situationerne forskellig fra par til par?
Hvad lægger du vægt på i din kommunikation med de gravide?

Hvordan forklarer du tallet?
Er det vigtigt at parret forstår det tal?
Når de er i lav risiko, så giver I dem jo ikke et tal, men det gør I når der er forhøjet risiko. Er det ikke nok bare at sige, at de er i forhøjet risiko?
Betyder det noget for den måde du taler med de gravide på om tallet er 1:30 eller 1:288?
Der er jo også risikovurderinger som kun næsten slår ud – som fx ender på 1:307. Hvad gør du så?
Synes du, at 1:307 er en høj risiko?

Hvor ligger din personlige cut-off mellem høj og lav risiko?

Er det en fordel for dig, hvis parret på forhånd har afklaret, hvordan de vil forholde sig i tilfælde af at der er forhøjet risiko?

Hvad gør du, hvis parret er i tvivl om de ønsker moderkageprøve? Prøv at give mig et eksempel.

Hvad gør du hvis parret ikke ønsker moderkageprøve? Prøv at give mig et eksempel.

- Er det vigtigt at de får talt med en læge?
- Tilbyder du dem andre undersøgelser?

Hvad er det så der sker, når nakkefoldsscanning med forhøjet risiko går galt, altså der er konflikt eller vrede og utilfredshed? Prøv at beskrive en situation eller et forløb hvor du synes at kommunikationen gik i vasken.

Moderkageprøven
Først skal jeg lige høre – sådan helt personligt – synes du så, at det er en god ide at par der kommer i forhøjet risiko vælger at få lavet en moderkageprøve?
I gør meget ud af at parret kan få moderkageprøven hurtigt. Gerne næste dag. Hvorfor er det vigtigt?
Hvad sker der, hvis parret skal vente en uge?

Er en moderkageprøve et risikabelt indgreb?
Hvad tænker du om abortrisikoen – er den høj eller lav?
Kan du beskrive en moderkageprøve, som du var med til og som du synes var svær eller gik skævt. Hvad skete der?

Hvad er det for en følelse du håber at parrene går herfra med – efter at de har fået lavet en moderkageprøve?

Svaret
Langt den overvejende del af dem, der får moderkageprøven, venter jo børn med normale kromosomer. Det er falsk-positive. Hvad tænker du om at den andel er relativt stor?
Ved du hvor stor den andel er – hvor mange er falsk-positive?

Hvad lægger du vægt på, når du ringer det gode svar ud til den gravide?

Har du – eller I som afdeling - nogen indflydelse på, om parret kan komme godt videre med graviditeten efter det gode svar?
Jeg har lagt mærke til at sonograferne ikke kommenterer den forhøjede risiko når parret kommer ind til misdannelsesscanningen – hvordan kan det være?

Hvis moderkageprøven viser kromosomfejl, er det så lægerne det tager over eller kan du også være involveret i den proces?

- Hvordan?
- Hvad lægges der vægt på i kommunikationen med disse par

En måde at forstå de gode forløb på, det er jo ved at undersøge, hvad der evt. kan gå galt. Kan du ikke prøve at give mig et eksempel på en af de her forløb med forhøjet risiko, som du synes kunne være håndteret bedre – enten af læger og sonografer, eller af det gravide par?

Samarbejde med kolleger / noget om ansvar
Hvordan vil du beskrive dit samarbejde med:

- Dine sonograf kollegaer?
- Lægerne?

Jeg har tit hørt jer tale om nødvendigheden af at have en ydmyghed i forhold til at scanne. Vil du ikke fortælle mig lidt om det?

Jeg oplever at I kommunikere meget og bruger hinanden, når I er i tvivl. En sonograf fortalte mig, at det kan være rart at dele ansvaret. Er det noget du kan genkende?

Er det dit ansvar at kromosomfejl eller misdannelser bliver opdaget?

I hører jo, når der fødes børn med hjertefejl eller misdannelser oppe på fødegangen. Hvordan påvirker det jer hernede på ultralyd?
Har du prøvet at overse eller ikke at kunne se noget, som dukkede op ved en senere scanning eller efter barnet er født? Hvad betød det for dig? Har det haft indflydelse på dig efterfølgende?

Jeg hører jer tit sige, at I – med den forhøjede risiko - sår en bekymring hos den gravide:

- Kan du fortælle mig lidt om det?
- Er det jeres rolle at mindske bekymring?

Afslut
Er der noget vigtigt i scanningssituationen som jeg har glemt at spørge dig om?
Noget som I vil spørge om eller tilføje?

APPENDIX 4: INTERVIEW GUIDE, WOMEN/COUPLES 1

Interviewguide til kvinder/par, der har valgt CVS og fået normalt svar

Intro:
Ultrakort om Stina

Et kvalitativt interview – jeg vil gerne have at I fortæller, hvad I har oplevet og overvejet i den her proces (det er den slags interview).

Stil endelig spørgsmål undervejs eller ret mig, hvis der er noget jeg ikke forstår eller er opmærksom på.
Hvis der er noget I ikke ønsker at svare på.

Spørge ind til det samme flere gange / på forskellige måder.

Jeg bruger betegnelsen 'sonograf' og 'den lille' eller 'barnet' – ok?
Sig til hvis jeg kommer til at sige noget, som I ikke forstår
Interviewet indgår i datamaterialet – hvis jeg bruger citater bliver de anonymiseret.
Publicering og endelig afhandling – tilbud om at få den tilsendt

Spørgsmål inden vi går i gang?

Grand tour
Jeg er her jo for at høre om jeres oplevelse med nakkefoldsskanningen, med at komme i forhøjet risiko og senere få lavet moderkageprøve. Jeg vil spørge mere specifikt ind til forløbet i løbet af interviewet, men jeg kunne egentlig godt tænke mig at starte med at spørge jer sådan helt bredt:

Hvis I nu skulle fortælle et par af jeres venner om, hvordan det var at være til nakkefoldsscanning, hvad vil I så sige til dem?

Kendskab til muligheden for fosterdiagnostik
Kendte I på forhånd til muligheden at blive scannet i uge 12

- Hvis tidl. Graviditet – spørg ind

Var I i tvivl om, hvorvidt det var noget I ville?

- Hvorfor / hvorfor ikke?

Hvad håbede eller forventede I at få ud af scanningen?
Havde I tænkt over det her med, at I ville få en risikovurdering for Downs Syndrom?

Har I selv nogle erfaringer med mennesker med Downs Syndrom?

- Hvor kommer deres erfaringer fra

Kendte I på forhånd nogen, der havde prøvet at få en forhøjet risiko for Downs Syndrom?

Havde I talt om eller taget stilling til, hvad der skulle ske hvis I fik en forhøjet risiko?

Nakkefoldsscanningen og valg af moderkageprøve
Kan du ikke prøve at fortælle mig – i så mange detaljer som muligt – hvad der skete til den nakkefoldsskanning og hvad I tænkte undervejs.
Opmærksomhedspunkter:

- Stemningen på vej herud
- Venteværelset
- Hvordan var det at se den lille på skærmen?
- Hvilke tanker flyver igennem hovedet når man ligger der på briksen.
- Hvordan synes I at jeres kontakt var til sonografen
- Kunne I følge med i sonografens arbejde / forklarede hun hvad hun kiggede efter og målte på?
- Fortæl, fortæl

Hvad tænkte du i det øjeblik hvor sonografen sagde 'forhøjet risiko'?
Havde I på noget tidspunkt under scanningen fornemmelse af, at I ville få beskeden i 'forhøjet risiko?
Synes I at sonografen hjalp jer til at forstå hvad det vil sige at være i 'forhøjet risiko'?

Synes I at det var en høj risiko?

- Ja/nej: Hvorfor?
- Prøv at fortælle mig mere om det

(Hvis parret taler meget om tallet:) Hvorfor er det så vigtigt at forstå det tal? (Hvorfor er det ikke nok, at sonografen siger forhøjet risiko?)

Har det tal haft betydning for jer efterfølgende?

- Forstå mellemregningerne
- Bruge det til at forklare

Synes I at sonografen informerede jer i forhold til at kunne tage stilling til en evt. moderkageprøve?

Oplevede I at moderkageprøven var en valgmulighed – altså noget, som man også kunne vælge fra?
Var det en vanskelig beslutning at tage?

- Hvorfor / hvorfor ikke

Hvilke tanker gjorde I jer på det her tidspunkt for og imod moderkageprøven?

- Abortrisiko

- Sikkerhed
- Andre undersøgelser
- Eksistentielle overvejelser

Var I afklarede omkring en beslutning efter samtalen med sonografen?

Havde du undervejs overvejelser eller spørgsmål, som du ikke fik stillet sonografen?
Var der efterfølgende noget, som du ville ønske at sonografen havde informeret om, spurgt dig om eller gjort anderledes?

Ventetiden
Prøv at fortælle mig om ventetiden mellem scanningen og moderkageprøven

- Hvad lavede I?
    - Aktiviteter, passiv, aktiv, udmattelse osv.
- Hvad talte I om?
    - Diskussion af oplevelsen, talte I om muligheden for at fosteret havde Downs? Talte I om hvad I ville gøre hvis den havde Downs?
- Talte I med nogle / ringede til nogle?
    - Familie, venner, under hvilke omstædigheder. Hvad talte I om? Holde noget tilbage?
- Søgte I information
    - Hvad ville I gerne vide? Hvorfor? Hvor søgte I?
- Var I bekymrede?

Moderkageprøve dagen efter:

- Set I bakspejlet, var det så en fordel eller en ulempe for jer at skulle vente til dagen efter med at få moderkageprøve?

Moderkage samme dag:

- Set I bakspejlet, var det så en fordel eller en ulempe for jer at få moderkageprøve med det samme, i stedet for eksempelvis lige at vente til dagen efter?

Moderkageprøven
Jeg vil gerne høre, hvordan I oplevede moderkageprøven og hvad I tænkte undervejs.
Opmærksomhedspunkter:

- Hvordan var stemningen på stuen
- Følte du dig ordentligt informeret undervejs?
- Oplevede I, at personalet tog jeres spørgsmål og ønsker alvorligt?
- Var der noget du synes, de skulle have spurgt dig om?

Scannede de dig efter moderkageprøven, så I kunne se fosteret?

- Betød det noget for dig?

Hvilerummet
Hvad snakkede I om bagefter, mens I var i hvilerummet.

Følte du dig tryg ved at tage hjem?

Hvad talte I om på vej hjem?

Havde du undervejs overvejelser eller spørgsmål, som du ikke fik stillet ved moderkageprøven?
Var der efterfølgende noget, som du ville ønske at de havde informeret om, spurgt dig om eller gjort anderledes?

Vente på svar
Fortæl mig om, hvordan det var at gå og vente på svaret.
Hvad var det for nogle tanker, der fyldte jer i den periode?

- Angst for spontan abort
- At skulle tage stilling til en kromosomfejl
- Overvejelser over fremtiden som familie

At få tiden til at gå…

- Hvad lavede I?
  - Aktiviteter, passiv, aktiv, udmattelse osv.
- Hvad talte I om?
  - Diskussion af oplevelsen, talte I om muligheden for at fosteret havde Downs? Talte I om hvad I ville gøre hvis den havde Downs?
- Talte I med nogle / ringede til nogle?
  - Familie, venner, under hvilke omstædigheder. Hvad talte I om? Holde noget tilbage?
- Søgte I information
  - Hvad ville I gerne vide? Hvorfor? Hvor søgte I?
- Var I bekymrede?

Var du gravid på en anden måde mens du ventede?

- Obs: distance til graviditeten

Påvirkede det dine følelser i forhold til den lille?

Hvad sagde jeres mavefornemmelser i ventetiden?
Har du på noget tidspunkt tænkt, at ja, den er nok syg?
Har du på noget tidspunkt faktisk været overbevist om, at ja, den er nok syg?

- Hvor ja: Hvorfor var du overbevist om det (kvalme, anelser i kroppen, man ved at man er i risiko)

Betød risikovurderingen noget for jer, mens I ventede på svar? Tænkte I på det tal?

Fortæl om tidspunktet, hvor telefonen endelig ringede.

Hvordan havde I det (give slip på bekymring?)

Tænkte du på abortrisikoen efter at du havde fået svar om, at kromosomerne var normale?

- Hvis ja: Hvor længe varede det?

Føler I jer nu mere eller mindre sikre på, at fosteret er sundt og raskt end I gjorde før nakkefoldsskanningen?

Nu og fremtid

Er du gravid på en anden måde nu, end du var før du fik en høj risikovurdering?
Kan du være 'helt almindelig gravid' nu – kan du lægge forskrækkelsen bag dig?

- Give slip på bekymringer
- Bekymringer der følger med
- Nye bekymringer

Tror du, at de erfaringer, som I har gjort jer i den her sammenhæng kommer til at få nogen betydning i fremtiden?

Hvad har været det værste eller det sværeste ved den her oplevelse?
Kan man på nogen måde sige, at der er noget ved den her oplevelse, der har været godt?

Når / hvis I nu bliver gravide igen – skal I så have lavet risikovurdering for Downs Syndrom?

- Hvorfor / hvorfor ikke?

Afslut

Noget som I vil spørge om eller tilføje?
Er der noget, som I troede vi skulle snakke om, som jeg ikke har spurgt ind til.

Debriefing: Opsamling på interview, spørgsmål til min forskning / 'de andre' deltager, udfyld skema med baggrundsinfo, tilladelse til evt. at ringe med spørgsmål senere.

APPENDIX 5: INTERVIEW GUIDE, WOMEN/COUPLES 2

Interviewguide til kvinder/par, der har valgt ikke at få invasiv diagnostik

Intro
Ultrakort om Stina

Et kvalitativt interview med fokus på jeres oplevelser og overvejelser i forbindelse med nakkefoldsscanningen og med at få et resultat, som hedder ' forhøjet risiko'.

Stil endelig spørgsmål undervejs eller ret mig, hvis der er noget jeg ikke forstår eller er opmærksom på.
Hvis der er noget i ikke ønsker at svare på

Spørge ind til det samme flere gange / på forskellige måder.

Jeg bruger betegnelsen 'sonograf' og 'den lille' eller 'barnet' – ok?
Sig til hvis jeg kommer til at sige noget, som I ikke forstår
Interviewet indgår i datamaterialet – hvis jeg bruger citater bliver de anonymiseret.
Publicering og endelig afhandling – tilbud om at få den tilsendt

Spørgsmål inden vi går i gang?

Grand tour
Jeg er her jo for at høre om jeres oplevelse med nakkefoldsskanningen, og med at komme i forhøjet risiko og jeres oplevelser i den forbindelse. Jeg vil spørge mere specifikt ind til forløbet i løbet af interviewet, men jeg kunne egentlig godt tænke mig at starte med at spørge jer sådan helt bredt:

Hvis I nu skulle fortælle et par af jeres venner om, hvordan det var at være til nakkefoldsscanning, hvad vil I så sige til dem?

Kendskab til muligheden for fosterdiagnostik
Kendte I på forhånd til muligheden at blive scannet i uge 12 – hvorfra?

- Hvis tidl. Graviditet – spørg ind

Havde I på noget tidspunkt været i tvivl om, hvorvidt det var noget I ville?

- Hvorfor / hvorfor ikke?

Hvad håbede eller forventede I at få ud af scanningen?
Havde I tænkt over det her med, at I ville få en risikovurdering for Downs Syndrom?

Har I selv nogle erfaringer med mennesker Downs Syndrom?

- Hvor kommer deres erfaringer fra

Kendte I på forhånd nogen, der havde prøvet at få en forhøjet risiko for Downs Syndrom?

- Evt. fravalg af CVS?

Havde I talt om eller taget stilling til, hvad der skulle ske hvis I fik en forhøjet risiko?

Nakkefoldsscanningen og valg af moderkageprøve

Kan du ikke prøve at fortælle mig – i så mange detaljer som muligt – hvad der skete til den nakkefoldsskanning og hvad I tænkte undervejs.

Opmærksomhedspunkter:

- Stemningen på vej herud
- Venteværelset
- Hvordan var det at se den lille på skærmen?
- Hvilke tanker flyver igennem hovedet når man ligger der på briksen.
- Hvordan synes I at jeres kontakt var til sonografen
- Kunne I følge med i sonografens arbejde / forklarede hun hvad hun kiggede efter og målte på?
- Fortæl, fortæl

Hvad tænkte du i det øjeblik hvor sonografen sagde 'forhøjet risiko'?

Havde I på noget tidspunkt under scanningen fornemmelse af, at I ville få beskeden i 'forhøjet risiko?

Synes I at sonografen hjalp jer til at forstå hvad det vil sige at være i 'forhøjet risiko'?

Synes I at det var en høj risiko?

- Ja/nej: Hvorfor
- Prøv at fortælle mig mere om det

(Hvis parret taler meget om tallet:) Er det vigtigt at forstå det tal? (Hvorfor er det ikke nok, at sonografen siger forhøjet risiko?)

Har det tal haft betydning for jer efterfølgende?

- Forstå mellemregningerne
- Bruge det til at forklare

Synes I at sonografen informerede jer tilstrækkeligt i forhold til at kunne tage stilling til en evt. moderkageprøve?

Hvilke tanker gjorde I jer på det her tidspunkt for og imod moderkageprøven?

- Abortrisiko
- Sikkerhed
- Andre undersøgelser
- Eksistentielle overvejelser

Havde I oplevelsen af, at begge beslutninger var 'tilladte' og noget personalet ville støtte op omkring?

Var I afklarede omkring en beslutning efter samtalen med sonografen?

Havde I undervejs overvejelser eller spørgsmål, som I ikke fik stillet sonografen?
Var der efterfølgende noget, som du ville ønske at sonografen havde informeret om, spurgt dig om eller gjort anderledes?

Evt. Samtale med læge
Kan I ikke fortælle mig, hvordan I oplevede samtalen med lægen?

Bidrog samtalen med lægen til jeres endelige beslutning? Hvordan / Hvorfor ikke?

Oplevede forskel på lægens og sonografens information?

Var I afklarede omkring en beslutning efter samtalen med lægen?

Havde du undervejs overvejelser eller spørgsmål, som du ikke fik stillet lægen?
Var der efterfølgende noget, som du ville ønske at lægen havde informeret om, spurgt dig om eller gjort anderledes?

Hvordan havde I det, da I to hjem ude fra Skejby? (glade, i tvivl, overraskede, lettede, følelsen af at have dumpet eksamen, afklarede, tungsindige med afklarede?)

Efterfølgende
Hvordan har I haft det efterfølgende?

Har det haft nogen indflydelse, at I fik den her besked om forhøjet risiko?

- Hvordan? Fortæl mig gerne mere om det…

Har I været i tvivl om, hvorvidt det var den rette beslutning?

Har I talt med venner og familie om at nakkefoldsscanningen viste forhøjet risiko for Downs Syndrom?

- Hvis nej: Hvorfor ikke
- Hvis ja: Hvad fortæller I? Hvordan reagerer dem I fortæller det til?

Er du gravid på en anden måde nu, end du var før du fik en forhøjet risikovurdering?

- Obs: distance til barnet

Kan du være 'helt almindelig gravid' nu?

Tror du, at de erfaringer, som I har gjort jer i den her sammenhæng kommer til at få nogen betydning i fremtiden?

Når / hvis I nu bliver gravide igen – skal I så have lavet risikovurdering for Downs Syndrom?

- Hvorfor / hvorfor ikke?

Afslut

Noget som I vil spørge om eller tilføje?
Er der noget, som I troede vi skulle snakke om, som jeg ikke har spurgt ind til.

Debriefing: Opsamling på interview, spørgsmål til min forskning / 'de andre' deltager, udfyld skema med baggrundsinfo, tilladelse til evt. at ringe med spørgsmål senere.

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