

# Bioethical concepts in theory and practice: an exploratory study of prenatal screening in Iceland

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Published online: 15 October 2010  
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**Abstract** A hallmark of good antenatal care is to respect prospective parent's choices and provide information in a way that encourages their autonomy and informed decision making. In this paper, we analyse the meaning of autonomous and informed decision making from the theoretical perspective and attempt to show how those concepts are described among prospective parents in early pregnancy and in the public media in a society where NT screening is almost a norm. We use interviews with Icelandic prospective parents in early pregnancy ( $N = 40$ ) and material covering the discourse around prenatal screening in the media over 5 years period. Our analysis indicates that both prospective parents and the public media include ethical terms in their rhetoric around prenatal screening although those concepts differ in their expression. We conclude that the context in which these decisions are taken does not encourage moral reflection. Prospective parents describe that there is a lack of dialogue with professionals when decisions are made about screening. With routine offer of screening the conceptualization of bioethical concepts finds its own way through a mainstream discourse which has limited connections to the theoretical notions. This has been neglected in the implementation of screening, as limited effort has been subject to audit with reference to explore how the offer of screening and informed choice is experienced among prospective parents.

**Keywords** Fetal screening · Autonomy · Informed decision · Prospective parents · Ethics · Experience

## Introduction

In accordance with guidelines on prenatal screening, the main role of health professionals is to inform prospective parents in a way that encourages their autonomy and informed choice (Directorate of Health 2006; NICE 2008). Although prenatal screening is routinely used in some countries to enhance reproductive choices of parents, routinization can be seen to reduce, rather than expand, choice. Construction of ethical concepts in the context of prenatal screening, although stated in protocols and policy documents, will affect the ongoing development and practice of screening. For example, Suter (2002) considers that incorporating screening in a traditional antenatal care impoverishes the informed consent process as the more routine a test becomes the less prospective parents and providers focus on ethical dimensions of the screening.

Although the literature emerging from the medical context has focused on the efficacy and possibilities of the new technology, other disciplines have explored decision making from the psychological, social and emotional aspect of screening. These studies have increased understanding of the difficulties that arise in relation to offering screening within the traditional antenatal care (Rapp 2000; Pilnick 2008). Other studies report on women's high satisfaction with the care they receive during pregnancy, intrapartum and postpartum, which actually supports the status quo of current service and explains why women are not likely to express a preference of something else (Van Teijlingen et al. 2003). At the same time it is also known that women's expectations of what prenatal screening can do are high as

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women believe that what is offered is the right thing to choose (Gottfreðsdóttir et al. 2009). Both supporters and critics of screening justify their decision by the same moral principles, as the right of the parents to decide for themselves. When women, however, are confronted with the choice of accepting or declining screening in real circumstances it has been described to create a tension in the decision making process (Chadwick 1999; Williams et al. 2005). In the Netherlands, this has been framed as a moral dilemma and is one of the main reasons why health policy in the country did not incorporate screening for Down syndrome for all women (Garcia et al. 2008). When routine screening is offered it is speculated that many women think about their decision but are left alone considering the moral implications of the screening (Williams et al. 2005). Garcia et al. (2008) suggest that parents' ethical reasoning for accepting or declining screening is based on personal ethical considerations, where personal feelings and views are context related. Normative moral principles are on the other hand used additionally to explain the decision further.

In the light of rapid uptake of prenatal screening, there is a growing urgency to explore the underlying ethical reasoning involved when complex decisions have to be made. This important issue has been raised in the context of pre-implantation genetic diagnosis, where a gap or a discrepancy between theory and practice has been reported (Zeiler 2004). Similarly, to our knowledge, however, studies on how bioethical concepts, are reflected in real circumstances and whether they have the same significance for prospective parents who accept and decline screening are scarce. Their ability to make decisions is however related to circumstances and whether pregnancy is understood as a normal or risky time (Williams et al. 2002; Smeenk and ten Have 2003). In modern societies, the media is likely to have a significant impact on public policy and public opinion. This has been highlighted in reports on technical improvements in health care, such as in genetics diagnosis (Petersen and Bunton 2002). In an Icelandic study on media discourse around the intended establishment of a Health Sector Database in the country, it was especially notified that there was a lack of true dialogue of the matter (Pálsson and Hardardóttir 2002). Another Icelandic study exploring in particular the presentation of the development of genetic technologies in the country, reported that the media did not serve as a source of critical debate, but encouraged the optimistic vision of the innovation both in the market and the medical context (Hjörleifsson et al. 2008).

The implementation of nuchal translucency screening in Iceland

Nuchal translucency screening (NT) was introduced in Iceland in the late 1999. The screening developed in the

UK following expansion of ultrasound technique and the introduction of first trimester biochemical markers in the 1990s. Combined with maternal age and length of pregnancy, the risk score for every woman for giving birth of a child with chromosomal anomaly, especially Down's syndrome, is evaluated (Nicholaides 2004). The uptake of NT screening rapidly became high in Iceland, even before national guidelines were formed in the country. In 2006, in the capital area where there is easy access around 87% of women accepted the screening. In general, there seems to be a tacit assumption within the medical domain that fetal screening is a desirable progress which will enhance reproductive choices of prospective parents (Chervenak et al. 2005). However, if women receive high risk score the option is either to continue the pregnancy or to have a diagnostic test. Women who receive abnormal result from the diagnostic test will have to choose selective abortion or to bring the pregnancy to term, as there is no therapy available in that situation.

In the light of this development, questions have been generated regarding informed choice, and autonomous decision making of prospective parents in the context of screening. These concepts have been the subject of debate and the expansion of prenatal screening has created new speculations of their characteristics. For example, with increasing detection of fetal condition for which treatment is available after birth and a demonstration of increased hormonal stress responses in fetuses, a shift in the status of the fetus to that of a patient is possible. This recognition highlights another dimension of choice which women are confronted with as there are obvious links between the concept of fetal pain and late abortions (Williams 2005). This paper aims to respond to the need for multidisciplinary work on how traditional ethical concepts are reflected in the clinical and social context. The following section of the paper presents an overview of our study material and the background. We then present theoretical perspectives on respect for autonomy, choice and informed decision. From there we go on to explore how the participating prospective parents frame their decisions to accept or decline screening and evaluate how those concepts are enacted or exercised through discussion. Finally, we analyze how the Icelandic context introduces and supports, informed decision making where we use the media discussion to exemplify the social discourse. In conclusion, we discuss the political and moral space where this development has taken place.

## Study background and methods

This paper reports on one aspect of a project which focuses on the decision making process around NT screening in

early pregnancy. For the purpose of this paper, we examine the significance of ethical concepts in the context of prenatal screening. We present an example of bioethical concepts in the literature where the focus is on respect for autonomy and informed decision making. This is discussed in the light of a brief overview of three models of professional–patient relationship which place different emphasis upon the key ethical elements of decision making. In order to set the study within a wider context it draws on two sets of data. Those two data sets were designed to complement each other where the first are interviews with prospective parents in pregnancy. We are concerned with straightforward understanding of how individual prospective parents interpret choices they are offered in the social context in addition to the media presentation of the offer of NT screening. By using extracts which reflect descriptions of the experience of the screening offer, we highlight how particular ethical concepts are described.

Twenty couples a total of forty individuals were recruited from health care centres in Reykjavík, the capital of Iceland, following ethics committee approval (05-125-S1). The number of participants in qualitative studies is often considered adequate when the collected data reach saturation and a common number may be 10–15 participants (Kvale 1996) although it depends on the focus of the study. The inclusion criteria were: cohabitation, age of mother between 18 and 35 years; and ability to express themselves in Icelandic. The midwives who provide antenatal care were informed about the background, aims and method being used and were asked to introduce the study to eligible women when they phoned to book their first visit. The participants included equally parents who had decided to accept and decline NT screening. The sample was purposive meaning that participants are chosen with a purpose to represent a location or type in relation to a key criterion (Ritchie and Lewis 2003). As such, due to the small sample of interviewees in the study no claim to generalize ability can be made. When participation had been agreed upon, a letter of introduction was sent. The expectant mothers were asked to inform their partners about the study following semi-structured interviews with each participant, in the 7th–11th week of pregnancy as the intention was to gain insight into how decisions in early pregnancy emerge. The following themes were explored: previous pregnancy and birth experience, knowledge of NT screening, communication with health professionals during this pregnancy, views on abortion, and experience of disability. Throughout this study Framework analysis was used, developed during the 1980's at the National Centre for Social Research in the UK (Ritchie and Lewis 2003).

Applying this approach, rigorous and transparent data management is facilitated such that all the stages involved in the analytical 'hierarchy' can be systematically conducted.

The first step is familiarisation by listening to tapes and reading fieldnotes or transcripts. In the second phase, the development of a coding scheme took place. Next, a comparison was made both between and within cases, following a charting or rearranging of the data according to its thematic content, either case by case or by theme. The identification of recurrent themes was compared between participants, followed by categorisation which is the actual form of presentation of the data in this paper. The transcripts were structured and clarified using NVivo Version 7, which is helpful for large and complex interviews, making them more amenable for analysis (Di Gregorio 2003). The second set of data includes examination of the public media material that the general public was exposed to and referred to screening. The method chosen was discourse analysis, which provided opportunity to study linguistic usage. A number of approaches to discourse analysis have been developed where the analytic commitment of the method is to study texts and talks in social practice. The focus is on language as the medium for interaction. An analysis of discourse becomes indirectly analysis of how people talk and how they act (Silverman 2006). The term discourse in this study is understood as 'historically specific, socially situated, signifying practices' (Fraser and Gordon 1994). This description highlights the understanding that discourse reflects both the historical time and the social context in which it developed and is used.

Moreover, television programmes, newspaper and magazine articles and booklets written for prospective parents, from the beginning of 2000 until the end of 2005 were explored, in all 53 items. Each text item was closely read for its portrayal of screening. The questions that guided the analysis were: How was the discussion presented? Who contributed to the debate and what was their argumentation? All the items were categorized after they had been carefully evaluated and assigned to a particular discourse, which led to the identification of three main themes. The data were initially indexed on a case by case basis, which allowed patterns and relationship between the codes to emerge within the data set. Here, analysis was performed by detecting and classifying the various occurrences of what was said about choice and decision making (Foucault 1980; Ritchie and Lewis 2003). The full results of these studies, discussing women's and men's considerations in depth and the analysis of the media discourse is published elsewhere (Gottfreðsdóttir et al. 2009; Gottfreðsdóttir and Björnsdóttir 2010).

### **Respect for autonomy in decision making: the mainstream notion and adoption in practice**

In our discussion, we will refer to the principle of respect for autonomy characterized by Beauchamp and Childress

(2001) as a right to make uncoerced and informed decisions. This is no doubt the most influential use of the notion of autonomy in the bioethical discourse and it has widely influenced practice through ethical guidelines and policy documents. According to this analysis, the main preconditions for an autonomous decision are (1) that patients are informed about medical treatment or study and the options relating to it; (2) that they understand the information; (3) that there are no controlling influences that determine their actions. Each of these conditions is context dependent and a matter of degree. Various standards have been put forth regarding appropriate disclosure of information, ranging from objective criteria of what is reasonable for professionals to provide and for patients to know about a certain treatment, to meeting the subjective needs of the individual person making the decision.

In the context of our discussion, it would seem that a mixture of objective and subjective standards is needed. Objectively, all prospective parents must be informed about the general aspects of fetal screening and, subjectively, they need to be informed about the particularities relating to their own treatment. The aim is not, however, that parents-to-be are fully informed, but sufficiently informed to be able to make an informed decision. Such understanding always takes place against a web of background beliefs or knowledge of the individual (Kristinsson and Árnason 2007) which can both facilitate and distort understanding. In the past years, a number of studies have highlighted that although the emphasis is to preserve autonomy and support informed decision making of patients, the manner in which health care is delivered can serve to undermine the role of the patient as an active partner in his health care (Hasman et al. 2006). Similarly, in practice the opportunity for couples concerned with making autonomous choices can be questioned as they become obliged to choose whether or not to use the technology, and they may be constrained in their discussion with the medical professionals which frame the issue for them (Zeiler 2004). It has also been demonstrated (McLeod 2002) how factors which affect self-trust of the decision maker can improve or undermine her decision making capacity.

In prenatal screening, where information about risk is provided in terms of statistical probabilities and possible outcomes, understanding can be particularly difficult for someone who is not versed in such a discourse. This has been reported in recent studies where most women favour the option of screening but, at the same time, have limited knowledge of the procedure and its implications (Williams et al. 2005; Gourounti and Sandall 2008).

The third criterion of autonomous decision making is that it is free from controlling influences. Obviously, the absence of controlling influences will never be absolute;

this condition can only be met to a greater or lesser extent. In the real world, people always act under various influences; therefore, it is important to consider the particular context of decision making and ask how the influences embedded in the situation may affect the self-determination of the agent. As pointed out by Marteau and Dormandy, an informed choice has two core characteristics: the decision is based on relevant good information and it reflects the decision-maker's values. The latter is insufficiently explored (Marteau and Dormandy 2001) and can be very difficult to evaluate. People acquire values and norms in a process of socialization, and autonomy implies that people are able to reflect critically on their values (Dworkin 1988).

In the context of fetal screening, many features need to be taken into account, such as the strong emotional aspect of the decision, the professional tendency to routinize the procedures, the medicalization of pregnancy and the strange mixture of needing to make a most personal and 'domestic' decision in a rather 'alien' hospital setting. However, the rhetoric of autonomy is such that it is difficult to argue against it without falling into the trap of giving the impression of arguing against individual rights (Kerr 2004). Therefore, it is important to gain insight into the context in which choices are made. This study takes place in a setting where, in 2006, around 87% of women underwent NT screening. These features will play a role in our subsequent analysis.

The conditions for autonomous decision making tend to be shaped by the models of patient–professional relationship that are predominant in the practice of health care. These models are ideal types which tease out dominant characteristics but need not be found in practice in pure form. A paternalistic model of the patient–professional interaction which pays little attention to the requirement of patients' decision making (Smith 1981; Veatch 1981), is particularly questionable in the decision making context of fetal screening where personal values, subjective beliefs and moral reasons play a significant role in weighing the risks and evaluating other information provided to the parents-to-be. These are nonmedical decisions and need to be freed from "the entrenched values and goals of medical professionals" (Beauchamp and Childress 2001, p. 82). Although this model can be expected to belong to the past, recent studies of professional–patient relationship have shown a gap between patients' desire for involvement and their experience (Coulter 2006).

The patient autonomy model, on the other hand, takes this personal aspect of decision making strongly into account and places the main emphasis on the right of the patients to make decisions based on their own values (Smith 1981; Veatch 1981). The main role of the professional is to provide medical information, preferably in a non-directive or even neutral way in order to free the

patient from the values and goals of the medical professionals. In line with this, the patient should make up her own mind, free from the controlling influences of the professional who should limit his role to the medical and technical aspects of the situation. This is reflected in the attempt to develop clinical guidelines and regulations about screening where autonomy of the patient is often emphasized but suggestions regarding communication of information tend to be lacking.

One feature of the patient autonomy model is that patients tend to be to be 'left alone' in their deliberations, which can cause a feeling of abandonment, anxiety and a loss of trust which may undermine his decision making abilities. Despite their differences, the paternalistic and the patient autonomy model share in effect a major characteristic which has questionable consequences for patient autonomy. Neither model facilitates conversations or dialogue between patients and professionals. Each in its own way, these models tend to be monological in the sense that their main emphasis is either on the professional communication of medical information or on the patient's communication of his personal values and preferences. They do not aim to facilitate dialogical deliberation as a vehicle of informed and truly shared decision making.

It is our contention that a communicative model which sees informed decision making as a cooperative task meets the conditions discussed above better than the other two models (Árnason 1994, 2000). Firstly, the best way to find an adequate disclosure of information for a particular patient is to have a dialogical exchange of questions and answers. Only in this way can professionals know what information patients care and need to have and what they do not. Secondly, a conversation between patient and professional will show better than other available means whether the patient has understood the information or not. Thirdly, good communication has two main objectives which relate to freedom from restricting factors: information, or freedom from ignorance, and emotional support, or freedom from fear and anxiety. Both cognitive and emotional factors can disrupt autonomous decision making and a dialogue where people meet in a joint task can serve as a midwife of good decision making. Such a dialogue, if authentically conducted and aimed at mutual understanding, also breaks up the institutional routine because it takes time and is not subject to the demands of efficiency and control. It is also the best way to build up trust which to many patients is more important than the exercise of self-determination.

It could be argued that a dialogical model of this sort is bound to strengthen the professional power in the relationship at the cost of patient autonomy. This is because the dialogue is inevitably asymmetrical as the patient has a weaker standing, both as a person in need of help and as

depending on the professional for information and understanding. In the case of ultrasound and fetal screening, this is particularly true (Nicol 2007), but these facts also provide support for the need for a communicative approach to decision making: the professionals know more about the treatment or study, the patients know more about themselves (Katz 1984), e.g. their own values and history. Both types of knowledge are needed to exercise shared decision-making or partnership approach to decision making (Coulter and Ellins 2007). We see our analysis of the prospective parents' decision making experience in antenatal care as one test of this.

There is an important difference here between the information aspect and the value aspect of the situation. The information relevant for making an informed decision needs to be conveyed and understood; the values of the person making the decision need to be clarified and critically reflected upon, each with a different aim: on the one hand that the person can make a decision that is informed and on the other hand that the person makes a decision that she can live with. A major complication in counselling is to provide an opportunity for reflection on values without directly affecting the decision. This is one reason why the autonomy model seems to be appealing: the person is given information but she should make up her mind without the influence of the professional. This model, however, is unlikely to ignite critical reflection about values and preferences which is part of the idea of autonomy (Dworkin 1988).

### **Interpretation of bioethical concepts in the context of prenatal screening**

In this section, we are concerned with the question whether parent's decision to accept or decline screening in early pregnancy is affected by ethical beliefs. In order to gain insight into the social context we also present few quotes from the media discourse to illuminate how certain ethical concepts such as choice, autonomy and informed decision making are presented.

#### **The experience of the screening offer**

All women in Iceland seek care within the primary health care system, except if the pregnancy is seen as high risk, then the care is provided within a special clinics (Regulation Health Care Centres 2007). In low risk pregnancies midwives attend all pregnant women throughout pregnancy, in cooperation with GPs and obstetricians if necessary. However, before signing up for antenatal care many women have had their pregnancy confirmed by their obstetrician who, in most cases, runs a private clinic. Of the twenty women who participated in this study, the majority had been to see an

obstetrician before signing up for their first antenatal visit and six had their pregnancy confirmed with a GP. Two women had already met their midwife. During this first contact, professionals are in a unique position to act in a way that facilitates the woman's understanding and promotes her autonomous decision making capacity if they frame their work within the communication model. It is of importance that expectant parents make decisions that are harmonious with their personal values and preferences; hence the informed decision making process must prepare them for the possible psychological and social ramifications of deciding to undergo screening, including the anxieties that might arise and the range of difficult decisions parents may face. This will not be achieved unless a dialogical exchange has taken place between the professional and the parents-to-be. In many interviews it was demonstrated that parents experienced that it was for them to decide on screening, but at the same time described a lack of discussion on issues related to technical knowledge of screening, and not least on implications of the screening in the wider context:

We went to the doctor, the GP, as soon as we found out [about the pregnancy] and he told us not to worry about anything being wrong. [We should] just base our expectations on the fact that we were young, at the optimal age, and so on... He did not mention the NT screening at all. I only know about it from a book I bought in the beginning [of the pregnancy], where it was briefly mentioned. (Woman no. 15).

I went to the general practitioner at the health care centre in our neighbourhood. She [the GP] was entirely impartial. She said that some people accepted the screening and some did not. She neither spoke for it nor against and left it entirely to me to decide and told me I could go home and contact her again if I decided to go for it. I did not have to make up my mind there and then. –But she did not tell me a whole lot, she just referred to the website and I have now read the information that is available there... I think it is a good idea to offer it [the test] (Woman no. 9).

These two women, who both decided to accept screening, experience the screening offer differently. The former woman who was expecting her first child is not given the opportunity to discuss the offer and the information disclosure is left out in the discussion. She describes how the GP chose to avoid the discussion about prenatal screening. The GP in the second quotation does not see it as his responsibility to explain the offer of screening but invites the woman to contact her again if she decides to proceed with the test. Hence, this woman is also left with having to make the decision with limited information.

Among some of the parents who declined, choice was experienced as an evaluation of options, which is likely to allow reflection on their ethical beliefs. The following example gives insight into how that was expressed:

I got information on the Internet. I read that there were mainly two chromosomal defects you screen for, apart from Down's syndrome. There you are looking at some probabilities and if the nuchal fold is increased then the risk for Down's syndrome is increased. (Woman no. 12)

Another woman described this by referring to the accuracy of the screening method:

I know this woman who had the screening and they [the midwife and GP] said to her that something was wrong and after that she had amniocentesis. Something was wrong there as well, but she decided to proceed with the pregnancy and gave birth to a normal child. I mean, I could not decide to have an abortion with such information (Woman no. 19)

In only a few interviews the women described situations when they were confronted with the option to accept or decline screening. That encouraged a discussion which reflected on individual experience:

I decided to phone my gynaecologist because I know him quite well... He said that we should just wait, which turned out to be the right thing to do. I had a very good discussion with him and he emphasized that this was a probability test, there were healthy fetuses lost in the process... he didn't say what to do but we discussed also what it is to be healthy... what kind of a child do you want to have. (Woman no. 20)

The woman had been waiting for a child for a number of years and although she was well aware of slightly increased risk of abnormalities because of her age she was not ready to face the tension that the screening would involve. She describes how she could express her worries with the physician which led to increased opportunity to make autonomous choices.

#### Generating and disclosing information on NT screening in the media

The implementation and development of prenatal screening can be seen through the lens of the media discourse, where the media represents the system which introduces the screening in each society. Analysis of the Icelandic media coverage of prenatal screening highlighted striking patterns. In an earlier paper, the analytic themes were described which dominated the discourse in the media around NT screening in the country. Most references to

fetal screening referred to professionals' perception of the screening as a progressive technique (optimism). This perspective was particularly dominating in the discussion during the first years, when the technique was being introduced. It was reflected in emphasis on the effectiveness of the screening and its superiority over amniocentesis which had been offered to women 35 years of age or older for many years (*Morgunblaðid*, August 29, 2000). As time passed, other issues became more apparent in the media debate. The repeated mention of choice by some professionals called upon promise for intentional discussion about the different perspectives of prenatal screening which incorporates disclosure about ethical beliefs and moral dilemma that prospective parents may be confronted with. However, only few items were identified which took this discussion further in the following years. In one item a theology student touched on the issue that the ethical debate was far behind the technology. She emphasized that a public discussion was needed to consider the pros and cons and how far the Icelandic society was ready to go in the implementation of new technology (*Morgunblaðið*, January 4, 2004). In another item an interview with an obstetrician in *Morgunblaðid*, which appeared during this time, the issue of choice is discussed, from the perspective of free, uncoerced choice and autonomy:

In my opinion it is the parents absolute right to accept or reject screening, as it is they who will raise the child. Parents' circumstances are different and there is a variation in how well they are prepared to handle difficulties which accompany illness or disability of their children." (*Morgunblaðid*, January 11, 2004).

In the interview these statements were not pursued by the journalist and were left standing without any further discussion.

Throughout the small number of TV news bulletins that could be found on the subject, differences in the discussion from the articles in the newspapers are noticeable. This is probably because more than one speaker takes part in the discussion each time which calls for argumentation from different perspectives. In such situation it is more likely that critical comments and moral dilemmas will be brought up. In one instance (*Kastljós*, August 11, 2005), where there were three speakers, one ethicist/doctor, a mother of a Down's child and a consultant, the concepts of choice and informed decision were prominent. The mother said that the information about the screening were only positively framed, based on the assumption that the life of children with Down's and their families is bound to be difficult. She further referred to the information people are offered, where the three trisomies are equally placed in the discussion, which is misleading and undermines the capacity of parents to make an informed choice. By contrast, the

consultant claims that people today are well equipped to make decisions "We should rely on people's judgement, people are better informed today to make their own decisions." Our interpretation is that by framing the comment in this way the consultant avoids the matter and places the responsibility on the parents by highlighting their ability and autonomy. However, this could also mean that the consultant experiences his role to facilitate the dialogue with the parents although it is not stated.

## Discussion

The answer to the question how ethical concepts are reflected in the clinical context is not clear cut. This study indicates, however, that both prospective parents and the public media include ethical terms in their rhetoric around prenatal screening although those concepts differ in their expression. As such, one can speculate that the parents hold on to other ethical beliefs than are articulated in theory. As the majority of women (87%) in the social context where the study took place accept screening, this small sample only provides an insight to prospective parent's experience of the screening and thereby we are not able to make any claims of representativity. However, despite the small sample our data was rich in content and reveals a wide range of descriptions of how women are provided with information and other resources required to exercise their choices. Therefore, we are able to say that many of the prospective parents are explicit about the choice they made, which must be considered a positive finding. However, a visible difference was described where some participants recalled situations where too little information had been provided or situations where alternatives had not been discussed. Few participants described an opportunity to discuss and reflect on the screening offer with health professional. When it comes to bioethical concepts as such, the ones, who accepted screening, were less clear about their moral values and beliefs, which can indicate that their attitude towards screening was more affected by compliance. Thus, one could argue that their values were in line with the norms that prevail within the society in general. As such, their autonomy to make an informed choice cannot be seen as coerced but affected by a number of factors. The value component was less visible in the interviews with some participants in this group and as such it was less clear that there were other choices to be considered in the situation. Among individuals who declined, moral values and beliefs were more discussed. This is understandable because their decision is in conflict with the prevailing social norm and thus they become more aware of the values upon which it is based. This does not necessarily mean that a decision to decline is more autonomous than a decision to accept, but it can be

regarded as requiring a more independent judgement (Dworkin 1988).

Marteau and Dormandy claim that in the context of screening the notion of informed choice has to refer to knowledge as well as values and beliefs of prospective parents (Marteau and Dormandy 2001). However, it was hardly ever described in the interviews that the participants were confronted with a discussion of informed choice of this kind by professionals. It is recognized that professionals in the context of screening find it difficult to construct the discussion of informed choice and, although they recognise the centrality of the concept in prenatal screening, there are many doubts whether it could be achieved (Rentmeester 2001; Williams et al. 2002). Also, the prominent view within the health service identifies numerous problems associated with Down's syndrome which can result in that information around screening is not questioned by professionals and the discussion is one sided (Alderson 2001). In our data, only in a small number of interviews was it actually possible to describe the discussion as cooperative or shared decision in the context of professional–parent relationship. One has to bear in mind, however, that those interviews are only with twenty couples and reflect on their experience of the situation.

Generally speaking, we found the presentation of screening in the media to be positive. This was reflected in two main issues: scientific achievement and the expansion of choice for prospective parents. Much of the items, however, frame choice and decision making in an idealistic way. They are sometimes superficial and lack connection with real situations, which corresponds to the autonomy model where the right to make an autonomous choice is highly emphasized and the responsibility rests with the parents first and foremost. This may affect other important aspects of patient–professional relationship (Williams et al. 2005). Furthermore, arguments are not given equal weight in the discourse nor do they have the same influence on the audience. As others have noted, it is difficult to make generalizations about the impact of the media on public opinion and public policy. However, the similarities between the views expressed in the media and in the interviews suggest that the understanding of bioethical concepts is socially constructed. In such situations, the meaning of bioethical concepts finds its own way through a mainstream discourse which has limited connections to the theoretical discussion. It is difficult to speculate if this actually promotes autonomy or facilitates informed choice in the context of screening in general, but it indicates that there is a considerable gap in the interpretation of those ethical concepts in the interviews and the media on the one hand and in theory on the other hand. These are complex effects of screening implementation which need to be incorporated in the discussions with prospective parents.

## Conclusion

There seems to be a consensus in Iceland that fetal screening such as NT should be the choice of prospective parents. However, the discussion in the media hardly reaches the level of a moral debate where the meaning of ethical concepts is taken into account. Despite the fact that some professionals were eager to highlight parents' autonomy, the discussion was hardly ever accompanied by deliberation to reach informed choice. Analysis of interviews with prospective parents does not indicate that informed decision is being facilitated in an informed dialogue. It has been pointed out that perhaps the routinization of screening limits moral reflection based on fundamental ethical concepts in the context and we believe that this present study supports that explanation. The Icelandic media mostly served as an amplifier for technological advance of NT screening and discussion of complex moral issues was scarce.

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