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A Localised South Island Study of Women's Experiences of Amniocentesis

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**Abstract**

This thesis evolved from a question about how women experience amniocentesis in a New Zealand context, and emerged as a localised South Island study of women's amniocentesis experiences. The research process involved several methods including participant observation of both amniocentesis procedures and the counselling sessions that precede them at 'Southern Hospital' Antenatal Clinic. In addition, three consultants who perform the procedures, the assisting midwife, and receptionist were all interviewed about their role in the clinic's practice of amniocentesis, as well as their understandings of the technology. Thirteen women (who were recruited through the Antenatal Clinic) were also interviewed retrospectively about their experiences of amniocentesis.

The collected data was then placed in the context of the international English language literature concerning prenatal testing. When communicating their experiences of amniocentesis it became evident that the women were telling stories, and so narrative analysis was used to frame the research. This perspective also allowed an investigation of further stories of amniocentesis, for instance, the stories of consultants, counselling sessions, medical discourse, popular culture, and the social scientists who have studied this procedure.

The findings of this thesis locate amniocentesis as embedded within our interconnected physical, social, and cultural worlds. Some of the many themes that emerged through the analysis of this research include motherhood as an ideology that intersects with the technology in various ways, the contested nature of choice, and centrality of disability (and so 'normality' and 'abnormality') to understandings of amniocentesis. The women’s stories also spoke about wider issues in society, such as the type of children that we want, the ways in which society privileges medicine and technology as a system of knowledge, and also amniocentesis as a site of gender negotiation, which identifies how the technology of amniocentesis can be approached with various agencies.
The 'point' of amniocentesis was also investigated from various angles, identifying the very complex and situated understandings of the purpose of the test. Lastly the concept of risk, which is central to the practice and understanding of amniocentesis was investigated, identifying multi-layered perceptions and influences of risk for both the women who experience the procedure of amniocentesis and the consultants who perform it.
Acknowledgements

I would like to firstly extend my gratitude to the participants of this research: The thirteen women (and their families) who gave up their time, opened up their homes to me, and shared their stories. Also the staff at the Antenatal Clinic, who accepted me into their workspace, and took time out from busy schedules to talk to me about amniocentesis. I would also like to thank the consultant who took on the task of recruiting women for this study, and Associate Professor Wayne Gillet, for his assistance with ethical approval and his gracious introduction to the field.

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Last, but not least, thank you to my family and friends for the various forms of support (good wine, food, advice, encouragement, firewood, money, and more wine). Most especially, thank you Jase, for your never-ending contributions of support throughout this research project, and for bearing the brunt of my stressed out times with a smile.
A note on terminology

Although I am aware that Down syndrome is the correct title for the syndrome associated with trisomy 21, I have used both Down's syndrome or Down's where referring to quotes from the interviewees in order to reflect social usage of the term. The term Down's itself is widely used and is culturally attached to understanding of the abnormality. I have usually referred to the midwife who assisted with the amniocentesis procedures as a midwife because that was how she described herself to me. However, I have also used the term nurse in some instances, as some consultants and women described her as such. The word fetus appears in North American spelling (except in some direct quotes from published literature) and I have used this spelling because the majority of the literature I read was North American and so I felt more comfortable using that spelling.
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1.

**The tip of the needle**

It was quite eerie watching the needle going in... the baby was actually reaching for the needle, and seeing her hand reaching toward the needle, it was...it was a funny feeling. I could see this needle going in and this hand sort of reaching, but I could see our baby and I could see the heart beating away and see that everything was okay while this was happening (Melissa).

This thesis has been undertaken as a study in ‘anthropology that breaks your heart’, as Ruth Behar (1996) has discussed in her book whose title contains this evocative phrase. Behar (1996: 5) eloquently describes such anthropology as:

> the most fascinating, bizarre, disturbing, and necessary form of witnessing left to us at the end of the twentieth century. As a mode of knowing that depends on the particular relationship formed by a particular anthropologist with a particular set of people in a particular time and place, anthropology has always been vexed about the question of vulnerability.

There is certainly something about the anthropological investigation of amniocentesis, on which this thesis is centred, that renders me vulnerable - vulnerable to the heartbreak and emotion that can surround such a taken for granted form of prenatal testing. For instance, one woman (Melissa) to whom I spoke for this thesis particularly opened her heart up to me when telling her story of the loss she experienced with her multiple miscarriages. During this interaction; hers of telling a story, and mine of listening, we both had tears in our eyes, and when I later transcribed her interview I was again taken back to that summer day and the story that was told around that kitchen table, while her daughters played in the adjoining room. For me, this study of amniocentesis has the potential to be anthropology that breaks your heart and this was especially salient for me when reading the words of women who
have experienced more tragic stories of amniocentesis, as explored in chapter three - words that once again elicited teary eyes.

I have held an interest in amniocentesis since my third year of university study, when I completed an anthropology paper concerning reproduction. My interest in the area was fuelled when, in a fourth year medical anthropology paper, I wrote a research essay about amniocentesis, for which I trotted down to the local antenatal clinic and asked the staff various questions. My fourth year history dissertation was also focused on women's reproductive health, although in an era long before the routine use of amniocentesis. In fact, it was this interest in the topic of amniocentesis and wanting to explore women's experiences of the technology in New Zealand that encouraged me to do my Masters.

Perhaps a small, but significant, aspect of my own family history, might explain why this topic of amniocentesis has been so pertinent to me. I was my parents' second child, born roughly two years after their first baby - Baby Alan - died when he was six hours old for unknown reasons. Growing up I was very aware of Alan's life and death. When I was eight, my Dad and his partner lost a baby - Baby Dara - during labour, and I was very involved with her death, holding her at the hospital, being given a photo of her and attending her funeral with the tiny white casket. Although I also have three younger siblings, who are fine and well - the vulnerability of babies and the knowledge that the beginning of a life can sometimes also be the end are central to my experience of babies and reproduction in my family.

Vulnerability is also central to amniocentesis, where the issues of life and death, and what constitutes a potential person and what does not, are part of the practice of amniocentesis and the interpretation of these prenatal tests. At first when I began to understand that much of this testing is carried out in order to terminate 'less than perfect' children, I was confused – these were wanted babies, what were the parents worried about – at least they were alive. However, through my education, and further study of amniocentesis, I have become very aware of the existence of various heartbreaking stories located around amniocentesis and the great difficulty in establishing one specific perspective from which to understand this cultural practice.
A narrative approach to amniocentesis

When I approached this subject, the aspect I was most interested in was how women experienced the process of amniocentesis, including the corresponding social interactions as well as the actual physical procedure. To find out about these experiences I wanted to talk to women who had been through the procedure, however I wanted to talk to them in a specific way. I was not for instance, interested so much in a structured questionnaire type interview, where I asked them questions about areas I deemed relevant. Rather, I wanted to elicit from these women their experience, and also what they felt was relevant to that experience in their own words (however, after this section of the interview, I did have various questions that I would ask if these had not been covered in their rendition). What I wanted to hear from these women, and what they presented me with – were stories. However, they were not only stories about experiences of amniocentesis, but also stories about; attempting to get pregnant, numerous miscarriages, the impacts of growing up with a severely disabled sibling, or being diagnosed with a chromosomal abnormality. Because these women communicated their experiences of amniocentesis to me through stories, narrative analysis emerged as an appropriate way in which to frame this research project.

Garro and Mattingly (2000: 2) have argued that storytelling (narrative) is the fundamental way in which people give meaning to their experiences. In fact many have argued that narrative is in fact central to how we live our lives. For instance:

We dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate, and love by narrative (Hardy, 1968, cited in Gergen and Gergen, 1988: 18).

Polkinghorne (1988) agrees and also Bruner, for whom narrative is the ‘organising principle’ by which ‘people organise their experience in, knowledge about, and transactions with the social world’ (Bruner, 1992: 3, cited in Cortazzi, 1993).

However, critics have also questioned the receptive relationship of narrative to the representation of experience. The concept of ‘naïve realism’ – that stories simply re-present previous actions and experiences has been
critiqued. Rather it has been suggested that narratives do not 'mirror' life actions and experiences, because narrative has a plot, and life does not, and a story has a narrator which life also does not. By having a plot a narrative has a beginning, middle, and end; because the ending is known the narrator knows where to start the story and what to include (Mattingly, 2000: 182-184). When the women whom I interviewed in this thesis for instance, were experiencing amniocentesis they did not know the end of the story – but when they were telling me about their experiences they knew the ending – they had given birth to a healthy baby. Another critique on the ability of narrative to re-present experience and action revolves around performance anthropology, which argues that social action and experience are oversimplified when interpreted through narrative. Critics have labelled the notion of 'action-as-text' fundamentally misleading and Edward Bruner (1984, cited in Mattingly, 2000: 186) has asserted that although there might be a correlation between life as lived, life as experienced, and life as told, 'the anthropologist should never assume the correspondence nor fail to make the distinction'.

Despite these critiques, narrative remains a relevant way to address people's experiences – and therefore a valid method through which to interpret this research - for a number of reasons. Rosaldo (1986, cited in Mattingly, 2000: 188) for instance, argues that it is important to keep the understanding that stories are 'experience near' because this is often how participants perceive them to be. 'The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives' (Frank, 1995: 22). Although narrative and experience might be different things, they share kinship, and so 'actions and narratives are intimately bound up with one another because of the nature of social action and human sociality' (Mattingly, 2000: 189).

Within this thesis, I have not presumed the stories the women tell to be simply mirror images of their lived experiences, rather I see these stories as altering social constructions (which may be read in various ways) that are important because they reflect not only how the women make sense of their amniocentesis experiences, but also highlight aspects of the social world in which the women live (Gergen and Gergen, 1988, Garro and Mattingly, 2000). One of the specific qualities of narrative that makes it relevant to my research,
is its ability to combine the analysis of the individual with that of society; and so be 'sensitive to the role of power in shaping cultural repertoires and discourses that a person employs to make sense of their experience' (Brown, 1987, cited in Rice and Ezzy, 1999: 126). For instance, although the direction of this thesis is women's experiences of amniocentesis, narrative analysis has allowed me to examine emerging themes within the stories, which tell us something about the wider society in which the technology is practised (see chapters three and four).

Aside from analysing the interviews with women who experienced amniocentesis, narrative analysis was also useful in understanding my participant observation of the counselling sessions, which were scheduled prior to the amniocentesis procedures. The consultants (who took these sessions) used these sessions (as I go onto argue) to shape an acceptable story of prenatal testing with a point. I have extended the idea of an acceptable story requiring a point (see Gergen and Gergen, 1988, Garro and Mattingly, 2000), in this thesis to develop an understanding of amniocentesis as a story with various points, depending on the viewpoint and position of the particular person or group.

Biomedical narratives of amniocentesis

This next section of the introduction will continue to look at stories about amniocentesis - focusing on those generated from the viewpoint of biomedical science. Although these stories are generally presented and understood as the 'truth', they are also cultural constructions that have been subject to interpretation and adaptation (see Lippman, 1994). Amniocentesis, as presented from this viewpoint, is located within the wider umbrella of prenatal testing, which includes; ultrasound, maternal serum screening, chorionic villus sampling, and the nuchal fold test.
## Prenatal Testing Options

<table>
<thead>
<tr>
<th>test</th>
<th>procedure</th>
<th>risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>amniocentesis</td>
<td>Usually performed around 15-18 weeks. Under ultrasound guidance a 20-22 gauge needle is inserted through the woman's abdomen and uterus and 20 ml of amniotic fluid is removed. The fluid contains fetal cells which are then cultured and analysed for fetal chromosomal abnormalities (Patient Information Sheet, 2003, Sciascia, 1999).</td>
<td>There is a roughly 0.5-1% increase in miscarriages. Some findings have also indicated associated neonatal respiratory distress and increases in postural deformities, such as talipes (clubfoot) and hip dislocation (Montemego and Soothill, 1997: 15-16). Less common risks include, fetal injury from the needle, and maternal injuries to the abdominal wall, bladder or small intestine (Oury, 1995).</td>
</tr>
<tr>
<td>ultrasound</td>
<td>Low energy, high frequency sound waves are used to produce an image of the fetus. This is performed abdominally or transcervially (Sciascia, 1999).</td>
<td>None that are known (Manning, 1999).</td>
</tr>
<tr>
<td>chorionic villus sampling</td>
<td>Involves extracting chorionic villi, which make up part of the placenta. This is performed either abdominally (similar to amniocentesis) or vaginally (Patient information sheet, 2003, Sciascia, 1999).</td>
<td>There is an increased risk of miscarriage, however the specific rate is disputed. Generally presented as roughly a 1.5-2% increase in miscarriages. There are also maternal risks of bleeding, or uterine infection (Oury, 1995).</td>
</tr>
<tr>
<td>nuchal fold test</td>
<td>An abdominal ultrasound performed at 11-14 weeks, which measures the fetal nuchal translucency thickness (fluid at the back of the fetal neck). A high level of fluid can indicate a chromosomal abnormality (such as Down or Turner syndromes), and the measurement is calculated with maternal and fetal age to give an estimated risk of chromosomal abnormality (Benacerraf, 1991).</td>
<td>As this test does not make a diagnosis, but recalculates an estimated risk, false positives or false negatives can occur (Sciascia, 1999).</td>
</tr>
<tr>
<td>maternal serum screening</td>
<td>This is a maternal blood test that is taken at roughly 14-17 weeks gestation. The levels of three hormones (unconjugated oestriol, aFP, and human chorionic gonadotropin), are tested and combined with maternal and fetal ages to give an estimated risk of abnormality (Patient information sheet, 2003, Sciascia, 1999).</td>
<td>See above.</td>
</tr>
</tbody>
</table>

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1. Amniotic fluid is mainly fetal urine and contains fetal cells.  
2. A patient information sheet concerning prenatal testing, which was produced by the consultants, was given to women before the procedure (see appendix one).
Amniocentesis is offered free of charge to women who are considered ‘high risk’, the subsequent cost of the test being met by regional health authorities\(^3\) (Consumer, 1995). Those who are considered ‘high risk’ include; women who are 35 and older (because the risk of having a baby with a chromosomal abnormality, such as Down syndrome, increases with maternal age), women who have already had a baby with a chromosomal abnormality, women (or partners) with a family history of chromosomal abnormalities, or those who have been indicated ‘high risk’ through screening tests (i.e. maternal serum screening or nuchal fold testing).

All of the women with whom I spoke had amniocentesis performed in hospital through the Antenatal Clinic, but some private obstetricians also carry out the procedure. Although the practice may vary in different settings, at Southern Hospital, women are usually referred by their GP or midwife, and the majority of women who have amniocentesis do so because of heightened risk due to maternal age. After referral, the receptionist for Women’s Health Outpatients, makes an appointment for a prenatal testing

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\(^3\) Regional health authorities are now called District health boards.
counselling session, and an appointment card is sent out to the women⁴. If
the women decide to have an amniocentesis after the counselling session, the
receptionist will organise this appointment, usually for between fourteen and
sixteen weeks, however some of the women I talked to were at eighteen
weeks gestation when they had the test.

After the amniocentesis, the amniotic fluid is labelled with the
women’s details and sent to a cytogenetics laboratory where the fetal cells are
cultured and tested for any abnormalities. The results usually take two
weeks, and the women will be called by their consultant and told the results;
if the result is positive for abnormality, the general rule is to ask them to come
down to the hospital for a consultation.

Locating narratives of amniocentesis within wider circulating
stories of prenatal testing

There are various stories and sources of information about prenatal testing
that exist in popular culture – stories that can strongly shape understandings
of technologies such as amniocentesis. An interest in these stories led me to
examine a number of magazine articles about prenatal testing, mostly from
women’s magazines – but also newspapers and more general publications⁵.
Other sites include scientific descriptions of the test (see figure one), and the
counselling sessions the women have with the consultants before they
undergo the test (these are discussed in detail in chapter four). However, for
the moment it is the popular culture sites of stories, which I would like to
explore more deeply.

There were several discourses⁶ present within these articles on prenatal
testing, including; discourses about the private sphere, idealised parenthood,
and medicine and technology. Through these articles prenatal testing is
identified as deeply located within the realms of the private sphere, and this
is communicated in several ways. First, they are predominantly housed in

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⁴ The referral letter usually includes the date of the woman’s last monthly period and her due
date. The receptionist uses these dates to try and book the woman into a counselling session
at twelve to thirteen weeks gestation.

⁵ In the analysis of these articles I have looked toward Shirato and Yell (1996) who have been
influenced by Foucauldian discourse analysis.

⁶ The concept of discourse refers to various ways of speaking, or meanings, attached to
specific institutions. However, Foucault was interested in the way discourses work to
’structure, classify, and normalise the social world’ and identified their power in their
Medical testing before a baby is born can tell you a lot, but it’s not as reliable or as comprehensive as you might think.

The perfect baby?


Why woman are saying NO to amnio

Believe it or not, more and more women are passing up invasive prenatal tests. Are they afraid of the procedure — or of what they might learn? SHE investigates. By Lisa Lombardi

Figure 4. (2003) ‘Why women are saying NO to amnio’, in SHE, pp. 86-7.
magazines of the private sphere – women’s magazines, and all of the articles which name an author name women authors – prenatal testing is located within the private sphere as women’s business. Second, the tone of the articles is that of sisterly advice, which directly addresses the reader:

So now you know...You’re pregnant! But even as you look forward to the thrill of cuddling your first born, be aware that in the next few months you may be facing big questions and awesome decisions (Welsch, 1995).

The use of anecdotal individual stories about prenatal testing experiences also locates the issue securely within the private sphere. For instance, the 1995 Consumer article ‘The Perfect Baby?’ included the stories of two women, Diane, whose story was titled, ‘It’s nice to know’, and Cathy, whose story was titled, ‘Avoiding a still birth’. Both of these stories worked to reinforce the subtle tone of the article – which presented prenatal testing in a positive light:

For Diane the testing was a positive experience, the medical people were helpful and explained everything carefully to her... ‘I think it’s a sensible thing to do if you’re as old as I am’...For Cathy prenatal testing not only spared her the grief of having a still born baby, but it also helped to provide reassurance in her subsequent pregnancies... ‘I’m very grateful for it – the technology saved me a lot of heartache’ (Consumer, 1995: 30-31).

By being thoroughly located within the private sphere, the issue of prenatal testing is individualised and presented as individual choice, which is an ideological move that depoliticises the broader social issue of prenatal testing (see Shirato and Yell, 1996:138).

Discourses about idealised parenthood are also evident within the articles. Aside from a focus on the joys of pregnancy and the positives of parenthood, discourses are prevalent concerning the type of baby that women/people/society covet – a perfect baby. The concept of the perfect baby was present in almost all of the articles, and was presented as something that both existed and was desired: ‘In this day and age, everybody expects a perfect baby’ (Barnes, 1990). The tests themselves were generally presented as a normal and routine part of parenthood: ‘In fact you’re almost an oddball if you turn them [prenatal tests] all down, especially if you’re well into your forties with your first pregnancy’ (Barnes, 1990).
Discourses concerning medicine and technology were also present within the articles, despite their highly personalised nature. Dense medical information was injected throughout the articles functioning to give them a sense of authority. In fact, the views of medicine and science were very much privileged within these articles which placed an emphasis on opinions of medical and scientific professionals who are described as 'experts'. These 'experts' 'advise' or 'warn' women and are invested with authoritative knowledge, which is often indicated by the long winded description of their position, for instance, 'Professor Carl Weiner...Professor and Director of Maternal Fetal Medicine at University of Iowa Hospitals and Clinics' (Barnes, 1990). In the context of prenatal testing it is made clear that the medical institution, to which many of these experts belong, holds the relevant knowledge, rather than the women who are negotiating prenatal testing.

In discussing the various stories of prenatal testing, Lippman (1994: 11-12) has identified that biomedicine is privileged in Western culture. She uses the term 'story' to emphasise that scientists choose aspects of their observations and research to present, they 'shape and interpret raw data to convey a message, reducing its complexity in order to tell a story'.

In our contemporary Western culture we tend to cling to the seemingly unproblematic belief that the pursuit of biomedical knowledge of health and disease is a sign of progress (Lippman, 1994: 11).

This was certainly true in these articles, where amniocentesis and other prenatal tests were generally presented as advanced technology: 'Amazing new technology means experts can tell you lots about your baby, ages before it's born' (Welsch, 1995).

Although my analysis of prenatal testing stories located within popular culture was smaller scale, being restricted to nine articles, it does offer up an interesting angle from which to investigate such technologies. Various other stories about prenatal testing and related issues, such as chromosomal abnormalities, or other new reproductive technologies exist within popular culture.

She argues that they do this the same way that novelists 'select some arbitrary slice of life to describe and interpret the external world' (Lippman, 1994: 12).
culture, in sites such as television documentaries and the internet and presumably are a useful source of further information (which may also shape understandings of prenatal testing) to women considering undergoing such testing. The next section of this introduction however, will turn towards another approach from which to frame women's experiences of amniocentesis—that of embodied experience.

Certainly, another location for storytelling around amniocentesis is through embodied experience: As sociologist Arthur Frank (1995) has identified, stories are embodied as they are told through bodies. Although Frank is referring to the stories of ill people being told through wounded bodies, the embodiment of stories is also relevant to amniocentesis experiences as these women told their stories through bodies that had been subjected to the physical procedure of amniocentesis. The concepts of embodiment and lived experience (derived from phenomenology), have been an important way through which anthropologists have approached storytelling: By ‘foregrounding individual performances and the quite specific actions, thoughts, and feelings of particular actors’ (Garro and Mattingly, 2000: 21). Merleau-Ponty is a central figure in the development of phenomenology, a standpoint which locates the self firmly in the body and in which, the body is identified as both object and subject (but never simply one or the other). Rather, ‘the body is my being-to-the-world’, and so it is through the body that we receive and generate all knowledge. Experience is central to phenomenology and Merleau-Ponty argues that experience is always embodied (Grosz, 1994: 86-95). Another central figure with regard to body theory is Csordas (2000: 4), who has called for theories of culture, self, and experience to be reformulated with the body at the centre of such analysis. Health and illness, as identified by Fitzgerald and Park (2003: 7), are areas for which Csordas has specifically argued the importance of lived experience. In fact; phenomenology, lived experience, and embodiment, would be an appropriate and interesting way in which to frame research about women’s experiences of amniocentesis and the following section examines stories of amniocentesis from the starting point of embodied experience and is relevant

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to this research project as it highlights the physicality of the actual amniocentesis procedure.

Cassell (2000: 31) for instance, has argued that surgery is embodied:

Surgery involves bodies – those of surgeons as well as patients. During an operation the body of the surgeon makes brutal contact with the body of the patient, piercing the envelope of skin, assaulting the flesh, violating bodily integrity. The patient’s body is irreversibly altered.

I extend this to amniocentesis: the needle pierces the woman’s skin, is pushed through her flesh and penetrates her womb. The procedure of amniocentesis is irrevocably physical. However, it is also important to point out that the embodied experience of this physicality is varied, depending on your position, i.e. the active body of the consultant, the resisting body of the woman, or the observing body of the anthropologist.

I start by doing the ultrasound and taking measurements to make sure the baby’s gestation is suitable. I also look at how the baby is lying, look for the placenta and make sure that baby is alive and it’s got a head and things like that. Then I check the fluid around the baby and try to find a pocket of fluid where I’m going to insert the needle, once I have found that, I use a pen without the nib out to make a pressure mark on the mother’s tummy, freeze the scan and measure how much of the needle I am going to insert – the distance from the skin to the middle of the pocket. Next I put down the ultrasound head, prepare the sterile area, and swab the abdomen with alcohol. I then put on one glove and just place the ultrasound probe again, which the nurse holds – she has also washed her hands and has sterile gloves on. She passes me the needle, which I insert in a firm motion rather than just a slow one – because you can ‘tent’ the membranes. On the screen you can see the needle going in the muscle wall of the uterus and into the pocket of fluid. I then take out the trocar, the amniotic fluid wells up in the top of the needle and the nurse puts the syringe on and draws the fluid off. Once the nurse has put the fluid in her pot and closed the lid, I take out the needle and make sure there is not too much bleeding. And while I put a bit of pressure on the site, I do another ultrasound and show the mother the fetal heartbeat and that there is still fluid around the baby.

Figure 5. Description of a typical amniocentesis procedure derived from the three consultants.

It is important to illustrate amniocentesis as an embodied experience for consultants, as this places their later comments about amniocentesis in the

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9 When I first wrote this sentence I described the woman’s body as passive, however this is how it appears from the embodied position of an observer. In fact, both the consultants and the women experience her body as resisting, for instance, the consultants emphasise the force that is required to push through the uterus.
Figure 6. The 'tools' for performing an amniocentesis.

Figure 7. The procedure room.
context of the actual procedure. For the consultants, the amniocentesis procedure entails them intruding into someone else’s body and they experience this as an embodied performance of competency (see figure 5). For the consultants, the embodied experience of the amniocentesis procedure as a performance of competency is also ritual\textsuperscript{10}:

You do this so many times, you’re like a boring old recorder - you do the same thing over and over and over again. So literally, if you record yourself you’ll find yourself saying the same thing, the same time, every time (Dr Jim).

The consultants bring embodied clinical and practical knowledge to the amniocentesis procedure. They have practical technical knowledge of how to perform the procedure, for instance, with what force and motion to insert the needle, and how to physically manipulate the ultrasound probe.

The consultants also have embodied knowledge of the body they are intruding into through practical experience, and referred to their practical knowledge of the physical uterus, describing it as strong and tough: ‘I don’t think of it as a fragile thing – I think of it as a really strong tough thing’ (Dr Robert). The embodied knowledge of medicine has been described as ‘knowledge sensed through and with the body’, including the senses of sight, sound, touch, and smell (Gordon, 1989: 269, cited in Cassell, 2000: 31-32).

An examination of amniocentesis in terms of embodiment is also important because the women’s stories indicated that they experienced amniocentesis in embodied ways. The women reacted to the physical intrusion into their bodies in varied ways, including embodied emotion, and embodied split subjectivity. Nina, for instance, found the procedure to be very painful, however when describing her most vivid memory of the procedure she concentrated on the emotions she felt during the procedure which she experienced in an embodied sense:

Just lying there on that pillow with the tears pouring out of my face and sort of being unable to move, and just the whole emotion – that would be worse than the uncomfortableness...I think it was probably the emotional overload of that day too, like it was three months of pretty hard pregnancy pouring out of my face onto a pillow really (Nina).

\textsuperscript{10}Mattingly (2000) has observed rituals within the everyday of biomedicine interactions from narrative analysis.
An embodied focus on the penetration of the needle was also experienced by some of the women as they reacted to their body being intruded upon. Lynette, for instance, described how the insertion of the needle felt in her body, 'It felt like the needle was really pushing and shoving around and I could actually feel the needle – quite a pushy sensation'.

However, most of the women described a sense of embodied separation from the fetus (split subjectivity) during the amniocentesis procedure, especially when looking at the ultrasound screen. Ultrasound has been identified by Harris, Conner, Bisits, and Higgenbotham (2004), as a central element of pregnancy that entails its own pleasures and dilemmas. One woman, Susan, who also cried during the procedure because she was concerned for the baby, described how she felt when watching the ultrasound screen during amniocentesis:

It was like you and the baby were completely separate things and I don’t think it really came together that one was inside the other. It was like you were looking into baby’s world and you didn’t comprehend it was your world as well...Right when they’re doing it and when you’re watching it on the screen you don’t think they’re doing something to you, you think they’re doing something to the baby (Susan).

This sense of split subjectivity was central to how many of the women experienced their bodies during amniocentesis, and so requires a broader discussion with regard to the embodied experience of pregnancy. Young (1990: 161-3) has written about pregnant embodiment and argues that the pregnant body experiences split subjectivity in a number of ways. First a pregnant woman experiences her body as herself, and yet not herself; the movements within her womb are not hers, and yet felt within her body. She also experiences split subjectivity as pregnancy challenges the boundaries of her body, 'In pregnancy I literally do not have a firm sense of where my body ends and the world begins'. Lastly, split subjectivity is experienced because during pregnancy, bodily self-location is experienced in the trunk of the body as well as the head.

Authors, such as Petchesky (1987) and Rothman (1993) have argued that reproductive technologies (both imaging techniques and bodily

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11 Harris et al. (2004); these findings were part of a larger Australian-based qualitative study on pregnant women's understandings of nutrition and wellbeing.
interventions) have influenced the fetus to be viewed as separate from the pregnant body. This has occurred in several different ways; first, by confusing understandings of inside and outside the pregnant body, and challenging the concept of pregnancy as an 'interior' experience. Second, the privileging of the visual over other senses in biomedicine, has allowed for the visual capacities of detachment and objectification, distancing the woman from the inside of her body (Petchesky, 1987: 65-8). Third, technologies, such as ultrasound, which work to make the fetus visible, do so through rendering the pregnant body invisible (Rothman, 1993: 113). Petchesky (1987: 65-8) has labelled this treatment of the fetus as being outside the pregnant body (simply because it can be viewed), as a political act that has negative implications for women. Women have become viewed as simply a 'maternal environment' and their personal embodied knowledge of their pregnancy and the fetus has been lost. This was visible in my own observations of amniocentesis procedures: The ultrasound probe is on the woman’s abdomen, but all eyes in the room are focused on the ultrasound screen; the woman is looking inside her own body from a distance, and she is so separated from her own body that it has to be translated back to her so she can understand it, by the 'expert' knowledge of the consultant.

'Gendering' consultants and the story of this research

This last section of the introduction will identify my approach to the consultants' gender and outline the process of the research. Cassell (2000: 32-3) has extended the embodied understanding of medical consultants (surgeons) to query what it might mean if the body of the surgeon is a woman’s body. This interested me, as one of the consultants I spoke to was a woman and I have altered her gender to that of a man in order to preserve her anonymity within this text. However this 'alteration' of identity has meant that I cannot discuss the gender differences of the consultants and the various influences this might have had on a procedure that intrudes into women’s pregnant wombs.

Western medicine has been traditionally dominated by men, and various surveys have indicated that women doctors are 'exploited and oppressed' within the profession (Pringle, 1998: 2). However, feminist
Rosemary Pringle’s (1998: 2-3) research on women doctors in England and Australia has identified factors, such as increasing female graduates, as influencing a shift within the medical profession, perhaps allowing for a profession more adaptable for women. She goes on to argue that ‘women doctors are simultaneously a part of (patriarchal) medicine and placed outside it’.

By altering the gender of one of the consultants from woman to man, I have chosen to avoid investigating these various concerns. However it is important to note that something shifted in my understanding of the consultant’s comments and insights after I altered her gender. Rather than thinking, as I had previously, when I read her comments – oh yes, you can tell she is a woman, after these comments were attached to a male pseudonym, they no longer made sense to me as coming from a woman (it is amazing how powerful the label of a gender can be). Although I have not concentrated in-depth on the consultants’ gender, I still ask the reader to make note of this alteration as they read through the following chapters.

Prior to engaging in the research for this study I had to gain ethical approval from the Otago Ethics Committee. Before granting approval, the committee placed conditions on the recruitment method, meaning that I was not allowed to interview women throughout the process of amniocentesis – rather only women who had received their results could be contacted to be included as participants in the research study.

The recruitment method was facilitated through one of the consultants, who indicated ‘appropriate’ research candidates12 and signed approach letters typed up by the secretary. Information sheets were also sent out in the same envelope, which indicated the direction of the research and included my contact details for the women to be able to ‘opt in’ to the study if interested. Roughly 60 of these letters were sent out and only fifteen13 women responded,

12 The Ethics Committee specified that the consultant was not to ‘select’ specific candidates, rather to be aware not to contact anyone who they felt might not be able to deal with the research. Women who had received a positive result for abnormality were contacted through the consultant, but none chose to be included in the research.
13 Although fifteen women responded, only thirteen were interviewed, as one was away for the duration of the research, and another had moved and was living too far for me to travel to interview.
and an initial low response rate encouraged me to include the alternative to 'opt in' by mail\textsuperscript{14} – which significantly increased responses.

Before I interviewed the women respondents I undertook roughly twenty five hours participant observation at Southern Hospital Antenatal Clinic. I observed four counselling sessions (these were held prior to the procedure and were taken by the consultants) and six amniocentesis procedures, and the women were asked by the midwife if they would allow an interested anthropology student observe – every women that she asked agreed. During this period I also spent much time ‘hanging around’ the clinic, talking to the midwife, waiting in the waiting room, or popping in to find out the times of upcoming appointments. I collected data from my participant observation by taking field notes, however I did not write these during the sessions as I felt it would be insensitive and distracting, rather I found a space in the cafeteria afterwards and then wrote down my notes.

During this time I also interviewed three of the consultants who perform amniocentesis procedures; these 35 to 60 minute interviews took place in their offices and concentrated on their views and understandings of the physical procedure and the counselling session that accompanies it. I also interviewed the clinic midwife (in a consultation room) and the receptionist (at her home) who organises both the counselling and amniocentesis appointments. Although I have not concentrated on these last two interviews in my thesis, they were useful in that they gave me more of a sense of depth as to who is involved in the process and how it is organised within the hospital.

The interviews with the women took place between October 2003 and February 2004. All of these interviews took place in the women's homes at a time that suited them – and to make these appointments I travelled over 1000 kilometres to various destinations within the lower half of the South Island. The main purpose of these interviews, which varied in length from 30 minutes to two and a half hours, was to elicit a story from the women about their experiences of amniocentesis. All of these interviews (including those of the hospital staff) were recorded and transcribed\textsuperscript{15}, and transcripts were sent

\textsuperscript{14} A pre-stamped and addressed envelope, as well as a short form for names, addresses, and phone numbers were included with the approach letters.

\textsuperscript{15} I transcribed all of the interviews, except two, which I paid to be transcribed (a confidentiality agreement was signed by the paid transcriber).
to those who wanted them so they could make any changes to the document they required.

To conclude this introduction, I will briefly overview the remaining chapters of this thesis. The following chapter will outline the women’s stories about amniocentesis, as they told them to me (I have included this section as I felt it important to give the women a chance to ‘speak’ before I turned to analyse their stories). I then turn to my understandings of these stories in the subsequent chapter (three) which is broken into three sections. The first section approaches amniocentesis from within the frame of motherhood, the second examines some of the underlying themes about society that these stories indicate, and the third highlights some of the stories missing from this research i.e. stories about positive diagnosis. Chapter four goes on to discuss the ‘point’ of amniocentesis from various angles, including the consultants, the women, and other commentators and includes a brief review of the current thinking on genetic counselling. The fifth chapter incorporates the stories of two of the women, Melissa and Sharon, whose stories were different from the others in that they revolved around risk. These stories will be examined through risk theory and the meaning of risk as it appears to the consultants will also be covered. The final chapter concludes the thesis and discusses the findings of this research project in a wider perspective, in addition to drawing out further possible topics of contemporary research in this general subject area.
As I commence in this chapter to relate the stories from the women who spoke to me I wish to be mindful that the women are sharing their stories with me, moreover they are still their stories, but they have changed shape as I have interpreted them, focusing on some elements and reducing others. As Denzin has asserted, we need to treat our data with respect as we do not possess the lives and stories we tell, rather:

They are lent to us, given provisionally, if they are given at all. They remain, always and irrevocably the lives and stories of those who have told them to us (Denzin, 1987: 17, cited in Rice and Ezzy, 1999: 126)

In the case of the women’s stories presented in this chapter I have attempted to stay with the central elements of their stories, and to do so in a way that the story stays true to them. My supervisor advised me of one way to do this, by writing each woman’s story as if she were standing behind me reading over my shoulder. I feel that in this section I have presented each woman’s story in such a manner that she would not disagree with what I have written – this was very important to me.

It is important, when undertaking narrative analysis, to make clear how the terms story and narrative are understood (Rice and Ezzy, 1999, Garro and Mattingly 2000). I have followed Arthur Frank’s (1995: 188, n. 5) use of the terms, and used ‘story when referring to the actual tales people tell and narrative when discussing general structures that comprise particular stories’16. In this sense I have looked to Gergen and Gergen (1988) and their discussion of narrative forms as a way of locating the women’s stories. Gergen and Gergen (1988: 24) have identified three basic forms of narrative, the stability narrative, the progressive narrative and the regressive narrative.

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16 However, Frank does note that this distinction can be hard to enforce because ‘narratives only exist in particular stories, and all stories are narratives’ (Frank, 1995: 188, n. 5).
The stability narrative is a narrative 'that links events in such a way that the individual remains essentially unchanged with respect to evaluative position'. The progressive narrative concerns narratives where the individual is engaged in a narrative that progresses his or her position, while a regressive narrative is the opposite of this. Gergen and Gergen (1988: 24) understand these three basic narratives to be the basis for building more complex narrative types. For example, most of the women's stories are of the more complex narrative of the romantic saga, which involves a series of progressive and regressive phases. The women's stories involve shifts between these phases, for instance delight at seeing the baby on the ultrasound screen, concern about the possibility of a miscarriage, the anxiety of waiting for the result, and the relief and reassurance that accompanies a negative result. Christine's story seems to be the one story that is predominantly a stability narrative, she knew that her baby would be fine, and the whole process did not faze her. However, most of the stories involve elements of all three narrative types.

Situated within these stories are the women's understandings about the point of amniocentesis - to give women choice and check the viability of the fetus, their reasons for having amniocentesis - for themselves, their families, or the fetus in question, and what they got out of the amniocentesis - a sense of reassurance.

I have included the synopses of these women's stories in order to give the reader a sense of the individuality of each woman. These women are not a homogenous group, rather they are located within individual life histories, communities, and possess individual agency.

The women share their stories

Nina and her story:

Nina is a 36 year old mother of three sons, an eight year old, six year old, and an eight and a half month old. She identifies herself as a Presbyterian, New Zealand European. Nina lives with her husband and children on a family farm in the rural South Island where she works as a part-time teacher at the local primary school.

The interview with Nina took place in the summer, at her farmhouse. I had a long drive through dry rural country and long gravel roads before I
found her house. Nina came out to greet me as I drove around the corner of the house, her husband was working, her two older boys at school, and the baby asleep during the interview, which took place at the kitchen table while we drank cups of tea.

Nina started her story by saying ‘I had always wanted to have three children and my husband always wanted to have two children’ - this was a ‘real debateable issue for years and years’. As a couple they had always been ‘irresponsible’ with birth control, and perhaps influenced by that, six years after the birth of her second son she found out she was pregnant. This pregnancy was ‘kind of a shock really’ and her husband took the news of the pregnancy ‘quite badly’.

Nina went to her doctors to confirm the pregnancy, and very early on the option of prenatal testing was brought up due to her age. When thinking about the option of this test, Nina realised that ‘this pregnancy was a bonus for me and I also realised that having a handicapped child would not be an option for me, and I thought it wouldn’t be very good for my marriage’.

She went to a specialist appointment in a local town, and ‘they were really, really, straight to the point and basically said... ‘if the baby has an abnormality what would you do?’ And I said ‘do I have to answer that now?’ And they said ‘yes you do’. Nina felt that she did not have the support of her husband and after taking a while to get her thoughts together she decided that she would go ahead and have an amniocentesis.

Nina and her husband drove down to the city on the day of the procedure, and experienced a very long wait in the waiting room; they had ‘to wait for like an hour and it was hot and it was just awful’. When they were called into the procedure room, the consultant first talked to her about the procedure, then asked if she still wanted to go through with it, and checked that if the baby was abnormal she would have a termination. Nina described the procedure as ‘one of the most emotional things I ever had to do’. ‘So I lay on the bed and I just cried and cried and cried and cried and tears were pouring out of my face...and the consultant kept saying, ‘she’s crying, she’s crying’, but they really couldn’t do a lot’. Nina described the actual procedure as ‘really, really painful...I just wished it would finish, it took forever’. At one stage, her husband, who was acting as her support person (although he did not like needles), ‘went green and basically fell on the floor
and the midwife, who was holding my hand, had to rescue him and take him out of the room’.

After the procedure was over Nina and her husband walked back to the car, and he put his arm around her to support her and told her that everything would be okay. Nina felt that this was the ‘turning point’ for him accepting the pregnancy as he had both connected to the baby on the ultrasound screen and also witnessed that she had been through an emotional ordeal. She described the actual procedure as the climax of her amniocentesis experience.

Next came the period of waiting for results, which Nina hated. There was some confusion and she had to wait an extra two days over a weekend to get her results. Then when she rang she found out that her consultant was away for two weeks so the receptionist had to call her back with the results. While waiting for that phone call she felt ‘a great fear that something was wrong with the baby’, however when the call came everything was fine. Nina handed the phone to her husband to find out the sex of the baby as she was crying with relief that everything was okay. When he told her it was a boy she felt a ‘very slight disappointment’ that it was not a girl. In recollection Nina described her experience of amniocentesis as very traumatic, ‘it was a hideous procedure and I’d never ever say to a woman that it was a breeze’.

**Diane and her story:**

Diane is 41 years old and has one daughter who was thirteen weeks old at the time of our interview. Diane describes herself as British and Anglican, and lives with her partner in a section of a large house near the centre of a southern city.

Her partner was not at home and her daughter was asleep during the interview, which took place upstairs at the kitchen table while (again) we drank cups of tea. Diane had left a note on the front door just telling me to come in and not to knock so as not to wake the baby.

Diane started her story by telling me that she had had an abortion when she was 22 years old, at the time it was ‘not right for her’ to have children. In fact, before she met her partner three and a half years ago, she actually thought, ‘I’m not going to have children’. Although having a child was not something she felt was at the ‘top of my priority list’, she and her
partner had said that if there ever was ‘an accident’ they would go ahead and have the child - and the conception of her daughter ‘was a little bit of an accident’.

Diane had talked to her midwife about amniocentesis and was also given information about it by her doctor. She and her partner felt that they really wanted to know if there was something wrong with the baby, and so she booked her appointment after her first scan. Diane recollected that at the time of the amniocentesis she thought that she would have a termination if the baby was diagnosed as having Down syndrome, however, on reflection Diane commented, ‘if I had found out the baby was Down’s I don’t think that I could have gone through with it [a termination] anyway...but I wanted to know beforehand to deal with it’. When Diane went to have the procedure, the consultant told her that she was not far enough advanced in the pregnancy to perform the procedure. However, they did have a ‘little chat’ and she was given notes, but ‘not really counselled at all about it and sort of told if things could go wrong’. Diane went back to have the procedure done, but had to wait and try and ‘walk’ the baby into the right position for the procedure. When she actually had the procedure, she was shocked that she was not given anaesthetic before the needle was inserted, because it was included as part of the amniocentesis procedure in the notes she had been given. However, she did not find the procedure ‘painful at all...the most painful thing was them actually taking the needle out’. Diane felt that the procedure ‘seemed to take forever’, because it took a long time to break through the wall of her uterus. Despite having a lot of faith in the consultant, Diane did not watch the procedure on the ultrasound screen because she felt it would ‘stress her out too much’. Instead, she got her partner to watch to make sure that the baby did not get ‘punctured or spiked’.

Diane felt ‘quite anxious’ waiting for the results because she did not want to be in a position where she would have to tell people that she had had a termination. The waiting period felt like a long time because she was over three months pregnant, and people were asking her why she was being so boring, and was not ‘going out and having a drink and partying’. Diane phoned the hospital and talked to the consultant to get the results, who told her that everything was alright. Diane and her partner were ‘just so pleased’,
and as soon as she found out that the baby was 'perfect', Diane was on the phone telling 'everybody and their uncle'.

**Tania and her story:**

Tania is 43, married with two daughters; a five year old and an eleven month old. Tania works as a typist and describes herself as a Catholic New Zealand European. She lives with her family in a new subdivision, in a suburb about 20 minutes out of the main centre of a southern city.

Tania was the first woman I interviewed for this study, and I met her after she had finished work and picked up her daughters from school and child care. The interview took place at the kitchen table, her husband was not home, her eldest daughter was playing downstairs, and her youngest daughter had a feed and then went to bed during the interview.

Tania had experienced amniocentesis procedures with both of her children. She first heard about the procedure from reading and through the recurring miscarriage unit – as prior to her daughters she had experienced 'a couple' of miscarriages. Tania found her first amniocentesis very stressful for a number of reasons; she was nervous because she had never experienced one before, she was concerned that if it was not done that day her husband, who had to go away for three weeks, would not be there, and she found the consultant 'insensitive'. However, she and her husband were sure they wanted to know if there were any problems. Tania felt as though the consultant spoke around her, rather than to her, and that he acted as if she was not there by talking to her husband instead of her. At one point he said that he could not perform the procedure because of the position of the baby, and Tania was very stressed because there was not another time that her husband could go with her and she did not want to have it without him. However, the consultant eventually agreed to perform the procedure which Tania felt was 'quite painful'. Tania had felt so strongly about the first consultant, that she recalled, 'I said to my husband later that if I saw him in the street I would probably go and punch him'.

Tania had to wait two weeks for the results of the amniocentesis, and she was called at work by her fertility specialist. There was, however, some confusion as he asked for someone else by name, but Tania recognised his
voice. He then had to call back after he had checked that there had been no mix ups with the results, and told her that everything was fine, and that it was a girl.

Tania’s second daughter was unplanned and Tania felt that she ‘really didn’t need to be getting pregnant at this age’; she decided to have an amniocentesis again because she wanted to know if there was anything wrong. This time she attended a session where she told the consultant about her previous experience and the consultant assured her that it would not be the same again.

Tania had to go back to the Antenatal Clinic four times before she had the procedure because the baby was in the ‘wrong place’. The first time the baby had its spine right where they needed to get the fluid from and the consultant felt it too risky to perform the procedure. When she actually had the procedure it was a lot less painful than the first one, in fact she ‘didn’t feel it at all’. Even though her husband was absent for this amniocentesis, Tania trusted her consultant and did not mind.

There was another two week wait for the results, which she received from a phone call by the consultant. Tania and her family were on holiday in the mountains when the results came through that everything was fine. However, the reception was quite bad and when she was told the sex of the baby the consultant said ‘female’, Tania heard ‘male’. She was so sure that she was carrying a girl she rang the consultant three days later to confirm and found out that she was right and it was a girl.

**Shona and her story:**

Shona is 41 and is mother to two boys, twelve years and eight years, and an eight month old daughter. Shona lives with her husband and children in a coastal village near a southern city, where she works as an early childhood teacher.

I drove out to interview Shona at her house on an overcast day, her sons were at school, her husband at work, and her daughter was asleep. We sat in the lounge during the interview, and with almost perfect timing her daughter woke up as we finished and had a visit before I left.

Shona started her story by telling me about her two sons, whom she described as ‘absolutely fine and healthy’. Her eldest son has one kidney that
is on the ‘right hand side and twice as large’, but functions well. Her younger son has club feet, which his grandfather also had. Shona stressed that her sons’ ‘problems’ were ‘not an issue at all to us’, and that she had the amniocentesis with her last pregnancy because it was part of the criteria she and her husband established before they ‘got pregnant’ with their very planned and much wanted third child. Shona had concerns about engaging in this pregnancy because of the ‘age barrier’, and so she and her husband decided that they would first try to have a child when she was 39 and ‘just try for a year’, and then if successful they would have prenatal testing to check that everything was okay. Shona emphasised to me that ‘the thought was not to have the perfect child’, but rather to be able to choose not to have ‘a child with huge difficulties in life’.

When she went to her doctor to confirm the pregnancy Shona recollected that he seemed ‘unimpressed’ because of her age, and the ‘do you realise there could be difficulties’ came up fairly early in the conversation. Her doctor recommended CVS because she could find out earlier in her pregnancy, but Shona and her husband decided on amniocentesis because it checked for more difficulties. Shona had known about the possibility of prenatal testing for about fifteen years, had done some reading on it at the library, and been given some information about it from her doctor.

Shona recalled having an ‘information session’ when she was around fifteen weeks gestation, where the consultant talked about how the procedure would be done and the risks of increasing maternal age. She recalled the session as being quite short and ‘slightly negative, centering on the negatives quite a lot’ – especially with the presentation of the probabilities as fractions compared to percentages.

Shona remembered having the amniocentesis when she was around eighteen weeks gestation – she found the actual procedure fine. The consultant was ‘lovely’ and the process ‘great’, she felt that the consultant was ‘really efficient at finding the fluid’. One upset during the procedure was when an observing midwifery student fainted: ‘she fell across the doorway so we had to step over her to get out – poor girl’.

Although Shona thought that she would have to wait two weeks to get the results, they were left on her answer phone ten days later and everything was fine. Shona found the waiting period to be ‘very anxious times’,
especially because she had found out about her sons ‘minor difficulties’ ‘while the children were in utero’. Because of this she felt ‘very, very, anxious’ when she had the following scans, however, the later scans were fine.

Susan and her story:

Susan is 38, married and has one daughter who is eight months old. She identifies herself as a New Zealand European and Anglican. She lives with her family in a house in a central suburb of a southern city, and works as a supervisor.

I interviewed Susan at her home one evening heading up to Christmas, her husband was at home when I arrived, but soon left to visit family. Her daughter was up and sat on her mother’s knee for most of the interview and went to bed for a short time at one stage. The interview took place at the kitchen table.

Susan started her story by telling me that she had been trying to fall pregnant ‘for quite a long time’, and there was concern because she had experienced ‘at least one miscarriage’, and she and her husband were both older.

Susan found out she was pregnant when she was ‘going through the workup test to be referred to the fertility service’, and was ‘absolutely delighted’. She asked her doctor about amniocentesis, and after they had decided to go through with it Susan recalled her doctor saying, ‘he wasn’t surprised that we’d said we would opt for termination because he said really people with science and medical backgrounds normally do because they understand the ramifications of genetic malfunctions and abnormalities much more than the normal public’.

Susan and her husband chose to have amniocentesis for a number of reasons; they were concerned as older parents that if something happened to them a child might be left that needed a lot of care, and because they wanted ‘a child with a really strong future’ Susan knew that ‘if there was something wrong that we would take the option of termination and try again’.

Susan remembered seeing a consultant at a session before the procedure who went over the available prenatal tests, what a termination would mean, risks, and asked about Susan and her husband’s fears and
concerns. Although they had already decided that they would have an amniocentesis, Susan felt the session helped her to ‘confirm what I thought I would do anyway’.

Susan had a preference to have someone other than a certain consultant and the Antenatal Clinic staff made sure that she saw another consultant. She felt that the consultant she did see was ‘really good’; he started by introducing himself and the nurse and going over the procedure in detail. The scan showed that the baby was ‘wriggling around like crazy’ and there was some concern that they might not be able to perform the amniocentesis. Susan recalled getting very ‘frightened’ of the baby’s movement, and crying on the bed, ‘but the consultant was really good, he actually stepped back and gave me some more time and let me see the scan’. Susan saw the position of the baby throughout the procedure and felt very reassured by the consultant. However, after the result she felt ‘terrified’ that she would miscarry and consequently took two days off work to rest. After waiting two weeks for the results the consultant left a message for Susan to call him, which she did and he told her that everything was fine.

Near the end of the interview Susan told me about her sister who was very ill and cared for at home for a few years before she died at age eighteen. Susan felt that the level of care and the stress that caring for her sister placed on the family might have influenced her to have the amniocentesis.

**Christine and her story:**

Christine is 38 years old, and has three children; two daughters aged ten and seven years, and a fifteen month old son. Christine describes herself as New Zealand European and lives with her husband and children in a village about a twenty minutes drive from a southern city.

I interviewed Christine mid-morning, when her husband was at work and her two older children were at school. Her son was up and very playful, he was entertained by playing with my bag or the tape recorder and took turns at climbing on either his mother or me.

Christine started by telling me a very short version of her experience: ‘I went and saw one of the consultants at the Women’s Health Clinic at Southern Hospital and then I had the amniocentesis and that was basically it’. However, throughout the interview Christine’s story became extended.
Christine's pregnancy was unplanned and she decided to have amniocentesis because her husband did not think he could cope with a ‘child who had a chromosomal disorder who was going to be intellectually and physically handicapped to a great extreme’. Her husband was also concerned because he was 50 years old and worried about a child who might need long term care – what was going to happen when he [Christine’s husband] was in his seventies? Christine stressed that she did not have the amniocentesis for herself, as she ‘was convinced that the baby was fine’, rather she did it for her husband because ‘he needed to know’.

Christine’s referral came through her midwife, and she recalled having an information session at the hospital prior to going in for the amniocentesis. Christine found the session to be ‘informative, so that you know what to expect and to be given options and to be told about the procedure’. Christine had known that prenatal tests such as amniocentesis were available for around fifteen years, but she was also given an information brochure at the hospital. She decided on amniocentesis rather than other tests because ‘amniocentesis gave us a definitive answer and there was less likelihood of problems than if I’d had the sample taken from the placenta’.

There was a fifteen minute wait before the procedure, and when she went in to have it done the consultant explained the procedure again, and also told her what was happening during the procedure. Christine did not recall actually feeling the needle being inserted – ‘just pressure’. She described the procedure as ‘not a bad experience’ with everyone ‘cracking jokes and carrying on’ and commented on the confident and relaxed attitude of the consultant and nurse.

Christine was not anxious while waiting for the results, which she received two weeks after the procedure when the consultant rang her at home and told her that everything was fine, like she knew it would be.

Karla and her story:

Karla is 42 and has two daughters, an eleven year old and a six month old. Karla describes herself as Maori and affiliates herself as Tuhoe and of Ratana religion. She works in insurance sales and lives with her husband and two daughters in a house in an outlying suburb of a southern city.
I interviewed Karla on a sunny morning, after arriving early I waited in my car. When Karla arrived her baby was asleep and so she put her to bed before we started the interview. Karla’s husband was at work and her eldest daughter was at school, and we sat in the lounge with (the prerequisite) cups of tea for the interview. The baby woke up near the end of the interview and sat on her mother’s knee.

Karla had her first daughter when she was 29, but was unable to conceive again when she tried for a second child. After having one cycle of IVF, which she ‘didn’t like’, Karla and her husband thought themselves ‘unexplained infertile’. So when Karla fell pregnant again, it was a ‘lovely shock’, although she would have preferred if it had been when she was younger, ‘but better that not at all’.

Karla asked her doctor about amniocentesis when she went to confirm her pregnancy, and was referred to the Antenatal Clinic through her doctor. She then had a meeting and a scan with the consultant at the Antenatal Clinic, where the consultant talked about the different testing options, ‘and all the information – told us what it was about’.

Karla had decided before she talked to the consultant that she wanted amniocentesis because of her age and because it was an unexpected pregnancy; ‘I wanted to know if the baby was okay or not’. Karla and her husband had decided not to tell anyone about the pregnancy until they received the results because ‘if the results were bad...we had agreed to terminate’.

The day of the procedure Karla had a short wait before the amniocentesis. She described the experience of the amniocentesis: ‘he just told me he was going to stick a needle in near my belly button to get the fluid out and I hate needles so I looked the other way’. Karla found the procedure ‘didn’t hurt’ and she did not feel ‘too stressed’ by it. Although she had planned to take the afternoon off work, she felt fine after the amniocentesis procedure and so after a cup of tea she went straight back to work.

Karla found the waiting period an anxious time because she ‘didn’t know whether to be excited or not. I didn’t want to build myself up until I knew everything was okay’. She also felt some concern that her results might be delayed as it was coming up to the Christmas period, but the consultant ‘pushed them through’ and after two weeks he rang her to say that
everything was fine. Karla recollected feeling ‘so relieved I forgot to ask what
the sex was – so I had to ring up later and ask’.

**Lynette and her story:**

Lynette is 41 and has four sons, eighteen years, twelve years, three years, nine
months, and two daughters, eleven years and six years. She lives in a house
with her husband and children in a coastal suburb near a southern city.

I arrived at Lynette’s house one morning, it was very hectic. Her
youngest son was playing and her husband and mother (or perhaps mother-in-law) were both at home and having a loud conversation near where the
interview took place, in the lounge. We sat on the couch with cups of coffee
while her youngest son played with the packet of biscuits I had brought.

Lynette had two amniocentesis procedures, one with each of her
youngest sons. She first heard about amniocentesis when she was pregnant
with her second youngest son at age 37, she was told by her doctor that it was
available if she wanted it. Lynette decided to have the amniocentesis the first
time because ‘it was our fifth child and I wasn’t that enthused about being
pregnant, so that I knew if there was a major complication I probably
wouldn’t cope’.

Lynette attended a counselling session before the procedure that
‘basically made you aware of what the risks were’, however she had already
decided that she was definitely having an amniocentesis before the
counselling session. She found the first amniocentesis ‘quite difficult’; she
went to the hospital with her husband and although she had been told that
there would be no pain only ‘slight discomfort’ she ‘actually found it
incredibly painful the first time and quite scary’. However, she did not say
anything to the consultant about the pain because ‘I thought that I was being
a wimp’. Lynette had to wait just under two weeks for the results, a time
during which she felt ‘quite anxious – actually that’s the hardest part
probably, the waiting for results’. She had organised that she would get the
results through her GP, who would ring her and get her to come down for an
appointment whether they were good or bad, ‘which was really nice, rather
than telling us something terrible over the phone’.
The circumstances around Lynette’s last pregnancy were quite different, 'he was a much wanted baby, and so even if the results hadn't been what we wanted, I probably still would have carried on with the pregnancy' – for this pregnancy the test was 'more for foresight'.

Lynette felt that she had 'a much better relationship' with the second consultant. He reassured her that the pain from the first procedure may have been caused by the size of the needle and stressed that it should not have felt so painful. Lynette felt that the consultant was 'very careful', and he did not perform the test the first time she went in because the baby was in a dangerous position. When she went back a second time it was fine, and Lynette found the procedure was only a 'slight discomfort'.

After another wait of less than two weeks the consultant rang Lynette with the results that everything was fine. When telling me her story, Lynette recalled watching the ultrasound screen during the amniocentesis procedures. She felt ‘incredibly bonded with the baby, just watching it move around on the screen, I remember thinking...it just seems so perfect’. After seeing the babies on the screen Lynette remembered feeling that it would have been ‘a really, really, hard decision to make’, to terminate the pregnancy if something was wrong.

**Emma and her story:**

Emma is 35 years old and was six months pregnant at the time of the interview. She describes herself as New Zealand European and lives with her partner in a house in a rural setting twenty minutes drive from a southern city.

I drove out to interview Emma one summer morning, after having some trouble finding the right house, I arrived. There was a big gate around the house to keep the dog in, which she opened for me. Her partner was not at home, and Emma, the dog and I sat in the lounge for the interview.

This was Emma’s first pregnancy. She had first had a blood test, which her midwife ‘jacked up’ for her through an appointment at the Antenatal Clinic. The consultant she saw gave her some pamphlets and talked to her about her options: Emma recalled that ‘once I saw that you could have a blood test I pretty much made up my own mind what I would do’. 
Emma was very concerned about having a child with Down syndrome because ‘I was getting older and they say the risk is higher once you get to 35’. She felt that she would ‘hate to have a kid with Down’s syndrome and I was going to do anything to eliminate any possibility of that’. Emma felt that she would not be able to ‘handle it’, and that her partner ‘would’ve hated to be stuck with a Down’s syndrome kid as well’.

Emma’s midwife rang her with the blood test results when she was out of town - they were ‘high risk’. When she got the results Emma thought, ‘oh shit there’s something wrong’, and her midwife told her that ‘I should come home straight away and get the amnio... well, see the consultant and talk to him’. However, the consultant told her not to rush home and there was an appointment card waiting for her when she did get home.

Emma went to the appointment to see the consultant who explained about the amniocentesis procedure, and told her that having it or not, was her decision. Emma recalled, ‘I just basically said, well I’m having one!’ She felt ‘a little bit nervous’ prior to the amniocentesis, but remembered it going smoothly: ‘I just went in and they put a scan on me to see where the baby was positioned and he put a dot where he was going to put the needle in, then put the needle in and sucked the fluid out’. Emma felt only ‘a little bit of pain’, and recalled that the staff had been ‘really good – it only took about five minutes’.

After an ‘anxious’ two week wait, Emma received the results when the consultant ‘left a message on the answer phone actually saying everything was fine, I was relieved’.

Jane and her story:

Jane is 38 and has two birth daughters, a five year old and a three month old, and three ‘grown up’ step daughters. Jane describes herself as New Zealand European and Maori, and affiliates herself with Ngai Tahu. Jane describes her religion as Spiritualist, and she lives with her two daughters and husband in a house in a coastal village not far from the centre of a southern city where she works as a dentist.

I visited Jane mid morning and when I arrived her little dog greeted me at the gate. Her husband was at work and her eldest daughter at school,
her youngest daughter lay in a bean bag during the interview. The interview took place at the dining table.

Jane had amniocentesis with her second pregnancy and she had found out about amniocentesis roughly eleven years ago, when a then 40 year old friend experienced one. Jane discussed various methods of prenatal testing with her midwife before having a meeting with a consultant at the Antenatal Clinic. The consultant explained the various methods of different tests, the conclusiveness of those tests, the time frames involved, and asked if Jane had any questions. Jane was given information to take home to read and she also talked to several friends about their experiences of amniocentesis. She knew that she wanted prenatal testing and just had to ‘affirm which method’. Jane recalled that it seemed ‘quite important and quite logical to me to choose the most conclusive method that was also bearing in mind minimal risk’ – she decided on amniocentesis.

Jane recollected that there were three main influencing factors on her decision to have prenatal testing. First, she was concerned about her age and increased risk, second, her experience of growing up with an ‘older brother who is severely intellectually handicapped’. Jane stressed that her experiences of growing up with her older brother were ‘heavy duty’ and that there were major impacts to family life, especially for her as a sibling. Jane remembered that she ‘felt quite strongly that I didn’t want to bring that into our family life. I mean I’ve been a step-parent to my husband’s three daughters...that have left home and it’s only now that we’ve come to having quite a calm smaller unit of family life and I wasn’t about to choose to make that a complicated scene’. A third influencing factor was that she had become ‘good friends’ with the obstetrician who had delivered her first baby, ‘I had talked with her and already knew the increased statistical likelihood of any genetic abnormality so I was already quite swayed in my mind’. Jane mentioned that her husband was ‘totally in agreement with everything’ she decided.

Jane’s husband accompanied her to the amniocentesis and she was feeling ‘slightly anxious’ before the procedure. Although Jane found ‘the idea of having a needle stuck in your abdomen wasn’t too flash’, the procedure went well. She felt ‘really confident’ in the consultant and reassured by being able to watch the screen and make sure the needle was not near the baby. The
insertion of the needle was 'just a very short prick' and only caused her 'mild discomfort'.

Jane had a two week wait for the results that everything was fine, which she found out first when the consultant called, and was later sent the results. Jane and her husband chose to find out the sex of the baby as 'it was a real interest factor' because her husband already had four girls. When they found out it was a girl Jane 'couldn’t believe it, I think I’d convinced myself till that time that we were probably having a boy'.

**Jessica and her story:**
Jessica is 37 and has a son aged sixteen years and a daughter aged seven months. She is married and identifies herself as New Zealand European and Anglican. Jessica lives with her family in a house on a large section in a small coastal village roughly 40 minutes drive from a southern city where she works as a senior teaching fellow.

When I spoke to Jessica on the phone to organise the interview, she mentioned that her husband was very interested and asked if he could participate in the interview, I thought this was a great idea.

The interview took place in the evening and Jessica asked me to come for dinner as well. I drove along the dirt roads and finally arrived at the house, we sat in the lounge and had dinner, all the family were there although Jessica’s son left the room when we were about to start the interview. We sat in the lounge and the baby was in an activity walker playing and eating while the interview took place. It was an intriguing interview, in some places it was a conversation between Jessica and her husband about the experience of amniocentesis, and they had many interesting insights. Throughout the interview I thought to myself, 'this is absolutely great'. The interview extended into the night and luckily I had brought extra tapes. When the topic was finally exhausted I made the long drive back to town thoroughly excited about the contents of the tape.

However, a qualitative researcher’s nightmare occurred, and when, months later, I went to transcribe the interview I could not hear it. I tried various machines in vain - the tape was inaudible. I spent two hours desperately trying to decipher what was being said, and came up with two sentences that I mainly had guessed. In a last desperate bid I rang various
audio businesses to see if there was any ‘machine’ that could enhance the voices, but I was told that it is an extremely expensive process that would require sending the tapes up to Auckland. As a poor student who had spent their only departmental funding on an oral history course, I retreated into failure. Jessica’s story had turned into a story of how my incompetence lost her voice and only some little slips of information that I quickly jotted down during the interview were left. I decided not to pursue another interview with Jessica and her husband, first because I did not wish to take up more of their time, and second because I felt as if there would be a rehearsed element to the interview. An aspect of the interviews that I really liked was how it often brought up issues the women had not thought of since their amniocentesis, if at all, resulting in the women often speaking out their thought process as they negotiated the rocky paths of their amniocentesis memories.

Jessica underwent a nuchal fold test, however, she and her husband did not feel as if they had made a conscious decision to have the test, it just seemed like part of the prenatal care package. The results came back ‘high risk’, and they were told this information at an appointment with a locum (as their doctor was away). They were thoroughly unimpressed with the way the locum handled the results, which were read out, and then when Jessica or her husband asked what they meant, the locum was not sure and had to look up a book. When the results were ‘translated’ the locum said, ‘Do not worry I will organise an amniocentesis through the Antenatal Clinic’. This seemed, to Jessica and her husband, like the next step. The results came back that the baby was fine, but the whole experience made a lasting impact on Jessica. She recalled feeling so strongly about the ‘complexities’ and added worries of having children at a later age, that she said if something had been wrong, she would have felt the need to go and educate people about the benefits of having children younger. She even mentioned something to her sixteen year old son about maybe having children quite late in life might not be such a good idea.

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These stories of amniocentesis fit within wider stories – they are not simply stories about amniocentesis. For instance, Nina’s story fits into a wider story of marital negotiation about a third child, Shona’s story is also a story about what degrees of abnormality a mother will accept, and Susan’s story of amniocentesis fits into the wider tale of her quest to have a baby, and the lengths to which she had to go to ‘achieve’ her daughter.

The stories these women told, emphasised that women do experience the process of amniocentesis in a number of different ways. A procedure that one woman may describe as ‘great’, may be described by another as a ‘hideous procedure’. While one woman may protest that she did not have a counselling session, another might refer to an ‘information session’ that helped her to choose which method of prenatal testing to use. Although these women’s experiences of amniocentesis were diverse, their results were all the same – negative, indicating that their fetus had no abnormalities. In the following chapter I will examine these stories in terms of motherhood and moral justification, and investigate some of the cultural stories and discourses located within the stories. I will also consider the stories that are missing from this research project – the stories of women whose amniocentesis procedure resulted in the termination of their pregnancy.
This chapter is a space where I will tell ‘my story’ of the stories the women told me – the women might agree or they might not. Although there are various areas that these stories of amniocentesis could have led me to examine – due to the limited space, I will only discuss three areas in this chapter. First I will explore how these stories, and amniocentesis in general, intersect with various ideologies of motherhood, and how the women justify their use of the technology. Then I will look at some of the underlying cultural narratives that the stories communicated. These will include narratives about the privileged position of science and medicine, amniocentesis as a site of gender negotiation, and the type of children that we want. Cultural discourses about choice and disability, which are central to amniocentesis, will be discussed in the chapter four. These women’s stories also highlighted the stories that they did not tell me, and the last section of this chapter will discuss the more tragic stories of amniocentesis-induced miscarriages and positive diagnosis that are missing from this research.

All the women’s stories were the stories of mothers (except Emma who was six months pregnant at the time of the interview) and so tell us something about motherhood. As Garro and Mattingly (2000: 24) have argued, understandings about appropriate behaviours and feelings shape narratives; and so it is pertinent to ask, what do these women’s stories say about the appropriate behaviours and feelings associated with mothers and motherhood?

Glenn (1994:1) has argued that there are various disputed ideologies of motherhood in contemporary society. Within Western society, there exists a dominant Eurocentric ideal of motherhood, which is influenced by an American middle-class idealised picture of motherhood and projected as
universal (Glenn, 1994: 1-3). From this perspective, a mother has unconditional love for her children, and is selfless, all-giving, and all-accepting (Thurer, 1994: xiii, Rothman, 1993: 6-7, Rapp, 1994: 217). The use of amniocentesis, as Rapp (1994: 217) and Rothman (1993: 243) have argued, does not fit within this dominant ideal of motherhood, which exists within wider historical and culturally diverse understandings of motherhood, and has been challenged by the experiences of women and mothers of various ethnicities, socio-economic realities, beliefs, and sexualities.17

Motherhood involves various contradictions; for instance in opposition to the dominant ideal there is a ‘darker’ ‘demonised’ side to motherhood in which mothers are smothering, destructive, and all-powerful – they hold the fate of their children in their hands (Glenn, 1994:11). A darker aspect of motherhood can be seen within the technology of amniocentesis and selective abortion, where women may judge the acceptability of their future children on the basis of their chromosomes. However, the element of the destructive and all-powerful mother is not just recent; rather the practices of infanticide, abortion, and sex selection have long histories in Western culture. Infanticide, through exposing newborns, was practiced in Classical Greece and Rome and the middle-ages (Thurer, 1994: 179). Forms of abortion were practiced in Early Greece and during the 17th century various ‘recipes’ existed to end unwanted pregnancies. In later years, women who were unable to have legal abortions turned to ‘backstreet abortionists’ with dire consequences – for instance, in 1960s America it was reported that thousands of women were dying each year from illegal abortions (Thurer, 1994: 72, 170, Rapp 2000a: 34-35). Sex selection also has a long history, in fifth century Athens around ten to twenty percent of female newborns were subject to infanticide, and in more recent history sex selection in countries including Korea, Taiwan, India, and China has utilised prenatal testing technology for this purpose (this is now illegal in some cases) (Bubeck, 2002: 217). Amniocentesis may be viewed as propelling women to make sometimes ‘tragic’ choices – however as the past history of infanticide, abortion and sex selection show, mothers throughout history have had to make equally ‘tragic’ choices. Instead, through amniocentesis these ‘tragic’ choices of motherhood are more visible and have been normalised according to the institution of medicine.

17 See Glenn, Chang, and Forcey (eds.) (1994) for further discussion.
Although amniocentesis might not fit with the dominant ideal of motherhood, it fits perfectly into the medicalised model of motherhood, which is located in technological society. Within medicalised motherhood, the female body is understood as a ‘defective machine unable to produce a healthy baby without technological assistance’, and the pregnant body is simply a container for the fetus, which exists as a separate being from the mother, who is not actively involved in the mechanical process of fetal growth (Davis-Floyd, 1996: 144-150). It is through this view of motherhood, where the fetus is ‘free floating, independent’ from the mother, that the fetus is viewed as a subject with its own rights; consequentially the rights of the fetus may be pitted against the rights of the mother (Shildrick, 1997: 25). Rapp suggests that a medicalised mother undergoing prenatal testing ‘may feel like an agent of quality control on the reproductive production line’ (Rapp, 1994: 216-7).

Although the medicalised model of motherhood has been highly critiqued, especially by feminists, it has been embraced by many women. This can be illustrated through anthropologist Robbie E. Davis-Floyd’s (1996) American-based study of the pregnancy and birth experiences of 32 pregnant women (professionals) who had hospital births and eight women who had homebirths. The women who experienced hospital births related to the medical model in how they viewed themselves, as well as feeling empowered by the technology associated with medicalised motherhood (Davis-Floyd, 1996: 134-6). Davis-Floyd identifies medicalised motherhood as pervasive in America, with around 24% of women having caesareans, 24% epidurals, and 90% episiotomies (for first time mothers) (Davis-Floyd, 1996: 127). The women in the study actively sought both caesareans and epidurals, and did so with agency to make pregnancy fit into their lives and their understandings of their bodies.

The use of amniocentesis reinforces the medicalised view of women’s bodies as fetal containers and pregnancy and birth as something which must

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18 Rothman (1994: 144) describes a technological society as one in which we ‘apply ideas about machines to people, asking them to be more efficient, productive, rational and controlled. We treat our bodies as machines, hooking them up to other machines, monitoring and managing bodily functions’.

19 Davis-Floyd contrasts this to the ‘holistic paradigm’, which understands the female body as an organic system and birth ‘as an ecological process that can only be harmed by dissection and intervention’ (Davis-Floyd, 1996: 129).
be monitored and interfered with, and just as the women in Davis-Floyd’s study sought out the technology, so too did many of the women with whom I spoke – a variety of women who used amniocentesis with various agencies.

Although women’s use of amniocentesis does fit within medicalised motherhood – it still sits outside the dominant ideal of motherhood and the stories told by the women worked to justify their actions in having amniocentesis. Just as Price’s research (1987, cited in Garro and Mattingly, 2000: 25) found that stories of illness conveyed the message, ‘I did the right thing’, so too did these women’s stories, and in a number of ways. First, some stories, such as Susan’s, explicitly communicated this, for instance, Susan recalled becoming upset during the procedure and felt that, ‘I knew if I’d gone out of it and I hadn’t had it [the amniocentesis] done that I wouldn’t have felt that I’d done the right thing’. Other stories implied that the woman had done the right thing by emphasising that they would have amniocentesis again; Diane, for instance, stated ‘I’d do it again, definitely if I became pregnant again because it’s something for my own peace of mind’. In fact all of the women (excluding Shona who stressed that there was no possibility that she would become pregnant again) indicated either directly, or in response to my questioning, that they would have amniocentesis again.

Jerome Bruner (1990) has argued that ‘to tell a story is to take a moral stance’ (cited in Rice and Ezzy, 1999: 126). In the context of the ethically complex reproductive technology of amniocentesis, the women telling the stories of their experiences certainly were taking moral stances. The women justified their use of amniocentesis through placing emphasis on the reasons why they themselves used the technology and they sought to tell convincing stories. Garro and Mattingly (2000: 11) note that ‘to tell a story is to seek to convince’ the audience ‘to see some part of reality in a certain way’, and Rice and Ezzy (1999:119) assert that narratives convince through ‘gripping drama and believable history’. This was the case in a number of the stories; and some women were more ‘convincing’ than others in compelling me to see their reality of why they had amniocentesis. While the overriding gain the women felt they received from the amniocentesis was a feeling of reassurance that their baby was fine; they also gave additional reasons which fitted into

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20 Gergen and Gergen (1988:20) identify narratives as symbolic systems that are used for social purposes, such as; justification, criticism, and social solidification.
three categories: ‘I did it for me’, ‘I did it for my family’, and ‘I did it for the fetus/baby’.

‘I did it for me’: Diane said that she had the amniocentesis, ‘because I wanted to make sure I didn’t have a Down’s syndrome [baby]’. Diane felt that having a child at an older age would be hard enough, and having a Down syndrome child would be ‘just like hard work’. However, further into the interview Diane commented that the amniocentesis was to prepare her in case anything happened, ‘for peace of mind’, rather than to terminate. Emma strongly asserted that she did not want a child with Down syndrome, and about having a child with Down syndrome, she said, ‘I basically thought well I just couldn’t handle it...it’s an extra pressure you don’t need – if you’ve got a choice’.

Comments such as Diane’s and Emma’s resonated within many of the women’s stories. Statham, (2003: 188) has identified a significant shift in women admitting their own quality of life as an influence of their choices surrounding amniocentesis. Whereas a decade ago women very seldom mentioned their quality of life as a reason, more recent research undertaken by Statham in the UK, has indicated that ‘impact of baby on self’ is a major influence for many women (Statham, 2003: 188).

Within the women’s stories I heard, disability and specifically Down syndrome was seen as something that many of the women felt that they would not be able to handle. Rothman (1993: 243) has argued that in a society with prenatal testing, ‘we ask individual women to look at their individual fetuses, and decide whether this child will be asking too much of her’. The majority of the women who told me their stories felt that a child with Down syndrome would be asking too much or at least a lot of them. In this sense, the women were using amniocentesis and the possibility of selective abortion of an abnormal fetus, to protect their way of life. This implies that if a disabled baby was born, they felt they would bear the burden they believed would accompany the birth, and so entails that support for families with disabled members may be lacking in our society. Rothman (1993:242) has argued that ‘the burden of child-rearing, of all child-rearing, has fallen overwhelmingly on individual mothers’: The level of support a woman
understands she will receive from society surely has some influence on whether she feels ably equipped to cope with raising a disabled child.21

Although I have simplified the reasons given by the women into three categories, the reasons the women gave were complex and situated both within the society in which they lived and the context of their individual lives and life histories. Nina’s explanation of her reasons for having amniocentesis and contemplating an abortion in the case of abnormality illustrates the complexity of the women’s reasoning:

It was mainly due to the fact that I had two healthy children already and the pregnancy was putting strain on my relationship. And I knew having worked with children with disabilities I realised the stress and the added life time commitment they put on a family and I just thought that what I had was really good, and I wasn’t prepared to probably sacrifice that to bring into this world a child with a disability.

Nina’s reasons for having amniocentesis were broad; she called on her past experiences of working with disabled children, looked to her relationship with her husband, and evaluated the worth of her existing family situation.

‘I did it for my family’: Another reason the women gave to validate their use of amniocentesis, was their family. Shona was concerned about specific levels of disability and mentioned spina bifida and Down syndrome as ‘major difficulties’ that would have a big impact on her, her family, and her other children. Jane felt very strongly that she did not want to bring the influences of a disabled child into her family life, and drew on her own childhood experiences of growing up with an older brother who was ‘severely intellectually disabled’. Christine’s reason for having amniocentesis was to alleviate her husband’s concerns as she herself knew that nothing was wrong with the baby. Christine’s reasoning illustrates that amniocentesis can be used by women for purposes other than the results the tests supply. Rather, through the act of having the test itself, Christine worked to satisfy her husband’s ‘need to know’ about the status of the fetus.

21 The invisibility of women’s labour in the home with regard to care of disabled children will be discussed below.
When a woman gave the reason she had amniocentesis as, to benefit her existing family, her actions can be seen as fitting with the dominant ideal of motherhood. She is showing concern for her family and the impact the birth of a disabled child might have on their quality of life.

‘I did it for the fetus/baby’: Only two of the women really discussed the idea that they had the amniocentesis for the fetus/baby. Susan recalled thinking during the amniocentesis procedure, ‘what I’m doing, I’m doing for the baby’. She and her husband were concerned that as older parents if something was to happen to them a child with a disability might be left without enough care and support. Shona expressed concern about the ‘major impact’ that ‘major difficulties’, such as spina bifida, could have on ‘that child’s life and the enjoyment of that child’s life’.

The concept of prenatal testing as beneficence towards the fetus from the mother has been discussed from a bioethics standpoint by numerous authors including, Faden (1994), Alta Charo and Rothenberg (1994), Clarkeburn (2000), and Purdy (2000). Ruth Faden (1994: 90), an academic concerned with issues of law, ethics, and health, has explored the ethics of mothering concerning genetic testing of fetuses. She identifies that within the role of motherhood there is a duty of beneficence towards children, which can be extended to apply to unborn children. This duty of beneficence assumes that mothers exist solely under the dominant ideal of motherhood, and so neglects other diverse realities of motherhood. From this stance Fadan has argued that pregnant women should use genetic testing if it could lead to intervention that could reduce or prevent disability or illness in the child after birth unless the only intervention the testing could lead to is termination and then the moral justification lies with considerations concerning existing children, other family members or oneself (Fadan, 1994: 95).

When a mother of normal intelligence prevents the birth of a child with Down syndrome...they may be legitimately furthering their own interests or those of others in their family or community. They cannot plausibly claim their action is in the

22 Purdy has argued that the debate about parental duties concerning genetic risk and reproduction has been complicated by its focus on prenatal testing and abortion, because of the complex ethical debate surrounding abortion. Instead, she argues that conception can sometimes be morally wrong on the grounds of genetic risk (Purdy, 2000: 123-4).
best interests of the child, who as a consequence will never be born (Faden, 1994: 95).

Bioethicist, Henriikka Clarkeburn (2000), has also discussed parental duties of beneficence towards unborn children and has argued that parents who are at risk of having a child affected by a condition that would cause that child’s life to be worse than non-existence have a duty to use prenatal testing and a duty to terminate an affected pregnancy. Clarkeburn (2000: 403) goes on to state that this does not apply to conditions where ‘the resulting life can be considered better than non-existence’.

The idea of a life worse than non-existence is also discussed by R. Alta Charo (Assistant Professor in Law and Medical Ethics) and Karen H. Rothenberg (Law Professor) (1994) with respects to ‘wrongful life’ legal actions. ‘Wrongful life’ actions are brought by a child against a ‘provider’ of prenatal genetic testing (and in some instances the child’s parents) for failing to give information to the child’s parents about prenatal testing or giving them the wrong results – depriving them of the choice to terminate the ‘affected’ fetus. Through these actions the child asserts that it would have been better off not to have been born than live with the specific condition (Alta Charo and Rothenberg, 1994: 112).

Amniocentesis intersects with ideologies of motherhood in various ways, and Rothman (1993: 6) has observed that the technology has created contradictions for mothers as it, ‘asks women to accept their pregnancies and their babies, to take care of their babies within them, and yet be willing to abort them’. Thus the technology encourages maternal acceptance as conditional ‘pending further testing’ (Rothman, 1993: 7).

Stories that speak: underlying cultural narratives

The stories that the women told me about their experiences of amniocentesis also speak about the cultural stories and discourses of the society in which

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23 Clarkeburn (2000: 402) proposes a condition in which life is worse than non-existence must be a ‘combination of continuous and non-palliative pain and a lack of opportunities to develop a continuous self’. Fadan argues that there are only a very small number of genetic disorders that could constitute a life worse than non-existence, and gives Lesch-Nyhan syndrome, a genetic disease that results in mental retardation, self-mutilation, and renal failure, as one possible example (Fadan, 1994: 93).

24 A ‘wrongful birth’ action is brought by parents against a ‘provider’ for the same ‘misconduct’. The harm in these cases is not that the child was born, but rather than the parents were deprived of their right to be informed of the condition and their right to terminate an ‘affected’ fetus (Atla Charo and Rothenberg, 1994: 112).
they live. Brown (1987: 58, cited in Rice and Ezzy, 1999: 126) has illustrated that narrative theory overlooks the separate analysis of individual identity and society, and rather, through examination of ‘vocabularies of motive and the grammars of interest that are encoded in and realised through various forms of discourse’ leads to a heightened awareness of the ways in which cultural repertoires and discourses shape individuals’ understandings of their experience.

Garro and Mattingly (2000: 24) also refer to the use of narrative in understanding the intertwining of the personal and the cultural:

Narrative becomes a vehicle for the problematic issue of representing experiences and events as seen from the perspective of particular actors and as elements of a cultural account that can tell us something about a social world, however local that world (Garro and Mattingly, 2000: 24).

Although the women’s stories are the individual stories of amniocentesis experiences, they are also cultural stories about the world in which they live. This next section will investigate some underlying discourses present within the stories i.e., the privileged position of science and medicine, amniocentesis as a site of gender negotiations, and the type of children that we want. Disability and choice - also underlying discourses within the women’s stories, will be examined in the following chapter.

The women’s stories about amniocentesis revealed cultural discourses about the privileged position of science and medicine. Science was viewed as positive progress; and this was indicated both implicitly and explicitly. By actually using the technology the women were positioning its existence as something positive. They also referred to the technology in a positive light; ‘to the best of our knowledge with today’s technology the baby was fine’ (Jane), ‘I mean it’s quite a safe procedure I think in this day and age’ (Diane). Some of the women also explicitly referred to the science of amniocentesis as a positive, Susan for instance commented: ‘it’s using technology for good’ and ‘I think it’s really using science for good’.

The women also placed their faith in the science behind amniocentesis and as many of the women felt they would terminate the pregnancy if the results indicated abnormality, a lot was riding on what the results of the amniocentesis told women about their fetus’s genetic well-being. However, the women seemed to place absolute faith that the result from the
amniocentesis would be the truth. ‘The amniocentesis gave us a definitive answer’ (Christine). ‘With the increase of technology, it [amniocentesis] is more accurate than the scans. It gives definite conclusive results doesn’t it, they’re definitely conclusive’ (Nina).

Medicine was also seen as holding a privileged position and the women expressed their faith in the consultants both in terms of knowledge, ‘I think I always value medical opinions’ (Nina), and practice. The women were placed in a physically vulnerable position through the process of amniocentesis – they had a needle inserted into their pregnant wombs by the consultant. As noted in the earlier chapter, Jane for instance, commented, ‘mentally the idea of having a needle stuck in your abdomen wasn’t too flash’, however, the procedure was made acceptable to the woman through placing their faith in the consultant who performed the procedure. Comments, such as, ‘I had quite a lot of faith in him’ [the consultant] (Diane), were typical of the women.

The women’s stories about amniocentesis also revealed discourses about the type of children that they wanted. The women indicated that they wanted children who would be easy and who would fit into their lives. They viewed having an ‘abnormal’, disabled, baby as something that would disrupt their lives, something that was; ‘like tough work’, ‘too much to deal with’, ‘extra pressure’, and ‘added stress and lifetime commitment’. Rather, they sought children who were the opposite, who did not involve those things, children whom they felt they could handle and cope with and who would fit into their lives. This idea agrees with how we generally live our lives in modern society. We live fast-paced lives, and we like the least fuss, complication, and added stress possible – we like things ready made. If something is wrong with a product – we just send it back and get a new one, simple. Is this how we are starting to see our children?

As well as wanting easy children, popular culture analysis (see chapter one) identifies the concept of the ‘perfect baby’ as a prevalent and sought after commodity in society. Some of the women did refer to ‘perfect babies’. ‘I’d rather know if she was perfect’ (Diane), and when looking at her fetus on the ultrasound screen Lynette recalled: ‘I remember thinking, well there can’t be anything the matter with it, it just looks perfect’.

25 This will be further discussed in chapter five.
Murray (1996: 133) has argued that prenatal testing and nondirective counselling ‘grants prospective parents the moral permission to seek a child as near perfect as possible, leaving it to those prospective parents to make their own definition of perfection’. However, he also asserts that this ‘quest for perfection’ is not a new phenomenon, but rather that it has a long history in Western culture, dating back to pre-Socrates Greek philosophy. Despite this long history, the nature of the quest for perfection has changed. Whereas historically, perfection was achieved through religion and the Divine, in more modern times science has been recognised as the ‘means to the ends of perfection’ (Murray, 1996: 133-4).

The perfect baby was not the only term the women used to describe the kind of baby they wanted, and some women specifically rejected the idea of a perfect baby, ‘The thought was not to have the perfect child’ (Shona).

We knew we wanted a...it sounds awful saying good, good isn’t really the word and perfect isn’t really the word either. We wanted an okay baby and to enjoy the pregnancy and enjoy the experience (Susan).

Rather, the type of baby the women wanted was an okay, or ‘normal’ baby; ‘I wanted to make sure I had a normal baby’ (Nina), perhaps the term ‘perfectly normal’ would be appropriate. Press, Browner, Tran, Morton, and Le Master (1998: 56-7) found, in their Californian-based study of 140 pregnant women, that the majority of the women were wanting ‘perfectly normal babies’ rather than ‘perfect babies’. Deborah Kaplan (1994:56, 2000: 133), (an attorney with a disability and an interest in disability public policy) has also identified a connection between the concept of perfection and the notion of normalcy in the context of prenatal testing\(^{26}\). Although the image of the perfect baby was brought up in a number of the women’s stories, generally the women wanted a normal baby - a baby that would easily fit into their lives without the extra, stress, pressure and tough work the women associated with an abnormal child.

Murray (1996) has argued that the attempt to produce children with certain characteristics (in this case normalcy) has an impact on the parent-child relationship. For instance, he argues there are consequences when we

\(^{26}\) The notion of normalcy in relation to prenatal testing will be further discussed in the following chapter.
view our children ‘as carefully and wilfully produced with just the right characteristics’; this rings a chord with one of Susan’s comments:

This baby is something that we very deliberately tried to achieve, we wanted a baby and we pulled out all the stops to have this one, and this little bundle of noise is the result that we did everything. I guess single-mindedly for us we did this (Susan).

According to Murray the consequences of this are a possible shift in the parent-child relationship, moving away from a relationship founded in biology and custom towards ‘more of an acquisition-like relationship’ (Murray, 1996: 135).

A child that is seen to be acquired is a child that is also seen to be a product or a commodity. Taylor (2000:391) identifies that the routinization of prenatal tests, such as amniocentesis, has resulted in concern that embryos and fetuses ‘are being reduced to the status of commodities’. Arguments concerning the commodification of the fetus can be located against other arguments concerning the commodification of the human body and its parts - blood, organs, labour, and reproduction are all aspects of the body that have been identified as commodified in certain contexts.

The role of prenatal testing in the commodification of the fetus can be explored through feminist Emily Martin’s metaphor of reproduction as a form of factory production, in which the doctor is a supervisor, the woman a ‘labourer’ whose ‘machine’ (uterus) produces the ‘product’ (baby) (Martin, 1989: 57). Within this metaphor prenatal testing serves the ‘function of ‘quality control’ on the assembly line of the products of conception, separating out those products we wish to develop from those we wish to discontinue’ (Rothman, cited in Taylor, 2000: 394). This metaphor also reduces women to the status of ‘unskilled reproductive workers, who produce the valued commodities through alienated labour’ (Taylor, 2000: 391).

Although the women identified that they did want babies with certain characteristics, such as normalcy, I believe they would be offended by the suggestion that they might have viewed their baby/fetus as a commodity. Rather, the fact that the women wanted normal babies makes sense – most would want a normal baby if that constitutes a healthy and a happy baby.

27 See Sharp, 2000, for an in-depth discussion.
The stories of the women also served to identify the process of amniocentesis as a site of gender negotiation. All of the women referred to their husbands or partners when talking about their decision to have amniocentesis. A majority of the women simply made a comment, much like Diane's: 'I think he said if I said I didn’t want to he’d have said that’s no problem, he would have been completely behind me' (Diane). These comments suggest that although men may be involved in decisions about amniocentesis, often, it is in a role of supporting the woman in the decision she has made.

However, I will now concentrate specifically on three of the women’s stories, which I consider illustrate some of the more complex gender negotiations that occur around the process of amniocentesis. Christine, for instance, emphasised that she had amniocentesis because:

My husband did not think he would cope with it being a child who had a chromosomal disorder who was going to be intellectually and physically handicapped to a great extreme...the reason I did it was not for myself, I did it because my husband wanted to know – I was convinced the baby was fine.

In this instance Christine worked to reassure her husband’s fears about an unplanned later pregnancy through going ahead with the amniocentesis. Rapp (2000a: 146) understands amniocentesis as a site of gender negotiations and refers to cases where women’s partners have insisted they have the test. Although Christine was not forced to have amniocentesis, she did feel that ‘there was a wee bit of pressure’ for her to go ahead with it.

Shona and her husband had discussed and decided on using prenatal testing before she even fell pregnant. They had agreed that they would probably terminate the pregnancy in the case of the fetus being diagnosed as having a ‘big problem’, such as spina bifida or Down syndrome. However, Shona also identified that she and her husband held contesting views of Down syndrome, and she wondered what would have happened if they had received a positive diagnosis:

I still wonder if we came to the point, because my husband’s had involvement, his mother was involved in IHC and he had a real affinity with particularly Down’s syndrome people and quite enjoyed their company. I know he had no real issues with having a Down’s child, whereas I had some issues with it. So I just
wonder if...we'd came to the crunch, I think he may have wanted to keep it.

Shona later acknowledged Down syndrome as a condition that 'would've caused me to terminate without as much heartache', and a 'grey area' for her and her husband. An implied site of gender negotiations is those 'grey sites' that may exist between partner's understandings and attitudes towards specific conditions, or disability in general. What happens when a couple disagrees on the action they should take after a positive diagnosis? It is possible that such disagreement could intensify the difficulty of such decisions. As many of the women only discussed the decision to have amniocentesis with their partner, contesting views between a couple could reduce a primary source of support for women in such situations.

Nina started her story by telling me about the conflict she and her husband experienced with her third, unplanned pregnancy. Nina felt she did not get a lot of support from her husband when she was making the decision about amniocentesis, and she had the amniocentesis because 'I was really paranoid about having a handicapped child and thinking it would wreck my marriage, and if I had two healthy kids I was lucky anyway'.

Nina found the early pregnancy really difficult and became quite upset during the procedure. However despite the 'traumatic' experience of the amniocentesis, Nina felt that it changed her husband's attitude towards the pregnancy:

> when it was all over we went back to the car and my husband was supportive and put his arm around me and told me that it'd be okay, so that was good...So it was probably the turning point for accepting the pregnancy for him when he saw the baby and probably saw what I'd been through (Nina).

For Nina, the amniocentesis worked, not only as a tool to check the health of the fetus, but also to connect her husband to the pregnancy, especially through the ultrasound image. Rapp (2000a: 147-148) has also identified this ulterior use of amniocentesis by women who are concerned about their partners' commitment to the pregnancy and so seek to engage the partner through the amniocentesis process.

Gender tensions could also exist around amniocentesis in terms of who would care for the disabled child who would often require extra care. Rapp
(2000a: 278) found that the mothers of disabled children with whom she spoke, estimated they spent an average of 25% of their time accessing services for their children. Traditionally women are seen as providing childcare, Diquinzio (1999: 131) has, for instance, identified maternal practice as ‘an instance of caring labour’, and despite a general movement of women into paid employment women are still perceived as responsible for childcare and domestic duties. Mann (1994: 33-4) has described contemporary division of familial labour as unjust; as women are taking on both ‘the economic burdens of their fathers while continuing to perform the traditional domestic duties of their mothers’. Rapp (2000a: 278) identified traditional division of labour in many of the families she visited with a disabled child – in these families mothers had significantly more involvement, than fathers, with the daily maintenance and transportation of disabled children. This leads Rapp (2000a: 279) to argue that ‘The traditional division of labour by gender makes all children, and perhaps especially, disabled children, mother’s work’. As domestic work, such as childcare, is often unrecognised as conventional work (Beneria, 2001) it is possible that the added labour of caring for a disabled child that would fall onto mothers could remain largely invisible.

Stories found, stories lost: missing stories and their absence

The women who told me their stories all had similar outcomes to their amniocentesis experiences, a negative result indicating no abnormality, and they all went on to have healthy babies. While their stories are important and representative of the most common scenario surrounding amniocentesis; the stories of other women, with more tragic experiences are missing. As well as the stories of women who simply refused to have amniocentesis in the first place, the stories of those who suffered an amniocentesis-induced miscarriage, or received a positive diagnosis and then had to choose between either terminating or continuing the pregnancy, are missing from my research. In this next section I have tried to bring out the voices of those who have had those experiences, relying as I do so on the research of others.

Miscarriage due to amniocentesis:

The risk of suffering a miscarriage after amniocentesis is one percent - twice the risk of a miscarriage in a pregnancy without amniocentesis (Kitzinger,
1994: 51), so roughly half of the women who experience a miscarriage after amniocentesis would have experienced one even if they had not had amniocentesis. The information sheet given to the women who had their amniocentesis through Southern Hospital’s Antenatal Clinic, states the following about post amniocentesis miscarriages:

Even if amniocentesis is performed technically correct, [sic] it has a 0.5% (1 in 200 women) chance of causing a miscarriage. If this were to happen it would usually occur in the first 72 hours after the procedure, symptoms to look out for include bleeding and loss of fluid from the vagina or worsening abdominal pain. If you have concern we advise you to contact your LMC [lead maternity carer] or the on-call gynaecology registrar who can be contacted through the hospital switchboard (produced August 2003).

If a woman experiences a miscarriage and then finds out that the result was positive for an abnormality, it is usually viewed as a miscarriage that would have happened anyway.

Although the women in my study did not experience an amniocentesis-induced miscarriage they did make some mention about how they might feel in that situation. Susan was particularly concerned about the possibility of a miscarriage, and took two days off from her physically demanding job to rest after the procedure:

I thought, I’m not going to work and then have to explain to everyone why I’d sooner not do those [physical] things – I’m just not going to do them. I’m going to think about me and the baby and that’s that. I’m taking two complete days off and that was aside from the day I had the procedure (Susan).

Susan told me that if things went wrong and she did have a miscarriage she would ‘never forgive’ herself. However, she felt by taking time off work and resting she did everything she could to ensure that that would not happen. Sharon (whose story is discussed in chapter five) is another woman who was terrified that she would miscarry. Sharon also took time off and rested, even spending a night in the city rather than travelling home in an effort to prevent a miscarriage - an event she described as ‘unliveable’. Susan had experienced previous miscarriages, which could perhaps explain the extent to which she went to prevent a miscarriage. However, several of the other women, including Tania, had also experienced previous miscarriages and yet
appeared to feel less concerned; 'I had had a couple of miscarriages anyway, so you know, if it is going to happen it is going to happen' (Tania). The comments of these women do not tell us much about the actual experience of miscarriage after amniocentesis (or fetal death due to amniocentesis), and I have relied heavily on Rothman (1993) for a glimpse of two women's experiences of this scenario.

Rothman relates two women's stories of amniocentesis-induced or suspected amniocentesis-induced miscarriages. After 'Stacey' (35 and married) had an amniocentesis the results came back indicating that everything was fine. However, she felt that her abdomen looked flatter and she began to bleed on and off. An ultrasound at the hospital picked up only one heartbeat (her own), and after a painful prostaglandin abortion failed, the fetus had to be removed by D&C (Rothman, 1993: 93). Stacey felt that the amniocentesis had caused the loss of her pregnancy:

What I believed happened is that during the amniocentesis the needle went through the placenta, pulling it away from the uterine wall...Probably then the placenta started to disintegrate, and then the fetus died (Rothman, 1993: 94).

'Patricia', (a physician) was another woman who lost her baby following an amniocentesis; she felt angry both at the loss, and at the way it was handled by her obstetrician. Below are some sections from an excerpt of the story she wrote about her experiences:

Our baby was dead. Yesterday's empty sonogram screen and the frightened, blank stares of my obstetrician had signalled her death...I sat frozen in my doctor's office and calmly made plans for today's second trimester abortion. From the numbness of my grief, I whispered, 'It was the amniocentesis'. The obstetrician, who had so eagerly, so cavalierly, so routinely (within minutes of confirming the pregnancy) scheduled me for the amniocentesis, the obstetrician who had so eagerly pursued the prized amniotic fluid despite two punctures and a massive uterine contraction, now turned to me and matter-of-factly pontificated, 'After a medically invasive procedure, it is possible...'. A wave of nausea chilled my body. The prostaglandin suppositories were beginning to take effect, to prepare my body to expel the inert, lifeless tissue within me...The waters would burst, two or three painful contractions would follow; and suddenly, she would pass away from me to lie motionless on the blood-drenched sheets. I would touch the fragility and utter helplessness...where would she go after the delivery? No funeral. No grave. The discarded waste of the pathology lab (Rothman, 1993: 94-5).
**Positive diagnosis: Termination or Continuation?**

Another story that is missing from my research is the story of women who received a positive diagnosis that something was wrong with their fetus. Although women who did receive positive amniocentesis results were contacted through my recruitment process, none responded. After reading the literature about these women’s experiences I can assume that perhaps their lack of participation reflected the very, tragic, emotional and personal experience of that time in their lives. Although only about two percent of women who have prenatal testing will receive a result indicating serious abnormality (Kolker and Burke, 1994:126) their stories are very important as a positive result implies the tragic loss of an imagined healthy baby.

Rayna Rapp (1984:318-19) has written about her experience of receiving a positive result after amniocentesis:

> When Nancy [the genetic counsellor] called me twelve days after the tap, I began to scream as soon as I recognized her voice; in her lab, only positive results (very negative results from a potential parent’s point of view) are reported by phone. The image of myself, alone, screaming into a white plastic telephone is indelible. Although it only took twenty minutes to locate Mike [her partner] and bring him and a close friend to my side, time is suspended in my memory, and I replay the call and my screams echo for indefinite periods. Results are not formally communicated by phone, but with a bit of intervention from our midwives and obstetrician, we learned that a tentative diagnosis of a male Down syndrome fetus had been made. Our fantasies for... our five months’ fetus, were completely shattered.

Statham (2003: 184), who herself terminated a pregnancy after a diagnosis of Down syndrome, has also written about the loss associated with a positive diagnosis. In her own experience she felt as soon as the consultant told her the diagnosis; ‘I lost the healthy baby that I had been expecting, that baby was gone, whatever decision I would subsequently make’. Other women have commented on the sense of a double loss:

> So I have two griefs really: the loss of my Down baby whom I saw on the ultrasound screen and whose heart beat I heard with
sonicaid, and the loss of the fantasy 'perfect baby' we all imagine when we're pregnant (ARC mother²⁸, cited in Statham, 2003: 184).

Statham has emphasised the importance of the sensitivity with how parents are told of the diagnosis as they may ‘relive over and over again the words that were used to them and the way in which they were said’ (Statham, 2003: 186).

In my mind the tape repeats itself endlessly. I can hear the genetic counsellor saying again and again, 'I'm sorry Adrian, I'm calling with some bad news. Are you alone? Would you like to get your husband to the phone?' (Adrian Miller, 39, white medical science writer) (Rapp, 2000a: 220).

However, both Rapp (2000a: 221) and Rothman (1993: 191) assert that there is no 'good way to get bad news'. The next step after being given a diagnosis of fetal abnormality is to decide what to do with that diagnosis. Although a few conditions can be treated in the womb, the majority cannot, and so the decision must be made between continuing or terminating the pregnancy – the majority of women opt for a termination²⁹.

Ending a wanted pregnancy is a multifaceted, complex process, which all the women with whom I spoke consistently identified as a profound loss (Rapp, 2000a: 225).

Rapp (2000a: 223-4), found that the women she had talked to who had terminated an abnormal pregnancy fell into two groups. First, those who more or less knew they would terminate the pregnancy if an abnormality was found, and so decided as soon as they heard the diagnosis. Second, those who worked through the decision process more slowly, eventually deciding on abortion. Rapp makes the point that an immediate and unambiguous decision does not mean that the woman suffered to a lesser extent: 'I feel fine about the decision, I'm fine with it. Nothing could have been more obvious. It's just that my heart is permanently broken' (Donna deAngelo, 38, white homemaker) (Rapp, 2000a: 224).

²⁸ ARC stands for Antenatal Results and Choices and is a UK national based charity that provides non-directive support for parents throughout the prenatal testing process, and also acts as a national voice, representing the views of parents in Parliament, the media, government bodies, and the national health service (http://www.arc-uk.org/welcomepage.htm).

²⁹ Although I was unable to find abortion rates on the basis of prenatal testing results in New Zealand, Rapp has cited local clinical studies in the US, giving a 90-95% abortion rate for the detection of Down syndrome (Palmer, Spencer et al, cited in Rapp, 2000a: 184).
Statham has identified couple’s perceptions about the severity of the abnormality as an influencing factor in decisions to have a termination (Statham 2003: 187-8), however, people do perceive abnormalities differently, and diagnosis is not unambiguous as it cannot determine fetal severity. She has also emphasised that termination is a hard decision, whether it occurs early or later in the pregnancy:

It may have been early, it certainly wasn’t easy. The decision to terminate may be straightforward, but living with it is possibly the hardest thing a woman and her partner will ever have to do (ARC mother, Statham, 2003: 190).

The fact that the termination involves a choice to end the baby’s life has also been identified as an extremely difficult aspect of selective termination:

Because I had a very serious relationship with that child, and to be carrying it around, wondering whether I was going to kill it or not was just very serious, I mean it’s feeling like you’re going to murder something that you’re very close to that’s inside of you, when you have the choice not to, and you’re choosing to, you know you’re choosing the most difficult thing (Margaret Thompson, 34, white psychologist) (Rapp, 2000a: 226).

The actual termination can be performed through two different techniques, either surgically through a D&E or through a process of labour in which the woman delivers the fetus; and although women may be able to choose the technique, it might be determined by gestational age (Statham, 2003: 190). The D&E procedure involves the insertion of specially prepared seaweed (laminaria) into the woman’s cervix 24 hours before the surgery. This works to dilate the cervix as the strips increase with size through moisture absorption, causing mild to severe cramps. The operation is performed either under general anaesthetic or heavy sedation and the fetus is removed surgically and usually dismembered. The operation duration is around fifteen to twenty minutes, and is generally viewed as safer for the woman, but more work for medical staff (Rapp, 2000a: 239).

Termination through a labour process involves a saline or urea injection into the uterus causing the separation of the placenta, killing the fetus; and/or the use of hormonal (prostaglandin) vaginal suppositories
(often used in late terminations)\(^{30}\). Side effects from the prostaglandin can include; fever, chills, nausea, and diarrhoea. Women usually labour an average of ten hours when delivering a dead fetus, and while this method requires less of the medical staff, is more dangerous for the labouring woman (Rapp, 2000a: 238-9).

The issue of fetal remains may be a concern when deciding on which method of termination women use, for instance:

> What decided my mind was no remains, I needed to take home the baby, even in a coffin to bury it properly. I couldn’t live with the idea of no remains, no one to visit in the cemetery (Tamara Levkoutz, 34, white, private school teacher) (Rapp, 2000a: 239).

Statham has brought attention to a number of practical issues around these terminations. The terminations usually take place in hospital either in a labour or gynaecology ward\(^{31}\), however, Statham points out that it can be distressing for women going through the labour of a dead baby to hear the cries of a newborn baby. Some couples can be concerned about what their baby will look like, if they choose to see them: ‘At first I was unsure whether to see him, because I didn’t want to be left with a horrible picture in my mind as facial abnormalities had been mentioned’ (Statham, 2003: 192). Staff can also be concerned if the abnormalities do not seem as severe as the parents expect (Statham, 2003: 191):

> When he took the baby out I immediately said, ‘can I see it?’ And he was a little doll, seven, eight inches long, perfectly formed, a tiny baby doll. He was beet red, and I couldn’t see anything wrong, but the nurse knew, she came forward, she showed me where the signs of Down syndrome were. And then the doctor stepped in and he showed me too. And I think they did it well, so I could be at peace with the little doll of a baby, so I would never think that there had been a mistake (Meeta Carbon, 39, Nicaraguan photographer) (Rapp, 2000b: 240).

Statham identifies that after the termination might be a very confusing and distressing time for couples, especially women, who could be left asking difficult questions, such as: ‘am I a mother or not? Have I had a baby or not? The answers are confusing; there is no baby, breasts are unexpectedly full of milk’ (Statham, 2003: 192). She goes on to argue that women require care after

\(^{30}\) In prostaglandin only induced abortions there is a five percent risk that the baby may be born alive (Rapp, 2000a: 239).

\(^{31}\) In Southern Hospital these terminations would be carried out in the delivery suite.
the termination of a wanted pregnancy, care that 'should acknowledge the
personal nature of parent's experiences and the impact on individual parents
of the death of their baby, and their role in deciding its death' (Statham,

The other option after a positive diagnosis is to continue the
pregnancy. Rapp (2000a) found that those women more likely to continue a
pregnancy after a positive diagnosis were women with; strong religious
affiliations, strong family or community support, or strong reasons through
their reproductive histories. Melissa (35, New Zealander / Maori, 'full time
Mum), for instance, was the only woman I talked to who felt that she would
not terminate a diagnosed abnormal pregnancy under any circumstances32.
Melissa identified her position as strongly influenced by her reproductive
history, which included three previous miscarriages. Melissa felt that those
miscarriages had left her with 'nothing', and she would not be able to
terminate a pregnancy and make that happen again; rather she wanted a baby
to hold 'no matter what'.

The decision to continue a pregnancy after a positive diagnosis is made
less often than the decision to terminate, and in consequence much less has
been written about the experiences of people of this scenario. I will rely
heavily on Statham, et al (2003), and Rapp's (2000a) discussion about women
with disabled children to attempt to draw out what the experience might be
like for some women.

Statham, Solomou, and Green (2003: 166-7) have drawn on the
unpublished findings of Statham and Solomou's UK based longitudinal study
(1996-2001) that examined the experiences of 72 women who had received a
prenatal diagnosis of fetal abnormality and continued the pregnancy. This
research indicated four main influencing factors that most parents considered
when deciding to continue a pregnancy: the severity of the abnormality, prior
attitudes and beliefs about termination, perceived impact (on themselves and
others) of having the baby, and gestational age at the time of diagnosis

32 Melissa's story is located in chapter five.
These following quotes give glimpses into how some parents have felt:

I don’t actually feel like a pregnant person. I feel like I’ve got a baby with a problem’ (Diaphragmatic hernia).

I felt really strange about the baby. I felt like somebody had taken away the healthy baby that I had inside me, and put one there with something wrong with it. It’s a horrible feeling. (Cleft lip) (Statham et al, 2003:169).

Some parents indicated that they found it hard to demonstrate the negative feelings they felt because of the optimism of people around them.

We had people right up to really the end saying, ‘oh, they can be wrong, they can be wrong’. You feel like screaming sometimes you know’. (Lethal chromosome anomaly confirmed by amniocentesis) (Statham et al, 2003: 169).

The need to identify and connect to the baby as not just a diagnosed abnormality encouraged some parents to seek the sex of their fetus:

I rang [consultant] again the next day. I said I would like to know what sex the baby is because... I’d bonded with the baby but I don’t want to think of it as our Down’s baby, I wanted to think of it as him or her’ (Statham et al, 2003: 170).

The authors suggest that ‘uncertainty and anticipation of an uncertain future characterises pregnancy for all parents with a baby with an abnormality’, and parents held various concerns about their future with their baby. These concerns included; ambivalence about the decision they had come to, varied attitudes of partners, the attitudes and reactions of other family members, and their ability to cope in the future. More practical concerns revolved around affording and finding childcare, and the costs of travel and time off work that the baby might entail (Statham et al, 2003: 170-1).

The authors found that parent’s opinions about the advantages and disadvantages of prenatal testing changed over time. Generally, during the pregnancy the advantages of the testing were concentrated on, such as; knowing about the abnormality, having choices, and time to prepare for the birth. However, when the topic was brought up again in interviews roughly

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33 Parents’ quotes are located throughout Statham et al (2003) and it is interesting to note the way these parents have been identified. I have been influenced by Rapp’s style of placing the women into context through their, age, ethnicity and profession. Instead, the abnormality of the fetus is privileged in describing these parents.
a year later, disadvantages as well as advantages were brought up highlighting some interesting tensions, such as: ‘preparation vs. a spoilt pregnancy’ and ‘the opportunity to make a choice vs. the difficulty of having to make a choice’ (Statham et al, 2003: 173).

Another interesting finding was the way some parents, especially mothers, felt that they had lost their experience of the birth, due to the emphasis assigned to the baby’s abnormalities and possible treatment rather than the mother’s birthing experience:

I mean it’s something that was a major, major part of my life, which was giving birth, is taking a back seat to the fact that this baby actually needs a lot of attention as soon as it’s born. (Diaphragmatic hernia) (Statham et al, 2003: 174).

Rapp observes that refusal of a termination after a positive diagnosis is rare, and describes the action as, ‘in effect rejecting the next step in the use of the reproductive technology’ (Rapp, 2000a: 183-4).

Rapp (2000a: 269-272) identifies having a diagnosed baby, specifically a baby diagnosed with Down syndrome as an experience that involves being; medicalised, ‘social-worked’, and networked. From birth, ‘a diagnosed baby is a medicalised baby’, who will see an array of medical practitioners such as, geneticists, paediatric cardiologists, neurologists, and paediatric surgeons. Often, early on, the baby and parents will be ‘networked’ into special education services that involve physical, occupational, and speech therapy (Rapp, 2000a: 272). Down syndrome babies and their parents are also likely to be ‘social worked’, often involving early intervention services bringing up the options of foster care and adoption; although some women do adopt out their abnormal babies, many found the suggestion offensive:

So at first I didn’t want to give her the baby. Who was she? Just some old maid, over 45, single, not what I wanted for my baby. What I wanted for my baby was the whole nine yards: White picket fence, dog, big brothers or sisters. A normal family. Then I realized, that was me, that was my family I wanted. And I couldn’t bear to keep this baby. So who was I to judge her, when she had the heart to take him? (Rapp, 2000a: 285).

Analysis of the stories these women told me, opened various areas to be investigated - aside from the select few that I have concentrated on in this
chapter. These women’s stories also brought up underlying ideas of individualism, how do we understand ourselves as individuals who have rights and choices, especially from the embodied experience of pregnancy when one self encapsulates another? Also the construction of the family, with regards to shrinking size and decreased support, and also as a unit that needs to be protected. These stories about amniocentesis also emphasised the concept of biology as destiny, in a world where our identity is increasingly determined by our chromosomes. In the following chapter I move on to examine the various points of amniocentesis as perceived by the consultants, the women, and numerous social scientists.
4.

The ‘point’ of amniocentesis

in order to count as an acceptable story there must be a point to the story (Gergen & Gergen 1988:20).

if they are absolutely sure they wouldn’t terminate an abnormal baby then there’s not a lot point having the test (Dr Robert - consultant).

I said I’d terminate the pregnancy because he [consultant] said there was no point in having the procedure done if that’s what you weren’t going to do (Nina, 36, New Zealand European, part-time primary school teacher).

Narrative analysis argues that an acceptable story must have a point (Gergen and Gergen, 1988). This point is generally understood as an event which is satisfyingly explained or a point which is made on an informal level and often at the end of the story. Such end points usually hold value and are understood by the audience as either desirable or undesirable. For example, the end point might be a certain character’s good fortune (how I escaped certain death), or a certain character’s ill fate (how I lost my love), and so on (Gergen and Gergen, 1988: 20-21).

A workable story must also answer the ‘So what?’ question. William Labov’s studies of storytelling highlight the central importance of this question to a story, for when a story is finished, the audience must not be left asking why it was told, instead, the story must answer the question ‘So what?’ and furthermore should ‘answer it so well that the question is never explicitly raised’ (Labov 1972, 1981, cited in Garro and Mattingly 2000: 4).

Therefore, if we turn towards the technology of amniocentesis; when we conceptualise amniocentesis as a story, what is the point of the story? As
my argument will demonstrate, there are numerous ‘points’ to the amniocentesis story, and these are viewed differently depending on where the storyteller is positioned. In addition, the story which one person or group tells about amniocentesis (although it may have a meaningful focus to them) might be a story that does not work for another person or group, for them the response to the story is ‘So what?’ This chapter will examine some of the various ‘points’ of amniocentesis, (aside from the physical point of the amniocentesis needle), and to accomplish this will draw on participant observation of four counselling sessions, interviews with three consultants about the counselling sessions, and interviews with thirteen woman who talked retrospectively about their experiences of the counselling session and the amniocentesis procedure to demonstrate the wide variety of ‘workable’ stories which amniocentesis generates. I will also draw upon literature concerning the scientists involved in the process, and the social scientists and observers of the technology, all of whom are located at various geographical, historical, and intellectual positions around the technology itself.

Genetic counselling

Within the rhetoric of choice and nondirectiveness surrounding the counselling sessions at Southern Hospital there exists a persuasive medical narrative that there is no point at all in a woman having an amniocentesis if she is not going to terminate an abnormal fetus. This narrative represents the consultant’s understanding of the purpose of amniocentesis and was derived from my participant observation of counselling sessions, as well as interviews with the consultants and the women. However, before discussing the counselling sessions at Southern Hospital and the findings which I drew from them, it is important to discuss first, the history of genetic counselling and the category of individualised behaviour into which these sessions fall.

Much of the literature on genetic counselling is based in North America, and discusses a system of counselling, undertaken by the specific position of a genetic counsellor, which is quite different from what I have observed in the context of Southern Hospital - where the consultants who perform the procedures also provide the counselling sessions for women and their support people. However, this is not the case throughout New Zealand,
and Susanna Finlay’s research with New Zealand cytogeneticists revealed four genetic associates (genetic counsellors) working in Wellington and her later research found genetic counsellors also working in Auckland (Finlay, 2004: pers comm).

The field of genetic counselling has an interesting history and according to Beth Fine (1993: 101-2) gained its roots from the eugenics movement of the 1900s. She goes on to identify the 1930s as a time of important influence over genetic counselling as it highlighted the area of birth defects as a prime candidate for medical research. This was greatly influenced by the increased control over infectious diseases, which significantly reduced the number of cases of infectious diseases. Consequently, as numbers of those cases decreased, the proportion of children with birth defects increased, encouraging medical attention (Fine 1993:102).

Genetic counselling was originally performed by medical doctors, researchers, and geneticists (who were mostly men), and was an aspect of their job considered ‘not high-status technical work: i.e. ‘just talking” (Rapp, 2000a: 56, Rothman, 1993: 35). Rothman (1993: 35) identifies that as counselling became more widespread in the American context, physicians turned the counselling work over to lower status and lower paid workers, in other words, genetic counsellors. The field of genetic counselling is now dominated by women, who are viewed as especially appropriate for counselling pregnant women, and Rapp (2000a: 56) describes the contemporary genetic counsellor as a ‘gatekeeper between science and social work’.

The career of genetic counsellor requires a professional Masters training degree usually involving two years of study; and although the curriculum is varied, it generally involves education in human and medical genetics, counselling skills, as well as a supervised clinical internship (Rapp 2000a:56-7). Genetic counselling training programs are based in North

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34 The eugenics movement had been widely respected in Western and Latin American countries, until being made unpopular by Nazi activities during World War Two. The eugenics movement sought to convince or force individuals to make reproductive decisions for the 'good of society', the more infamous of these measures were mass sterilisation and the killing of people viewed as ‘unworthy’ to live or reproduce (Kolker and Burke 1994:167-8).
America, the United Kingdom, and Australia\textsuperscript{35}, and training for New Zealand-based genetic counsellors is supervised by the Human Genetics Society of Australasia (HGSA) (Dixon \textit{et al} 1995)\textsuperscript{36}.

The HGSA was formed in 1977 and provides a professional forum for various disciplines collected under the title of human genetics – including genetic counsellors. In 1993 a subgroup, the ASGC was formed, as a professional body for genetic counsellors, which represents the views of genetic counsellors and has a membership of around 100 people, located in Australia, New Zealand, and some countries in Asia (HGSA web page: www.hgsa.com.au/agsc/about.html). Professional bodies, such as the ASGC, assert that genetic counsellors are expected to be; caring, accepting of diversity, unconditional, supportive, educational, and nondirective (HGSA web page: www.hgsa.com.au/policy/asyccoe.html, Leroy, 1993).

Much of the literature on genetic counselling has focused on the ideal of nondirectiveness\textsuperscript{37}, which is generally viewed as intrinsic to the practice of genetic counselling (Rapp, 2000a, Rothman, 1993, Fine, 1993, LeRoy, 1993, and Lappe, 1993). However, is nondirectiveness in genetic counselling even possible? And if so – is it ideal? Although the three consultants I spoke to all felt their counselling was nondirective, I identified, what I believe to be various elements of directiveness during my observations of these counselling sessions: Such elements of directiveness have also been observed by others (see Rothman, 1993). For instance, there have been comments that it is impossible for a counsellor to remain completely nondirective, as the counsellor’s personal beliefs and attitudes may be revealed through nonverbal communication and tone of voice, which can ‘dramatically’ influence decision-making (Fine, 1993:107, Lappe, 1993). Accordingly, Kolker and Burke (1994: 168) argue that ‘genetic counselling by its very nature implies value judgements’. For instance, the vocabulary used in such sessions

\textsuperscript{35}In 2000 there were 28 training programs running in North America (Rapp, 2000: 57). Training programs are also situated in Australia and the United Kingdom. (http://www.gradschools.com/listings/out/genetic_cnsl_out.html)

\textsuperscript{36}In 1995, a report was put forward to the National Advisory Committee on Core Health and Disability Support Services, titled \textit{Priorities for Genetic Services in New Zealand}. This report indicated that the numbers of clinical geneticists and genetic counsellors in New Zealand were inadequate. It was recommended that an optimal national genetic service would have 1.0 FTE clinical geneticist per 500,000 people, and ideally 2.0 FTE genetic counsellors assisting each clinical geneticist (Dixon \textit{et al} 1995:16).

\textsuperscript{37}Kolker and Burke (1994: 167-8) argue that the stress genetic counselling places on nondirectiveness stems from a desire to distance itself from the ‘abuses’ of the eugenics movement.
includes words like 'abnormality', 'defect', and 'recurrence risk' – all terms that (according to Nance (1993)) connote a value stance\(^{38}\) (cited in Kolker and Burke 1993:168).

However, although 'good' genetic counselling has traditionally and fundamentally been viewed as nondirective, there have been some calls for this to be re-evaluated. Shiloh (1999:86), for instance, identifies that nondirectiveness results in counsellors denying advice to the common calls for guidance from those they are counselling. She notes that this denial of advice can hinder the counselling relationship, and refers to an argument by Deci and Ryan (1985), who suggest that in some situations people might not want to be in control of their 'choice'. This was certainly true for at least one woman interviewed for my research, Nina (36, New Zealand European, part time primary school teacher), who complained that being told it was her 'choice', was 'not really what I needed'. Instead, it is also important to acknowledge that self-determination, and personal choice, can include the choice to 'relinquish control' to another person (Deci and Ryan, 1985, cited in Shiloh 1999:87). Kolker and Burke (1994: 45), argue that instead of 'condemning directiveness, it might be more productive to debate what permissible directiveness is and what is impermissible'.

After reading this literature on genetic counselling and prior to my participant observation of several counselling sessions, I had held several assumptions about what these sessions would entail. Basically, I had believed that they would be taken by a genetic counsellor, or a person trained in counselling this particular group of women. I had also believed that these sessions would be nondirective, and quite scripted - not that they would not cater for the individual woman - but that every woman would be told the same information. This, to my great astonishment, was not the case. While I observed a strong rhetoric of nondirectiveness throughout all the sessions, underneath this I perceived what I believe were elements of explicitly directive counselling. The counselling sessions I have come to understand

\(^{38}\) A 'forced choice' questionnaire (Abramsky and Fletcher, 2000) indicated that people found; the term 'abnormality' more worrying than 'a variation from the usual', a condition that had the word syndrome or disorder attached more worrying that one without, a technical word, such as trisomy, more concerning than the less technical description, such as an extra chromosome, and a proportion (1 in X), more worrying than the corresponding percentage (Abramsky, 2003: 74-5).
were used by the consultants to shape an acceptable story of prenatal testing, a story with a point.

Participant observation of four counselling sessions

I observed four amniocentesis counselling sessions at Southern Hospital Antenatal Clinic between July 29th and September 15th, 2003. Three of these counselling sessions were with women considered 'high risk' due to their maternal age, and one 'high risk' due to a previous pregnancy of a chromosomally abnormal fetus. By coincidence, each of the counselling sessions was taken by a different consultant. This could have influenced my overall impression of these sessions, which was that they were all quite unique. One consultant actually referred to this, and talking to me after I had sat in on his session, commented, 'so that was my spiel, we all have our own spiels, and I alter mine depending on the individual woman'. Such an idiosyncratic working style has been noted to be typical of hospital consultants - they all get to do it differently (Fitzgerald, 2004).

During my observations at Southern Hospital the receptionist would inform me when the counselling sessions were scheduled. I would arrive approximately fifteen minutes early, indicate to the midwife that I had arrived, and wait in the waiting room. She would then ask the woman when she arrived in the clinic if she would mind an interested social science student observing, and each woman whom she asked agreed. This next section turns to my observations of the four counselling sessions, and is based on my field notes of each of the sessions.

There were two specific things that I expected to hear in each of the counselling sessions, which I did not. I expected the women to be told that although amniocentesis indicates whether the fetus has, or does not have a chromosomal abnormality; it cannot tell her how severe that abnormality might be. For example, the physical and mental disability of Down syndrome can range from mild to severe (Rapp, 2000a: 188-9). I also expected the women to be told of the risks of amniocentesis aside from miscarriage. Placental separation, fetal injury from the needle, and fetal deformities, such as club foot, are all risks of amniocentesis, and despite their minimal numerical risk, I had assumed they would be brought up during the counselling session. In fact these risks were not brought up during any of the
four counselling sessions I observed, and in one session where a woman’s husband asked if there were any other risks aside from miscarriage; he was told specifically ‘no’.

**Amy and her story:**

Amy’s was the first counselling session I observed - she is a 36 year old teacher who was twelve weeks pregnant at the time of the session. As Amy’s appointment was outside the visiting hours she was ‘buzzed’ into the obstetrics/gynaecology ward through an intercom.

![Figure 8. The counselling room.](image)

Amy’s session is a prime example of a major theme I picked up in most of these sessions; there was an explicit rhetoric of nondirectiveness framed in the language of individual autonomous choice. Amy was told by the consultant, for instance:

[consultant] This is a very personal decision and it’s also a very tough decision.

[Amy] Yes, it is.

[consultant] We used to recommend procedures for women, but not anymore. Now it is your decision, again, it is a very personal
decision, but we will support you in whatever decision you make.

However, underneath this explicit rhetoric of self choice, there was a covert and pervasive directive aspect to the counselling session, in which the consultant sought to shape what was to be Amy’s story into an ‘acceptable’ story that would include the screening of her fetus for abnormality.

After the consultant had told Amy about her possible risks of Down syndrome due to her age, he went on to discuss her options:

[consultant] There are two possible pathways that you can take; either screening or diagnostic testing. The first pathway is a screening test that measures the thickness of the nuchal fold at the back of the baby’s neck through a scan. Now this does not give you a definite answer, instead the thickness of the nuchal fold and maternal age are considered and you get a percentage of the possible risks of abnormality. The other path is a diagnostic test – amniocentesis, which gives you a definite yes or no answer, although there is a risk of miscarriage.

[Amy] That would be my worst fear.

The consultant emphasised that only two pathways could be taken by Amy, either a screening test or a diagnostic test - the option to do nothing, to have no testing or screening was not brought up at all. From repetitions of this scenario I have come to the conclusion that such a decision – to do nothing – is not considered by any of the consultants to be an acceptable story.

The directiveness of this counselling session was made especially clear near the end of the session, when Amy made her decision:

[Amy] I think I’ll go with the screening test.

[consultant] Okay, how about we see how that goes and what the estimated level of risk is, if it is low then maybe leave the amnio, but if it is high then maybe go with it.
From this perspective, the nuchal fold test, which does not indicate a certain diagnosis, but rather a recalculated numerical risk, is a ‘catcher’ of women who choose not to go ahead with the amniocentesis immediately. It is presented as a no-risk, non-invasive alternative, however, if a woman’s re-estimated risk level is high, then the amniocentesis decision will be revisited.

Beth and her story:

Beth’s counselling session was taken by Dr Jim and as she and her husband had come from a town four hours drive away to have the test; her counselling session was booked for 3.00pm and the amniocentesis procedure for 3.30pm. I am going to concentrate on two interactions within this counselling session; first around the medical narrative and second centred on Beth’s use of the nuchal fold test. Both interactions illustrate how the counselling session can be used by the consultants to fashion ‘acceptable’ amniocentesis stories.

The medical narrative that there is ‘no point’ having an amniocentesis if you would not terminate an abnormal fetus came up quite early in the counselling session:

[Dr Jim] What we need to know is what you would do if you found out your baby would have a chromosomal abnormality?
[Beth ] I would abort.
[Dr Jim] Ok, because there is no point putting the baby at risk, if the information is not going to change anything.

In my analysis of this episode I argue that Dr Jim is fashioning an acceptable story, he checked that Beth would ‘correctly’ abort her pregnancy if the results were positive, and then emphasised that there would be ‘no point’ having the procedure if she would not do this.

Near the end of the session Dr Jim flicked through Beth’s file and noticed that she has already had a nuchal fold test.

[Dr Jim] You have had the nuchal fold test?
[Beth ] Yes.
[Dr Jim] Do you realise that your results indicate that you have a really low risk, only one in 986?
[Beth] Yes.
[Dr Jim] Ok, that is a really low risk, if this result was not going to reassure you why did you have it done?
[Beth] The doctor...it was easy.
[Dr Jim] Yes, but you have put yourself under extra distress, if these results were not going to reassure you, there was no point having it done. Some women would see this result and decide there was no reason to have the amniocentesis, as it causes a risk, of miscarriage, when the risk of an abnormality is low.

Dr Jim continued, saying that he is not trying to convince her not to have the test.

This interaction in the counselling session left me with the sense that Beth had been reprimanded. Dr Jim’s frustrated reaction to Beth’s nuchal fold test could be understood as his frustrated reaction to a story he does not see as making sense, a story without a point. The same way that he views there being ‘no point’ in a woman having an amniocentesis if she will not terminate an abnormal fetus; there is ‘no point’ in a woman having a nuchal fold test if a low risk result will not reassure her. This was one of several instances when it appeared that the consultant and the woman were talking at each other, but were each involved in different conversations or stories. The consultant’s story was centred on his view of the ‘rational’ use of the nuchal fold test. While Beth’s story appeared to be centred on her individual use of the nuchal fold test, which she had undergone because her doctor had described it as easy and non-invasive. She had received a low-risk result, and this result, and her experience of the nuchal fold test did not appear to have distressed her. As I observed these counselling sessions, I was aware on several occasions of conversations or stories that appeared to by-pass each other. This could be influenced by the complex process of communicating with a ‘lay’ person, once one is trained in medicine39.

39 Byron J. Good and Mary-Jo Del Vecchio Good (1993: 89-98) write about the complex process of learning medicine and the way that medical students learn another way to see things, and another language in which to communicate. It is this process of communication in different languages where conversations can take place between two people, but actually on completely different levels. Each person is telling a story that makes sense to them, but does not make sense to the other.
The literature has many examples of a medical professional reprimanding someone, usually a woman, with regard to prenatal testing. Rapp has described an occasion where a 40 year old woman gave birth to a baby with Down syndrome. The woman’s doctor was angry with her; he had assumed that she had had an amniocentesis and yelled ‘how could you let this happen, you’re forty’ (Rapp, 2000a: 263). I understand these as reprimands for people not following a ‘medically rational’ course of action - for people having a story without a point. This consultant reprimanded the woman because he thought for her story ‘to be rational’, then at age 40 she should have had amniocentesis, and aborted an ‘abnormal’ fetus. Although Beth’s consultant reprimands her to a lesser extent, it appears to be for similar reasons - Beth’s story does not make sense to Dr Jim; it is a story that does not have a point. He thinks it rational that she have the nuchal fold test only if ‘good’ results would reassure her, and he thinks it rational that her results, indicating a ‘low risk’, should be enough reassurance not to have an amniocentesis. Dr Jim uses the counselling session to try and shape, out of Beth’s story, a story that he can understand.

Despite some of the comments I have already made about these counselling sessions it is important to recognise that the women themselves have agency. Just because I might view the consultant as directive, or question some of their comments it does not mean that these comments changed the woman’s decision. The terms of ethical approval for my study did not allow me to interview women whose counselling sessions I had observed to discern what their decisions eventually were. For instance, Beth may have come to the appointment with a strong opinion, and have gathered information about amniocentesis, and her decision might already have been made, and remained uninfluenced by the consultant.

40 Differing views of Down syndrome will be discussed later in the chapter.
41 Although I know that Beth did undergo amniocentesis as I observed the procedure immediately after the counselling session, I do not know what the results of the procedure were and I was not able to interview her to talk to her about her experiences.
42 I wonder if this had anything to do with her experience as a nurse, perhaps coming into contact with a number of severely disabled people. I relate this to my mother who spoke to me when I first became interested in amniocentesis in my third year of study – a time when I was thinking quite negatively, having done quite selective readings on the topic. Mum, who has trained as a psychiatric nurse, said that she would have used it for a late pregnancy. She related her opinion to her experiences nursing at Cherry Farm in the 1980s. She said, that some people spend their life banging their head against the wall and screaming, and that is not a life she would want for a child of hers.
**Cat and her story:**

Cat is under 35, and has a healthy fifteen month old daughter and was eleven weeks pregnant at the time of the counselling session. Prior to having her daughter she had lost a female fetus diagnosed with Turner’s syndrome at 21 weeks. Both Cat’s mother and her daughter attended the counselling session. Cat’s experience of Turner’s syndrome had been severe - she told me that due to problems with Jane’s kidneys, she would not have survived the womb.

I will concentrate on two excerpts from my field notes about Cat’s counselling session. After discussing the current pregnancy the consultant mentioned screening:

[consultant] So you have had an amnio before and talked the risks over with a consultant?

[Cat] Yes, I had it with this one [indicating her daughter], because we found out it was a girl we checked for the Turner’s syndrome. I’d like to do a scan for sex again like we did for this one, for the Turner’s.

[consultant] Okay that is fine. There is also a new screening scan now – the nuchal fold test, which checks the thickness at the back of the baby’s neck and screens for chromosomal abnormalities.

[Cat] That is the first thing we noticed with Jane, she had a big fluid sack at the back of her neck.

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43 Turner’s syndrome involves missing the second sex chromosome, resulting in the fetus developing as a female with only one X chromosome. Turner’s syndrome can involve a constitutional abnormality, in which every cell in the body is affected, or a somatic abnormality in which only certain cells or tissue is affected. The somatic abnormality is a mosaic form of Turner’s syndrome, and those who have it are likely to be less severely affected than those with the constitutional version. Although it is commonly thought that individuals with this syndrome are intellectually disabled, this is not usually true. However there are a wide variety of associated physical problems, such as kidney problems. Girls with a constitutional abnormality of Turner’s syndrome are usually very short and do not generally develop secondary sex characteristics without hormone treatment (Rothman, 1993).

Kolker and Burke (1994: 9) use the prenatal detection of Turner’s syndrome to highlight what they view as a ‘problem’ with prenatal testing. The problem being the ability of prenatal tests to identify conditions that only cause mild disabilities, such as Turner’s syndrome, and as the pertinent questions: Which fetuses should be aborted? And who is to decide?

44 Cat named her baby/fetus whom she lost (this is not the real name).
[consultant] We could try to do the screening test a bit later and try to sex the fetus at the same time – but the nuchal fold has to be done at another clinic.

[Cat] That’s fine.

[consultant] And if they can’t sex it up there then you can come down here and do it a bit later.

[Cat] Okay.

[consultant] So if you want to go ahead with that I could book an appointment for you right now if you want?

[Cat] Yes, that would be great.

During this interaction I felt that the consultant did not fully explain the nature of the nuchal fold test, before he booked it for Cat. Nuchal fold tests are quite ambiguous, they do not indicate ‘yes or no’ the fetus has or does not have a chromosomal abnormality, rather the levels of risk are simply recalculated which, as already mentioned in chapter one, can lead to false positives or false negatives.

This counselling session also included aspects of what I observed to be miscommunication between the consultant and Cat. The consultant commented:

[consultant] The nuchal fold test picks up a variety of chromosomal abnormalities and also screens for Down’s syndrome.

[Cat] Oh no, Down’s is not an issue for us – it’s just the Turner’s.

[consultant] Well actually, all women do have a risk of having a Down’s syndrome baby, so it is in the big picture.

This interaction was another example where the consultant and the woman appeared to be speaking in different conversations – telling different stories. Yes, they were both talking about what the nuchal fold test picks up, but their understandings seem to by-pass each other. Cat could have meant a number of different things by her response. I took the consultant to understand her as saying that Down syndrome is not an issue for her because she is under 35. However, she could have quite easily meant that Down syndrome is not something that she is concerned about screening against. She had come to the
counselling session bringing her past experiences of a fetal chromosomal abnormality with her. She had experience with Turner's - it was her main concern. Cat said that Down syndrome was not an issue for her; but she was told the opposite. Again I argue that what I observed was the consultant seeking to shape an acceptable story for Cat, one which included the diagnosis of Down syndrome as a potential problem to be alert for.

**Dana and her story:**

Dana is 36 years old and was twelve weeks pregnant at the time of the counselling session and she has a healthy four year-old daughter. Her husband also attended the counselling session, although he arrived late as he had trouble finding the clinic. The consultant was joined by a specialist halfway through the session. After Dana agreed for me to observe the counselling session, we sat in the waiting room together for about ten minutes. During the wait she told me a bit about her situation:

> [Dana] I am thinking about maybe having amniocentesis because of my age – I am 36, but I'm quite anxious about it because we've been trying to conceive for two years now. We actually had started to think about IVF, and had a meeting with a specialist about that course of action - when I found out I was pregnant.

![Figure 9. The waiting room.](image-url)
[Willow] Is this your first pregnancy?

[Dana] No, I have a four year old daughter, and I’m worried because she is so excited about getting a new baby brother or sister and I just wouldn’t know what to tell her if things went wrong.

(The complications of biomedical testing for the social configuration of pregnancy have been well explored in the book, *The Tentative Pregnancy* by Rothman, [1993]).

I again want to concentrate on two aspects of the counselling session. First the consultant gave Dana a lengthy description/explanation of chromosomes, paying much attention to trisomy 21 (Down syndrome) and how it differed from ‘normal’ chromosomes. This carried on for some time and was a very complex scientific description. Although I hate to admit it, within about two minutes I had completely lost any connection to what the consultant was saying - it sounded as if he was speaking a different language; I missed the point of this story entirely. This influenced me to focus fully on Dana, who unlike me, appeared to be following what the consultant was saying very well. She leaned forward in her seat, and nodded her head and interrupted when she had a question. This was an occasion where the consultant and the woman were having the same conversation – sharing the same story, but it was one which by-passed me, the observer.

Despite Dana’s apparent comprehension of the consultant’s communication of complex scientific processes; this conversation highlighted the important, and sometimes ambivalent communication of science. Amniocentesis involves the understanding of complex processes: Although the procedure itself may sound simple; the amniotic fluid is removed, tested, and then you are given a result, understanding the procedure involves (as I mentioned earlier) another way of thinking, speaking, and seeing (Good and Good, 1993).

Halfway through the consultation Dana’s husband was shown in by the midwife and near the end of the session a specialist entered and introduced himself. Both Dana and her husband (‘Vincent’) asked a number of questions during the session:

[Vincent] What are the different degrees of Down’s syndrome?
[consultant] Well, they can range from mild to moderate intellectual handicap, some physical handicap and more chance of leukemia and congenital heart defects.

[Vincent] Are there any other risks from the amniocentesis aside from miscarriage?

[specialist] No.

[Vincent] Well in England I remember cases of babies being born damaged from the needle – with a needle stuck through the head and so on.

[specialist] We use ultrasound to guide the procedure, and yes problems have occurred but this was when earlier amniocentesis was introduced. Because of the problems they have shifted it back to fifteen-sixteen weeks.

Later in the session Dana also asked a number of questions:

[Dana] How about the timing, do you have to choose either amnio or the nuchal test?

[specialist] No, we could organise a nuchal fold for next week, the results would take roughly a week and then there is still time to do an amnio if you would like.

[Dana] Well, how many amnios do you guys do? What do most women choose to do?

[specialist] While we do quite a few amnios, the introduction of the nuchal fold test has created a trend towards women using the new test – and it is often used to help women make a decision about amniocentesis.

From my prior conversation with Dana in the waiting room, I understood she and her husband to be an academic couple. Perhaps this influenced the level of comfort or self confidence the couple had in this situation, because they were the most engaged with the counselling session out of all the sessions that I observed.

The couple left the session without having made a final decision, and were given the consultants’ pager numbers and told to page them in the next
couple of days with their decision. I left the Antenatal Clinic about five minutes after the couple and on going through the ‘buzzer’ door met Dana coming back through, ‘we decided to have the nuchal test’ she told me as she walked past, on her way to inform the consultants of their decision.

These counselling sessions highlighted instances of what I believed to be miscommunication between the women and the consultants and influenced me to question whether they might tell different stories about these counselling sessions and perhaps different stories about the point of amniocentesis itself. The following section of the chapter will focus on the interviews with three of the consultants, and attempts to broach some of these issues.

The consultants discuss the ‘point’ of amniocentesis

The interviews, which I subsequently undertook with the consultants further highlighted, the ‘role’ of the consultants’ in shaping an acceptable story. The medical narrative concerning the ‘point’ of amniocentesis was present during all the interviews with the consultants, however to different degrees. Dr Jim placed the most emphasis on the medical narrative, repeatedly stating in various ways that there was no point having amniocentesis if a woman would not terminate an abnormal fetus:

I mean if the mum will...keep the pregnancy whatever, the procedure is worthless; you can’t take an invasive test that may cause a problem, without being prepared to act upon the result, for the sake of knowledge, this is not really right; if you’re not prepared to change the management of your pregnancy, if you have a baby with chromosomal abnormality, I don’t think this is for you; I find it unreasonable to do any test without being prepared to act upon the result (Dr Jim).

Dr Jim could also been seen as fashioning an acceptable story of amniocentesis through placing a strong moral judgement on the use of amniocentesis in an ‘unacceptable’ way. Having amniocentesis in a situation where a woman would not terminate an abnormal fetus would be; ‘not really right’, ‘unreasonable’, and render the procedure ‘worthless’.

Despite this strong emphasis on fashioning an acceptable story of amniocentesis, Dr Jim also stated that it is the woman’s choice. ‘But if she still
wants to have it, that’s fine. I mean you can’t choose for people’ (Dr Jim). However this rhetoric of choice was still embedded within disapproval of a story that would include a woman having an amniocentesis and then not terminating an abnormal fetus. ‘I can’t really choose for people, but I wouldn’t advise it’ (Dr Jim).

The medical narrative was also present in Dr Robert’s interview. Although he did not seem to emphasise the narrative as strongly as Dr Jim, he was certainly aware of it.

If they are absolutely sure they wouldn’t terminate an abnormal baby then there’s not a lot of point having the test; The point [of amniocentesis] is, the point is to make a diagnosis of the baby’s chromosomes... I think the general idea is that they can then terminate the pregnancy if the result is abnormal (Dr Robert).

Dr Robert also presented this narrative within a rhetoric of choice, ‘it’s a choice thing’; ‘it then gives them the information to make a decision on what they would do’. However, this rhetoric of choice is presented differently to Dr Jim - Dr Robert did not place moral values on doing the ‘wrong’ thing. Instead, he mentioned that in some cases women do have amniocentesis and then keep an abnormal fetus and actually gave a reason for this.

I think the general idea is that they can then terminate the pregnancy if the result is abnormal, but not everyone will do that; There are a small group of women that would like to have the test so that they would know, so that they could prepare themselves. And that’s again their choice.

The medical narrative of amniocentesis was also present in Dr Paul’s interview, although on a different level. Consider the following interview extract.

[If] you’re looking for an abnormality and that couple feels they would terminate the pregnancy if the baby’s abnormal I see it in a bit of a different light than someone just wanting to know yes there’s a high risk, they’re not going to do anything about it...In that case I would like the risk, the threshold, to be a little bit higher.

So what if a woman was like, I want an amnio to know in terms of preparation for the family so that they know if it’s going to be a Down’s baby. Would you think that was a good enough reason?
Yes. No it's quite acceptable for them. It's just you know you would, personally I would like to, but the threshold of actually doing amnio is just a little bit higher in that situation. You know you wouldn't want to take risks too often. Do you understand what I am trying to say?

*So you would want there to be quite a high risk that there could be an abnormal fetus?*

Yes that's it. The chances need to be a little bit better before you'll take that risk of the amnio just to know. But in principle it is an acceptable reason for me to do it.

Although Dr Paul's interview was not as explicit as the others, aspects of the medical narrative were present. Dr Paul views a couple terminating a pregnancy if the baby is abnormal in a different light than 'someone' just wanting to know. I think that Dr Paul views the latter as problematic, although he does not quite put his finger on it; he knows that he feels differently about this situation.

The way he explains this is very interesting. I interpret that if he were to do an amniocentesis 'just to know', he would like there to be a higher chance that the fetus would have an abnormality. Why is this? Is it so that there is less chance that a normal fetus could be lost by an amniocentesis-induced miscarriage? Something is inferred by Dr Paul, which I think is consistent with all of the consultants; and in fact is central to the medical narrative. It is a value judgement on the use of amniocentesis; just wanting to know about abnormality does not have as much moral worth as terminating abnormality. This speaks volumes about 'abnormality' – it is something to be terminated. The terms 'normality' and 'abnormality' flow freely in the counselling sessions and in discussions about prenatal testing; however attached to these terms are significant moral values; what constitutes potential personhood and what does not.

The counselling sessions are used by the consultants to shape an acceptable story of amniocentesis that has a point, and from the consultants' perspective this is about reducing the risk they feel they are susceptible to
through performing the procedure. The medical narrative that there is 'no point' having an amniocentesis, if a woman would not terminate an abnormal fetus works to endorse this action as the 'right' option for women who undergo the testing. However, I do not wish to imply that this medical narrative that was present in Southern Hospital's Antenatal Clinic is uniformly present everywhere amniocentesis is performed, rather, it is influenced by the local context in which the procedure is performed (see Good, 1995).

Global versus local stories on the point of amniocentesis

Biomedicine (cosmopolitan or western medicine) is a globalised, international phenomenon that is cultivated through an international political economy of bioscience, and by an international community of educators and bioscientists. However it is also ‘taught, practised, and consumed in local contexts’ (Good, 1995: 461). Good provides examples of how local contexts can influence biomedicine:

When professional prestige among medical practitioners in settings such as American teaching Hospitals is measured by the competent use of the most advanced, often 'experimental' biotechnologies, when an esteemed Korean professor of medicine proudly documents his competence in terms of the three hundred patients he sees a day, when a young Peruvian physician has limited antibiotics and scarce resources and thus requires his two hundred patients per day to mention but one symptom...the brute facts of local practice and political economies defy any reified analysis of 'biomedicine' (Good, 1995: 461).

Good asserts that even when biomedicine is compared in societies that have similar wealth and biomedical interests there are still significant differences; such as in definitions of 'competent or good doctoring', practice patterns, and standards of clinical care. Good uses the example of clinical narratives (such as the medical narrative concerning the point of amniocentesis present in Southern Hospital) that 'doctors generate for and with patients about diagnoses, disease course, and treatment'. These narratives are described as 'routinely framed by local cultural assumptions about how physicians should shape patient experience' (Good, 1995: 461-2).

45 The consultants' concerns about the riskiness of amniocentesis are discussed in chapter five.
Biomedicine is influenced by local culture and political economies; and is socially and culturally situated rather than a singularised body of knowledge and practice (Good, 1995: 462). This applies to amniocentesis; so that while the purpose of amniocentesis in Southern Hospital may be illustrated by the prevalent medical narrative – the point of amniocentesis could be understood in a variety of different ways internationally and within New Zealand.

Rapp (2000a: 13) argues that the practice and impact of, and attitudes towards amniocentesis, are ‘simultaneously globalized and localized’. Globally, there appears to be a consensus as to how genes should be described and the technology is available basically worldwide. The local influences the extent of the technology’s use, and the social implications of that use, and Rapp goes on to highlight some differences in the practice of amniocentesis internationally. Rapp (2000a: 32-3) identifies that apart from the US, most Western developed nations have a national health policy, which has influenced a number of aspects relating to the provision of the procedure; including recommended age, cost efficiency, and the directiveness or neutrality of the counselling around amniocentesis. The US, where the ‘decision to have or reject the test, and to continue or end a pregnancy should a serious fetal disability be diagnosed are, in principle, sacrosanct’ is contrasted to practices in England, Germany and Hungary. In England a study of obstetricians by survey revealed that three-quarters ‘required women to agree in principle to terminate an affected pregnancy before they perform the amniocentesis’. In Hungary and Germany directive counselling is quite acceptable and while a woman may change her mind, any response to a ‘positive diagnosis’ beside abortion is seen by medical administration as ‘a waste of scarce national medical resources’ (Farrant, 1985:113; Wertz and Fletcher, 1987, 1989a, 1989b, cited in Rapp, 2000a:33).

Generalisations have been made about the point of amniocentesis in the West compared to the ‘Rest’. Whereas, in the West, amniocentesis appears to be primarily used to prevent the birth of a disabled baby – in some countries, such as Korea, Taiwan, China, amniocentesis (and similar technologies) are also used to prevent the birth of a female baby (Bubeck, 2002: 217, Kumar, 1992). Social pressures, such as the one child policy in China and the (now illegal) practice of bride burning in India, influence this
which, as previously argued, fits into the ‘darker’ side of motherhood. Wertz
and Fletcher (1992: 241) relate sex selection to selection on the basis of
disability and argue that in the background of sex selection there is a:
‘popular desire for the perfect, tailor-made child...for some, control over the
child’s sex seems a logical extension’ (Wertz and Fletcher, 1992: 241).

The medical narrative, which serves to fashion an ‘acceptable’
amniocentesis story with a point, is present in some of the women’s stories in
a number of ways; they are aware of it, they reject it, and also incorporate it
into their own narratives. Some women seemed to be aware of the
pervasiveness of the narrative; ‘I really felt that they kept saying, you know, if
the abnormality arises – then there’s a termination’ (Nina, 36, New Zealand
European, part time primary school teacher); ‘It was sort of made clear to me
that possibly if I went through with it and didn’t have a termination that I
could be sort of, almost time-wasting’ (Christine, 38, New Zealand European).
Other women rejected the medical narrative – they would not necessarily
terminate the pregnancy if the results showed an abnormal fetus. Jane (38,
New Zealand European/Ngai Tahu, Dentist) stressed what a difficult
decision it would have been if she did decide to terminate the pregnancy, but
‘fortunately I didn’t have to even get to that point’. Jane saw the procedure as
involving two steps; the first being the decision to have the amniocentesis:

I didn’t want to think beyond that step, you know I didn’t want to
think of the consequences of, you know, if we had any feedback
that we were going to have to make some decisions on. It was
enough to, emotionally, choose to have that test done and then I
thought well I’ll face the next step when and if we come to that
(Jane).

Melissa (35, New Zealander/Maori, ‘full time Mum’) was aware of the
medical narrative, but rejected it for herself; she recounted her specialist
asking ‘if you’re going to keep the baby anyway, is there any point having an
amnio?’ However for Melissa there was a point:

We had decided to have the amnio, but we were going to keep that
baby no matter what. So some people will think, oh why bother
going through an amnio? But we’d thought about that a lot and
with already having lost three babies we wanted to keep our baby
no matter what. And if it died, it died. But if it did go to term and
then die shortly afterwards we at least had a baby to hold, even for
that short amount of time, whereas we've lost all our others and had nothing (Melissa).

Some women incorporated the medical narrative as part of their stories; Nina, Shona, and Susan's stories would be acknowledged by the consultants as acceptable stories that had a point.

The specialist still asked me about the procedure and said if the results were positive and the baby had an abnormality – what would you do? And I said I'd terminate the pregnancy because he said there was no point in having the procedure done if that's what you weren't going to do (Nina).

The decision to have an amnio for me, is a decision to terminate if there is a problem because otherwise why are you there? (Shona, 41, New Zealand European, Early childhood teacher).

He [the GP] said he wasn’t surprised that we’d said we would opt for termination because he said really people with science and medical backgrounds normally do because they understand the ramifications of genetic malfunctions and abnormalities much more than you know normal members of the public (Susan, 39, New Zealand European, Supervisor).

During the interviews I asked the consultants, the midwife, and the women, what they thought was the general point of amniocentesis. The varied responses of the hospital staff to the women illustrate different views of its central purpose. The midwife, Dr Robert, and Dr Paul all saw the purpose of amniocentesis as ‘to make a diagnosis’, and Dr Jim’s view of the point of amniocentesis tied into the medical narrative and emphasised that if a woman was not prepared to change the management of her pregnancy after a positive diagnosis, then amniocentesis was not for her. The women gave two main reasons as the point of amniocentesis; first that it gave choice, and second that it checked your baby for abnormality. I want to concentrate and further elaborate in the next section of this chapter on the main points of amniocentesis as given by the women in their interviews with me.

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46Melissa was an exception; for her the point of amniocentesis was ‘to come to terms with what could possibly be’.
The point of amniocentesis for the women

When choice was emphasised as an answer to my question, ‘what do you think is the general point of amniocentesis?’, it was done in a very positive sense. Nina, for instance, responded: ‘I guess it’s giving women choice...women have a choice really in what they are doing with their bodies’. However, when simply discussing the experiences of amniocentesis, choice was sometimes presented in a less positive light, as previously noted. When referring to the possible choices/decisions amniocentesis might entail (to terminate an abnormal fetus) some women felt that choices/decisions in this context would be difficult. For instance, Lynette commented, ‘After seeing them on the scan it would be a really...hard decision to make’.

These last comments illustrate that there are also less positive aspects to the choices surrounding amniocentesis. Perhaps the women were in a sense ‘buying in’ to the positive rhetoric surrounding women and choice that is intrinsic to the women’s rights movement. This will be discussed in more depth later in the chapter, but now I will turn toward the other main point of amniocentesis identified by the women - avoiding disability.

The women also saw the point of amniocentesis being to check that their baby did not have an abnormality, and comments such as Diane’s, which saw the purpose of amniocentesis ‘to check the baby hasn’t got that chromosome short’, were frequent. Generally the women held very negative views about disability and felt that having a disabled child would include; hard work, stress and pressure, life-time commitment, and restricted life hopes for the child. Some of the women referred to their negative experiences with disabilities:

I’ve got a niece who’s four now and she’s...very handicapped. I mean she’s four and she’s only just starting to crawl, she only says a couple of words...it wasn’t something that appealed to me (Karla).

Although a couple of the women mentioned positive aspects of Down syndrome47, ‘you do see beautiful little Down’s syndrome children’ (Lynette), the majority of comments were quite negative. Shona felt that if she had found out her fetus had Down syndrome it ‘would’ve caused me to terminate

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47 Down syndrome was focused on by many of the women, the consultants in the counselling sessions, and also the literature on prenatal testing.
without as much heartache'. Emma expressed her own and her partner's feelings about having a Down syndrome child:

'I'd hate to have a kid with Down's syndrome, and I was going to do anything to eliminate any possibility of that', 'He [her partner] would've hated to be stuck with a Down's syndrome kid as well'.

The women stressed that they wanted babies that were normal - they did not want abnormal, disabled babies. Nina described herself as more concerned about the risks of fetal abnormality than the risk of miscarriage, 'I was so concerned about having a child with an abnormality...I guess I wanted to make sure that I had a normal baby' (Nina). Susan extended this want of normalcy to 'everyone', 'I think everyone out there really wants a normal healthy baby that can expect a normal life' (Susan, 38, New Zealand European, Supervisor).

So what do these women see as the purpose of amniocentesis? I believe that Susan voiced what most of the women implied by their comments: 'The number of Down's syndrome children are quite high. And I think it's [amniocentesis] being introduced more regularly as a tool to avoid those things' (Susan). Therefore, a major point of amniocentesis identified by these women was that it assisted them in avoiding having a baby with a disability - specifically Down syndrome. The following section will place the women's views as to the point of amniocentesis within the context of the literature.

Choice and disability elaborated

The purpose of amniocentesis was identified as providing choice by another group central to the process of amniocentesis - the cytogeneticists who culture the cells and communicate the results to the consultants. Anthropologist, Susanna Finlay researched three of the five cytogenetics laboratories in New Zealand that perform prenatal genetic testing and interviewed a number of cytogeneticists for whom the point of amniocentesis is personal choice. The cytogeneticists see themselves as facilitating this purpose of personal choice through the provision of an information service. They were concerned about the way the information they provide is communicated - there is not a lot of 'point' ensuring their work is high quality and nurturing cells to 'nail down' a
diagnosis, if that diagnosis is misinterpreted or exaggerated by consultants (Finlay, Fitzgerald, and Legge, in press).

you just hope the clinicians out in the antenatal clinics...are passing the information on in the correct way. We fax the report out to them and just hope the information isn’t misconstrued at any point and the patient fully understands it (Joseph) (Finlay, Fitzgerald, and Legge, in press).

There is concern about the consequences of what might happen if this was to occur:

if they were inappropriately counselled it would be quite worrying to know that a lot of these awkward diagnoses that generally would have a fairly favourable outcome would be terminated as a consequence of misinformation (Peter) (Finlay, Fitzgerald, and Legge, in press).

The concept of choice is a popular one, and Rapp (2000a: 37) identifies choice as market-driven in contemporary North America (and I would argue much of the developed Western world, including New Zealand). ‘The concept of choice, the desire for choice, and the experience of choice pervade modern life and reconstitute modern law to fit the culture of choice’ (Friedman, 1990: 74, cited in Gregg, 1995: 9). Robin Gregg (1995: 11) has observed that ideas and language of choice are persuasive within feminism, and the right to choose is ‘an essential value and a key organising theme’ for both feminist activists and the women’s health movement. For instance, the concept of choice was intrinsic to the abortion debate with the ‘pro-choice’ slogan to support women’s right to a safe and legal abortion.

Amniocentesis is provided within the rhetoric of choice - women can ‘choose’ whether or not to use the technology. As none of the women I talked to were placed in the situation of having to make a choice following a positive diagnosis, it is important to also focus on how women in that situation have understood choice. Rothman (1993), Rapp (2000a), and Sandelowski and Jones (1996) all discuss understandings of choice around women in this position.

Sandelowski and Jones (1996: 353) position the stories of women (and couples) who had to choose after finding out about fetal abnormality, between the prevailing cultural story of prenatal testing, that it expands
women’s reproductive choices, and the counter-cultural primarily feminist story of prenatal testing, which emphasises a lack of choice.

The authors argue that there were various understandings of choice in this context and identified five different narratives of choice that varied according to where the participants located the moral agency for the outcomes of their pregnancies. Participants with a lethally impaired fetus told a ‘nature’s choice’ story, those with an impaired but viable fetus told a ‘choice lost’ story, of the participants with an impaired but viable fetus and the option to terminate, those who continued the pregnancy told a ‘disowned choice’ story, while those who terminated told a ‘close choice’ story. Those participants with a lethally impaired fetus and no option to terminate told a ‘choice lost’ or ‘choice found’ story (Sandelowski and Corson Jones, 1996: 367-8)48.

Rothman (1993: 176-180) described choice in the context of choosing between an abortion of an abnormal fetus, or raising a disabled child as ‘the tragedy of choice’ arguing that the rationalising and controlling of a tragedy does not make it less of a tragedy and also that the actual choices offered by the technologies are ones that women find hard to live with: ‘Taking the least-awful choice is not experienced as ‘choosing’ really. It is experienced as being trapped, caught’ (Rothman, 1993: 180-181).

Rapp (2000a: 225-226) also found varied understandings of choice when talking to women who had been placed in the position of having to make a choice after a positive result. For many women of diverse backgrounds, who had aborted an abnormal fetus, the concept of choice was ‘unbearable’, instead these women suggested there was in a sense no choice ‘I had to have an abortion’, ‘it was a forced choice’. Other women spoke about their thankfulness that they had the choice, ‘it’s better to know than not to know, to have the choice rather than not to have the choice at all’ (Rapp, 2000a: 226).

The argument that prenatal tests give women choice, is highly criticised. Gregg (1995) draws feminist perspectives on procreative choice,

48 In ‘nature’s choice’ stories nature had determined the outcome, and the couple was not choosing between life and death – but time of death. ‘Disowned choice’ stories described choice that was not the couple’s to make, and ‘choice lost’ stories concerned couples who had found out about fetal abnormality, but at a stage too late to terminate. ‘Close choice’ stories were about how close the choices had been, and ‘choice found’ stories indicated that a choice was made despite the odds (Sandelowski and Corson Jones, 1996: 357-9).
which are useful in a discussion of amniocentesis and choice⁴⁹. The radical feminist perspective argues that choice regarding reproductive technologies is ‘illusionary’, because those choices are socially ‘constructed and constrained by male domination and patriarchal power’ (Gregg, 1995: 16-17). With regard to prenatal testing Rothman (1993: 14) argues that amniocentesis and selective abortion ‘are being used to give the illusion of choice’, and encourage women to view the experience of pregnancy through the eyes of men (Rothman, 1993: 114).

According to the radical perspective, the very existence of the technologies, encourage their use. Carole H. Browner, a Professor of Psychiatry and Anthropology, and Medical Anthropologist Nancy A. Press (1995: 320), assert that once a prenatal test exists a woman’s refusal of that test is not a neutral choice, rather:

refusal carries the explicit rejection of technical expertise and implies a reluctance on the part of the expectant mother to do everything in her power to assure the health and well-being of her developing fetus.

Gregg (1995: 19) locates the radical feminist critique of reproductive technologies within a wider critique of patriarchal control over women’s bodies and their reproductive processes: For instance the shift of childbirth from the sphere of midwives and homebirths to that of doctors and hospitalised births. Although some (see E. Papps and M. Olssen, 1997) have identified a shift back towards midwives and home births as a sign of reducing patriarchal control over women’s reproduction - prenatal testing can be seen as the ‘backdoor’ through which patriarchy has regained and perhaps even strengthened its hold over women’s reproduction.

A socialist feminist perspective on choice surrounding reproductive technologies adds to the critique of patriarchy a critique of capitalism and argues:

⁴⁹ The liberal feminist perspective is less common in the literature on prenatal testing; this perspective does not view reproductive technologies (including amniocentesis) as either inherently good or bad, but rather asserts that all women should have access to these technologies. According to the liberal perspective, once barriers are lifted and women are involved in the various elements of the technologies, and the technologies are available to all women – all women will have reproductive freedom of choice and this will be a good thing (Gregg, 1995: 11-13).
The social relations of both production and reproduction support domination and exploitation, and the existence of that inequality prevents women from having real procreative choice (Gregg, 1995: 21).

Socialist feminists critique reproductive technologies for three main reasons. First, the technologies have been ‘developed and implemented by men’ (Gregg, 1995: 22); second, they encourage the commodification of the reproductive process, as they have also been developed and implemented under capitalism. Lastly, these technologies also ‘contribute to women’s alienation by separating women from the products of their reproductive labour’, by identifying the fetus as distinct from the pregnant woman (Gregg, 1995: 22).

Overall, socialist feminism argues that women’s choices surrounding reproductive technologies are connected to the social, political, and economic contexts in which they live. From this perspective, choices to use prenatal tests, such as amniocentesis, are socially constructed, and subject to pressures and influences, and so not real choices (Gregg, 1995: 26).

Rothman (1993: 11) discerns that although we have ‘gained the choice to control the quality of our children, we may rapidly lose the choice not to control the quality, the choice of simply accepting them as they are’. I wonder if we might already be well on the way of losing that choice... ‘I wouldn’t have an amnio in the first place if I was going to accept them as they were’ (Shona). Abnormal, disabled babies were not seen as acceptable, which leads to the next purpose of amniocentesis the women identified – that it avoided disability.

The purpose of prenatal testing and the selective abortion of disabled fetuses, ‘is inherently concerned with the existence, or avoidance, of disability in society and in individuals’, and communicates the message that either living with a disability, or raising a disabled child ‘is such a grave burden that it is morally permissible and medically appropriate to take extensive measures to ensure that such children are not born’ (Kaplan, 1994: 49, Asch and Fine, 1988, cited in Press et al, 1998: 50, Murray, 1996: 131). In many instances disability is perceived negatively, and this pervasive perspective is often based on the assumption that those with disabilities experience lesser...

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50 It is through this critique that prenatal tests are viewed as providing ‘quality control’ over unborn fetuses as discussed in chapter four.
quality of life (Kaplan, 1994: 51-2). This has been contested by many people who live with disabilities and lead 'normal' lives that can include; mainstream education, career, marriage, and children: Rather, the disability rights movement asserts that disability, to a large extent, is socially constructed and that many of the hardships experienced by the disabled are caused by architectural, technological, legal, or attitudinal barriers in society – not the specific disability (Kaplan, 1994: 52).

The disability rights movement contends that selective abortion discriminates against the disabled and bioethicist Lynn Gillam (1999) has identified two distinct discrimination arguments: a 'slippery slope' argument and a conceptual discrimination argument. The 'slippery slope' argument views a causal relationship between selective abortion and discrimination against people with disabilities and asserts that prenatal testing used to selectively abort disabled fetuses leads to greater discrimination against people with disabilities than currently exists (Gillam, 1999: 164). The conceptual discrimination argument instead focuses on the nature of selective abortion and its underlying values and claims it in itself constitutes discrimination against people with disabilities. It is this argument which contends that the selective abortion of a disabled fetus sends the message that the life which the unborn disabled child would have, would not be worth living (Gillam, 1999: 164). Gillam argues against both critiques, asserting that despite the fact selective abortion may offend and distress people with disabilities, this does not mean it causes discrimination or is morally wrong (Gillam, 1999: 170). Disability rights activist, Christopher Newall, has responded to Gillam's position and argued that prenatal testing should be examined as oppressive, rather than discriminating against the disabled (Newall, 1999).

Prenatal testing with the purpose of avoiding disability, 'implicitly assumes some norm of ability' (Lippman, 1994: 23), and the concept of normalcy has been discussed by Lennard J. Davis\(^{51}\) (1997: 9) who contends that you must look towards the construction of normalcy, rather than the construction of disability, in order to understand the concept of the disabled body. 'The 'problem' is not the person with disabilities; the problem is the

\(^{51}\) Davis is a Professor of English, Disability and Human Development, and Medical Education; and has also written about his experiences growing up as a hearing child with deaf parents.
way that normalcy is constructed to create the ‘problem’ of the disabled person’ (Davis, 1997: 9).

Despite ideas of conforming to the norm being persuasive within Western society, the concept is relatively young, only emerging around the time of industrialisation (Davis, 1997: 9). Davis (1997: 11) has observed that statistics were very influential to the construction of normalcy, and it was French statistician, Aldolphe Quetelet who created the concept of *l’homme moyen* (the average man). The concept of the average man was quite important and became the example to live up to, ‘the average became a kind of ideal, something one wanted to be’ (Davis, 1997: 12). However, in contrast to the ideal, the norm suggested that most of the population should fall within the category of the norm. The bell-shaped curve was applied to calculate the norm, with deviants (such as people with disabilities) falling outside the norm (Davis, 1997: 13-14).

The concept of the norm is intrinsic to prenatal testing, as women have to decide what characteristics they view as falling outside the norm. As increasingly more ‘unwanted’ characteristics are able to be tested for, the edges of what constitutes the norm become smaller, increasing those characteristics that are seen as abnormal. However, what is normal and what is abnormal is contested - Down syndrome, for instance, is understood in multiple ways.

Rapp (2000b) completed two years of participant observation in a New York City support group for parents with Down syndrome children and interviewed various families. She found multiple understandings of Down syndrome held by medical professionals and parents. Although some medical professionals held sympathetic and more positive views of babies with Down syndrome – others were quite negative, viewing these babies as ‘wrong babies’ who are incurably damaged (Rapp, 2000b: 186-7).

Rapp (2000b: 190) identified many barriers that restrict Down syndrome newborns from the category of normalcy, including medical language and diagnosis and a common lack of family resemblance; and support groups can help parents to ‘normalise a child as a family member, not only as a medical diagnosis’. Many of the families Rapp (2000b: 192) talked to

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Quetelet (1796-1847) utilized the ‘law of error’ used by astrologers to locate a star by plotting all the sightings and then averaging the errors and applied it to human characteristics, such as height and weight (Davis, 1997: 11).
held very different views of Down syndrome to the women in my study, pulling on the positive characteristics of the children:

They’re always feeding you all this negative stuff about the extra chromosome, all these disabilities, but I think it’s something positive. Maybe the extra genetic stuff carries some mutation that causes positive things, too...all that heart, that generosity, the lovingness, the feeling one with the world, those qualities, that’s the positive side they never talk about. And it’s genetically built into them. Those are traits, too (Judy Kaufam, white nurse, mother of a seven year old with Down syndrome).

Rather than focusing on abnormality many parents would normalise their children through an acceptance of, rather than emphasis on difference, and it was in this sense that Rapp identifies a double discourse of both difference and normalisation. For instance, the physical differences that characterise Down syndrome, such as eye and facial bone structure and low muscle tone is instead viewed as ‘adorable and appealing’ (Rapp, 2000b: 197-8).

As the contrasts between these parents of Down children and the women in my research illustrate, ideas of normalcy are contested: While some people view those with Down syndrome as abnormal - positing them as deviants on the bell-shaped curve of normal babies, those who parent these children attempt to normalise them through accepting and celebrating the very differences that exclude them from the norm.

The methods of approaching Down syndrome certainly appear to have changed: A university library search listed sixteen titles that dealt with Down syndrome children in families and growing up. All of the titles, bar one, were written in the 1970s and 1980s, and there is a noticeable lack of titles for the past fifteen years at least. Perhaps this is reflective of a shift in ‘dealing’ with Down syndrome, from working to fit such children into family life – to selectively aborting affected fetuses. Although I was unable to find statistics referring to the number of Down syndrome babies born, I would suggest that numbers of these births may have significantly decreased over the past fifteen years as prenatal testing and screening has become more routine. The last section of this chapter will concentrate on various purposes of amniocentesis, as identified and argued by social scientists.
Social scientists and the 'point'

One identified purpose of amniocentesis is that it benefits society by sparing the 'expense of coping with diseased and disabled offspring' (Shaw, 1984, cited in Gates, 1994: 184). In terms of cost-benefit analysis, providing free amniocentesis procedures and terminations of genetically abnormal babies costs less than supporting a severely disabled person through life (Kolker and Burke, 1994: 5). Of the women I spoke to, only Susan commented on this:

And there's some part of it [amniocentesis]; I guess it's a selfish thing that the government and the medical thing wants all babies to be normal and not have babies that are a burden to society (Susan).

However, amniocentesis can also be viewed as negative for society as it reduces diversity.

Another purpose of amniocentesis identified by social scientists is that it benefits women in a number of ways – through enhancing their quality of life, granting reassurance, and increasing autonomy (Lippman, 1994: 14-15, Gates, 1994: 185-190). When amniocentesis and the associated termination of disabled fetuses is viewed as enhancing women's lives, this assumes that raising a disabled child would necessarily reduce women's quality of life. This certainly corresponds to the thoughts of the women I spoke to, who, as previously noted, viewed disability quite negatively.

The test did provide most of the women I spoke to with reassurance, and comments such as Karla's were typical: 'it reassured me for the rest of my pregnancy'. However, the test can also grant false reassurance, as it does not indicate a wide variety of possible 'problems' (Gates, 1994). Nina was one woman who experienced some level of false reassurance; although the amniocentesis results indicated that the baby was fine, he actually had dilated kidneys:

About amniocentesis...I guess it's only showing...the chromosomal results, but there are still other things that can obviously happen because now I've got this little glitch with these kidneys that are dilated. I've still got to deal with those even though they're not major, so it's still just a chromosomal test, kind of a test in isolation (Nina).

Gregg has related a more tragic story of false reassurance: 'Sarah' (40 years old) decided to have all the testing she could (chorionic villi sampling,
maternal serum screening, and ultrasound) to check on her pregnancy, ‘Let’s put it this way. I’m forty years old, and without the diagnostic tests that are available I wouldn’t have risked a pregnancy’ (Gregg, 1995: 3). Sarah had felt that these choices granted her procreative control; all the results came back fine – she had done everything to insure a healthy baby. However, when her son was born he suffered from numerous physical and neurological birth defects – so severe that despite extensive treatment he died at sixteen days (Gregg, 1995: 7).

Another argument concerning the benefits prenatal tests grant women is that they can increase the autonomy of pregnant women by giving them more power over the type of children they will bear (Gates, 1994, Lippman, 1994: 14-15). However, according to Gates, ‘while the test does provide options to women at risk, it is not clear whether patient autonomy is actually enhanced through the test’ (Gates, 1994: 188-90).

Social scientists themselves have pondered the purpose of prenatal tests and come to view the ‘point’ in a number of different ways. Two strong threads of thought are apparent; that amniocentesis transforms women’s experience of pregnancy, and that it repositions women so that they are forced to judge the value of their fetuses.

Rothman has argued that amniocentesis has altered women’s experiences of pregnancy through reconstructing understandings of pregnancy as a production process (Rothman, 1993: viii). The changing experience of pregnancy has created, what Rothman has termed, the tentative pregnancy; ‘a woman’s commitment to her pregnancy under the conditions imposed by amniocentesis can only be tentative’ (Rothman 1993:101).

Rothman has argued that the tentative pregnancy changes how and when women publicly and personally acknowledge their pregnancy. For instance, she identified that many women did not publicly wear maternity clothes until after they had received a negative result. Rothman described women as experiencing ‘suspended animation’ with regard to fetal movement; whereas most medical sources identify movement usually occurring between 16-20 weeks gestation, many women did not experience movement until 23 weeks – after they received their results (Rothman 1993:98-95)

53 ‘Suspended animation’ is described as a method women might utilise to psychologically defend themselves until a positive test result shows the presence of a baby – rather than a ‘chromosomally damaged fetus’ (Rothman 1993:98-104).
104). Most of the women I talked to seemed to have experienced at least some element of a tentative pregnancy; by not telling friends or family about the pregnancy until after they received the results. However, this idea of the tentative pregnancy is not new – many generations of women have, for instance, refrained purchasing baby clothes until after 30-35 weeks of pregnancy in case 'something went wrong', and in the same light it is considered bad luck to throw a baby shower too early in the pregnancy. The tentative pregnancy has been critiqued by Statham (2003: 186-7), who argues that despite the concept of a tentative pregnancy being widely accepted as truth within social science there is no evidence to suggest that women who received a positive diagnosis felt that their pregnancy had been tentative.

Lippman (1994: 26) also argues that prenatal testing changes women's experiences of pregnancy through creating a 'lifestyle' for pregnant women; transforming a variety of experiences and understandings. These transformations have included; pregnancy now occurring according to 'testing time' rather than 'women's time' (Beeson, 1984, cited in Lippman, 1994: 22) and a reduced level of attachment to the fetus (Lippman, 1994: 22). The tests have also shifted understandings of abortion by allowing geneticists and obstetricians 'to impose a 'choice' for abortion covertly, if not overtly, when they decide which fetuses are healthy, what defines healthy, and who should be born' (Lippman, 1994: 23).

Prenatal tests have also worked to create a social category of the 'older woman' (Nelkin and Tancredi 1989, cited in Lippman, 1994: 25), in New Zealand the entrance to this category starts at age 35 – the age when women are provided with free amniocentesis by the government54. The women in my study identified themselves with the category of 'older women', and the majority gave age as the main reason they were concerned about fetal abnormality. According to Lippman prenatal tests are portrayed 'as a tool for the already negatively stereotyped woman in her middle years who wants or needs to circumvent features of aging', and as reliant on chronological age and implying 'after some arbitrary age she is a failure'55 (Lippman, 1994: 25-6). Negative feelings about older mothers were certainly present in the

54 Note the existence of books specifically for 'older Mums', such as Birth over Thirty-five by Sheila Kitzinger, encourage this separate identity for older childbearing women.

55 However, it is important to note that it is a biological fact that 'older women' are at a higher risk of both maternal complications and fetal problems.
interviews I conducted, for instance, 'I'm not particularly in favour of older mothers...if I had a preference I would have been younger' (Karla).

Amniocentesis and other prenatal tests reposition women creating new roles for them. Gregg (1995: 3) views prenatal tests as positioning women both negatively and positively. On one hand these technologies may provide new avenues for medical and social intrusion into women's reproductive process, their bodies, and their lives. However, on a more positive note, these same technologies may also provide women with choices that could grant them greater reproductive control.

Rapp (2000a) is one of the strongest commentators on prenatal testing – her research spans decades and includes fieldwork with women who have experienced amniocentesis; genetic counsellors; cytogeneticists; and support groups for families with Down syndrome children. She views the impacts of amniocentesis as two-fold whereby women are both constrained and empowered. While women are held accountable for each individual pregnancy, they are also individually empowered to decide their limits of voluntary parenthood (Rapp, 2000a: 317-18). Thus she eloquently describes the construction and routinization of amniocentesis as:

> turning the women to whom it is offered into moral pioneers: Situated on a research frontier of the expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standard for entry into the human community (Rapp, 2000a: 3).

There are multitudes of different views as to the 'point' of amniocentesis and this chapter has forced me to ask myself what I view as the 'point' of amniocentesis - it is a question that I cannot answer. The practice of amniocentesis is so very complex and multidimensional, it contains many threads of meaning – some of which I have pulled together for this chapter. On one level amniocentesis facilitates the prevention of chromosomally abnormal people, and so it is a form of 'quality control' of potential people. However, this does not sit well with my experiences of the women I spoke with. These women were nice people, they welcomed me into their homes, asked how my journey was, and some invited me for dinner, or at least a cup of tea. They introduced me to their babies, the 'amnio babies' or showed me photos if they were asleep. These women loved their children, and they did not seem like women who would subject their children to 'quality control'.
Yet most of the women stressed that they did not want a disabled child, a ‘Down’s syndrome child’ - they wanted a normal baby, and they were willing to terminate an abnormal baby to achieve that goal. The ease with which this was explained troubled me, and sometimes frightened me – there was an element of these conversations that I was not so comfortable with – that perhaps I did not like. Anthropologist G. A. Fine (1994) writes about what he calls ‘the ten lies of ethnography’; one of these lies is that the researcher should not dislike their participants. While I did not dislike the women I talked to, I would admit to disliking aspects of the conversations I had with them – aspects I found somewhat frightening.

I am in a privileged position from where I have access to a number of different arguments about the various purposes of amniocentesis. I have had a great deal of time to read a variety of literature about prenatal testing, talk to women who have experienced the technology, observe both amniocentesis procedures and the counselling sessions that precede them, as well as talk to the consultants who perform the procedures, and yet I am unable to identify a specific ‘point’ of amniocentesis. Contrast this to the women I talked to, they are mothers, they have jobs, and partners, they fit this procedure, the practise of which, is extremely complex and multidimensional with implications that pull at heart strings, into already busy and sometimes hectic lives. Nina, for instance described her life at the stage when she was going through the process of amniocentesis: ‘Apart from feeling really nauseous...I was still trying to carry on with part time work and had two kids at home and a husband that wasn’t doing much to help me’. As Sharon, commented, ‘it’s brought a lot to my mind, but it’s done and it’s dealt with and you move on’.

There does remain however, a further aspect of amniocentesis which this research highlighted and which I have not yet discussed, and that is the nature of risk as it is understood by various participants in this social practice. For instance, judging, evaluating, qualifying, reducing, and avoiding risk are all further ‘points’ of amniocentesis and the following chapter will discuss the relationship between risk and amniocentesis in more detail.
5.

*Risky procedures, risky women, and risky bodies*

The concept of risk is an intrinsic element of the practice of amniocentesis; it brings to the fore the risks of having an abnormal baby and the procedure itself is risky, having an associated risk of miscarriage. The risks surrounding amniocentesis are not, however, that simple. There are multiple understandings of the risk of this procedure depending on where the individual is positioned in relation to the test. This chapter will first examine the stories of two women; Melissa and Sharon, for whom risk is central to their experience of amniocentesis, but in different ways. Their perceptions of risk and the influence it has on them are examined through three versions of risk theory; governmentality, risk society, and work on the female body as a risky body. The biomedical perspective of risk will then be examined and shown to be an important aspect of the consultants' understandings of risk. However, the consultants also have several other readings of risk that influence their view of amniocentesis as a risky procedure most particularly for those who perform it.

**Melissa**

Melissa is a 35 year old mother of two daughters; a three year old and an eight month old. She identifies herself as Catholic and a New Zealander who is descended from Maori, although she is not sure of her Iwi. Melissa is married and is trained and has worked as a nurse, but is at present a ‘full time Mum’; she lives in a central Otago town with her husband and daughters.

Melissa’s story starts with the discovery of her genetic disorder; she has a balanced translocation of the P (long) arms of chromosomes 9 and 17. An example of a chromosomal translocation is shown below where the bottom tips of chromosomes 8 and 14 are exchanged (translocated).
Melissa understands this genetic disorder to have caused her to have three miscarriages. She first miscarried at thirteen weeks gestation, then at six weeks with her next pregnancy, then had a pregnancy come to term (her eldest daughter) before losing her next pregnancy at nine weeks. After her second miscarriage Melissa had wanted testing to find out what was wrong, but was told she could only have it if she had three miscarriages. After her third miscarriage Melissa again requested testing, but was told she was not eligible because she had had a healthy baby. After ‘kicking up a real stink’, Melissa was given the test which diagnosed her disorder. She was recommended to have amniocentesis with any subsequent pregnancies, and did with her last pregnancy, which resulted in the birth of her healthy now eight month old daughter.

Melissa’s story of amniocentesis is about risk; however it is a different risk to that of which the other women feel in danger. The other women are mainly concerned about two risks; either that their baby will have an abnormality or that they will suffer an amniocentesis-induced miscarriage (some of the women also mentioned concerns about the baby getting ‘spiked’ by the needle). Melissa on the other hand is concerned about a specific risk that she has previously experienced on three occasions: the risk that she will
lose her baby and be left with nothing - not even 'a baby to say hello and
goodbye to'. Melissa's past experiences have influenced her to view this as
her major risk, but also to see there being an alternative to this risk that does
not involve the termination of an abnormal fetus:

Yeah, well during my training we had a baby...that was born,
microcephalic - tiny brain, and I was involved in that labour. And
they took it off, they said it won't live, they took it off all its life
support, but the whole family, it stayed in the hospital, but the
whole family came in everyday. The big brother, you know, 'this
is my baby sister', and it was just wonderful seeing them bond
with this baby and that was one of the major factors in my
decision, to influence my decision, that I want a baby to do this
with. If we were going to have a baby and even if it had died
before it was born or only lived a few hours we could have that. I
did not want to terminate another baby and have nothing again.
I've already had three nothings, you know absolutely nothing, and
we didn't want to go through that again. If I'd never had a
miscarriage, if I was faced with this decision and had never lost
any children beforehand I don't know what my decision would be.
It could have been completely the opposite; it might have been I
don't want to know it. I'll never know because I'll never be in that
position. But for me I had lost three babies and I had nothing to
show for it, and it wasn't going to happen again.

Melissa was externally labelled 'high risk' by experts during her pregnancy. I
will look towards a 'governmentality' perspective of risk to discuss the
underlying factors of why she was labelled 'high risk' and how that external
label continues to influence her. The governmentality perspective on risk
stems from the work of Michel Foucault who first created the concept as a
way to understand 'the characteristics of liberalism as a mentality of
government' (Rabinow & Rose, 2003: x). The term to Foucault meant three
things, firstly:

The ensemble formed by the institutions, procedures, analyses, and
reflections, the calculations and tactics that allow the exercise of
this very specific albeit complex form of power, which has its
target population, as its principle form of knowledge political
economy, and as its essential technical means apparatuses of
society (Foucault (1978) in Rabinow & Rose, 2003: 244).

The tendency that, over a long period and throughout the West,
has led toward the pre-eminence over all other forms (sovereignty,
discipline, and so on) of this type of power – which may be termed
'government' – resulting, on the one hand, in the formation of a
whole series of specific governmental apparatuses, and on the
other, in the development of a whole complex of knowledges [savoirs] (Foucault (1978) in Rabinow & Rose, 2003: 244).

The processor, rather, the result of the process through which the state of justice of the Middle Ages transformed into the administrative state during the fifteenth and sixteenth centuries and gradually becomes 'governmentalized' (Foucault (1978) in Rabinow and Rose, 2003: 244).

Danaber, Shirato, and Webb (2000) identify two changes that Foucault viewed as influential to the emergence of governmentality; a change in what comprised government and governmental care, and a shift away from centering on who has power and influence, to a rationality based on the ways in which power can be exercised most efficiently (Danaber and Shirato et al., 2000: 89). These changes in thinking, for Foucault, shaped two distinctive kinds of knowledge; a diplomatic military aspect that was concerned with 'external policy security', and 'policy' which was understood as 'a set of technologies and institutions responsible for internal stability and prosperity' (Danaber and Shirato et al., 2000: 89-90). With the addition of economics, these forces and technologies were 'extremely powerful'. When the population of the state is viewed foremost as a resource, then the fitting role of the state is that of population management (Danaber and Shirato et al., 2000: 90):

This required the production of knowledges that would allow the state to scientifically analyse that population, which was followed by the introduction of policies that both regulated behaviour (for the good of the individual, which meant at the same time, for the good of the state), and kept the population happy and healthy – and therefore productive (Danaber and Shirato et al., 2000: 90).

Relating governmentality to risk, Lupton looks to the relatively late development of a large network of 'expert knowledges' that are accompanied by 'apparatuses and institutions built around the construction, reproduction, dissemination and practice of these knowledges' (Lupton 1999a: 4). Through this development 'experts' have a role in 'constructing and mediating' discourses on risk, which serve to control and discipline bodies through voluntary self discipline rather than coercive or violent means (Lupton 1999a: 4). Risk itself is one of the 'strategies of disciplinary power' that is utilised by
authorities to manage and survey individuals and populations so that they are positioned to assist the goals of the democratic state (Lupton 1999a: 4).

Lupton links governmentality to risk in pregnancy by concentrating on apparatuses of biopolitics that work for the state and other authorities (religious, medical, commercial, therapeutic, society, cultural) to ‘discipline and normalise citizens, to render them docile and productive’ (Rabinow and Rose, 2003: xi, Lupton 1999b: 61). Normalization is one of those apparatuses and is useful in talking about pregnancy and risk. It involves gathering information about populations and studying it statistically; through this individuals can be compared to populations and identified as falling inside or outside the norm. Those that fall outside of the norm are encouraged to work towards falling back inside the norm (Lupton 1999b: 61). The apparatus of normalization is utilised on pregnant women by the authority of medicine to discipline citizens. The individual pregnant woman is compared to statistically analysed populations of other women:

[Medical practitioners] use a statistically derived model of the ‘normal’ pregnancy as the standard against which to measure or calculate the ‘progress’ of each woman’s pregnancy (Gregg 1995: 85).

The individual women are calculated as falling either inside or outside the medical model’s ‘norms’ of pregnancy. If they fall outside, intervention is required to push them towards the norm:

Medical norms about the stages of pregnancy and childbirth are associated with protocols that require [medical practitioners] to intervene when a woman’s pregnancy differs from those norms (Gregg 1995: 85).

Those that fall outside the norm are often labelled as ‘high risk’ and ‘to be designed [sic] at ‘high risk’ compared with others is to be singled out as requiring expert advice, surveillance and self regulation’ (Lupton 1999b: 61). As a woman who had miscarried three pregnancies, Melissa’s body was perceived as unproductive by the institution of medicine and herself. Melissa’s chromosomes are outside the norm and because of this she was labelled by ‘expert knowledges’ as ‘high risk’. As a ‘high risk’ individual she was encouraged to work her way back within the norm, this involves producing healthy offspring. Also as an individual labelled at high risk,
Melissa was given expert advice; she was referred to a specialist, and frequently talked to other medical professionals including her GP and a midwife. Melissa was also the subject of surveillance; she had had four ultrasound scans by the time she was at fourteen weeks of gestation, she went through the Early Miscarriage Unit, which involved regular visits into a hospital environment where her progress at becoming pregnant, or continuing a pregnancy with a ‘viable’ fetus was monitored, and she underwent amniocentesis which scrutinised the ‘quality’ of her fetus’s chromosomes. Melissa also partook in self-regulation. She regulated her body by monitoring the amount and type of exercise that she allowed her body to do; monitoring what food she ate and how it was prepared; limiting or restricting her intake of alcohol; and ‘choosing’ to go ahead with the prenatal test of amniocentesis that was recommended to her. In this sense, risk is a strategy of disciplinary power that is utilised by the authority of medicine to survey and manage Melissa into a position where she is aligned with the goals of the state as a productive body.

Melissa can also be identified as an ‘autonomous, self regulated citizen’; an ‘idealized figure’ within the study of governmentality. The self regulated citizen is an important element of governmentality; it attempts to minimize any risks that they might be vulnerable to, to ‘police their own behaviour’ efficiently enough to require only guidance from ‘expert knowledges’, and to generally partake in activities that serve to fulfil their best interests (Lupton, 1999b: 61-62). As a self regulated citizen Melissa attempted to minimize the risks she was vulnerable to – she saw one of those risks as miscarrying again and so asserted her right to ascertain whether there was a genetic basis for this problem so that she could understand why she was miscarrying. After she knew about her chromosome disorder she minimised her chances of having another miscarriage by deciding that her fifth pregnancy would be her last – she planned to regulate her body so that she will not become pregnant again. Melissa policed her behaviour so that it fitted with encouraging a healthy pregnancy – she did this by monitoring her intake of food, alcohol and exercise. As a self regulated citizen Melissa required only advice from the ‘expert knowledges’ – she was advised to have an amniocentesis – she was not forced, and was under the impression that it was her decision to make. Lastly, Melissa served to fulfil her best interests,
which did not involve the termination of an abnormal fetus. This goes against what the medical authority/institution views as the primary point of amniocentesis: to terminate abnormality. As a self regulated citizen Melissa worked to fulfil her best interests, which for her involved having a baby to hold 'no matter what'.

Melissa's story of amniocentesis revolved around risk. Through a governmentality perspective Melissa can be identified as a pregnant body that was subjected to intense government. Her body was governed by the apparatus of normalization, pathologised, and labelled 'high risk' by expert knowledges. Although encouraged to be a docile body, Melissa acted in her own best interests as a self regulated citizen, going against the medical institution through asserting her right to testing even if she would not abort an abnormal fetus.

Within the 'governmentality' perspective, amniocentesis can be viewed as a tool of the apparatus of 'normalization' that has a variety of functions. Firstly it works as a method of comparing individuals to populations, identifying those outside the norm and so at 'high risk'. In some cases other comparative techniques, such as the nuchal fold test, which compares the measurement of the individual fetus's nuchal fold to the 'norm' of a population of fetuses, has already identified the pregnant woman (and fetus) as 'high risk'. In these cases amniocentesis is a method of surveillance to check on the fetus. The results also encourage practices that bring women back towards a 'normal pregnancy', either through the 'keeping' of a normal fetus, or the termination of an abnormal fetus.

Amniocentesis can thus be understood to work to 'discipline and normalize citizens, rendering them docile and productive bodies' and is a specific technique that disciplines pregnant women's bodies identified as outside the norm either due to maternal age or other risk factors. Amniocentesis works to make the pregnant woman's body productive. A female body is viewed as productive when it produces healthy offspring; the procedure influences the termination of abnormal offspring - the product of a non-productive body. The following section turns to discuss Sharon, a woman for whom risk was central to her experiences of amniocentesis, infertility, and pregnancy.
Sharon

Sharon is 38 years old and has a seven and a half month old daughter. She identifies herself as a Presbyterian and a New Zealand European, and works as an occupational health nurse and a practice nurse, but is currently on leave. Sharon is married and lives on a farmlet just out of a southern town with her husband and daughter.

Sharon starts her story by telling me that she had major surgery when she was pregnant with her daughter. Sharon and her husband had been trying to have children for eight years and were seeing a fertility specialist when she had thyroidectomy and laparoscopic abdominal surgery. Four weeks after the surgery Sharon found out that she was eight and a half weeks pregnant and so had been four weeks pregnant at the time of the surgery. Sharon went on to have a nuchal fold test and an amniocentesis, which revealed some mosaicism; however her daughter was found to be healthy after a blood test at five days old, which was performed due to a 'bungled' cord blood test.

Sharon views herself as a 'risky person' living in a risky world. After she found out she was pregnant these risks proliferated and intensified. She recalled feeling at risk of having an abnormal fetus or a disabled child, having a miscarriage, being blamed and feeling responsible if either of those two outcomes occurred, and also at risk of losing the pregnancy and remaining childless. Sharon understood herself as a pregnant woman living in a society that is risky: a 'risk society'. Lupton (1999b), draws on Ulrich Beck's theory of a 'risk society' to understand why there is this proliferation of risk discourse around pregnancy.

The 'risk society' is explained by Beck (1992: 9-10) as the 'new form' of modernity, which is beyond its 'classical industrial design'. 'Reflexive modernisation' is viewed as central to the 'risk society' in a number of ways; generally it works to demystify understandings of science and technology, as well as modes of existence in work, leisure, the family and sexualities, just as the privileges of rank and religious world views were demystified in the 19th Century. Beck (1992: 12-13) describes the 'guiding idea' of 'reflexive modernization' in two ways; first through the argument that while in classical industrial society the 'logic' of wealth production dominated the 'logic' of risk production, in the risk society this has been reversed. In the 'risk society' the
'logic' of risk production and distribution is developed in comparison to the 'logic' of the distribution of wealth. The risks and consequences of modernity lie in the middle; they cannot be reversed and threaten the life of plants, animals, and human beings. 'Reflexive modernization' is also connected to what Beck (1992: 14) describes as a 'transformation of the foundations of change':

The system of co-ordinates in which life and thinking are fastened in industrial modernity – the axes of gender, family, and occupation, the belief in science and progress – begins to shake – and a new twilight of opportunity and hazards comes into existence – the contours of the risk society (Beck, 1992: 15).

The 'risk society' theory draws on wider macro-levels to understand why there has been an intensification of concern about risk in modern societies. (Lupton 1999a: 3). Two aspects of 'risk society' theory are useful to investigate Sharon's understandings of and position within a risky world; first the macro-level influences of increased risks and second Beck's understandings of individualization.

There are several macro-level shifts that help to explain the intensification of risk discourse around pregnancy that Sharon was experiencing, which I will now discuss. For instance, there has been a general decrease in family size in industrialised societies, with many families consisting of only one or two children. Sharon's experience is consistent with this as she has only one child and does not think she will have any more. Her older sister went through several cycles of IVF, but they failed and she is now childless. This reduction in the number of children has led children to be viewed as 'a 'scarce resource' whose success must be ensured' (Beck-Gernsheim, 1996:145, cited in Lupton 1999b: 67); and because children are now limited, parents invest more in each individual child. Lupton argues that the emphasis on avoiding and reducing risk during pregnancy is part of the greater goal of creating the 'best possible child'; in other words attempting to produce a 'perfect child' (Lupton 1999b: 68)\(^5\).

This idea is certainly helpful in understanding Sharon's story of risk. She only has one child and had been trying to conceive for years prior to that

\(^5\) The concept of wanting a 'perfect child' relates to the commodification of children, as discussed in chapter three.
pregnancy; the pregnancy 'was a very precious pregnancy, very, very, precious'. Sharon feels that the time and effort she puts into her baby now will benefit her with having a loving baby and child in the future; and she views having amniocentesis as one of those things that she did to ensure a loving child in the future. For Sharon, amniocentesis was 'another progressive' towards that goal. Sharon spoke about the kind of baby she had aimed for: 'I guess you are aiming for the perfect baby. Yeah, perfect means sort of nothing that's out of the ordinary'.

The second macro-level shift, which Lupton mentions is the proliferation of technologies such as ultrasound and amniocentesis which test the fetus for 'abnormality', or provides a diagnosis of 'normality', to ensure such perfection. Lupton sees the introduction of such tests as intensifying risk discourses around pregnancy through the choices that they entail, the implicit actions they suggest, and the way in which their existence allows a woman to be held accountable for her baby's abnormality if she chooses not to undergo testing (Lupton 1999b: 69). Sharon underwent all the testing that was available to her; she had numerous ultrasounds, a nuchal fold test (she actually knew the technician who performed it and he trialled the 'latest' program on her). These results indicated that she had something like around a one in 1000 risk of having a baby with a genetic abnormality, however Sharon went on to have amniocentesis as well: 'I guess having amniocentesis was a check'. The technologies that Sharon used opened her pregnancy up to a central part of the proliferation of risk discourse that permeates pregnancy with the very existence of such technologies encouraging women like Sharon to utilise them to their full potential.

The shifting role of women in the labour market is a further macro-level influence of the risk discourse around pregnancy (Lupton 1999b: 68). Women in contemporary industrialised societies have become significantly more involved in the labour force than in pre-industrialised societies. This shift has also influenced the way women view themselves; rather than viewing their lives as devoted to family, women in modern societies (especially those with high levels of education and professional careers) now seek success and identity through their work (Lupton 1999b: 68). According to Beck-Gernsheim (1996) this contrast between the world of work and the world of motherhood has positioned childbearing as a major risk in itself.
Having children is today the structural risk of the female wage-earning biography: indeed, it is a handicap, measured by the female yardstick of a market society (Beck-Gernshein, 1996: 146, cited in Lupton, 1999b: 68).

If just having a normal child is viewed as a handicap, Lupton argues that having a disabled child must be even more of a handicap for women's position between the world of work and the world of motherhood (Lupton 1999b: 68). Sharon is a worker; she is a trained nurse and has worked in a variety of fields, as a practice nurse, an occupational health nurse, and in the gynaecological field. She is a woman who has been involved in the world of work for a long period of time and at age 37 she is just entering the world of motherhood. Sharon did not say that her position in the labour force had influenced her to try to avoid having a baby with an abnormality, however she does say that her husband 'in his honesty said he would find it really difficult to look after a 'special needs' child...I don't know how I would cope'.

One last shift that has influenced the proliferation of risk discourse around pregnancy is the move in modern societies towards individualization; a central element in Beck's 'risk society' (Lupton 1999b: 67). Beck-Gernshein explains the move towards individualization as a change in people's life course. The life course of people in pre-industrial times was very much pre-shaped. This is contrasted to the life course of people in modern societies, which is 'more open and malleable' (Beck-Gernshein, 2000: 123).

Individualization...means that each person's biography is removed from given determinations and placed in his or her own hands, open and dependent on decisions (Beck, 1992: 135).

This move in life courses towards individualization has both positive and negative implications. On the one hand it has expanded options and choices, but on the other hand more demands, controls, and obligations fall to individuals (Beck-Gernshein, 2000: 123, Beck-Gernshein, 1996: 140, cited in Lupton, 1999b: 67).

In the individualized society the individual must therefore learn, on pain of permanent disadvantage, to conceive of himself or herself as the centre of action, as the planning office with respect to his/her own biography, abilities, orientations, relationships and so on (Beck, 1992: 135).
Lupton relates individualization to a new understanding of risk. Historically, danger was understood to be controlled by fate in Western societies. In contrast, individualization has influenced people by positioning them as 'choosing agents' who see themselves as having a high level of control over the degree to which they are exposed to danger and thus as responsible for placing themselves at risk. Therefore, through individualization 'risk is primarily understood as a human responsibility, both in its production and management' (Lupton, 1999a: 4).

Sharon is a prime example of a person living in an individualized society. She views herself as exercising a high level of control over her life course; 'I'm of the mind that things are how you're going to make them be'. She understands herself to be responsible for the management of the risks around her and so works to control those risks. Before she had her daughter a major risk to Sharon was that she would end up childless so she worked to manage that risk in a number of ways; she led a 'puritan' life, 'I might have had a Baileys once a month, but you know I don't know what a Baileys drink is like now'; and she underwent surgery to correct problems that she thought might have contributed to her infertility.

Once pregnant, Sharon worked to control and manage the risks of which she felt to be in most danger; for example she had a 'great fear' of suffering an amniocentesis-induced miscarriage. Sharon went to much greater extremes than the other women to protect herself from an amniocentesis-induced miscarriage; she wanted 'optimum conditions' to prevent a miscarriage and utilised her medical knowledge to ensure those conditions. Because she was worried about 'sitting up - pressure on the uterus that decreases the blood oxygen flow', she stayed the night in the city following her amniocentesis so she did not have to travel home sitting up. Instead, that afternoon after the procedure she lay down and rested, 'I think I was lying there waiting to feel pains, for a miscarriage'. So why did Sharon go to much greater lengths than the other women to prevent the risk of miscarriage? I believe it is because of an experience she had in her nursing career that made the risk of an amniocentesis-induced miscarriage much more real to her than to the other women.

I can vividly remember looking after a lady that had an amniocentesis because she was young and her second child had a
chromosomal abnormality...and it all went fine and then she miscarried. And I can remember nursing her, like right when she had that, like she rang the bell...and I was really pleased her husband was on the other side of the bed with her, and I just lifted back the sheets, and thankfully he couldn't see it. I said, 'you’ve actually just delivered your baby'; so I knew, I knew the real risks.

There is however another side to this extended sense of responsibility for one’s life course - blame. If individualization has influenced people to see themselves as responsible for their lives, in turn, they are also positioned as to be blamed for negative events (Lupton 1996: 67). Sharon underwent a thyroidectomy and laparoscopic surgery when she was four weeks pregnant – although she and her medical professionals did not realise she was pregnant at the time. A blood test was taken before the surgery, which Sharon had assumed included a pregnancy test – but it did not. Although Sharon did not know she was pregnant during the surgery she feels ‘to blame’ for subjecting her fetus to the risks of surgery.

I probably do beat myself up and say well why didn’t I ask that doctor who did that blood test to tell me I was pregnant? I guess I put a big emphasis on not asking questions, particularly because I'd worked in the medical profession. That was one thing I didn’t ask, that I felt responsible [for].

Sharon sees herself as the one who put her fetus at risk through having the operation, ‘I couldn’t have bombarded my baby with anything worse than what I did, unknowingly, unintentionally’. For her, amniocentesis was a way of ‘trying to make up for that’, of trying to right a wrong she felt she had made.

Aspects of Beck’s ‘risk society’ theory thus are useful to understand Sharon’s concepts of risk, which are central to her experience of pregnancy and amniocentesis. Particularly, the way in which Sharon conceives herself to be responsible for the management of the proliferation of risks that surrounded her during pregnancy.

The prevalence of risk in Sharon’s story can also be examined through the concept of the female body as a risky body. Sharon is living in a ‘risk society’, but she has internalised this concept so that she is also living in a risky body: ‘Oh I knew I was a risk person anyway’. Her body is a dangerous body that poses threats and entails risk. One of the risks of her non-pregnant body was that of infertility; and so intervention in the form of thyroidectomy
and laparoscopy surgery were used as an attempt to control her uncontrollable body.

Mary Douglas (1966), Elizabeth Grosz (1994), and Deborah Lupton (1999b) all illustrate the concept of the female body as a risky body. Lupton refers to the classification of bodies as ‘civilised’ or ‘grotesque’. The ‘civilised’ body is a self-contained body that is ‘tightly regulated, dry and proper’ and cultural. This is in contrast to the ‘grotesque’ body, a body that is unregulated and has boundaries that threaten to burst open; it entails a transgression between inside and outside (Lupton 1999b: 78). Earlier writers have also discussed the concept of the ‘grotesque’ body, or image. Mikhail Bakhtin (1968) referred to the ‘grotesque’ when discussing the work of Rabelais, a classical author in the tradition of folk humour. The bodies of ‘grotesque realism’ are ‘ambivalent and contradictory; they are ugly, monstrous, hideous’ (Bakhtin, 1968: 25) This is contrasted to ‘classic’ body, which is ‘a strictly completed, finished product’ that is ‘fenced off from other bodies’ and holds no signs of its growth or proliferation’ (Bakhtin, 1968: 29).

Women’s bodies tend to be culturally classified as ‘grotesque’ rather than ‘civilised’ because of their supposed leakiness, their propensity to be ruled by reproductive organs and their emotions rather than their reason, their openness to the world (Theweleit, 1987; Grosz, 1994 cited in Lupton 1999b).

Consideration of bodily fluids illustrates the female body’s position as ‘grotesque’. Douglas (1966: 121) identifies all margins as dangerous; and ‘matter issuing from [body orifices]...is marginal stuff of the most obvious kind’. Various bodily fluids are ranked on levels of control, disgust, and revulsion, so that ‘saliva and genital excretions are more pollution worthy than tears’ (Grosz, 1994: 195, Douglas 1966: 125). Female bodies are associated with leaking fluids; and Grosz queries if the female body in the west;

Has been constructed not only as a lack or absence but with more complexity as a leaking, uncontrollable, seeping liquid; as formless flow; as viscosity, entrapping, secreting...lacking self-containment...disorder that threatens all order (Grosz 1994: 203).

The female body positioned as a ‘grotesque’ body is dangerous, polluting and threatening to boundaries of social control. It is therefore a body that needs to be controlled, in Sharon’s case, through surgical intervention.
Pregnancy certainly extended Sharon’s understanding of her body as a ‘risky’ body.

I was under shared care of an obstetrician and a midwife because I had a number of risk factors, you know, first my delivery, my age, the infertility, my surgery, you know the list grew till I think I had about eight risk factors.

I had placenta previa and a vaso previa; and placenta previa is where the placenta is either down low or right across the cervix, it was over, but I also had the blood vessels over there which is even more risky. When that was found out....I had to have a minder 24 hours a day.

Sharon’s risky pregnant body continued to pose threats even at the birth, which was an unscheduled emergency caesarean. The pregnant body is also positioned as a risky body by theorists. Douglas describes things that are marginal and cross boundaries as sites of danger and vulnerability (Douglas, 1966: 121). The pregnant body is a prime example of this; it ‘challenges notions about bodily margins: it is an anomalous bodily state, a body in transition from one state to another’ and so is a source of ‘social pollution’ that requires social control (Lupton 1999b: 78). Sharon’s extremely risky pregnant body was controlled by intervention. The inside of her body was monitored by numerous ultrasound scans, her risky body was pierced by the amniocentesis needle which sought out information on the fetus at risk within; and her risky body was placed under 24 hour surveillance by a ‘minder’. All of this in an effort to control this ‘risky’ pregnant body, which Lupton describes as ‘a phenomenon beyond social control’. Sharon’s story of her pregnancy and amniocentesis experience sounds like a perilous journey that involves a dangerous villain close to home, in this case her embodied self. This fits well with how Tsing views the contemporary journey of pregnancy:

Pregnancy, childbirth, and childrearing are no longer seen as easy and ‘natural’ routes to womanhood, but as fraught with sacrifices, perils, and challenges that women must surmount (Tsing 1990: 282, cited in Lupton 1999b: 66).

Biomedical perspectives of risk

A biomedical perspective of risk that is rational and scientific is persuasive within discourse on prenatal testing including amniocentesis. The biomedical
perspective of risk aligns with both, Deborah Lupton's 'technico-scientific'\textsuperscript{57} perspective, which she identifies as entrenched within disciplines such as science, medicine, engineering, and psychology, and Ortwin Renn's (1992) description of technical risk perspectives\textsuperscript{58}. Through these perspectives, risk is understood as a 'taken-for-granted objective phenomenon'; risk is something that can be calculated and is understood as an absolute truth (Lupton 1999a: 2). Lupton describes it as a rationalist\textsuperscript{59} approach in which measurement and calculation of risk by scientific 'experts' is the most suitable way to deal with risk (Lupton 1999a: 2). Like most risk discourse in medicine, risks within prenatal testing discourse are presented as unmistakable facts; the risk of the occurrence of chromosomal abnormalities and the risk of miscarriage due to amniocentesis are both presented in this light, as illustrated through this medical article, which outlines the risks of having a Down syndrome child at birth, by maternal age:

The incidence of fetal trisomies is directly related to maternal age. The risk of having a child with a risk of Down's syndrome increases in a gradual linear fashion until about age 30 and increases exponentially thereafter. The risk of having a child with Down's syndrome is 1 in 1,300 for a 25 year old woman; at age 35, the risk increases to 1 in 365. At age 45, the risk of having a child with Down's syndrome increases to 1 in 30 (Newberger 2000: 825-32).

Renn identifies technical risk perspectives as differing from economic\textsuperscript{60}, psychological\textsuperscript{61}, and sociological\textsuperscript{62} perspectives of risk. The social sciences

\textsuperscript{57} Bruno Latour defines techno science as a term that describes 'all the elements tied to the scientific contents no matter how dirty, unexpected or foreign they seem' (Latour, 1987: 174).

\textsuperscript{58} Technical perspectives of risk are used to 'reveal, avoid, or modify' the causes that can lead to the unwanted effects. They anticipate potential physical harm to humans or ecosystems, average these over time and space, and use relative frequencies to specify probabilities (Renn, 1992: 59).

\textsuperscript{59} Rationalism was a foundation of the Protestant Ethic, which Max Weber argued was central to the birth of capitalism. Rationalism includes a sense of reduction, where the 'problem' is viewed away from influencing factors, such as the social or cultural. It is in this sense that the biomedical perspective of risk is viewed apart from its wider social, cultural, and historical contexts (Weber, 1985, Giddens, 1985, Jary and Jary, 2000, Lupton, 1999a: 2).

\textsuperscript{60} Economic perspectives on risk are the most similar to technical perspectives, and seek to estimate the degree of satisfaction or dissatisfaction connected to a possible outcome (Renn, 1992: 61-2).

\textsuperscript{61} The psychological perspective on risk substitutes scientific ways of assessing probabilities with the strength of belief that people have about the likelihood that any undesirable effect will occur. This perspective includes all undesirable effects on people that they associate with a specific cause, and it does not matter whether these 'cause-effect' relationships represent reality or not (Renn, 1992: 66).

\textsuperscript{62} There are numerous sociological and anthropological approaches to risk. Renn identifies that all of these concepts of risk 'have in common that humans do not perceive the world
have critiqued technical perspectives of risk in a number of ways that serve to highlight some of the perspectives' characteristics. Critiques of technical risk have included the following observations; technical risk perspectives do not recognise that people's values and preferences influence what they view to be an undesirable effect, the techniques utilised by technical risk perspectives cannot capture the complexity and uniqueness of human interactions and consequences, and actual risks may be increased by the institutional structure of managing and controlling risks, which is prone to organisation failure (Renn, 1992: 59). Critiques of technical risk have also centred on the power that this perspective can grant one group of people over another:

Dominance of science in risk policy making provides too much power to an elite that is neither qualified nor politically legitimated to impose risks or risk management policies on a population (Jasanoff, 1982, cited in Renn, 1992: 60).

Technical perspectives of risk are identified as 'narrow' in that they exclude social and cultural impacts. However, Renn argues that this 'narrowness' is also a strength and that technical risk perspectives do serve a purpose by providing the best knowledge about actual damage that is 'logically or empirically linked with each possibility of action' (Renn, 1992: 61).

The concept of risk has changed over time and I will draw on the work of Mary Douglas and Aaron Wildavsky, and also that of Ulrich Beck to examine this shift. Writing in 1982 Douglas and Wildavsky argue that the previous ten to fifteen years had seen a significant shift in the way we view our environment and our place in it. 'Confidence about the physical world has turned into doubt. Once the source of safety; science and technology have become the source of risk' (Douglas and Wildavsky, 1982: 10). They viewed this shift as influenced by a 'complex historical pattern of social change' that had led to a sectarian outlook. This sectarian outlook has three positive commitments; to human goodness, to equality, to purity of heart and mind; and two main dangers; worldliness and conspiracy (Douglas and Wildavsky, 1982: 10).

Worldliness within 'today's' sectarian outlook is found in big organisations and the associated 'big money' and market values – which ‘all

with pristine eyes, but through perceptual lenses filtered by social and cultural meanings' (Renn, 1992: 67).
deny equality and attack goodness and purity’. The danger of conspiracy involves transporting evil into an essentially good world. This was once understood as Satanism and witchcraft, but now as ‘hidden technological contamination that invades the body and nature of man’ (Douglas and Wildavsky, 1982: 10-11).

Beck also views a shift in the understanding of risks that has situated technology and progress as ‘risky’. Beck writes about a shift from the classical industrial society to the (industrial) risk society, where the understandings of science and technology are being ‘demystified’, just as the privileges of rank and religious worldviews were in the nineteenth century (Beck, 1992: 9-10). In the risk society the ‘logic’ of risk production dominates the ‘logic’ of wealth production, influencing a shift from the factory-related and occupational hazards or risks, of the nineteenth and first half of the twentieth century, to the risks of the risk society. Beck terms the risks of the risk society, which involve irreversible threats to the life of plants, animals and humans, as ‘supra-national and non-class-specific global hazards’: hazards which are not restricted by time (they threaten future generations) and not limited to certain localities (they cross national borders) (Beck, 1992: 12-3). Thus the biomedical perspective of risk can be located within understandings of technico-scientific or technical perspectives of risk, and in the wider historical context of risk perceptions.

Within the biomedical perspective of risk, ‘expert’ views of risk as ‘accurate’ and ‘scientific’ assessments are contrasted to lay people’s views of risk, which are seen as ‘biased’ and ill-informed (Lupton 1999a: 2, Renn, 1992: 60). This judgement on lay people’s understanding of risk was certainly present in the interviews with the consultants, which I will now discuss in more detail.

All three of the consultants referred to the women as not really understanding the risks; ‘they don’t understand actually what it means risk wise’ (Dr Jim). Two reasons were given for why the women’s understandings of risk ‘aren’t completely correct’, as noted by Dr Robert. First; an inadequate level of understanding, ‘they don’t have an abstract idea of what a big risk means’, ‘I think they underestimate and sometimes overestimate the chance of anything actually being wrong’ (Dr Paul). The second reason relates to misinformation, for as Dr Robert explains, they send out information sheets that
detail the risks to women before the counselling session. In his words: 'The other reason we made the information [was] so that they could have it in advance so they actually had some of those myths destroyed before they actually came through'.

In the context of Southern Hospital the biomedical understanding of risk is very strong. Within the interaction around prenatal testing the consultants perform the role of 'experts' who identify, calculate, and communicate the taken-for-granted facts of risk to the women. This interaction of risk communication is an important one. Steve Rayner (1992: 85) describes the dominant understanding of risk communication; as simply a transmission of quantitative information about the probabilities of risk from one person to another with the least amount of distortion. Following the dominant understanding of risk communication; the consultants at Southern Hospital communicate risk in two main ways; through an information sheet and through a counselling session. The information sheet was written by one of the consultants and includes a table of the risks of chromosomal abnormality in relation to maternal age and gives general information on a number of prenatal screening and diagnostic procedures (see appendix 1). The counselling session involves the woman and any of her support people, coming into the hospital to talk to a consultant about the risk and the different options of prenatal testing; this session is booked prior to the amniocentesis procedure. However the dominant model of risk communication, like the scientific-rational approach to risk, is missing some fundamental aspects. Apart from simple information transmission, risk communication also involves 'developing shared meaning among individuals, institutions, and communities and establishing relationships of trust' (Rayner 1988a, cited in Rayner 1992: 85). The counselling sessions were viewed by all three consultants as incredibly important for their communication of risk to the women.

The counselling session is to go right back to the beginning and explain what their risk of actually having a problem which may be based on a population risk, such as an age, or a specific risk, such as having a scan with an abnormality of the baby on it. So to talk about what their risk is, to talk about what the procedure involves and what the risks are of that procedure (Dr Robert).
Dr Paul described the importance of the counselling; 'On a scale of one to 100, probably about 110'. For all the consultants the purpose of the counselling session is to communicate risk, and they view the importance of that session as extremely high. This contrasts markedly with how the women viewed the counselling sessions. Although a few women did feel as though they had had a counselling session, the majority did not, or viewed it as an information session rather than a counselling session. When asked if they had had a counselling session before the amniocentesis most women responded: 'No, not at all' (Diane); 'No I didn't' (Sharon).

Just prior to the needle going in – I mean he sat briefly with us, there was the nurse and the consultant and he sat briefly and basically got our consent. They did say it was a counselling session – but it was more, ok you’ve thought about it, are you going to go through with it? If the baby is abnormal will you terminate the pregnancy? And that was about it really (Nina).

The counselling session appears thus to be of less importance to the women than the consultants. Although the counselling session is a time of information transmission, the fact that many of the women did not even recall attending one indicates that there is a significant lack of communication between the two groups.

The biomedical perception of risk is intrinsic as to how consultants view risk around the process of amniocentesis, however it is not the only way that the consultants understand risk. The consultants indicated that they understood the risk associated with amniocentesis in a number of different ways. For instance, the act of performing an amniocentesis procedure on a woman involved a risk of accountability for the consultants. Dr Jim questions why there is ‘fragmentation’, as he terms it, between the person who performs the procedure and the person who takes the counselling in a North American context.

When miscarriage happens they’re [the woman who miscarried] not going to go back to the genetic counsellor and say, ‘well I had a miscarriage’. They would go back to the person who performed the procedure and say ‘we had a miscarriage, you didn’t tell us about that’. So I think the person who does any procedure should take the counselling for it, nobody else.

Amniocentesis is risky for the consultants, because if something goes wrong and there is a complaint - it comes back to them. Because doctors in New
Zealand are not subject to malpractice suits, as they are in the US, there is a perception that complaints do not have much impact on them. Gaeline Phipps (2002: 27) however, has argued that this is not the case. She stresses the impact to a professional’s reputation as a ‘far more serious and frightening prospect than a threat to the pocket of their insurer’. Investigations of complaint in New Zealand are carried out in what Phipps calls a culture of ‘shame and blame’, and the impacts on doctors are high.

A study by Cunningham (2000) found that New Zealand doctors involved in investigations of complaints suffered negative impacts both in immediate feelings and long term impacts (Cunningham, 2000, cited in Phipps, 2002). The immediate feelings included; guilt, self-questioning, a reduction in the capacity to practice, loss of trust in current doctor-patient relationships, impact on relationships with family and colleagues, and a need for meaningful support. The long term impacts included; emotional responses and effects on the way doctors perceived themselves, the erosion of goodwill towards patients, the development of negative defensive medicine strategies, a negative effect on doctor-patient relationship with patients, and a change in perception towards other subjects of complaint (Cunningham 2000, cited in Phipps 2002: 27). The doctors in this study clearly viewed themselves to be at risk through performing the amniocentesis procedure, and I would argue, used the counselling sessions as a tool to protect themselves from that risk. This could perhaps explain why the counselling sessions are viewed as so important by the consultants compared to the women, many of whom, as I previously noted, did not even recall having the counselling session.

When I stick a needle into someone’s uterus I want to know that the decision was made based on relevant information, I mean I suppose the counsellors [genetic counsellors] would give relevant information, but it’s good for me to know that, you know, how they got to that decision because in the end I’m taking the risk when I do the procedure (Dr Paul).

The consultants also understand themselves at risk through performing the actual physical procedure of amniocentesis: Sticking a needle into someone’s uterus is a risky business. Atul Gawande, a surgical resident at a Boston Hospital, writes;
Medicine is, I have found, a strange and in many ways disturbing business. The stakes are high, the liberties taken tremendous. We drug people, put needles and tubes into them, manipulate their chemistry, biology, and physics, lay them unconscious and open their bodies up to the world. We do so out of an abiding confidence in our know-how as a profession. What you find when you get in close, however – close enough to see all the furrowed brows, the doubts and missteps, the failures as well as successes – is how messy, uncertain, and also surprising medicine turns out to be (Gawande 2002: 4).

Learning to perform a procedure can be a time of enormous stress for doctors. Gawande talks about learning to put in a central line in his fourth week of surgical training. Risks involved in the procedure include bleeding or lung collapse, but the chance of these happening is less than one case in 100 - in experienced hands. Gawande’s hands, of course, (at this time) were anything but experienced, and his text reveals the many attempts on various patients it took before he could ‘correctly’ place a central line (Gawande 2002: 11-21).

In a similar manner, the consultants also talked about learning to perform amniocentesis; Dr Jim described the learning process;

Like anything in medicine; apprenticeship. You watch it, do ultrasounds, and then do several supervised, then you fly alone, then you teach one. Watch one, do one, teach one.

Dr Paul thought it might have felt like any other procedure when he first performed amniocentesis; ‘which means you hope for the best, sounds horrible doesn’t it? But it’s, yeah I suppose it’s true’. Dr Robert found it scary performing his first amniocentesis procedure:

I still find them a little bit scary, simply because I’m sticking a needle, not only into the mother, but into the baby’s sac. I know also that it’s a very anxious thing for the mother and partner; I know how they feel so I think that makes me feel a bit more anxious when I actually do them.

Empathy with the patient, as Dr Robert is describing, could be another influencing factor as to why the consultants feel ‘at risk’ by the procedure. All of the women with whom I spoke for this project had confidence in the consultant’s skills (except for Lynette and Tania who both have had two amniocentesis procedures, and who both felt much more confident in the

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63 The central line is a ‘tricky’ procedure, which involves threading an eight inch long line into the patient’s vena cava, the main blood vessel in the patient’s heart (Gawande 2002: 11).
consultant who performed their second procedures). When asked if they felt confident in the consultant's skills, 'yes, totally' (Karla) was a common response. Some women described themselves as having confidence or faith in the consultant, 'I had a lot of faith in the consultant' (Melissa), 'I felt really confident in the obstetrician' (Jane). This faith in the consultants could cause the consultants themselves to feel morally obliged to perform a procedure without complications, even if it is out of their control. The riskiness of the procedure and the fact that the women have placed their faith in the consultant's abilities may have influenced a sense of risk to the consultants morally.

Anthony Giddens (1991) has written about faith in experts within modernity. Giddens identifies a key feature of modernity as the disembedding of social relations from local involvements; this is linked to the 'deskilling' of day-to-day activity. We no longer understand much of the day-to-day aspects of our lives; rather we place 'faith' in those we view as 'experts' of the particular system we are involved in (Giddens, 1991: 209-210):

All of us have some kind of 'faith' in the systems that surround us and enter into the most intimate parts of our lives – the systems that provide water, generate food production, transport us from one place to another, interpret health and disease and a multitude of other things (Giddens, 1991: 210).

Although this chapter on risk concentrates primarily on just two of the women's stories, stories that differed from the rest, it is also important, before moving on to the conclusion, to look at how the other women in this study viewed risk. For most of the women amniocentesis implied two risks; first the risk of having a baby with a genetic abnormality and second the risks of the actual procedure, such as losing a baby through suffering an amniocentesis-induced miscarriage. The women with whom I spoke, the majority of whom would probably be considered middle class, dealt with the risk of abnormality through intervention – through amniocentesis. They then dealt with the risk of an amniocentesis-induced miscarriage through faith in the medical institution; which holds a position of power through knowledge, 'I think I always value medical opinions' (Nina). The consultants, as personal representations of this power of knowledge, were the experts in whom the women had faith. In contrast, Rapp, in her study of the social impact of amniocentesis in America, talks about women who refuse amniocentesis, (a
group which by design, my own research did not include). Although there were wide ranging reasons for refusing in her study, a number of women who declined the procedure dealt with the risk of abnormality through faith; either religious faith or faith in their body’s ability to produce a healthy baby (Rapp, 2000a: 69, 177). Both these groups of women (from my study and from Rapp’s study) have ‘faith’, just in different things.

Rapp also discusses women’s understandings of risk as diverse, asserting that from the women’s point of view, depending on their past experience, any risk could seem like 100 percent or zero (Lippman-Hand and Fraser, 1979a, 1979b, cited in Rapp 2000a: 69). As an example, she contrasts the statistical understandings of some low income African-American women to that of middle-class women.

When a woman has given birth to four other children, comes from a family of eight, and all her sisters and neighbours have had similar histories, she has seen scores of children born without recognizable birth defects. This homegrown sense of statistics can be quite powerful. As a mother of three at City Hospital put it, ‘It’s almost like gambling – you aren’t likely to hit the jackpot’ (Rapp, 2000a: 69).

This is contrasted to middle-class professional women who usually would have a different sense of ‘homegrown’ statistics given their own reproductive histories. Childbearing for these women generally occurs later in life and usually involves only one or two pregnancies. There are also likely to be fewer children within their network of friends and family: For a professional woman of 36, who is pregnant for the first time, ‘the epidemiology of chromosomally abnormal births describes a universe into which her experiences in trying to control the world well may fit’ (Rapp, 2000a: 69-70). This rings true for Jane (38, Ngai Tahu / New Zealand European, Dentist) when she spoke about deciding which prenatal test she was going to use.

I...already knew the increased statistical likelihood of any genetic abnormality so I was already quite swayed in my mind that, I forget what the increased percentage was, but it’s statistics and you either pay attention to them or you don’t, but that had influenced me.

However some of the women also questioned the presentation of the statistics in retrospect.
I certainly went into it thinking there was more chance than there was, and a lot of those graphs saying, showing this huge increase after you hit sort of 35 onwards to 40. But when you look at other, I mean you look at lotto for goodness sake; the chance of you winning anything small, you know, is one in whatever – 49, but you know I never win those either (Shona, 41, New Zealand European, Early childhood teacher).

The interviews with the women and the consultants reflect the diverse constitutions of risk that revolve around the prenatal diagnosis of amniocentesis as it occurs at Southern Hospital. This resonates with the wider academic field of risk perception as well as the more specific social science endeavours that have focused on amniocentesis. In the following chapter I move on to conclude this thesis, highlighting the main points of interest in the study and further areas of interest which deserve investigation.
6.

Amniocentesis – a test in isolation?

The final chapter of the thesis turns us towards the conclusion in a study of anthropology that breaks your heart. It is always difficult to end a study, especially one that has opened up so many questions and further areas that I am interested to follow up – however, end it must. The following section seeks to place the study in context through considering the important elements of the research process, what was successful and what was less successful. It will also discuss the specifics as well as the broader implications of the findings.

This research project was fuelled by the question; ‘what are women’s experiences of amniocentesis in New Zealand?’ From this starting point the research process involved: reading relevant (mostly international) literature, participant observation of counselling sessions and amniocentesis procedures, interviews with women who had experienced amniocentesis, interviews with consultants who both take the counselling sessions and perform the procedures, as well as the midwife who assists the procedures, and the receptionist who books the appointments. In understanding the data I have drawn on narrative analysis and so looked at the various stories that surround and are generated by amniocentesis. This framework has allowed for an approach that captures both individuals’ understandings of their experiences and also speaks of the broader influences of the society upon those individuals and which they help to create.

The findings of this research project both support and at the same time disagree with, the international literature concerning experiences of amniocentesis. In agreement with the literature, this study explores the complex nature of the practice and experiences of amniocentesis and highlights discourses of risk, choice, and disability - three themes common throughout the English language literature on this practice. However, due to the small-scale and localised nature of this study, it was unable to, as much of
the literature has, focus on the influences of varying religion, ethnicity, and socio-economic positions to understandings and experiences of amniocentesis. This would be central to a more in-depth understanding of the technology in a wider New Zealand context, and is an area that requires further research.

An important area where this study has differed from the literature is in its description and analysis of the practice of the genetic counselling sessions that prenatal testing entails. In contrast to most of the literature, these sessions were taken by the consultants who also perform the procedure rather than by a specific genetic counsellor. Furthermore, participant observation and interviews with these consultants highlighted an important experience of amniocentesis that is missing from the literature – the experience of the person who inserts the amniocentesis needle. As I argued in my analysis of their interviews, these consultants themselves feel at risk by performing the procedure, and so use the counselling session to shape acceptable stories of amniocentesis. In fact, one of the most successful elements of this research was the participant observation, which allowed me to gain a sense of the practice of amniocentesis and its ‘ins and outs’ before speaking to women about their experiences.

It is important to stress that the women who shared their stories with me were not a homogenous group, but individuals whose experiences of amniocentesis were influenced by their particular life histories. However, in saying this, all of these women did receive a similar result that there were no abnormalities and so their stories ended with a healthy baby. This is indicative of the least successful aspect of this study, the significant absence of the stories of women who have received a positive test result that indicates the presence of fetal abnormality. These stories, which usually end with the termination of an abnormal fetus rather than the continuation of the pregnancy, are often tragic stories, and as the literature illustrates, such outcomes can be devastating to women and their families. Therefore, it is extremely important to hear these stories from a New Zealand context and find out (in a sensitive manner) what support these women and their families receive and what support they might require.

One of the women who told me her story, Nina, referred to amniocentesis (in the context that it just tests for chromosomal abnormalities),
as 'a test in isolation', and this phrase stuck in my mind - amniocentesis as a test in isolation - you go to the hospital, you have it done, you get the result - it's over. This is how some women might experience amniocentesis - and so therefore it is a truth of the amniocentesis experience. However, I would argue that rather than a test in isolation, amniocentesis is embedded within our physical, social, and cultural worlds in numerous and interconnected ways.

Amniocentesis, an irrevocably physical procedure, is experienced through the body and so is embedded within our physical world. Therefore it is an embodied experience that is dependent on your position to the procedure - the active body of the consultant, the resisting body of the woman, or the observing body of the anthropologist. It is an embodied interaction, in which one (or two) embodied self/selves is pierced and intruded upon by another embodied self.

Amniocentesis is also performed within and around various social interactions and so is embedded within our social world. For instance, the counselling session is one social interaction surrounding amniocentesis that is a contested site of communication and understanding between the consultants and the women. Whereas the consultants place much stress on the importance of these sessions, many of the women maintained that they did not attend a counselling session at all - despite it being routine practice within the Antenatal Clinic which they attended. Within this setting of the counselling sessions the consultants partake in the practice of genetic counselling - it has been debated whether this practice should consist of directive or non-directive counselling. Elements of directive counselling were certainly present in the sessions I observed, in which the consultants sought to shape acceptable stories of amniocentesis with a 'point'. Gender negotiation is another site of social interaction surrounding amniocentesis. Through these negotiations most of the women were placed as in charge of the amniocentesis decision, a decision they were viewed as primarily responsible for due to their role as mothers.

Amniocentesis is also embedded within our cultural world, and both generates, and is generated by numerous cultural understandings, of which motherhood is one. The technology intersects with ideologies of motherhood in various ways, and although it might not fit within the dominant Western
ideal of the all-accepting and all-giving mother, it does correspond with both the medicalised view of motherhood and with what I have termed the ‘darker side’ of motherhood in order to encapsulate the nightmarish responsibilities over life and death which motherhood has always entailed.

Understandings about the kind of babies that we want (and those we specifically do not want) are also central to amniocentesis. A perfectly normal baby is seen as the desired ideal and is contrasted to an undesirable ‘abnormal’ (disabled) baby. Prenatal tests, such as amniocentesis, have a role in assisting the avoidance of the birth of undesirable babies and have been criticised for encouraging the commodification of babies. As commodities, babies are ‘a means to an end’ (the end being a certain type of lifestyle that does not involve disability) rather than an end into themselves.

In fact, amniocentesis is also located within cultural understandings of and attitudes towards disability, which are often quite negative. For instance, the women I spoke to generally held very negative views about disability, most specifically Down syndrome. These views compel my curiosity: Just how do New Zealanders perceive the impact of that extra chromosome, which pathologically labels a person Down syndrome, on their ability to live enjoyable and ‘normal’ lives. Although the birth of a disabled (abnormal) baby was viewed as a negative in itself, it was also viewed as being accompanied by a burden of hard work, stress and pressure that would be borne to a great extent by solely the mother and so disrupt her ideal lifestyle.

Amniocentesis is also located in relation to cultural understandings of choice, which is a concept of growing popularity seen as fundamental within Western society. The concept of individual choice has been especially pertinent within feminist movements that utilised a ‘pro-choice’ slogan to campaign for women’s rights to safe and legal abortions. Prenatal tests, such as amniocentesis, have been presented within this rhetoric of individual choice, which works to link choices around testing to feminist advocacy of choice as a woman’s right. However, the extent to which the practice of amniocentesis constitutes choice has been critiqued, especially by feminists who question the extent to which this so-called choice actually exists. Even if choice does exist in the context of prenatal testing, we need to ask if individual choice (and so individual responsibility and individual blame if anything goes wrong) is really the best way to approach decisions around
amniocentesis? Maybe it is, however it is also important to note the diversity of pregnant women, some of whom may themselves be disabled. Disability rights groups have argued that prenatal tests and the selective abortion of disabled fetuses is a practice which is discriminatory or oppressive towards the disabled. This leads to questions around the privileging of rights, as the right of women to choice is pitted against the right of the disabled to not face discrimination. This is very complex terrain and requires further investigation.

Amniocentesis is also deeply connected to cultural understandings of risk. As the risky stories of Melissa and Sharon, and various theories of risk illustrated, the nature of risk is very complex. Understandings of risk impacted on these women’s actions, decisions, and their embodied sense of self. Risk was also central to the consultants, who not only understood risk from a biomedical perspective, but also identified amniocentesis as especially risky for those who perform it. In fact, the centrality of risk to pregnancy and the practice of amniocentesis is reflective of the pervasive nature of risk in contemporary society – it is increasingly the way in which we view our lives. However, it is also important to note that amniocentesis is not simply passively embedded within these complex interconnections, rather it also serves to reinforce various physical, social, and cultural understandings of the world in which we live.

One of the questions this research has forced me to ask myself is, ‘what is the point of amniocentesis?’ Diverse answers of those located at varying positions to the technology have beckoned me; the point is; to give choice, to avoid disability, to make a diagnosis, to benefit the woman, the fetus, society. It is a question that I have been unable to answer with any coherency – rather I acknowledge that even from my privileged position, with access to varied literature, and time to mull over the question, it is so very complex that I have only been able to identify the diversity of some of the answers. As this thesis has strived to illustrate, amniocentesis is not just a routine and relatively straight forward procedure – rather it is situated within a complex milieu of social interactions and abstract understandings, which work to shape women’s experiences of the technology.

As the women in this study illustrated, the technology of amniocentesis can be engaged in multiple ways. The women did not feel as if
their lives were determined by the technology, rather they approached amniocentesis with various individual agencies, and used it to fulfil different purposes, from placating a partner’s concerns, to avoiding the birth of a Down syndrome baby. It has not been the purpose of this thesis to argue if the practice of amniocentesis is right or wrong, instead it has found that the practice of this prenatal testing technology is problematic. It is problematic, because not only is amniocentesis embedded and influenced by various aspects of society, but the decision making which unfolds around the test results also work to transform society. The practice of amniocentesis implies things about society, it implies things about motherhood, disability, and the type of children we expect and will accept. It also implies things about biology, and stresses how supremely powerful biology can be when it is viewed as an individual’s destiny.
Bibliography


ELECTRONIC SOURCES:


Appendix 1
ANTENATAL SCREENING

You have been referred to the antenatal clinic to discuss antenatal screening with one of the doctors. This leaflet contains information that you may find helpful.

The vast majority of babies are born with no abnormalities but all women, whatever their age, have a small risk of delivering a baby with physical and/or mental handicap. In some cases the handicap is due to a chromosomal abnormality. Antenatal screening looks at the risk of a mother having a baby with a chromosome abnormality. Of babies born with a chromosome abnormality, Down syndrome (trisomy 21) is the most common.

The chance of this happening increase with a mother's age, as shown in table 1. The age of the baby's father does not affect this risk. Other women at risk are those who have already had a baby with a chromosome abnormality or who are known to carry one themselves. In the beginning of pregnancy, the risk that the baby has a chromosome abnormality is higher than at birth because many affected babies die naturally during pregnancy.

Table 1. The risk of a chromosome abnormality in relation to maternal age.

<table>
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<tr>
<th>Maternal age (years)</th>
<th>Risk trisomy 21</th>
<th>Risk any chromosome abnormality</th>
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<td>At amnio/At EDD</td>
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<td>20</td>
<td>1 in 1528</td>
<td>1 in 385</td>
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<td>30</td>
<td>1 in 909</td>
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<td>46</td>
<td>1 in 17</td>
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<td>47-49</td>
<td>1 in 45</td>
<td>1 in 16-18</td>
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Both screening tests and diagnostic tests are available in New Zealand and are described individually below. Screening tests give a more accurate estimate of risk of the baby having a chromosome abnormality than using age alone. They do not, however, tell you for sure that the baby has normal chromosomes. Even if the risk is low the baby could still have a chromosome abnormality but the chance of this would be small. To know for sure if the baby has normal chromosomes you would need to proceed to a diagnostic test. These tests are invasive and carry a 0.5-2% risk of causing miscarriage. This risk needs to be weighed up against the risk that your baby actually may have a chromosomal abnormality.
Screening tests.
There are two screening tests available in New Zealand.

1. Nuchal Translucency Scanning (NTS)
This test is an abdominal ultrasound scan which is performed from 11-14 weeks with a full bladder. Occasionally the view is not clear and it may be necessary to perform a vaginal scan (after the bladder has been emptied). At this scan it can be confirmed that the baby is alive and assess the gestational age by measuring the size (crown-rump length). The nuchal translucency (NT) thickness is the black space (fluid) at the back of the baby's neck as shown in the picture below (figure 1). Most babies have some fluid that can be seen on ultrasound but if there is more than a normal amount, the risk of a chromosome abnormality is increased. To calculate the risk a computer programme is used that combines the NT measurement with your age and the age of the baby. This test will pick up 80% of babies with Down's syndrome, or other chromosome abnormalities, and has no risk to the pregnancy. Depending on the new risk a diagnostic test may be indicated.

Figure 1. Ultrasound picture of the NT measurement
(as indicated by the white calipers +)

2. Maternal Serum Test
This is a blood test that can be carried out from 14 completed weeks of pregnancy to 17 completed weeks. 7mls of blood is taken and sent to National Women’s Hospital, Auckland where it is processed. The test looks at 3 hormones in the blood (unconjugated oestriol, aFP and human chorionic gonadotrophin). A calculation is then carried out using these levels along with the gestation of the pregnancy and the mother’s age. It takes about a week to get the result. This gives a new risk and once again it would depend on the result whether a diagnostic test would be indicated. How good the test is at picking up a problem varies with age as shown (table 2).
This test is not helpful with a multiple (eg. twin) pregnancy.

Table 2. Detection rate of Down syndrome, using maternal serum screening, in relation to maternal age.

<table>
<thead>
<tr>
<th>Maternal Age, years</th>
<th>Prediction detection rate, % of Down syndrome cases</th>
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Diagnostic Testing

If your risk estimate is more than 1:250 we can offer an invasive test.

1. Amniocentesis

Amniocentesis involves taking some of the amniotic fluid (water) from around the baby. The baby's kidneys make most of the fluid (urine). It also contains cells shed from the baby (skin, lungs and bladder). The cells are cultured and as they divide the chromosomes are analysed. Taking fluid does not harm the baby and it re-accumulates very quickly (about 24 hours).

Amniocentesis is usually performed from 15 weeks onwards. This is carried out in the antenatal clinic. Firstly an ultrasound scan is performed to measure the baby and to look at the fluid around the baby. Sometimes there is insufficient fluid and you are asked to return the following week. To perform the amniocentesis your tummy is cleaned with an alcohol solution and using the ultrasound as a guide, a needle is directed into the pool of fluid surrounding the baby. About 15 to 20 mls of fluid is drawn into a syringe and sent to the cytogenetics laboratory. Occasionally the needle has to be put in more than once. Local anaesthetic is not routinely used as the needle itself is very fine and most people find it only causes mild discomfort.

Figure 2. Diagram of Amniocentesis

It takes about two weeks to get the result, as the cells have to be cultured. When your result is available we will contact you by telephone. If there is an abnormal result we will ask you to come back to the clinic so that we can discuss what it means.
Even if amniocentesis is performed technically correct, it has a 0.5% (1 in 200 women) chance of causing a miscarriage. If this were to happen it would usually occur in the first 72 hours after the procedure. Symptoms to look out for include bleeding or loss of fluid from the vagina or worsening abdominal pain. If you have concern we advise you to contact your LMC or the on-call gynaecology registrar who can be contacted through the hospital switchboard on 03-4740999.

Rarely the cells from amniocentesis fail to grow (approximately 1 in 1000). If this happens the procedure needs to be repeated. This is usually known before the full two weeks. Another rare problem that can occur is when the result shows what is known as a “pseudo-mosaicism”. This is where most of the cells are normal but one cell line has become abnormal in the artificial environment of the culture. With this result we consult with the medical geneticists who advise if this is the explanation or if they are concerned that the baby is abnormal. This happens in the order of 1 in 1000.

2. Chorionic Villus Sampling

This is another diagnostic test. It involves taking small amounts of chorionic villi, which make up part of the early placenta. These cells almost always have the same chromosomes as the baby. The chorionic villi cells are cultured in the laboratory for 7 to 10 days. This test can be done from 10 weeks onwards. It has a higher miscarriage rate than amniocentesis at 1% (1 in 100 women). Because of this we do not routinely offer this test but there are circumstances when it would be appropriate.

A final note

In conclusion, we hope this has given you some background information on antenatal screening so that you can make informed decisions. At your appointment we can answer any questions you may have and organise testing as you wish.

Whatever you decide we would still recommend a scan at 20 weeks to look at the baby’s anatomy and exclude most physical defects.

Finally, it is important to remember that your baby is probably normal. Even if you have a 1% risk for a chromosome abnormality, seen as a “high risk”, there is a 99% chance that your baby is normal.

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