The impact of Individualization on Pregnancy Practices: the case of Prenatal Diagnosis

By
Alphia Possamai-Inesedy PhD.
School of Social Sciences, UWS

Alphia.possamai@uws.edu.au
0410 135 414

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Abstract
Risk, according to the works of Beck and Giddens, has become a force of social change. It can be seen to actively shape our concept of health, desire for perfection, and our relationship to technology and responsibility. These themes will be employed in the following analysis of the use and impact of prenatal diagnosis on the pregnant woman. It will be argued that amongst the unforeseen consequences of this form of technology are not only the increased choices that the expectant woman is faced with but also the increased responsibility. Because of the emphasis on responsibility towards one’s own health, within high modernity, as well as notions of perfection, parents are rapidly becoming faced with an obligation to use these technologies for not only the future of their child but also to secure their own future. What is of essence in this argument is not only the obligations and responsibilities towards one’s life path that Beck’s notion of individualization focuses on, but also a voluntary compulsion to actively engage with science and technology to fulfil these obligations.

Introduction
Prenatal Diagnosis (PD) is understood as ‘a cluster of technologies used for assessing the chromosomal and genetic normalcy of fetuses in utero’ (Rapp, 1998: 45). This relatively new and constantly evolving technology, what King (1995) and Petersen (1998, 2002) have termed the ‘new genetics’, promises populations free from genetic disease accomplished solely through ‘therapeutic’ abortions. It can be argued that this ‘new eugenics’ operates on an implicit level rather than the explicit form that was found in earlier eugenics movements. The earlier movement focused on populations and coercive control, the new on the individual and personal choice. As King (1995: 25-26) argues:

‘One way or another, we are all going to be dragged into the regime of gene management, that will, in essence be eugenic. It will be in the name of individual health rather than for the overall fitness of the population, and the managers will be you and me and our doctors, not the state. Genetic change will be managed by the invisible hand of individual choice, but the overall result will be the same, a coordinated attempt to ‘improve’ the genes of the next generation on the way’
The concept of choice that King speaks of is problematic for women in an environment in which pregnancy and motherhood are increasingly subject to public control through the concept of risk (Petersen, 2002; Possamai-Inesedy, 2006). The incorporation of new genetics into this new public health philosophy is sending a message that individuals have a right to health, but equally important a right to information that will enable them to minimize their own contribution to disease and disability through ‘choice’ (Petersen, 1998). We now have the ‘right to know’ and are implored to make ‘informed choices’ about our health care. However, it has been suggested that women, due to the constant increase of medicalisation of pregnancy and childbirth are drawn into the employment of prenatal technology without a complete understanding of the technology itself or the consequences of its employment (Rothman, 1998). ‘Choice’ in this context is devoid of what can be argued to be its more conventional base of control, power and alternatives.

**Individualization**

Individual health, increasingly informed by this ‘new genetics’ emphasizes Beck’s notion of the ‘imperative of avoidance’, and also that of Beck and Beck-Gernsheim’s (2002; Beck-Gernsheim, 1996) account of the ‘planning project’. The following article will argue that pregnancies, within a risk society have developed into a planning project where constant work and attention on the part of the individual is required. As Overall (1987: 104) states ‘childbearing is not something that merely happens to women, but is a process in which women are (or can be) actively engaged”.

This project of the self requires planning, rationalization and sharply illustrates Beck’s concept of individualization. For Beck, we now reside in a world where we have witnessed a disintegration of traditional norms, which then forces the individual to choose their life path – often on a daily basis. With this new found responsibility comes new forms of blame, negative outcomes as a consequence of our choices come to be seen as our own ‘fault’. Increasingly, an active and self-directed approach to life is
expected from the individual of the “individualized society”, and this implies a *skilful* handling of and reaction to all that it entails (Beck-Gernsheim, 2000).

These themes will be employed in the following analysis of the use and impact of prenatal diagnosis on the pregnant woman. It will be argued that amongst the unforseen consequences of this form of technology are not only the increased choices that the expectant woman is faced with but also her increased responsibility. Because of the emphasis on responsibility towards one’s own health within high modernity, as well as notions of perfection, parents are rapidly faced with what Beck-Gernsheim (2000) labels voluntary compulsion, but what my respondents (described below) viewed as an obligation, to use these technologies for not only the future of their child but also to secure their own future. As expressed in Beck’s notion of individualization, what is of essence in this argument is not only the obligations and responsibilities towards one’s life path but also, what can be termed, a voluntary obligation to actively engage with science and technology to fulfill these duties.

**Prenatal Diagnosis within the Australian Context**

Evaluation of participation rates in PD programs is difficult as Australia not only lacks a national policy framework of prenatal screening but states and regions vary in method of data collection and collation. Recently O’Leary et al. (2006) undertook a survey of screening programs for Down syndrome and other fetal anomalies in Australia to determine operation and policy frameworks. A by product of this research was an evaluation of data concerning State by State participation rates of first and second trimester prenatal screening rates. The research revealed a 2.5 fold increase from the 17.8% participation rates of 1999 to 44% in 2004. The overall screening participation varied across States as well as age and insurance status. Rates ranged from 80% participation in South Australia to only 17% in the Northern Territory. In NSW there was a 60% screening participation where only 23.9% of women tested were over the age of 35, with a mean age of women screened at 32 years. However, 51% of invasive tests, such as
amniocentesis and chorionic villus sampling, performed in NSW are attributed to advanced maternal age (AMA).

The following section outlines the use of prenatal screening and testing within the Australian context, from the recorded experiences of 45 birthing women from New South Wales (NSW) stemming from three separate birthing fields; namely the private hospital, the midwifery led birth center, as well as homebirth mothers. The project did not intend to reach quantitative conclusions, but rather to develop an understanding of a relatively recent phenomenon of women seeking out and indeed actively engaging with a medicalised pregnancy and birth. Although PD has become a routine aspect of pregnancy care the intention of the research was not to attempt to understand how women approached these tests. However, through the women’s narratives, it quickly became apparent that prenatal diagnosis was a part of their landscape of pregnancy care. Although one of the themes of the interview schedule addressed the use of screenings such as ultrasounds, all respondents addressed the issue of prenatal screening and testing, whether that was to discuss their decision to make use of them or not to.

**Voluntary Obligation and Prenatal Diagnosis**

Prenatal screening and diagnosis are examples of New Reproductive Technologies (NRT) that are supposedly providing the very best of care and range of possible choices in maternity care. The introduction of these new technologies, which are used for determining the ‘normality’ of the foetus, introduces and forces upon the pregnant woman of the 21st century a broad range of risks and decisions to make based on risk statistics. What is of interest is the reaction to these tests expressed by the 45 women interviewed. For a minority (4%), the screening procedures and tests were avoided, for some they were hesitantly employed (47%) and for others actively pursued (49%). Yet all respondents engaged with the screening and testing on some level and for those who did employ the technology, many expressed feelings of security once the results were in. All negotiated the new responsibility that has been slowly
but surely forced upon the pregnancy and childbirth environment, or what Donovan (2006) terms the ‘inescapable burden of choice’.

The following section will demonstrate that although many respondents derived security through the knowledge that was provided to them through the ultrasound many others expressed this same security occurring simultaneously with feelings of anxiety, detachment or insecurity. For instance, Tracey, a 29-year-old private birth mother of two spoke about her feelings of anxiety and responsibility over the use of the ultrasound as a screening device:

When I had Luke [her first child], I had the same ultrasound at the same weeks, you didn’t have to sign any documents, three years later you had to be signing all these documents to say that you’d been instructed that you had so many percentage chance of having a Downs Syndrome baby. Then you had to sign another document to say that you refused to have the amniocentesis. I’m not even in the age group for having them. I spoke to my obstetrician this time about it, I said that I felt really uneasy about all these forms being signed, I said ‘is there a chance that the baby is going to be Downs Syndrome?’ He said ‘no, it’s mandatory now, so people can’t come back and say my baby’s got Down Syndrome, I wasn’t told, or didn’t know that I had a 32% risk chance’. But that uneasy feeling then went through my whole pregnancy, that maybe it is Downs Syndrome, and I don’t even know. Maybe I should have an amniocentesis.

It became apparent that many of the respondents of this research were confronted with very similar scenarios. Indeed, of the 45 respondents only two homebirth mothers decided to not undergo any form of prenatal screening or testing, including this ultrasound which is carried out between 18-20 weeks which is used as a screening test.
It seems as technology develops, responsibility is expanding. The concept of responsibility has been adapted to the new options of reproductive medicine and prenatal diagnosis and is interpreted in the way of a qualitative selection taking place before birth, perhaps even before conception (Beck-Gernsheim, 2000: 130-131). As we can see from the voice of the respondents, the terms used here often do not spell out the goal directly; rather they use the technological, administrative language, or as Barker (1998) calls it ‘biomedical rhetoric’. For example, the words ‘prevention’, ‘risk’, and prophylactic measures’ abound. As Beck-Gernsheim (2000) argues: Prevention and prophylactic measures have positive meanings within modern society, they are rational and sound like they are for the good of the patient. “They point to goals which are widely accepted because they serve the interest of the individual (maintaining health, avoiding pain) as well as the interests of society (cost savings)” (2000:131).

With the advancement of technology within science, and medicine, new options are constantly opened up, but at the same time responsible behavior is widened. This becomes even more evident when discussions with the respondents turned to screening tests such as the triple test or tests such as amniocentesis or CVS. As stated above, in Australia all women over the age of 35 are offered amniocentesis or CVS to check for any genetic abnormalities of the foetus. All of the respondents who were in either the private system or birth centre system over the age of 35 were confronted with these tests. Each of them spoke about the difficulty of either contemplating undergoing the test or the consequences of doing so, although it should be noted that some employed the test more as a matter of course rather than actively deciding to do so. Helene underwent the tests with her second pregnancy and found the experience quite distressing regardless of her original reasons to do so. Here she succinctly expresses the tentative nature of her pregnancy during this time period:

I decided to have the ultrasounds, and I think because I was 35 at that time you had to do other tests. Blood tests, and something with the neck, so they could combine that.

I decided to do this because of my age and the risks that it carries, so I went along with all the tests that they wanted, but I wasn’t really happy because they, for me I
felt like it put on a lot of stress on your pregnancy, because you always had to wait for tests to come out, and it could always be wrong. I felt that was very hard for me. I felt thrown away from myself, feeling that I knew what I was doing, and all those tests would sort of barge in to me, that’s what I felt.

Although it is noted that tests are offered to woman over a certain age group it quickly became apparent that these screening and tests were being offered to women at even earlier ages. Angie, a 26-year-old mother of one, describes her interaction with her obstetrician over screening for Down syndrome:

Alphia: So the obstetrician mentioned Downs Syndrome, but you said you were 26 when you fell pregnant.

Angie: Well that’s the thing, I said, he asked if I wanted to test for Downs, or this is the test for Downs, and I said I wasn’t in the high risk group, and he said ‘well you don’t know whether or not you’re in the high risk until you have the test’. I said ‘don’t you have to be older’, and he said ‘well your risk does increase with age, but there’s other risk factors as well, age is only one of them’. It kind of freaked me out, because I had believed that I wasn’t high risk Downs because of my age.

Alphia: How did that interaction make you feel?

Angie: Really insecure, so then I thought I’d better get the tests done. The tests go something like, the standard is you’ve got one in 875 chance of having a Downs baby, and then after they do the test the odds change, either higher or lower. So, you either then say you’re one in a hundred, and then you might want to get more testing done, or they’ll say you’re one in 4,000 or whatever, which is what I was. It’s very odd, because there’s a doctor at the ultrasound place who then explains the results to you. He was very, because they test for other things as well, I don’t even know what now, but they did other things, I think there were four things, and he was very clear
to say ‘this is your chance, but it’s only a chance, it doesn’t mean you’re not going to have a Downs baby’.

As Beck-Gernsheim (2000, 2002) argues the language that surrounds these practices is of central importance. The language used within these interactions, as expressed by the respondents, constitutes their lived reality. From these interactions they reflexively manoeuvre their way through this particular stage of pregnancy. What is important to note, as we can see clearly in the case of Angie, is that the choice of particular words shapes thinking and action. Prior to this interaction Angie was secure in her knowledge that she was ‘low risk’ in relation to her baby having a condition such as Downs Syndrome. However, her obstetrician’s emphasis on the inability to know this for certain without the objective scientific evidence provided by the screening test directed Angie down one particular avenue of thought and action. Because of this particular interaction, Angie’s experience and perceived reality of her pregnancy shifted from her carrying a healthy baby to her carrying a baby that could potentially have Down syndrome. Interestingly, whilst the respondent’s aim was to seek reassurance, the end result was a sense of apprehension about the health status of her infant that lasted until the birth. Paradoxically, she sought reassurance from the ‘language and legitimating power of “objective” science’ (Browner and Press, 1997), which led her to feeling insecure through the ambiguous results of prenatal diagnosis. In this instance this example emphasizes the double edged nature of science – it can offer no certainty yet aims to provide ultimate security.

As previously stated, there were a relatively small number of women in this research that refused to undergo any prenatal screenings or tests. Interestingly, there was a clear demonstration of a reflexive approach in their decision-making, perhaps to an even greater degree than the respondents who did undertake them. As we can see above, many of the respondents who undertook the various screenings and
tests did so because the routinization of the tests either did not make them question it fully or they felt ‘goaded’ into it by the language used by their primary carer.

Conclusion

From the various experiences recounted by the respondents of this study, it is apparent that the discourse that surrounds the use of prenatal screening and testing, is emerging as one imbued with a technological moralization. To be a responsible citizen and parent one must submit to the process of these tests. The onus of health is increasingly being placed on the shoulders of the expectant couple, but more centrally on women. The genetic form of medicine assigns women substantial duties for ensuring the health of their children. Women are supposed to undergo the anxiety producing process of prenatal testing (Rothman, 1994). If the tests find that there is a genetic deficiency in the foetus, women are supposed to abort their pregnancies, facing the loss of a wanted child as well as the reality of a later term abortion (Condit, 2000).

It is no wonder that Beck argues “people are condemned to individualization” (1997: 96). The act of making oneself the centre of the conduct of one’s life necessarily equates to the expansion of responsibility for the crises that befall one during the course of a lifetime. We have the freedom to choose, but as argued by Beck and Beck-Gernsheim (1995; 2002) and Beck-Gernsheim (2000) that freedom also carries the crushing responsibility to make the right life choices. Nevertheless this freedom does not equate to women being able to make authentic choices that fully express their autonomy (Lippman, 1999). Freedom of choice masks the changing societal trends that ‘effectively either preclude or mandate certain options for women’ (Lippman, 1999: 283), such as the supervaluation of nature, intuition and trust in natural bodies over technology and science (Davis-Floyd & Davis, 1996). As Davis-Floyd (2000) argues: “Choices come and choices go: as we gain the choice to travel the promising but
perilous paths of bio-technology, seeking to conceive, to bear babies that we know in advance to be healthy, to give birth to babies that remain so, we lose the choice to travel other paths” (280). Surely we must question not only the path that we are currently traveling, but also the paths that are slowly but surely being closed to us.

References:


\[1\] Interviews were semi-structured in nature and employed the birthing narrative to inquire into women’s constructions of their ideal births and their actual experiences. All interview material was later transcribed and analysed thematically with the aid of the qualitative software NVIVO.