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Prenatal diagnosis: From policy to practice. Two distinct ways of managing prognostic uncertainty and anticipating disability in Brazil and in France

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ABSTRACT

Prenatal diagnosis (PND) has gradually established itself as part of the pregnancy monitoring process, with a view to reducing the number of births of children exposed to disability by combining the use of biomedical tools with laws that authorise abortion in cases of foetal pathology. This article looks at how laws which vary from one country to another modulate the way in which PND practices are organised on a daily basis, determine the discourse of practitioners and lead them to adopt specific stances during prenatal consultations with couples coping with a foetal anomaly. We present a comparative ethnographic study, which took place between 2009 and 2011 in France and Brazil, in reference units, based on observation of consultations, professional meetings, and interviews with health practitioners. The fact that access to abortion due to foetal pathology is possible in France, and criminalised in Brazil, conditions how doctors analyse the framework of their medical practice and approach the issue of disability with couples during consultations. In France, practitioners would appear to be satisfied with a professional framework that they themselves created. Faced with prognostic uncertainty, the legal obligation to inform encourages them to discuss all of the potential complications of the diagnosed anomalies and leads them to provide probabilistic information about the life of the child to be, supported by evidence-based medicine. In Brazil, in the public service, the lack of access to abortion has created a malaise among practitioners who criticise this impediment to the objective nature of their practice and to the quality of the information that they provide. Some use prognostic uncertainty to direct the thoughts of women and couples towards the dynamics proper to each individual human trajectory within a given family and a specific social environment.

1. Introduction

For more than three decades, prenatal diagnosis (PND) techniques have been developed in numerous countries, with a view to detecting foetal anomalies and preventing disabilities at birth. These techniques have significantly modified the way in which pregnancies are monitored, leading to standardised use and to the regulation of PND practices. Initially implemented in countries where abortion is legal, as part of the biomedicalisation of clinical practices (Clarke et al., 2003), PND has spread to other countries where legislation on abortion is restrictive, thus raising the issue of discrimination in healthcare provision (Novaes, 2000; Ballantyne et al., 2009).

Over this same period, disability has been the object of reflection and debates, which have affected its conceptualisation and transformed both the related social representations and policies, and the day-to-day experiences of disabled people. Now dynamically defined as an interaction between a social situation and a state of impairment, disability encompasses all types of restriction to social participation. Promoted by disability studies, this conception differentiates between people, impairments, and the social experience of disability (Shakespeare, 2014). Now widely diffused throughout the field of rehabilitation, it encourages methods of care, which take account of the diversity of situations, of interactions with the environment and the plasticity of human development, particularly in children. These transformations do not appear to have penetrated prenatal medicine as much as they should have. Although prenatal professionals are on the front line, counselling couples during this period, more often than not they

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continue to consider the disability as “equivalent” to the pathology and struggle to foresee the range of its social consequences (Ville, 2011).

PND practices have been the object of numerous social science studies relating in particular to the information given to women about techniques and associated risks (Marteau and Dormandy, 2001), to the factors which influence decisions on whether or not to have tests and/or to terminate a given pregnancy (Rapp, 1999; Garcia et al., 2008) and to the difficulty to remain non-directive for healthcare professionals during consultations (Williams et al., 2002). However, the results are rarely analysed in relation to modes of regulation and organisation of practices. Studies which analyse these practices through the prism of disability more frequently focus on how said practices discriminate disabled persons and impact their everyday lives (Saxton, 1997; Parens and Asch, 1999; Alderson, 2001) than on the way in which the issue of disability is approached by PND professionals during consultations. Yet this is a contextual factor that is likely to influence women's decisions (Risoy and Sirnes, 2014). Furthermore, one might think that the type of information provided is linked to the way in which practices are organised locally. Indeed, a comparative analysis of Down's syndrome screening in France, England and the Netherlands shows that the ways in which care is organised impacts the time devoted to informing couples (Vassy et al., 2014; Rosman, 2014).

The research presented in this article is based on a comparison of PND practices in France and Brazil, countries which benefit from similar technological development and equivalent training in prenatal care, but where there are differences in the regulations governing PND practices and in the legislation on abortion.

We make the hypothesis that above and beyond the cultural and religious differences (Gammeltoft and Wahlberg, 2014), the modes of regulation proper to each country affect how practices are organised and how practitioners approach disability. We will test this hypothesis by trying to intersect two types of data: the reflexive discourse of practitioners in each country regarding their own practices; and observations of prenatal monitoring/counselling sessions in the two countries. Before we begin analysing our results, it is necessary to recall certain key elements in the management of PND practices frameworks in each country.

2. Reminder of the local contexts of PND regulation

In France, prenatal monitoring includes the combined detection of foetal chromosomal anomalies and three ultrasounds reimbursed by the French national health service and available to all pregnant women. Although it is not obligatory, screening for Down's syndrome is generally perceived as a routine examination and the vast majority of women (84%) choose to have it. Between 2005 and 2007, 87% of all cases of Down's syndrome have led to medical terminations (Khoshnood et al., 2010). Abortion has not been an offence against the person since 1975 and French law differentiates between pregnancy termination due to “maternal distress”, which is allowed up to the twelfth week of pregnancy, and termination due to foetal pathology or “medical termination”. The latter can take place “at any time during the pregnancy, if the woman so requests and if two doctors accredited by a multi-discipline centre for prenatal diagnosis *(MCPND)* certify that there is a “high probability that the unborn child has a particularly serious condition which is recognised as incurable at the time of diagnosis.” The cost of the procedure is covered by the health system. Detailed data are recorded every year by the “Agence de la Biomédecine” (a government agency).

In Brazil, ultrasounds are not officially included in prenatal care (Ministerio Da Saude, 2000), but they are nevertheless widely practiced and mainly take place in the private sector at women's own cost (Chazan, 2007). Since 1988, the “unified health system” (sistemo unico de saude) offers free healthcare for one and all in public hospitals, which, however, suffer from a lack of infrastructure, practitioners and major logistic difficulties (Paim et al., 2011). Under the public health care system, genetic screening is not available to women on a regular basis. The middle classes, who represent about 25% of the population, have the benefit of private health insurance (convênios) partly paid by their employers and organised in selected medical centres (Neri and Soares, 2002). In this case, some insurance companies reimburse the access to prenatal diagnosis and genetic screening. A very rich but small fraction of the population (just a few percent) opts for medical care without any reimbursement. This population can ask for any type of prenatal screening. In the vast majority of cases, it is during an ultrasound in a private centre that foetal anomalies are detected (Mirlesse and Ville, 2013). After a short announcement and little or nothing in the way of an explanation, women are referred back to their obstetrician or to their healthcare centre (Chazan, 2011). In Brazil, the law considers abortion to be a crime (except in the case of rape, threat to the woman's life and, since 2012, anencephaly (where the foetal brain and skull does not develop properly). In the case of lethal foetal pathologies, it is possible to apply to the courts to request a termination of pregnancy. However authorization is far from systematic. More often than not, the triple context of repressive legislation, a highly inegalitarian society and powerful religious impregnation mean that poor women monitored in public health care centres bring into the world children with malformations. Epidemiological studies show that there are far fewer births of disabled children among the wealthier classes (Costa et al., 2006, Ramos Guerra, 2008), which suggests that earlier diagnosis of foetal malformations might allow discreet access to illegal terminations of pregnancy (Horovitz et al., 2013). Yet whilst the question of backstreet abortion is omnipresent in Brazil (Diniz et al., 2009), abortions due to foetal anomalies have very little visibility, even in medical literature (Guilhem, 2007).

3. Method

Our analysis is part of wider research on “the issues of prenatal diagnosis in the prevention of disability”. The aim of this large comparative study in France, Great Britain, Holland and Brazil was to analyse the relationships between local PND structures and the treatment of disability in prenatal care.

The data were gathered between 2009 and 2011, following authorisation from the local ethics committees concerned. The second author carried out the fieldwork in Brazil, in a public referral centre for foetal pathologies in Rio de Janeiro and in several private centres, as part of her doctoral work. The analysis includes observation of more than eighty ultrasound, foetal medicine, genetic and perinatal paediatric consultations, and approximately twenty interviews with specialists and trainee practitioners.

French data were collected by the first author in three referral centres. They are based on observations of approximately 300 similar consultations, forty-two meetings in multi-disciplinary prenatal referral centre. Researchers were introduced to the women at the very beginning of the consultation and the objective of the research was briefly explained. Consent was asked and given by the women for each observation or interview in accordance with the requirements of the local ethical committee. Discussions with health professionals were based on semi-structured interviews covering professional trajectory, the organisation of practices, interactions with colleagues and patients, and the ways in which women are informed of the health of their foetuses. Information was also gathered during a witness seminar organised in Paris in