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### Achieving the desirable nation : abortion and antenatal testing in Colombia : the case of amniocentesis

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## Chapter 5

### Amniocentesis in the clinic

#### The making of patients; or on entering the human community

*... I do believe that maternal-foetal medicine is the quality checkpoint of humanity. Here we are able to say "you pass, you don't".*

Dr Torres, specialist in maternal-foetal medicine, Interview 2007

*I should like to propose that the goal of perinatal medicine for the next century will be the pursuit of neonatal excellence. Every baby should be born a healthy baby.*

Sciarra (1992: 5)

The above quotations state in a nutshell one aspect of maternal-foetal medicine as it is today: the search for *neonatal excellence*. In the previous chapter I have shown how obstetrics became the medical practice of dealing with what were seen as pathological births, and then later came the problematisation of *normal* pregnancies. The biological processes of pregnancy and of giving birth came to be reframed as difficult and risky procedures in need of monitoring and handling by obstetricians (c.f. Hiddinga & Blume 1992). Further, in Chapter 4 I presented the ways in which, for the Colombian case, the endeavour of bringing pregnancies to a 'happy end' inserted smoothly into the discourse of eugenics, hygiene, modernisation, and progress of the early and mid 1900s. A 'happy end' to a pregnancy supposed the delivery of a healthy baby that would constitute a healthy citizen. In that sense, obstetrics was experienced and practiced by physicians as a nationalistic project for achieving a healthy social body. The history of amniocentesis can then be seen within the history of the monitoring of pregnancy, and a striving for the production of healthy people.

In such a process, a particular ideal of a human being and citizen is reinforced: one that values *able* and productive individuals, and devalues those who, given their conditions, are seen as *disabled* and cannot be rehabilitated. People with cognitive differences – having Down syndrome for instance – belong to such a group of undesirable individuals, as shown in Chapter 3.

In this chapter I continue to address the medicalisation of pregnancy and the close monitoring of the foetus via antenatal technologies, to show how today medical and scientific efforts on reproduction remain focused on bringing pregnancies to the same ‘happy end’.

Although innovations in obstetrics and paediatrics have helped reduce maternal and infant mortality, there remains the felt need to care for women and foetuses that during pregnancy present complications or variations to the (changing) standards set by medicine, and so fall into the category of ‘high risk’. Technological innovations in foetal monitoring during the decades of the 1950s, 1960s, and 1970s included sonography (Sánchez-Torres 1991; Blume 1992), amniocentesis – its early use for studying the amniotic environment, its later use for determining RH incompatibility, and subsequent use for detecting chromosomal and genetic variations – and the development of the electronic monitor for foetal heartbeat (Sánchez-Torres 1993; Queenan 2002; Dunn 2006). All of these, coupled with the expansion of neonatal intensive care units and the concern for reducing maternal death before, during, and after delivery, set the scene for a bifurcation between caring for the foetus on the one hand, and for the pregnant woman on the other; these two elements became the focus of distinguishable endeavours (Petchesky 1987; Sciarra 1992; Sánchez-Torres 1993; Queenan 2002; Dunn 2006). Today, the subspecialty encompassing them is known as maternal-foetal medicine (which became the centre of attention for many obstetricians), perinatal medicine (which became the focus of many paediatricians), or foetal medicine (which involves both). The term maternal-foetal medicine was first coined in the United States in 1972 (Dunn 2006), as part of efforts for institutionalising this subspecialty. However, interests in foetal development and efforts to reduce maternal and infant mortality emerged long before that year, as the previous chapter has shown. In Europe,

caring for the foetus was generally known as perinatal medicine (Sakamoto 1992; Sánchez-Torres 1993; Queenan 2002; Belizán 2002; Dunn 2006). In Colombia, on the other hand, maternal-foetal medicine and perinatal medicine are widely used as interchangeable terms, and is only practiced by obstetricians. One interviewed specialist explained that:

The term maternal-foetal medicine refers more to the US school, whereas perinatal medicine comes from Europe, basically the UK ... In general they are very similar, well they are the same, only that in the UK there is a stronger focus on foetal therapy and intervention, but here [in Colombia] both names refer to the same thing (Dr Rincón, Interview 2007).

Within the framework of maternal-foetal medicine, fetuses considered to be pathological became the specialty's core interest, thus making the foetus its primary work object. The foetus gained the status of a distinctive patient, with agency and personality, amongst other available statuses<sup>50</sup>. Casper (1994a) shows how, as early as 1972, the foetus was starting to be portrayed by Liley – a founding father of foetal medicine – as having personality of its own and being the primary agent in the pregnancy process, 'very much in command of the pregnancy' (Liley, in Casper 1994a: 310).

Today, maternal-foetal physicians regard the foetus-at-risk (of having a given condition) as their patient. In the words of an interviewed specialist:

We [maternal-foetal specialists] see the foetus as a patient, the mother as a patient, and the unit mother-foetus as a patient, and all have different needs (Dr Cifuentes, Interview 2007).

Nevertheless, and despite Dr Cifuentes' explanation, one should look critically at the making of the foetus into a patient (Casper 1994a; 1994b; 1998; Isaacson 1996; Rose 1994;

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<sup>50</sup> Casper (1994a) shows that within medicine and science fetuses may acquire different statuses. 'Among the diverse constructions of fetuses in science and medicine are person, patient, research material, tool, therapeutic technology and tissue resource. Each of these constructions conveys particular attributions of humanity, such as agency or personhood' (Casper 1994a: 308).

Petchesky 1987; Williams 2005). This is not only because in making the foetus into a patient the pregnant woman, more often than not, becomes a passive, almost non-human actor, reasonably considered as merely 'the best heart-lung machine available' (Casper 1994a: 312). It is also because as the foetus becomes a patient, it necessarily acquires several other human attributes, namely humanity, agency, and personhood. These are attributions that patients, in general, have. Nonetheless, when looking at foetus-patients that have been given humanity as an attribute, one should do so 'in light of historical constructions of women, people of colour, certain ethnic groups, the mentally [ill], the physically disfigured, workers, prisoners, and animals' (Casper 1994b: 841), as all such groups have sometimes been considered less than human. Humanity, then, should not be taken for granted, because:

... humanity is a constructed (and often contested) identity or subject position, rather than a fixed natural state of being. It is social, historical, political, contextual, fluid, and often technologically mediated, and has much to do with power and its distribution (Casper 1994b: 841).

One should bear in mind that not only is the attribution of patienthood – and thus degrees of humanity – to the foetus problematic, but also that patienthood is neither naturally given to all fetuses, nor will all those labelled as patients remain as such. The designation of patienthood, along with the many other attributes that it implies, is not static (c.f. Casper 1994a, 1994b, 1998; Williams 2005).

Drawing on Casper's (1994a, 1994b) take on foetal patients and on humanity as an incremental attribute, in this chapter I look at the consequences (both political and ontological) of the process by which fetuses to which patienthood has been ascribed lose such a status when seen as possessing characteristics deemed 'incompatible with life'. Revolving around the category of patient, I explore how foetal patienthood is made and unmade in the context of the amniocentesis process. That is, I explore the way in which amniocentesis is enacted in daily life, and how, in turn, it produces practices, moments, categories, and distinctive patients who are inserted into a particular idiom of risk and anomaly.

My argument is that the functions attached to and enabled by amniocentesis – as practiced today – in combination with selective abortion (both through de-penalisation but also as a well-established, though unofficial, practice), respond to deep-rooted imaginaries regarding normal and abnormal individuals, and to obstetrics' perceived function of 'helping people to be born well'.

In order to address and develop my argument I make two claims about patienthood. Firstly, that the status of foetal patienthood is dependant on foetal conditions. In many cases, confirmation of a suspected condition – a suspicion that allows the maternal-foetal physician to make the foetus into a patient – enables the same physician to take patienthood away, and thus makes the foetus suitable to be aborted. Secondly, by achieving the status of patient (in distress), the woman is inscribed into and participates in the construction of fetuses with chromosomal conditions as being 'incompatible with life', and of people with disabilities as 'undesirable'.

By using the metaphor of a scenario for approaching the subject matter of this chapter, I present my argument in three steps. Firstly, I introduce the daily context in which amniocentesis takes place, namely a high-tech medical unit that deals exclusively with so-called high risk pregnancies. I do so in order to show how women and fetuses are inscribed roles within the framework of risk of a chromosomal condition. Secondly, I present and problematise the very practice of amniocentesis by illustrating the various moments and circumstances that surround the staging of the woman and the foetus as two different asynchronous patients, and the consequences that such a staging represents for the pregnant woman. Finally, I address the matter of diagnosis communication by pointing out the ways in which disabilities and medical conditions are constructed in the social space of a clinical department specialised in maternal-foetal medicine. I show how the diagnosis of foetal chromosomal variations (which are understood and conceptualised as 'incompatibilities with life') within the antenatal medical scenario entail the foetus' loss of patienthood, and so render it susceptible of being dismissed. Concurrently, the same act supposes that the woman can regain her status as a patient in full use of her agency (as she has to make a reproductive decision, but also because she is made into a patient in need of psychological and emotional support).

I conclude that the way in which patients in antenatal care are constructed makes them either visible or invisible. This is consequent for the category of patient in itself, for the woman's role during pregnancy, for the conceptualisation of the foetus, but most importantly, it perpetuates attitudes and understandings towards people with cognitive disabilities as undesirable.

Given the focus and aim of this chapter, I choose not to bring women's and couples' voices in relation to amniocentesis to the fore. I do so in order to highlight clinical dynamics and encounters as I experienced them during fieldwork. That is, I focus on what I saw in terms of the medical encounter, especially on the part of health staff. Women's and couples' viewpoints are explored in Chapter 6.

#### Department of Foetal and Maternal Care and Medicine: identifying patients

For a total of seven months I conducted ethnographic fieldwork in Bogotá, at three different scattered locations of a Department specialised in maternal-foetal medicine<sup>51</sup>. This Department belongs to one of the biggest health care providers in the country, *Salud*.

All three locations provide the same ultrasound and amniocentesis services and are attended, to a great extent, by the same group of specialists; though the three facilities are intended for different populations<sup>52</sup>. Nevertheless, follow up, further diagnostic exams, and confirmation of diagnosis (of foetal or of women's conditions) are centralised in one main location, situated in the northern part of the city and housed by *Salud's* clinic for pre-paid medicine. The second location is situated in the mid-western part of the city, housed by a health care centre. Only pregnant women, children to be vaccinated, and dental care users,

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<sup>51</sup> For practical reasons, however, I will refer to the Department in the singular, regardless of the specific location in which a particular observation or conversation took place.

<sup>52</sup> Health care in Colombia is divided into two population groups: *Contributivo* (to contribute, to pay) and *Subsidiado* (subsidised). People under the *Contributivo* are again divided in two: *Empresas Prestadoras de Salud* (EPS – Health Provider Companies) and pre-paid medicine. By law, all Colombian citizens and residents, if their economic capabilities permit them, must be registered with one EPS. All users of EPS have, in theory, access to the obligatory basic health care plan, called *Plan Obligatorio de Salud* (POS), as designed by the Ministry of Social Protection. But each EPS can decide whether it offers more services, as is the case with amniocentesis, of which *Salud* covers half of the procedure. Nevertheless, most health care provider companies offer to their users, as well, the option of having pre-paid medicine in combination with the obligatory EPS. Such users have to pay a higher monthly premium and so they have access to additional medical care, services, facilities, exams, procedures, and so on. People using pre-paid medicine often have the EPS with the same company.

all under the EPS system, attend this centre. The third site, located further west, provides for both pre-paid and EPS users. It serves as well as a teaching clinic and hosts a medical school. In the near future, the latter facility will move to a bigger place within the same clinic and will also absorb the mid-western location.

In the words of Dr Sossa, founder and chief of the Department, such a facility started out:

... as an idea of mine, it was born seven years ago ... [when] the country was going through a crisis in the health care system. Hospitals that functioned as institutions were closed down. The hospital Lorencita Villegas de Santos was the place in which this entire story about maternal-foetal medicine started. It was the place in which I did my fellowship, but it [the discipline] was rather incipient. When I finished my studies, due to political reasons, the hospital closed down. Then, the country was left with no maternal-foetal medicine ... In 1999, I was working as an attending obstetrician in the delivery room of this clinic [situated in the main location of the Department] and so I presented a project for creating the Department. With many bureaucratic and jealousy complications, and with the support of Dr Pinedo [a rather influential obstetrician in the clinic] the Department came to be a reality ... I linked up the Department with a program that the clinic [and *Salud* in general] had for reducing perinatal mortality. To make that link helped a lot for the booming of the Department because before that the referral of women, to us, was optional. But by linking the Department to such a program, all women that presented alterations had to be referred to the Department, and later all pregnant women were referred to us. That is how it works now ... One thing that catapulted the Department is the staff meetings for foetal congenital anomalies and advanced therapy. It [the meeting] includes, as you have seen, all specialists that concern a case and that will be eventually assisting the delivery ... Another important thing about the Department is the psychological therapy offered by Jimena; in that way we can provide better and integral care to our patients (Interview 2007).

A common characteristic of the three locations of the Department (as they were at the time of this study) was the spatial constraints they all have. Examination rooms and hallways are scarcely able to accommodate the number of people and amount of furniture that they are supposed to host. Consultation rooms, in themselves, are not necessarily small

by definition. However, the furniture makes the space shrink. The bed for the pregnant woman to lie on, the ultrasound machines that vary in size and specialisation depending on the location they are placed at, screens for showing the foetus, VCR and DVD recorders for documenting procedures and ultrasounds, chairs for companions to sit on, cabinets for keeping medications and utensils, and posters of foetuses that appear to be floating in what can only be a woman's womb (although the woman is invisible in the pictures), all crowd the space.

In addition to such material denseness, invisible but not imperceptible is the permanent noise. The soundtrack of the Department is composed of the white noise produced by the ultrasound machine, the constant beeping of machines, the almost permanent ring of two indefatigable telephones, and the hum of people talking, walking, and the occasional crying (sometimes shouting) of women after the confirmation of a foetal diagnosis or of foetal death. In combination with the noise there is the intense smell of antiseptics, disinfectants, alcohol, iodine, anti-bacterial soap, anti-bacterial hand wash, and the strong smell of the linen – which I can only name as *clean* – which completes the ambiance of the Department.

With regard to the people, the locations are no less hectic. More often than not, the sites are at their fullest capacity, which makes mobility rather difficult. To the usual count of one specialist in each location one must add, per shift: two to four fellows in maternal-foetal medicine, one to four residents in gynaecology or radiology, one nurse, one secretary, and a fully booked schedule that starts receiving pregnant women every fifteen minutes from 07:00 till around 18:30, Monday to Friday, and from 07:00 till noon on Saturday.

The Department is teeming. Yet, two words suffice to describe the Department's concerns: *risk* and *anomalies*. The Department exists either for ruling out risk or for diagnosing a condition. This is done by providing different diagnostic services to all women who belong to *Salud*<sup>53</sup> at very specific moments in their pregnancies. Such services are foetal genetic ultrasound (11<sup>th</sup>-14<sup>th</sup> week), performed for ruling out foetal morphological conditions that can relate to chromosomal variations (with a special emphasis being placed on determining the risk of Down syndrome); detailed ultrasound of foetal anatomy (21<sup>st</sup>-24<sup>th</sup>

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<sup>53</sup> Either as EPS or pre-paid users.

week) that examines the development of 'all foetal parts, paying special attention to the face, the brain, the heart, the stomach, the intestines, the kidneys, and the limbs', as stated in the Department's brochure; and foetal well-being ultrasound (30<sup>th</sup>-34<sup>th</sup> week), for establishing foetal growth and movement, position and appearance of the placenta, quantity of amniotic fluid, and placental functioning (Department's brochure).

Women visit the department for the first time usually somewhere between the 11<sup>th</sup> and 14<sup>th</sup> week of their pregnancy. At this point, it is possible to determine the *risk* of carrying a foetus with Down syndrome or another chromosomal variation. It is worthwhile to stress that *Salud* offers – and practices – genetic ultrasound to all pregnant women who use it as their main health care provider, even if there is no suspicion of such a possible risk. This service is seen by specialists, fellows, staff members, and also women and couples as good, competent, and integral antenatal care for pregnant women and their foetuses. The service of systematically providing genetic ultrasound to all pregnant users is grounded on the assumption that every woman and couple wants to know this information regarding their foetus, for these conditions are constructed and experienced by physicians and staff members as something women should necessarily rule out. In this context, in which the assumption of consent forms the foundation for the very way of performing the service, *informed consent* is not even contemplated by physicians. As one fellow expressed once:

I just read an article about how they do these [genetic] ultrasounds in London. They were debating about whether one should ask informed consent from women ... I never thought about that before, you know? We never ask informed consent for that exam. I mean, it is an ultrasound, and you think all women want to have it, I mean, who does not ... but perhaps we should contemplate the informed consent (Dr Isaza, conversation 2007).

Women who attend these particular appointments indeed do so '*for checking on the baby*', but they are not expressly informed that specific variations are being determined through such tests, such as markers for Down syndrome or other chromosomal variations. This sort of information is usually given either right before, during, or right after the ultrasound examination, if at all. Information is delivered as part of the practice of '*keeping*

*contact with women'*, but it is not seen as relevant for consent to be sought before performing the examination.

In such a scenario of *presumed consent*, all pregnant women and their foetuses are labelled as potentially being at risk. The latter is at risk of having a chromosomal, genetic, or morphological variation. For the former, the category of being *at risk* revolves around the possibility of carrying such a foetus. That is how the making of the pregnant patient – the woman and the foetus simultaneously – at risk takes place.

Another element that contributes to the making of the pregnant patient-at-risk is the possibility for undergoing a serum test (Alpha-fetoprotein) in order to provide extra markers for the determination of the risk of carrying a foetus with Down syndrome. For this test, however, informed consent is needed as the costs involved are neither covered by the EPS nor the pre-paid premium. Hence, the woman needs to consent not merely to *knowing*, but also especially to *paying*. If a woman has had the Alpha-fetoprotein test before attending the genetic ultrasound, her serum results are compared and evaluated in light of the ultrasound information.

The making of the pregnant patient-at-risk continues in the event of a) a foetal morphological variation – detected via ultrasound – that can be related to a possible chromosomal condition (for instance, an augmented nuchal sonolucency, the absence of the nasal bone, the presence of cleft lip and palate; as explained by Dr Sossa), b) if the woman's age (36 and over) positions her in a statistical bracket of being at an elevated *risk* for carrying a foetus with Down syndrome (Sánchez-Torres 1993; Rapp 2000; field notes 2007), c) if there is family history of chromosomal variations, or d) if the woman carries an infection that can be transmitted to the foetus (e.g. toxoplasmosis). In such situations, amniocentesis enters the antenatal scenario.

In general terms, the amniocentesis process<sup>54</sup> starts during the period of the 13<sup>th</sup> to the 18<sup>th</sup> week of pregnancy (field notes 2007). Given that most amniocenteses are performed on women older than 36 years of age, it is provided mainly for ruling out Down syndrome.

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<sup>54</sup> I refer to amniocentesis as a process, for the actual taking of the sample marks but the start of a long process filled with anxiety, ambiguity, fear, and uncertainty. I recognise as the end of the process the moment in which amniocentesis results are handed to the women and couples, and when a reproductive decision is made in cases of foetal chromosomal variation.

The test is seen as a tool for gathering important information for women and couples. In the words of one maternal-foetal specialist:

We [in his practice] provide women with the possibility of knowing the status of their baby ... The majority of amniocenteses are performed to rule out Down syndrome ... if you are an older woman, say you are 40, you know the risk [of carrying a foetus with Down syndrome] is higher so you want to have an amniocentesis ... Down syndrome is not the most recurrent chromosomal alteration, but it is the one that has the longer life ... it [a person with Down syndrome] is something with which women have to live for many years, so you would want to know that in advance ... (Dr Cifuentes, Interview 2007).

Although amniocentesis tests for all known numerical and structural chromosomal variations, and despite the fact that Down syndrome is not the most frequent of chromosomal or morphological foetal variations, such a condition has been made into a frightening one for prospective parents, who are constructed as being *at risk* of carrying such a foetus, especially so for women older than 36 years.

However, depending on the specific results of the genetic ultrasound, other foetal chromosomal conditions may be suspected, and thus amniocentesis is done to rule them out. In such cases all other foetal chromosomal variations have the same fate as Down syndrome: they are labelled, constructed, and experienced by physicians and staff members as pathologies, and women are *at risk* of carrying a foetus with such a condition.

Regarding informed consent, all women who undergo an amniocentesis must sign an informed consent form. It mentions the potential risk of miscarriage and the possibility of infection carried by amniocentesis. Yet consent is not only necessary due to the risks amniocentesis involves for the foetus' life; it is also sought because of its invasive nature, for it is the woman carrying the foetus to be studied, and it is her body that is to be intervened with, pricked, and touched. She needs to be informed in order to be able to agree or disagree with undergoing the exam.

However, when asked about the importance of informed consent, all of the specialists and most of the fellows interviewed agreed that the centrality of informed consent had more to do with the risk of pregnancy loss than it had to do with the fact that the test is an invasive intervention into the woman's body. It is seen as a formality to avoid legal consequences in the event of miscarriage, and not as an informational requirement on the part of the woman and her partner to know about the nature of the procedure, and the sort of results they might expect. Dr Sossa explained it as follows:

No one gets an amniocentesis without signing the informed consent form. I don't want to be held responsible for a miscarriage. They are told about this in advance and they decide to undergo the procedure (Conversation 2007).

Informed consent is seen by specialists, fellows, and staff members as a formality, which comes in the shape of a form. It is thought adequate to convey only the information that specialists are obliged to give when amniocentesis is presented to women and couples for the first time. And thus in Dr Sossa's above account, and as voiced by all of the other specialists and fellows, it is clear that from the physicians' point of view, amniocentesis is a decision taken by the woman and her partner. In their accounts, physicians express the view that they do not press women, under any circumstances, into having amniocentesis:

No, I never put pressure on a woman to have an amniocentesis. That is her call. Maybe she is not interested in that information (Dr Sossa, Conversation 2007).

We as scientists have to be neutral at all times. That means that you never guide a patient in any direction. You just present the information and they make the decision (Dr Isaza, Interview 2007).

However, despite the apparent effort at neutrality expressed by the physicians above, the way in which information is given to women and couples shapes, to a great

extent, their decision. To my question about whether women, before undergoing an amniocentesis, were aware of what it entails, how it is performed, and how long the results will take, physicians looked at me in disbelief and replied with comments such as:

Of course, women are explained about the exam. We explain them all about it. We talk to them in a very clear way, especially about the risks. So, if they agree they sign the informed consent form and we do the procedure (Dr Torres, Interview 2007).

Nevertheless, physicians recognised that information regarding an amniocentesis procedure is not always understood by women. Some doctors were confident in their ability to convey the message in such a way that the woman has enough relevant information for deciding upon the procedure:

Yes, yes, we always explain all to women. But, it is not always clear for them, and we notice that. So what we can do is ask them to think about it, to go home and discuss it with their husbands and to come back later when they are sure about their decision. But in general, women understand what the exam is about, what the risks are, and what we are looking for (Dr Arroyo, Interview 2007).

But physicians' efforts for providing information in a comprehensible way is somewhat limited, as they recognise that there exists a part of the population that, due to their socio-cultural background, cannot follow medical terminology. Such women are seen as in a lower position, so doctors need *'to step down a level'* and inform them *'in terms that they can understand'*:

Most of the women we attend to know about amniocentesis before we even mention it. But there are others who really never finish grasping quite well what is amniocentesis, or chromosomes. We cannot bridge that cultural and educational gap, so we have to step down a level and talk to women in terms they can understand (Dr Isaza, Interview 2007).

What becomes problematic about '*stepping down a level*' is that physicians decide what type of information, and how much, is relevant and needed for the woman who, from their point of view, 'never finishes grasping quite well what is amniocentesis'; yet physicians expect them to make a decision about it.

But just like the practice of amniocentesis, the issue of informed consent is nuanced. When an amniocentesis is performed because the woman is older than 36 years of age, and there is no other marker of *risk*, specialists present the test as an option; as additional and valuable information that women should have. Once there are more markers of risk, amniocentesis is presented as somewhat necessary; it becomes the responsibility of the woman to know the health status of her foetus (Lupton 1999)<sup>55</sup>, as the following quotations show:

There is an exam that can tell us if the baby is alright. At your age you have more risk of having a baby with Down syndrome ... We will introduce a needle there, where the baby is, and we will take some of the amniotic liquid. It is a quick exam, very easy, and you can be sure your baby is alright ... there is a very small chance of miscarriage, but it is worth it, amniocentesis helps us to know how the baby is (field notes 2007).

Given your age, you may consider the possibility of having an amniocentesis. With a needle we will take out a bit of the liquid you have in your belly so we can know if your baby is alright (field notes 2007).

Do you want to have an amniocentesis? It tells us if the baby has Down syndrome. *Partner of the woman*: 'Do you think it is necessary?' *Dr\_\_*: 'No, well I do not see anything wrong [during the ultrasound], and the tests [Alpha-fetoprotein] are alright. *Partner of the woman*: 'So you are saying we do not need the other exam?' *Dr\_\_*: 'Well no, but if you want to be a 100% sure you might want it.' *Partner of the woman*: 'But you do not see anything

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<sup>55</sup> Lupton (1999) offers an articulated notion of risk to which the pregnant body is subjected. The author emphasises the individualisation and agency that pregnancy has nowadays, which leads to the conceptualisation of women as being responsible for their reproductive choices and of the health status of their children.

wrong, you tell us...' Dr\_\_ : 'No I don't see anything wrong.' *Partner of the woman*: 'OK then not' (field notes 2007).

We found that the baby has \_\_\_ [conditions are often referred to by their medical name]; there is this exam, which will tell us if the baby is alright or not. With a needle we will take a bit of the liquid you have in your belly. It doesn't hurt a thing. The exam has a very small risk of producing miscarriage, very little, but I have to tell you that. You have to pay it yourself, the insurance covers the needle and my job but you have to pay the lab work (field notes 2007).

We need to do an amniocentesis because the baby has the nuchal sonolucency rather augmented. We need to make sure there is not a chromosomal condition ... we will extract, with a needle, some of the liquid in your belly. It is a very easy exam. It does not hurt, but it has a very small chance of inducing miscarriage ... but we need to do this exam to make sure what the baby has (field notes 2007).

Notwithstanding the contradiction between how specialists say they present amniocentesis and the way in which such a presentation actually happens, apparently for doctors, women, and partners alike, the information conveyed is considered enough and is understood sufficiently for decision making. Yet when I asked women who were waiting to be called in to have their amniocenteses if they knew what the procedure was about, and why they were having one, they provided answers in which not only were some aspects of amniocentesis misunderstood, but further, the issue of *choice* regarding the exam appeared rather absent:

Yes, they [the specialists] will take some liquid from my stomach, through my belly button and check on the baby. The doctor said that I should have this exam in order to make sure that the baby is alright because of my age. You know, at my age I have to be more careful and there can be problems with the baby (Omaira, 41 years).

Well, the doctor found that the baby has the somnolence augmented [sic]<sup>56</sup>, so he explained that we need to do this exam to make sure that the baby is fine. He explained that, through my belly button, they will take a bit of the liquid I have in my stomach ... The doctor also said that the exam may cause miscarriage, but that the possibility of that is very small (Isabel, 42 years).

In the previous ultrasound [the genetic ultrasound] the doctor found something in baby's little head. An Andy Walker [sic]<sup>57</sup> and he said that the amniocentesis [sic] will tell us what is wrong with the baby. I do not remember if he explained the amniocentesis, but we looked it up in the Internet and now we know all about it (Eliana, 32 years).

There are various points of relevance in the above accounts. For instance, women made reference to having an amniocentesis in order to '*know if the baby is alright*'. Further, when women spoke about what was possibly *wrong with the baby*, they relied on what they recalled to be the clinical diagnosis of the foetus. However, the ways in which women referred to the possible foetal conditions reveal that they were undergoing amniocentesis in a situation which combines compliance with medical advice and a search for reassuring information about their *baby's* status. In their recall of the way in which doctors explained amniocentesis, the women demonstrated how, to a degree, they had translated what they expected and imagined about the exam. There were women, however, who were rather more aware and better informed about amniocentesis; not because the physician had explained it thoroughly to them, but because they already knew about the existence of a test for Down syndrome<sup>58</sup>.

The abovementioned elements emerging from women's accounts might indicate various things. Firstly, that what is relevant for women is the result of the amniocentesis, and not so much the technicalities about how such a result is arrived at. Secondly, that information regarding amniocentesis is not neutral, and neither is it received in a neutral way. Third, that depending on the context, the emotional situation, and the women's and couples' interest and anxiety at that particular moment, some aspects of the information

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<sup>56</sup> She meant augmented nuchal sonolucency.

<sup>57</sup> She meant Dandy Walker.

<sup>58</sup> I explore women's motivations and relationship with amniocentesis in the following chapter.

transmitted by the specialist may stick, whilst others may be overlooked. That is, if the message a woman or couple receives is 'your baby is not well', that bit of information may obscure any other information received, including, for instance, the technicalities of the amniocentesis. And finally, that despite the neutrality physicians presume to have, they clearly direct women to make the decision to *choose* for an amniocentesis, as it is an exam for '*knowing if the baby is alright*'. In doing so, physicians overemphasise not only the need and the wish for delivering a '*normal baby*', but also the pathologisation and undesirability of foetal chromosomal conditions.

In such a scenario of risk establishment, women and fetuses are staged simultaneously as patients. The woman's concerns are, to some extent, considered by the specialists. However, as shown above, the main concern for the physician is establishing the condition of the foetus. This early interest in the foetus limits the attention women receive in relation to particular informational needs they may have, for such information is often not covered by physicians. Women's status as patients thus starts to fade away. But the women themselves also contribute to their own 'backgrounding' (being placed in the background), as they ask very few questions regarding amniocentesis, and accept as the physicians' (and also their own) main focus the status of the foetus. The fact that they ask few questions might indicate, as I said before, that the knowledge conveyed is not made relevant for them, not translated well into their lives or that of the baby, and also that what interests them is the result and not so much the process of an amniocentesis.

Nevertheless, it is not until the very moment in which amniocentesis takes place that women are placed *off stage* of the antenatal care scenario and the foetus becomes a central protagonist.

#### Doing amniocentesis: the foetal patient

The staging of the foetus as a patient, distinct from the woman carrying it, is performed by both women and physicians. In the context of maternal-foetal medicine, the foetus is seen 'as an embodied actor within a pregnant woman's uterus' (Casper 1994a: 308); the women in turn regard the foetus as their *baby*, an altogether different entity from them.

Even though the motivations and practicalities of the staging of amniocentesis are experienced differently by physicians and women, making the foetus into a patient involves the backgrounding of women, who are cared for 'lest their actions or their bodies cause irreparable damage to the fragile foetal patient' (Casper 1994a: 313).

The aim of this section is to illustrate the moments and circumstances in which the foetus becomes a patient, and the woman carrying it is moved *off stage* of the antenatal scenario.

In the context of amniocentesis, since women themselves are not ill they seek specialised medical knowledge and expertise for their babies<sup>59</sup> which, as women expressed it, *might be sick*. Women, at this point of antenatal services, do not feel they are a patient; they hand over the benefits of such a status to their babies. As reported elsewhere, women all around the globe seek amniocentesis, mainly for reassurance (c.f. Marteu & Drake 1995; Rapp 2000; Hunt et al. 2005). Based on the information the exam provides, some women hope for possible medical treatment for their babies, others want to be prepared for the arrival of a child different than expected, and yet others want to know the foetus' status in order to be able to choose whether or not to have it (field notes 2007)<sup>60</sup>.

Specialists and fellows in maternal-foetal medicine handle the foetus as a patient (c.f. Casper 1994a, 1994b, 1998; Isaacson 1996; Rose 1994), but also as a research and educational case which could enrich their knowledge and expertise (c.f. Casper 1994a, 1994b, 1998; field notes 2007). The foetus acquires the status of a *distinct* patient from the moment risk is suspected, but only fully becomes a patient when amniocentesis takes place.

*Lights off:* In a dark, impersonal clinic examination room the pregnant woman lies on a single bed covered in a white sheet. The specialist in maternal-foetal medicine asks her if she has any last minute questions; this is either answered by a silent shake of the head, or by the voicing of her fear of pain or possible damage to the 'baby' caused by the needle. Some

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<sup>59</sup> All interviewed women considered and referred to the foetus as their baby. Many had already given it a name and were preparing a room for the arrival of the new member of the family.

<sup>60</sup> Women's motivations for undergoing amniocentesis, and their reactions towards amniocentesis positive results, will be the focus of the next chapter.

women cry in anguish before entering the room, though they do not share this with the specialist. The physician explains that the needle will not touch the foetus and that amniocentesis *does not hurt a bit* (although none of the attending specialists or fellow students in this department have first hand experience of amniocentesis since they are all male). One last time the specialist explains the procedure to the woman in a warm and gentle tone. While he is locating the foetus, and the nurse is preparing the woman's abdomen with iodine soap and foam in order to make the surface sterile, some interchange between the doctor and the woman takes place. Usually physicians ask women about their jobs or other activities, then explain that soon they will do the amniocentesis, 'which does not hurt', and reiterate 'that the exam is needed to be sure that the baby is fine' (field notes 2007). Sometimes, specialists give away *exciting* information, as for instance the foetus's sex. Such conversations may be interpreted as an attempt to reduce women's anxiety; but it is also a sort of preparation for a momentary goodbye, as from now on and for many days to come, the patient – and thus the specialist's (and also the women's and couples') concern – will be the foetus. When the foetus has been located and the woman's abdomen cleaned, with a calming tone the nurse says: *'OK mommy, put your arms behind your head and do not move; you'll be alright'* (field notes 2007).

*Lights on:* The foetus' presence fills the room, and the light coming from the screen in which the foetus is visible nuances the shapes and bodies present. The most important visible presence now is the tiny little foetus we all can see thanks to the ultrasound machine. As all eyes are fixed on such a small being, it suddenly appears very big.

Once the foetus is located, the specialist can decide where to do the puncture to avoid foetal or placental damage. He then asks either the nurse or a resident to pass him the Spinocan #22 – a hollow needle with a transparent needle hub for extracting the amniotic liquid – the liquid that holds information that will influence life or death decisions regarding the presence viewed on the big flat screen above everybody's heads . All are silent, as if time had stopped.

Performing an amniocentesis requires two to three people. The attending specialist is the busiest one. With one hand he locates the foetus, helped by the ultrasound machine's transducer which makes the foetus visible to everyone in the room. He directs the transducer to check constantly on the foetus and the placenta during the five to eight minutes that the amniocentesis lasts. With the other hand he punctures the pregnant abdomen, introducing the almost 9 centimetre long needle into the uterus of the woman lying on bed. Either a nurse or a resident extracts the amniotic liquid (1 cc per week of pregnancy) filling two syringes. The same person withdraws the needle and cleans the women's abdomen. During this time, the focus is on the foetus and on the amniotic sac; no eye contact is made with the woman. The specialist's eyes move back and forth from the transparent uterus on screen to the woman's stomach to check on the needle. As expressed by the chief of the Department, '*my hands are my eyes*'. It is the hands which have mastered the coordination of movements that allow the uterus to become transparent, the foetus to be seen and checked on, and the needle safely inserted. There is little need to look at the body lying on bed, as the skin only makes the foetal patient invisible.

If during the amniocentesis procedure a conversation takes place, it is between the specialist, the resident, and the nurse, as when the specialist gives instructions. The woman is only addressed if she moves, if she expresses more pain and discomfort than *usual*, or if she attempts to touch the needle. If the woman asks a question, it may be answered after a long silence, or may never be answered at all.

In most cases, a companion is allowed to be in the room. When this happens they mostly avoid watching the pricking of the stomach, and thus they too fix their eyes on the screen in search of the foetus, or cast them down to the floor. If the companion is the woman's partner, they are often visibly anxious. Sometimes they sit still and quiet next to the woman, which also prevents the possibility of eye contact. If due to spatial constraints the partner cannot be in the room, they are invited by the nurse to watch the procedure on a screen located above the nurses' desk: '*Daddy, it is too crowded here, you can watch on the screen over there*' (field notes 2007). This means that partners in fact are not accompanying the woman during the procedure (even when sitting or standing next to her), but the foetus (through their fixed attention on the screen).

Women, in the vast majority of cases, close their eyes at the moment of the puncture; some remain like that during the whole procedure. Others, once the needle is inside them, open their eyes and look at the screen. In some cases, women search to make eye contact with their companion. In many cases, women moan in discomfort when the needle pricks the skin and when the liquid is been extracted. Many cry during and after the amniocentesis procedure, and again while expecting the results.

Once the needle is out the world moves again.

The nurse takes the two syringes with amniotic fluid to her desk, leaving them lying on the desk while she writes the woman's name on an envelope in which she will place the syringes containing the warm, yellowish liquid. It is astonishing for the untrained eye to see the syringes handled so nonchalantly, as something of no importance, even though they bear all that data, all those decisions, and all the prospective parents' – and particularly the woman's – anxiousness. The liquid, until that time unknown to me or the prospective parents, which was inside the woman's body and is supposed to carry good or bad news, seems so irrelevant and out of place when left carelessly on a desk in the absence of medical equipment, yet in a medical setting.

In the meantime, attention is turned back to the woman; she is congratulated for *'doing well'*. In all cases, women ask about the state of the foetus. The specialist explains that he is checking on the foetus' heartbeat and that he is making sure that there is no placental bleeding. After such precautions are taken, the foetus leaves the screen and once again becomes invisible to the naked eye. However, it remains the patient. Recommendations and precautions are given to the women regarding the care they need to exercise in order to minimise the risk of miscarriage: to stay home, to keep complete repose for the day, and in case of abdominal pain or the presence of blood to rush to the Emergency Room. There is no particular recommendation for the woman herself regarding what to do with the growing anxiety she will feel while expecting the results.

The foetus has taken centre stage. This will remain the case for the twenty to twenty-five coming days that amniocentesis results take to be ready, and sometimes even longer.

In the event that the amniocentesis was performed due to findings in the genetic ultrasound, while waiting for the results the foetal patient undergoes several further ultrasound checkups in order to document its development and rule out morphological variations associated with the different possible chromosomal conditions. Women are asked to pay several visits to the Department; they usually have to travel long distances, and have to wait for hours before they get to see the specialist who, in turn, acknowledges only the foetus and neglects their concerns.

An example illustrates this point well:

7.00 a.m. Northern Clinic. Today Eliana and her husband Carlos had an appointment with Dr Sossa. I spotted them in the waiting room on my way into the Department. I sat and talked with them. Eliana said they were doing better, getting used to the idea that their baby girl had something wrong. They had also decided to stop looking on the Internet for the foetus' potential condition, because they had no clear idea of what their 'baby' had. It was better to wait until they had a clearer diagnosis. So far, Dr Rincón had found a growth restriction, a missing artery in the umbilical cord, and a Dandy Walker [an incomplete formation of the cerebellum vermis].

Around 8.30 Dr Sossa called them in ... Eliana and Carlos had no idea why they were supposed to visit the clinic that day, though I knew that the doctors were looking at the foetus' heart because I had asked Dr Torres before he entered the examination room. Their questions were answered by a heavy silence.

I sat at the front desk. The microphone of the evaluation room was on while Dr Sossa was dictating to Daniela [a nurse] foetal measurements, allowing me to listen to the brief conversation Eliana and Dr Sossa held. In the dark room, Eliana had been lying on a bed with her husband standing next to her, both in absolute silence, until Dr Sossa had finally decided to talk after around 8 minutes of examinations. *'That is either trisomy-18 or -13, I'm pretty sure'*, he said, addressing Dr Torres. Eliana's natural question to such a statement was: *'What is that, Doctor?'* To which Dr Sossa bluntly answered after a long silence: *'An incompatibility with life'*. Then he fell silent again, and a couple of minutes later he left the room.

The foetus' heart was impossible to spot. Eliana and Carlos will have to come back again tomorrow morning. After Eliana and Carlos left, Dr Sossa called the genetics laboratory asking for Eliana's amniocentesis

results; he was told that the results would take yet another week to be ready (field notes 2007).

The above account exemplifies the relegated place women's concerns have once they are moved *off stage* of the antenatal scenario. Such an account also shows the way in which women receive news regarding their future baby, charged with connotations such as '*incompatibility with life*'. The use of this sort of statement makes one wonder, once again, about the neutrality physicians presume to have when interacting with their pregnant patients. What does it mean for a woman to be told that her 'baby' has 'an incompatibility with life'?

The Department provides an educational programme for clinical fellows. During all examinations the specialist is accompanied by a fellow in maternal-foetal medicine and residents of different specialties. Discussions of possible diagnoses take place right then and there in front of the pregnant woman. In her analysis of teaching hospitals, Fox (1974: 119) highlights that patients 'are expected [and subjected] to permit medical students and physicians other than their own to interview and examine them and sometimes to participate in their care'. Patients experience increased discomfort in teaching hospitals due to the constant scrutiny they undergo everyday without being asked, acknowledged, or informed (Fox 1974). But women attending an antenatal facility for foetal diagnosis in a teaching hospital are, to some extent, neglected twice. They are not only unacknowledged, as patients in teaching hospitals usually are, but are also constantly overlooked as attention is given mainly to the foetus as the primary patient. The foetus is staged, seen, and treated as the *patient*, albeit a rather silent one, with whom communication is somewhat complex if not impossible. Moreover, the foetus is a particularly convenient patient that does not visibly or audibly demand information and sympathy. Thus, physicians can communicate solely to one another in sophisticated medical terms, accompanying such interchanges with faces, frowns, and sounds that convey a preoccupation and a message that the situation of the foetus is *serious*.

However forgotten and overlooked women are, they are lying on the bed listening to such fragmented information and observing the physicians' body language, which they then

try to make sense of and match up with their own understanding of the situation: the consequences that a particular health condition may represent for their family and for the life of their future child. As imperceptible as it may seem, women do exercise the limited agency they have – and I say limited because as I have shown women are not made full participants in the process of foetal diagnosis – by demanding information and explanations about their foetuses' status not only to specialists, but also to fellows, residents, nurses, and eventually even to me<sup>61</sup>. Women also looked up the diagnosis, terms, and procedures discussed by specialists and fellows on the Internet. Such information does not bring peace, since it is often difficult to understand in terms of the terminology and practical consequences for their lives; but gaining that information was felt as a way of being involved in the diagnostic process.

Although in most of the cases, after amniocentesis results arrive the woman returns to the *on stage* mode, there are circumstances in which the staging of the foetus as a patient is prolonged. This happens when a concrete diagnosis cannot be attained because amniocentesis results unexpectedly come out negative, yet there is ultrasound evidence that shows foetal structural variations. In these circumstances, women remain for quite some time *off stage*, for both specialists and women alike want to continue further examinations of the foetal patient in order to establish a diagnosis.

Diagnoses of this type are not straightforward and are therefore highly uncertain. Physicians' reaction when uncertainty takes them by surprise is to remain silent in front of the women, who in turn experience this lack of information, and the anxiety and anguish that goes along with it, as unbearable. Furthermore, in the search for answers, doctors incorporate many possibilities, which may include making the woman responsible for the ambiguity or misdiagnosis.

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<sup>61</sup> Many times I was confronted with couples' questions regarding their foetuses' status. Although I emphatically explained that I have no medical training, questions kept popping up. Eventually, I made the decision to provide the (non medical) information that I had and that I could manage, such as dates of results delivery, appointment schedules, what an amniocentesis is, what a trisomy and a monosomy are, and other such related issues.

09.00 a.m. Northern Clinic. As always, Eliana had a million questions which she posed to me [the researcher]. Her first question was if they could already discard the trisomy-18. She also asked whether the Doppler was needed because her placenta was damaged, and if it was damaged because she was not eating essential food [specific vitamins and minerals]. Eliana asked me about the baby's appearance when born; if she was going to have a big head, if she was going to be too small in size; if she could talk and move. Eliana also asked me why the doctors were returning to diagnoses that had been discarded: *'as the belly button and the thing in the brain, the Dandy Walker<sup>62</sup>'*. I told Eliana that unfortunately I had no answers to her questions and I encouraged her to ask them to Dr Sossa. In response to this, Eliana replied: *'Yes, I can ask him that, but he will not answer. He never answers. Every day Carlos and I say: Ok, today we will know what is wrong with the baby girl, today is the day when they are going to explain us everything. But not, always are exams and exams and no one tells us nothing. I already gave up. I know I will walk out today without knowing nothing about the baby'*.

Around 11.15 Eliana was called in. Dr Torres was the one to examine the foetus today. He was blunt, as always: *'Yes, you have a Dandy Walker, and I think you must have been lost in counting your last period'*. Eliana was visibly upset by such a statement and she looked at me in exasperation. Once Eliana left the examination room she turned to me and said: *'I wonder if he treats his wife in this way'*, and then added, *'Please let me know how you can get lost in your own counting, when you keep a calendar and you do mark every time you get your period?'* She was 100% sure of the date of her last period and she could even tell me the exact day when she and Carlos conceived the baby.

After Eliana left I asked Dr Torres why they never gave information to the women and he said: *'I really do not know what is wrong with it [the foetus], so I prefer not to open my mouth. Go home, do some research and wait for the [staff] meeting to take place'*.

As seen in this section, when the foetus gains the status of patient it supposes the loss of visibility and importance of the woman. However, women can and do regain their status as prime patients.

### Communicating news, constructing disabilities, making the woman the patient

In such a scenario of risk, diagnosis, and fragmented communication, women are expected to make a decision regarding the future of their foetus. Interestingly enough,

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<sup>62</sup> As defined by Healthline: 'Dandy-Walker malformation is a congenital (present at birth) condition involving several abnormalities in the development of the brain. The malformation appears to result from destructive processes, such as inflammation or trauma, which block the circulation of cerebrospinal fluid (CSF) inside the head after the brain has been formed in the embryo.' Online source: [http://www.healthline.com/galecontent/dandy-walkermalformation?utm\\_term=Dandy%20Walker%20syndrome&utm\\_medium=mw&utm\\_campaign=article](http://www.healthline.com/galecontent/dandy-walkermalformation?utm_term=Dandy%20Walker%20syndrome&utm_medium=mw&utm_campaign=article)

specialists assume that women follow the discussions that take place while diagnosing the state of the foetus, even though, as I have shown, they are more often than not placed in the background. Decisions about continuing or interrupting a pregnancy are therefore based on patchy information founded on partially communicated and imperfectly understood medico-cultural terms and values, and on the woman's own understandings of disabilities. Most importantly, reproductive decisions come out of the uncertainty of not being able to comprehend fully the foetus' condition, and of not knowing what life would be like with a child with that particular condition.

Diagnosis is not always a straightforward process. As shown previously, uncertainty surrounds foetal medicine. As a way of coming to terms with uncertainty, the Department has enabled a medical meeting for Antenatal Diagnosis of Congenital Anomalies and Advanced Therapy. The meeting takes place every other Monday from 19:00 to 21:00-21:30. One format the meeting can take is that the fellows present the cases they are participating in, with the attending specialist backing them up. The fellows are graded depending on their presentation, and are therefore questioned about specific matters that they are supposed to know and see in the ultrasound images that illustrate each case. Another format for the meetings is that the attending specialist presents the case, though the questioning of fellows also takes place. Thus the meetings function on two levels: at the educational level they serve the purpose of quizzing fellows, while at the professional level specialists discuss with other colleagues the best way to go about each case. The idea of the meetings is to attain, in an interdisciplinary manner, consensus on diagnosis, prognosis, and possible treatment. That is why neonatologists, neurologists, radiologists, neuro-radiologists, paediatricians, surgeons, cardiologists, geneticists, specialists in maternal-foetal medicine, and the Department's psychologist, all attend such meetings. Each specialist gives his or her opinion regarding the foetus' state, according to his or her focus in medicine. The foetus is still very much the focus at the meetings; however, the woman's reproductive future and her emotional and psychological health start to receive attention. Nevertheless, in most cases no consensus can be achieved, given that much still needs to be learnt about foetal diagnosis on the one hand, and that all discussion revolves around images of a body inside another body on the other.

Such a public airing of uncertainties can be interpreted in two ways. Firstly, the meeting can be seen as an act of territorial professional demarcation, in which professional boundaries cannot be crossed. This is enacted by the display of knowledge and the demonstration of power, which perpetuates the established hierarchical order in which fellows constitute the last link among the medical professionals. Secondly, the public discussion of uncertainty and diagnoses legitimates the following staging of the woman as the prime (and sole) patient, who now has the duty to make a reproductive decision; a life or death decision regarding her foetus. However erratic, abstract, and sometimes mistaken it may be, a diagnosis is finally achieved. With that, women recover fully the status of patient and come to *centre stage*.

When a diagnosis is finally made – usually based on interpretations and information gathered through the extensive examinations performed on the foetus, and on (confirmed) assumptions about women's needs – the woman returns. The foetus is now placed *off stage* and thus loses the status of patient. For the foetus, to lose the status of patient not only supposes losing the leading role, but also losing all human attributes that had previously been conferred on it. Eventually, after a diagnosis is made, more often than not the once foetal *patient* may be dismissed and aborted by the same specialist that made it into one.

There are two ways for women to return to the *on stage* mode, and in the great majority of cases they are accompanied by their partner; although the latter never becomes a patient, for the woman's wishes and concerns are the focus of physicians and health professionals. The first way in which women return to patienthood is when the amniocentesis produces an expected negative result, and thus women are sent back to their obstetrician to continue *regular* antenatal care. This is the case for women who undergo amniocentesis either because their age positions them as being *at risk* of carrying a foetus with Down syndrome, or because of the sheer need for reassurance, even in the absence of any related marker of a possible aneuploidy<sup>63</sup>. The second case is when amniocentesis results support physicians' expectations of chromosomal variations, or when the results of the test become irrelevant because the foetus' condition is detected by other means to be rapidly worsening.

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<sup>63</sup> Aneuploidy is the modification in the chromosomal count of 46 XX for women and 46 XY for men. See Moore & Persaud (2006: 161).

In the following section I focus on the second scenario. The purpose of this section is twofold: a) to show how women return to the *on stage* position in the antenatal scenario as a patient in full use of her agency – because a reproductive decision has to be made – and as a patient in need of emotional and psychological support; and b) to illustrate how, by the way diagnosis is communicated, the Department constructs and construes disabilities and foetal chromosomal and developmental variations as inherently problematic, traumatic, and burdensome.

In cases when amniocentesis results are positive, as expected by specialists, or when the foetus' condition worsens by the day, women stop seeing their former obstetrician and are centre staged, thus continuing to be part of the Department's concerns. At that point her pregnancy becomes a *high risk pregnancy*. *Foetal malformation*, as foetal conditions are referred to by the Department's staff, is considered a *risk factor* for the woman's health and well-being (Department brochure; field notes 2007). To carry a foetus different from what the woman and the couple expected is seen as a source of emotional distress and profound sadness. In physical terms, the fact that the woman has to undergo delivery also supposes extra risks than those considered as normal (c.f. Hiddinga & Blume 1994). Although to deliver a baby with developmental variations does not *per se* increase a delivery's risks, the fact that the baby has a condition considered to be serious makes physicians view such a delivery as an unnecessary risk and a waste of resources, which could be prevented by having an abortion:

[T]here are some malformations that have no chance of living, but do endanger the woman's health as delivery always has its risks (Dr Castro, Interview 2007).

[A] delivery is risky in itself, so if the woman wants to keep the foetus she will face a delivery, perhaps a Cesarean section that involves even more risks. It is safer to have an early abortion than to have a delivery of a malformed baby, plus fewer resources are needed. When a malformed baby is born all sorts of resources are needed, not only during delivery but after, like the NICU and maybe surgeries and that will last during all the baby's life (Dr Rincón, Interview 2007).

Due to current state of the art technologies available in advanced foetal therapy, the Department is acquiring and mastering the relevant expertise for dealing with fetuses with surgically modifiable conditions. But much still needs to be learnt, and more technical and technological innovations need to follow in order to make surgery a feasible option for many fetuses with developmental variations (Casper 1994a, 1994b). Further, there is as yet still no treatment available of any kind for altering chromosomal or genetic conditions.

With such extremely limited possibilities for treatment, the foetus loses its status as *patient* and becomes the condition it has been diagnosed with. Thus, when explorations are concluded and the foetus has been studied, and after the woman's body has been penetrated and made transparent, the once again invisible foetus is returned back to the womb as a condition. The woman then becomes a patient *with a diagnosis of a malformation*, as physicians and staff say, bypassing the foetus. Although the woman does not have a malformation herself, the fact that her foetus – which is no longer a patient but a condition – has one converts the woman into a patient. This is very much like when a person is diagnosed with heart failure, though the major difference is that the heart has never been made into a patient as the foetus has (c.f. Casper 1994b). The woman as patient not only suffers the *diagnosis of a malformation*, but she is also expected to make a reproductive decision regarding her foetus. Needless to say, such a move back to centre stage adds anxiety and confers onto the woman the immense responsibility of deciding who will enter the human community (c.f. Rapp 2000; Brookes 2001). In other words, with the diagnosis of an untreatable foetal condition, the woman, previously ignored, returns as a patient in need of care and 'treatment' for *her* condition – a *malformed* (and assumed unwanted) foetus.

Diagnosis is communicated through a mix of highly sophisticated medical terms and categories, and is then *translated* into laymen's terms so that women and couples can *follow* physicians. Although physicians do believe that women undergo psychological distress when informed about foetal conditions, specialists and fellows inform prospective parents in a blunt, detached manner, which in turn increases women's feelings of uncertainty, fear, and desolation. When communicating the diagnosis, the possibility of abortion may be raised, either by the women themselves or by the physicians, who present it as 'one option of *treatment*' (Dr Sossa, Interview 2007).

10:00 a.m. Northern Clinic. Dr Torres is in the examination room with Patricia and Iván. The amniocentesis results are not ready yet. Dr Sossa suspects a trisomy-21 and Dr Torres suspects a Turner Syndrome<sup>64</sup> [45 X]. After a long, thorough, and silent ultrasound, Dr Torres says that he sees that the foetus has hydrothorax. That complicates the diagnosis. He says: *'The heart is surrounded with liquid, and the baby is very swollen'*. Dr Torres adds: *'You know you could abort if you want, this is an incompatibility with life. Most likely the baby will die in utero'*. To this news Patricia asks, with an almost imperceptible voice: *'Will that [the death of the foetus] harm me?'* Dr Torres: *'No, it will not harm you at all. If it dies it will be necessary to remove it but it will not harm you...'* Patricia: *'No, I do not want to kill my child'*. To which Dr Torres answered: *'That is your decision; I just had to inform you about the options you have'* ...

Dr Torres leaves the room in search of Dr Sossa, who needs to confirm the diagnosis. Two minutes later Dr Sossa and Dr Torres return to the room in which Patricia and Iván have remained in deathly silence, holding hands and crying. Dr Sossa repeats the ultrasound and says: *'Yes, it has hydrops'* and to Dr Torres adds: *'and see the heart?'* It is the usual teaching experience. Patricia asks whether the baby is suffering. Dr Sossa explains: *'The baby is full of liquid; the baby is very sick'*. Dr Sossa leaves the room again and Dr Torres stays with Patricia and Iván, telling them that their baby will probably die in a couple of weeks and that they need to make an appointment with Jimena, the psychologist, though he provides no information whatsoever regarding why they should see a psychologist. Dr Torres asks Patricia to put on her clothes and he says goodbye (field notes 2007).

The reason why Patricia, as with all women *'diagnosed with a malformation'*, needs to visit the psychologist is because of the shared conviction that *all* women, after a diagnosis of a foetal condition, undergo emotional distress. Nevertheless, physicians assume that care for women's mental and emotional well-being is an issue for the Department's psychologist alone, and that what affects women's emotional stability is the diagnosis itself, rather than the accumulation of stress and fear that the diagnostic process as a whole entails. No attention is paid to the extent to which the whole process moulds women's and couples' reactions to a diagnosis, and shapes their decision making processes: the long waiting time; the continuous ultrasound check-ups (or that one ultrasound that suffices for determining a developmental variation); the medical exchanges about the foetus; the secondary role that

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<sup>64</sup> As defined by the Merriam-Webster online dictionary, Turner syndrome is a 'condition that is typically associated with the presence of only one complete X chromosome'. Online source: <http://www.merriam-webster.com/medical/turner%20syndrome>.

women and couples play; and the combination of all such factors being conducted in a detached way (filled with negative connotations about the foetus' condition).

Due to the way in which diagnosis of foetal chromosomal variations is perceived by staff members, and the way in which it is communicated to prospective parents, antenatal conditions are construed as inherently difficult, traumatic, and as a burden to prospective parents, especially to women. This approach to chromosomal variations adds to the notion of *incompatibility with life*, and hence the need to offer emotional support in order to overcome the tragedy, and physical care in the event of an abortion or a *high risk* delivery.

For women who decide to continue the pregnancy, medical resources and emotional therapy are made available up to delivery, so that *'they can adapt to their real baby, and can be prepared for facing people and society once the baby is born'* (Jimena Estrada, field notes 2007). For women who decide to abort (who are the great majority), emotional support is also offered so *'women and men can have a proper mourning process, in which the bond with the baby is reinforced, and then they can say goodbye to their baby'* (Jimena Estrada, Interview 2007).

Specialists, fellows, staff members, as well as Colombian legislation (see Chapters 2 and 3) see abortion as a 'treatment' for helping women to overcome the trauma of the diagnosis of foetal chromosomal and developmental variations. In this sense, the practice of abortion and the notion of trauma go hand in hand with the category of 'incompatibilities with life'.

In this context, however, trauma has multiple and interrelated connotations. One such connotation is that women are in psychological distress because they are carrying a foetus different from the one they imagined; they are constructed and understood as grieving:

With a diagnosis of [foetal] malformation we have to understand that women start a mourning process ... we manage grief as the loss of the ideal, or the dreamt about child, or the thought of a child. That one is lost. There is already a first loss and now there is the confrontation with the real child. That requires a process of adjustment in the family, an adaptation of the roles of father, mother and child ... there is a need for adaptation of the parents and the child, so they can face the wider family and society (Jimena Estrada, psychologist, Interview 2007).

It [amniocentesis positive results] is always very sad. That's pretty normal [the sadness]. All [foetal] malformations are very sad, especially for women (Dr Cifuentes, Interview 2007).

Of course it is always difficult for them [women]. They all are in shock, and then they start presenting the physiopathology of grief, always (Dr Álvares, Interview 2007).

To receive a diagnosis is terrible, terrible: rejection, negation, wrath, and then acceptance. After that, after understanding what the foetus has, many ask if they can abort (Dr Castro, Interview 2007).

Trauma related to 'loosing the expected child' also refers to the possibility of delivering a being that is not even worthy of being called a baby, for it is seen as 'a monstrous thing':

To be told that the child you are expecting, for whom you have already bought some things and all that, to know that the baby is sick, that maybe it is even a monstrous thing, that is harsh. That is very traumatic for the woman (Dr Arroyo, Interview 2007).

Connected to this latter point, some of the staff members believe that women undergo mental and emotional distress because of the perception that it is more difficult for women and couples to cope with death after birth than with selective abortion. Many also refer to the special difficulty brought about through the encounter with a possibly severely malformed foetus which has a very short lifetime. Abortion, in these situations, is conceived as being more beneficial for women's overall well-being.

It is very traumatic for women to deliver. Abortion is easier for them. If the baby is born then they see it. They have felt it [the foetus] for so many months, the bond is stronger and then, they have to see it die (Dr Arroyo, Interview 2007).

[I]t is very traumatic to see the baby dying after birth or dying during delivery. But it is also very traumatic to see the little monsters that they sometimes are. It is very traumatic. That is why I think it is better to interrupt [the pregnancy] (Nurse Daniela, Interview 2007).

Nevertheless, foetal diagnosis of chromosomal and developmental variations does not only include severe conditions that endanger the future baby's life. As explained earlier, obstetric ultrasounds and amniocentesis look as well for physical and chromosomal variations that do not endanger the existence of the baby-to-be. Yet, the diagnosis of conditions such as Down syndrome – or other chromosomal variations that imply cognitive differences but are not imminently life threatening – is also perceived by staff members as problematic and traumatic. This perception relates to the prospective family life that women and couples will have if such children are born, as Dr Sossa expressed in a medical meeting:

Neurologic development plays a most important role in the child's social adaptability. Adaptability is difficult when there is a neurologic diagnosis, and it is difficult especially for parents, so that is why they choose to interrupt the pregnancy and that is why we accept those terminations [of the pregnancy] (Dr Sossa, medical meeting 2007).

When taking into account the future potential for a *disrupted* family life, prospective parents are seen as undergoing '*shock*' and '*distress*', as they must think about how to combine their life plans with their '*real child*' (field notes 2007). Conditions that do not suppose a short life span for the future baby, but which do imply a deviation from the *standard of normality*, result in most staff members rendering people with disabilities and cognitive differences as irremediably burdensome, as a negative life changing event that should rather be prevented:

It is very difficult of course, the whole life plan changes, now you are stuck with something [a child with cognitive differences] that will last so many years. I mean the idea of having children, seeing them grow and watching them finally leave home in search of their own life, that will never ever happen with a child like that. You are

stuck your whole life with that, so you might as well consider not going through that situation (Dr Torres, Interview 2007).

It is very difficult, those children [with cognitive differences] need a lot of attention and care, and you have to think about that before having them. If the parents are not willing to do that then it is good for them to interrupt [the pregnancy] (Dr Arroyo, Interview 2007).

For women it is very difficult [foetal diagnosis] because they have to think about what they want to do with the pregnancy. They have to think if they want to live their lives dependant on their child or not. If for them [women] that baby is going to be an awful burden and they get very anxious, then it is better for them to interrupt (Dr Rincón, Interview 2007).

When specialists engage in diagnosis and prognosis, they base their communication with women and couples in medical categories that in most cases are exceptionally abstract. All reference to the life of the future child is framed by such categories. They produce the illusion of a unified experience of disease or disability that, in turn, defines the identity of the future child, now discussed strictly in the Department's medical language. In other words, when presenting a prognosis for a foetus with a chromosomal or developmental variation, such a prognosis is inflicted with medical values which have their own assumption of what a *normal life* entails. This typically neglects the fact that social understandings and consequences of health conditions vary through time and are informed by cultural norms and individual values, and the fact that neither medical nor cultural values are static and separate from one another (c.f. Shakespeare 1998; LeBreton 2004). However distant medicalised views of chromosomal variations and cognitive differences may seem, they do resonate with women's and couple's own understandings of people with disabilities, deeply rooted as they are in the Colombian imaginary of *able* and *disabled* people. This, as shown in Chapter 4, praises productivity and despises and fears people with different capabilities and cognitive differences, for they are rendered as 'unproductive' and so 'a social burden'. Thus, women's and couple's reactions to amniocentesis positive results

typically resonate with the negative input and depiction that these conditions have, both for the specialists and also within the wider socio-cultural context (c.f. Hashiloni-Dolev 2006).

These views and understandings of foetuses with chromosomal variations or cognitive differences imply the idea of a *fixed standard* baby that some get and some others do not; that the idea of homogeneous normality is inherently good. What does not comply to the standard is seen as inherently bad and becomes a family tragedy, while 'normal' children are, in contrast, eventless and suppose no sacrifices. This is why women, couples, and specialists concur in their views that the birth of a child with a chromosomal or morphological condition that (could) suppose a cognitive difference invariably implies extra efforts in emotional, economic, and social terms. These perceived extra efforts enable such conditions, susceptible for producing cognitive differences in the child to-be, to be framed within the category of 'incompatibilities with life'. In the words of one husband: *'we better interrupt this one and maybe later we get lucky and get a healthy baby'* (Carlos, 35 years, Marin); or as expressed by one of the specialists: *'for some parents a baby with Down syndrome is like an incompatibility with life'* (Dr Cifuentes, Interview 2007).

As mentioned before, it is in this context of regarding disabilities as merely medical and highly problematic that women are staged as patients in need of medical care of various types, abortion being one such type. In the event of an abortion, specialists bridge the difficulties of ending the developmental process and the existence of their previous patient (the foetus) by explaining that *'although scientifically, academically, and sometimes emotionally there are implications of losing the foetus, it is only the woman who can decide what to do with that pregnancy; we [specialists] cannot impose [upon] a woman to deliver such a child'* (Dr Cifuentes, Interview 2007). Specialists regard the imposition of delivering a child different from the average as wrong, since delivery is an issue that concerns only the woman herself, *'given that she is the one who has to take care of that baby for as many years as it [the baby] lives'* (Dr Torres, Interview 2007).

One could say that it is in the context of selective abortion decision making and practice that women fully exercise their role as patients and demand the rights that being a

patient entails. This is especially visible in cases in which physicians do not agree to grant an abortion, if they consider that the condition of the foetus is not severe enough. Under such conditions, the most interesting shift takes place. Once women have exhausted the resource of pleading for an abortion due to foetal 'conditions incompatible with life' (of many sorts, but mostly Down syndrome), women allege that such a pregnancy threatens their mental health and well-being, ratifying in this way their status as patients (see also Chapter 3). As seen in Chapter 2, the Court used the World Health Organisation's definition of health<sup>65</sup> when de-penalising abortion in cases which may endanger the woman's health. Women can therefore claim that their mental health and well-being is jeopardised by carrying a foetus with a chromosomal condition, and in most cases women are granted abortion. In the words of two staff members:

Since de-penalisation, all cases of foetal conditions are aborted. Women either say it is an incompatibility with their life, or say they are in terrible distress. It is one way or another that women get legal abortions nowadays and doctors do not care about that. They [doctors] are no longer in danger of being prosecuted, so they do not care who aborts what (Dr Villa, Interview 2007).

I find some cases really worrying. Parents are aborting everything because they know they can. Since de-penalisation most of them [prospective parents] say they want to abort because the baby is incompatible with life, even if the baby is not. In the very rare cases that doctors deny the procedure prospective parents say that such a child is an incredible burden and that the woman is not able to handle it. And I know that is not true, at all. I know that they are absolutely capable of dealing with a disabled child. But they keep on insisting and so they opt for saying that the pregnancy is attempting to harm their mental and emotional health. That is when they are sent to a psychiatrist who, most of the time, gives women the green light to abort (Jimena Estrada, Interview 2007).

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<sup>65</sup> Mental health is an integral part of this definition (<http://www.who.int/mediacentre/factsheets/fs220/en/>).

Either way, in most cases women and couples can access a legal abortion in the event of a foetus that does not fit their life plans. Such a shift in motivations takes place and is valid because the woman is the patient, and as a patient her will governs.

In summation, antenatal conditions and future disabilities are made problematic and burdensome on three different but related fronts: the Department in which conditions are diagnosed; in society where people with cognitive differences are looked down upon for being a burden; and lastly at the legal level, in which to carry a foetus and deliver a baby with disabilities is understood as *torture*, for women are *traumatised by* such events. The woman, as a patient, should not be subjected to that treatment.

#### Final comments

In the Department of Foetal and Maternal Care and Medicine, when asked the specialists who participated in this study invariably said that the role and function of maternal-foetal medicine is to care for pregnant women and their foetuses, and to provide prospective parents with what is considered valuable and important information regarding their foetus so that they can make 'informed' reproductive decisions. Nevertheless, some were as open as to state that '*maternal-foetal medicine is the checkpoint for humanity*' (Dr Torres, Interview 2007). Despite apparent differences in perceptions of the role of maternal-foetal medicine, everyday practices and conversations – the product of long term interactions among these professionals – conveyed the view that although chaotic, maternal-foetal medicine does indeed serve as the checkpoint for entering the human community; a goal that resonates with obstetrics' overall project, as shown in Chapter 4.

The use and availability of amniocentesis splits up the woman and foetus and enables the staging of them as two different syncopated patients. The distribution of distinct patienthood is consequential for both the woman and the foetus: for the woman because she is initially made invisible and to some extent neglected; while for the foetus the allocation of patienthood is problematic because it is tentative, as the status of patient excludes the

category of 'incompatibilities with life' given the direct link that the category has with selective abortion. Foetuses that once were constructed as patients may lose such a status when a diagnosis is made, and also may be aborted by the same physicians who once depicted them as a patient.

Through the way in which diagnosis is determined and communicated, coupled with the subsequent treatment that women receive – as primary patients once again in need of psychological support for coping with the adverse news of being *diagnosed with a malformation* – foetal conditions supposed to carry cognitive differences are constructed as inherently problematic and demanding. Such an approach perpetuates attitudes towards and understandings of people with cognitive differences as undesirable. The abortion of such a foetus becomes not only an option, but also a recommendation, as the pregnancy of a foetus with a condition 'incompatible with life' is a *torture* for the woman, and the birth of such a child implies a social and familial burden.

The tension made by naming the foetus a patient is then resolved in two ways. Firstly, this is done by shifting the status of patient to the woman. Secondly, through the allegorical act of returning the foetus to the womb, physicians make it a matter that concerns no one but the woman carrying it. This latter point is also culturally and legally backed up by the shared and internalised recognition of pregnancy as a woman's matter, part of her utmost intimate and individual sphere; without considering that individual reproductive choices do have an impact on – and are impacted by – the wider social composition (c.f. Paul 1998).