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

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Summary

This is a study of discrimination. I investigated the relationship between abortion de-penalisation on the grounds of foetal morphological or chromosomal variations, on the one hand, and the availability, use, functions, and meanings attached to amniocentesis in Colombia on the other. The central research question addressed in this study is then: *How has the use and availability of antenatal technologies such as amniocentesis, in combination and interaction with the practice and de-penalisation of selective abortion, helped articulate a Colombian social imaginary of desirable citizens?*

My core argument is that, in Colombia, the abovementioned definitions of the foetus, changes to the legal status of abortion, the practice of selective abortion, and the desire to know one's foetus' karyotype, are interrelated elements that respond to deep rooted understandings of what a desirable citizen, family member, and human being should be. These roots run across time and space. They have been discussed for more than one hundred years, and they gain shape and meaning in different geographical and cultural locations. In other words, the de-penalisation of abortion in Colombia grew out of a long history of discrimination, in combination with the availability of antenatal testing technologies, and constitutional changes designed to secularise the country. Similarly, the practice of selective abortion and the use of amniocentesis as they are today (and have been for many years), resonate with a socio-cultural context of which discrimination against specific groups of people has long been a structural feature. Central to contemporary discourse, and legislation, is the umbrella category of 'conditions that make life non-viable'. The ways in which practices and social imaginaries are intertwined become visible when one looks carefully at this category, also referred to as 'incompatibilities with life'. I argue that such a category is multiple (Mol 2002), plastic, and ambiguous, referring not only to 'biological life', but also to 'social life' and lifestyles.

Within this framework, I find it important to approach amniocentesis as a social phenomenon and not only as an individual matter. Such a technology provides information upon which decisions regarding a population's composition are made, whilst at the same time significantly shaping law, family planning, and attitudes towards people with disabilities (c.f. Shakespeare 1998; Rapp 2000). But it is also paramount to see amniocentesis as a vehicle for exploring the category of *normal.* Where is it produced? What and whom does it represent? How and why did it become so visible?

This study locates amniocentesis within the wider socio-cultural and historical context of Colombia, starting from the understanding that the functions, uses, categories, and repercussions attached to and produced by a particular technology depend on a given time-space scenario (Latour 2002). This sheds light on how the individual practice of amniocentesis, and the apparently individual concern of selective abortion, relates to, informs, shapes, and is shaped by abortion de-penalisation.

In order to be able to conceptualise amniocentesis, the practice and de-penalisation of abortion, and eugenics, I have relied on two theoretical concepts that help clarify the connections between them. These theoretical concepts are the *social imaginary* (Gaonkar 2002), and *biopower* (Foucault 1976, 1980). Both concepts are useful theoretical and methodological tools.

The two aforementioned theoretical concepts provide a basis for approaching the practices of amniocentesis for foetal karyotype, selective abortion, and abortion de-penalisation, and structural discrimination in the form of eugenics. The concepts are articulated through the use of insights from Medical Anthropology, Science and Technology Studies, and Disability Studies. I also make use of some of the theoretical contributions of the anthropology of law, especially for understanding penal changes in relation to the practice of abortion.

The study is based on interpretative qualitative research, which relies on the ethnographic methods of direct social observations, interviewing, and case studies (Bonilla-Castro & Rodriguez Shenk 1995; Hardon et al. 2001), as well as on discourse analysis (Howarth 2000), and historical media and library archives.

In order to be able to understand the practice of amniocentesis as performed in clinics as well as by individual families, and also to understand abortion de-penalisation in cases of foetal conditions that 'make life unviable', it was necessary to engage in two different fieldworks. Given that what interested me was the relationship between the two seemingly different and separate topics, the methodology that best suited this fieldwork was what Marcus (1995) called multi-sited ethnography.

In order to understand amniocentesis practice and use I conducted a seven month long hospital ethnography in three locations within the Department of Maternal and Foetal Medicine of one of the most prominent private health care providers in the country. In combination with the direct social observations at the clinics, I also interviewed the chief attending specialist, a senior specialist, students of the specialisation of maternal-foetal medicine (at that time three men), and the attending psychologist. Furthermore, I held multiple conversations with all staff members (specialists, fellows, residents, psychologist, nurses, and secretaries) over the course of the fieldwork. In addition, I interviewed twenty two women, and in some cases their partners. At the clinic I met nineteen women, sixteen of whom underwent an amniocentesis and one cordocentesis, plus three women who decided not to have the amniocentesis.

As important as the current practice of amniocentesis is, the history of amniocentesis in the country is equally important for it reveals continuities and changes that help to elucidate the complex dynamics of this technology. In order to reconstruct a history of amniocentesis in Colombia, I interviewed the first Ob-Gyn practicing in Colombia to publish on amniocentesis in Colombia.

There were two other sites for the ethnography. One was a permanent seminar, organised jointly by the bioethics network of the National University and the Ministry for Social Protection, with the intention of discussing the aftermath of abortion de-penalisation, one year later. Once the permanent seminar had concluded, a National Forum was organised in order to bring the discussion points addressed at the seminar to different parts of the country.

I also used archival research. In order to account for the abortion debate and the public image of amniocentesis I conducted archival research on media coverage of these topics.

Finally, and in order to be able to elucidate and understand the roots of discrimination in Colombia I consulted library archives from the early 1900s, which contain documents from the thinkers, educators, jurists, and physicians who formed the eugenics movement in Colombia, as well as those who constructed and implemented the hygienist movement, that was later to become 'public health'.

Reading this book

The book is divided into two parts. The first accounts for the wider socio-cultural and historical context, and thus addresses the abortion debate and de-penalisation, the history of amniocentesis in Colombia, and the eugenics movement in the country. The second deals with the actual experience and daily life of amniocentesis at the Department on the one hand, and with the personal experience of the sample of twenty two women who were in contact with amniocentesis on the other.

The chapters constituting Part I are as follows. Chapter 2 is an overview of the development of the abortion debate, in which I pay careful attention to the lawsuits that triggered a new version of the debate and made abortion de-penalisation possible. I analyse and problematise the features of this debate, and also analyse Sentence C-355/06, by which abortion was de-penalised. I focus on the case of 'foetal malformation that makes life unviable outside the uterus' (Sentencia C-355/06: 287) and highlight the central role played by antenatal technologies in achieving and articulating this case of abortion de-penalisation. In Chapter 3 I analyse the permanent seminar and the National Forum as public nation building scenarios, in the year after abortion had become de-penalised, and look at how actors such as geneticists and specialists in maternal foetal medicine, involved with foetal diagnosis, shape and are shaped by abortion de-penalisation.

Finally, Chapter 4 addresses two interrelated topics: the history of amniocentesis in Colombia, and the history of the eugenics movement as it occurred in this country. By focusing on the history of amniocentesis in Colombia, I am able to show how the technology has changed over the years, as a result of technological innovation in the fields of obstetrics and human genetics, while at the same time providing the means and the possibilities for transforming such fields (c.f. Latour 2002). In highlighting the nature of the eugenics movement in Colombia, a link between hygiene, eugenics, and obstetrics becomes evident. This allows me to articulate today's individual reproductive choices with deeply-rooted national ideology, and socio-cultural discriminatory practices and attitudes towards specific groups of people, or more precisely, towards people with intellectual and cognitive differences.

Part II relates the actual practice of amniocentesis, and discusses individual experiences of being confronted with the exam and with the possibility (or the reality) of being faced with a positive amniocentesis result. Thus in Chapter 5 I start by accounting for the current reality of amniocentesis. I focus on the problematisation of maternal-foetal medicine as a practice in which the category of patient is mobilised in various ways and attributed differently to the foetus and to women. The focus of the volatile category of 'patient', as performed at the Department, is twofold. Firstly, it highlights the secondary – almost invisible – role of women in the larger process of foetal diagnosis, and secondly, it elucidates the way in which disabilities are constructed within the medical environment as a

family disruption and as a life mishap. Such a construction of disabilities and of people of disabilities allows for a legal abortion in cases of chromosomal variation.

Finally, in Chapter 6 I address the individual experience of first deciding whether or not to undergo an amniocentesis, and second, when relevant, of deciding whether or not to bring the pregnancy to term after a positive amniocentesis result. Through individual narratives I underscore that there exist distinctive socio-cultural attitudes towards amniocentesis and selective abortion, and that the individual experience of a specific pregnancy plays a major role in deciding which way to go. A consequence is that it becomes difficult if not impossible to generalise about individual relationships with either practice. In this chapter I therefore relativise both technological and socio-cultural determinism, to open space for the individual experience as a dynamic constituent of the socio-cultural and historical context.