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Moral Bearing: The Paradox of Choice, Anxiety and Responsibility in Taiwan

Li-Wen Shih

> Because you can't see it [the foetus], it [the process of pregnancy] is very stressful. Because it is uncontrollable, you worry about its [the foetus'] condition. It is as if you had paranoia. (Mu-En Yo, 34 years old, second pregnancy)

Prenatal screening and testing (PST) is a generic term that refers to a set of medical procedures that test the health of the foetus and pregnant women.[1] It is, for example, routine that pregnant women undergo several ultrasound scans in many parts of the world. The words *screening* and *testing* are used in different situations. Screening is for those who do not have a history of family disease and is used to see if they or their foetus nonetheless might carry certain kinds of genetic disease or congenital malformations. Techniques of screening include maternal serum screening (MSS) and the nuchal translucency scan. Testing, on the other hand, is

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for those who are suspected of or known to be carrying a specific genetic disease as well as for those who have come out with a screening result that indicates high risk. Prenatal testing can be performed by either invasive or non-invasive methods, with amniocentesis being one of the most widely used invasive methods requiring the insertion of a needle into the uterus to extract amniotic fluid at around 15–17 weeks gestation.

In Chinese, "chan qian jian cha" (產前檢查) means prenatal examination or check-up, and this term includes both screening and testing. In Taiwan, people usually use "chan jian" (產檢) as an abbreviation and both "chan qian jian cha" and "chan jian" are used to refer to both screening and testing. As such, prenatal examination in Taiwan can be either screening or testing and includes a range of different medical procedures that pregnant women undergo. It does not refer to a woman's specific health condition or family genetic disease history. Moreover, it indicates that both screening and testing are implicated in prenatal examinations, and many pregnant women are actually not aware of this ambiguity and the differences it masks. To emphasise this blurriness, I use the term "PST" in this chapter not simply as an abbreviation but also to reflect its medical and social practice in Taiwan.

In Taiwan, when women become pregnant, they routinely have PST which is sponsored by the National Health Insurance (NHI) system and regulated by the *you sheng bao jian fa* (優生保健法) or "Eugenic Protection Law". They are entitled to have ten free sessions of PST. According to an official survey, 97.21% of Taiwanese pregnant women underwent PST in 2008 (Department of Health, Executive Yuan 2009: 49), and in 2013 around 90.9% of pregnant women had ten sessions of PST (Ministry of Health and Welfare 2013: 23). It seems to be "natural" for most pregnant women to undergo a series of PST procedures as the pregnancy advances. But what is the significance of PST? As I will show, the experiences of pregnant women in Taiwan provide us with a particular answer to this question which is shaped by the kind of society they live in.

When conducting fieldwork to investigate women's experience of PST in Taiwan in 2008 and 2009, I had an impression that my participants worried a lot. On average, the participants in my ethnographic study underwent around 13–15 sessions of PST—more than what the

Department of Health recommends. There were particular issues that concerned them. The health of the foetus was one of them. Their worries led me to investigate further how women in Taiwan experience PST through observations in prenatal care hospitals and clinics, by interviewing 35 women (in some cases their husbands as well) and also by asking them to make a drawing of PST which was then discussed during interviews. As I will argue, their anxiety is related not only to technological and medical practice but also to the social construction of responsibility for prospective mothers in Taiwan. In particular, the construction and routinisation of PST technologies as selective reproductive technologies (SRTs) compel women to judge their own foetus, turning them into the kind of moral philosophers that North American anthropologist Rayna Rapp described as "moral pioneers" to highlight how developing PST technologies produce new ethical decisions for pregnant women. In her book *Testing Women, Testing the Foetus*, Rapp (2000) suggests that women act like moral philosophers when faced with decisions about whether to accept further testing or refuse it during routine prenatal care. As Laura Heinsen (this volume) also discusses, Rapp argues that the women she interviewed in New York who were using or refusing amniocentesis can be seen as moral pioneers because they are historically the first generation to face moral decisions about whether to terminate a pregnancy depending on the health condition of the foetus; a decision previous generations did not have to face. When women are constituted as subjects at the intersection of either choosing to have a disabled child or terminating their pregnancy they are "culturally" positioned as moral philosophers who have to judge what kind of child can enter our community.

Since Rapp's pioneering study which was carried out in the 1990s, SRTs have advanced globally, and women throughout the world cross moral frontiers during the course of prenatal care. As Danish Anthropologist Tine M. Gammeltoft (2014: 18) observes, "in China and Vietnam, present-day population policies focus on the improvement of population quality", so to improve pregnancy outcomes through enhanced prenatal care becomes an important issue in those countries. In Vietnam, Gammeltoft observes that this brings women anxiety and uncertainty, particularly those women who receive PST results indicating that their foetus has an abnormality. In a country haunted by images of malformed

and disabled children blamed on Agent Orange which circulate through media reports and television programmes, Gammeltoft shows how pregnant women actively tried to avoid seeing such images for fear that the images would stay in their mind thereby negatively impacting their foetus (Gammeltoft 2014: 95). Even in a country like Denmark, which emphasises the importance of individual choice, eugenic orientation is still embedded in the prenatal care system. Laura Heinsen (this volume) uses the term "moral adherers" to illustrate how routinised prenatal care practices in the Danish welfare state implicates a "collectivized responsibility of selection" that has integrated into individual/reproductive choice, and that this results in Danish women taking PST for granted as part of routine prenatal care, uncritically adhering to the tests. Choice is never only personal, and that is because it reflects one's social belonging (Gammeltoft 2014). In Tsipy Ivry's (2010) book *Embodying Culture: Pregnancy in Japan and Israel*, Ivry uses two prenatal care models: "environmentalism" and "geneticism" to discuss women's experience of PST in Japan and Israel. In Japan, Ivry shows how physicians emphasise pregnant women's roles as the "'makers' [through weight control and proper nutrition during pregnancy] of their babies rather than the receptacles of genetically determined, 'ready-made' babies" (Ivry 2006: 459), which helps explain some of the resistance to routinised PST she met among doctors. The point being that no matter which prenatal care model women experience, these models are always connected to their social-cultural settings.

During my fieldwork in Taiwan, I observed that almost all of my participants persistently worried about the health of the foetus throughout the whole pregnancy, not just when they had to decide about amniocentesis or other tests. Significantly, as I will show, most of the women in my study are concerned about the burden to society when imagining a disabled child. Because of the health care system, medical practices as well as social and family values in Taiwan, women in my study encounter different difficulties than those in America or Europe. To highlight the specific Taiwanese social and cultural context, I use the term "moral bearing" to indicate Taiwanese women's situatedness at a moral frontier in Taiwan. The idea of "bearing" is, according to Merriam-Webster online dictionary,[2] the way in which a person moves, stands or behaves; and it also means *to bear* from its verb which is "to accept or endure (something)" or

"to support the weight of". In addition, a bearing can also be a machine part that makes it possible for one part of a machine to support another. In this chapter, I take these meanings to imply women's moral enacting in PST in a context where societal expectations and personal desires are often conjoined. Because they bear concerns about their foetus's health and the burden to society when imagining a disabled child, pregnant women actively undergo different routine prenatal checks and these checks bring them anxiety. In the following sections, I use my participants' experiences of PST to illustrate how their anxiety is triggered by their sense of responsibility of having a genetically healthy child which is based on the notion of *you sheng* (優生) or "superior birth", and also how their decisions, in return, help to reshape this moral terrain.

Prenatal Care in Taiwan: *Maternal Health Handbook and You Sheng*

In Taiwan, after ten weeks of confirmed pregnancy, a woman will receive a copy of the *Maternal Health Handbook* (*yun fu jian keng shou ce*,孕婦健康手冊) from their obstetric clinic or hospital (Fig. 5.1). Its purpose is to introduce the different stages of pregnancy and to provide information on different kinds of genetic diseases to pregnant women. It is also a documentary record for obstetricians to keep track of the health of both the foetus and the woman. As noted earlier, pregnant women can have ten free sessions of PST by showing their *Maternal Health Handbook* when visiting an obstetrician. With this handbook, women will be referred to different scheduled PST programmes, including ultrasound scans and MSS. Therefore, in Taiwan, the *Maternal Health Handbook* is seen as both an identification of the woman and a document for medical records.

The *Maternal Health Handbook* is published by the Taiwanese government and is informed by the "Eugenic Protection Law" (literally "superior birth protection health law"). This law was passed in 1984, regulating birth control, including fertility, prenatal care and abortion. *You sheng* is often translated from the English term "eugenics", which has a stigmatised association with ethnic superiority. In Chinese, *you* (優) means "the best" or "superior", and *sheng* (生) as a verb means to give birth or to produce,

Fig. 5.1 The front cover of the *Maternal Health Handbook* (Chinese version)[3]

while as a noun it means "production" depending on the semiotic context. Hence, the term *you sheng* in Chinese means "superior birth" and has a positive meaning in Taiwan. However, as historian Yueh-Tsen Chung (2002: 11) suggests, when this term is used in the context of PST, it seems to be strongly related to the option of terminating an undesired pregnancy, for example, following the discovery that a foetus is carrying a genetic disease or congenital malformation. This connection has perhaps surprisingly not resulted in the term *you sheng* being viewed negatively in the general public. Different public opinion investigations (Discovery Channel 2003; Fu 2004: 245; 2005: 125) have shown that the public generally is positive towards the development of this type of selection. Without entering a discussion on foetal rights (which is relevant but not within the scope of this chapter), but instead with a focus on pregnant women's experiences, this chapter shows that choosing a child from a *you sheng* perspective is far from unproblematic as it turns women into what we might think of as "moral bearers" during their pregnancies amidst considerable gestational anxiety.

Tracing Taiwanese Women's Experience of PST

Sunny Days and Rainy Days

On 27 February 2009, a television news report about an infant born without a right hand described the parents accusing the obstetrician of medical carelessness because it was not discovered during ultrasound scans (Fan 2009). Although the news media reported this for only two days, it significantly affected pregnant women at the time of my study. It shocked couples who feared that it might happen to them and also affected obstetricians who were flooded with enquiries from couples seeking reassurance on this matter. During my observations in prenatal care hospitals and clinics, many couples were concerned about this issue. Obstetricians responded by trying to show pregnant couples where their foetus' hands were and even counting the foetal fingers carefully, making sure the couples saw what they were being shown. Whilst conducting interviews with pregnant women, interviewees would ask me if I knew the news. What made the biggest impression on me was that whilst my participants told

me it would be really terrible and unbelievable if it happened to them, it was not the obstetrician's medical error per se, rather it was the possibility of having a child with this kind of problem that seemed to trigger their anxiety, underlining how pregnant couples in Taiwan fear anything that might be wrong with the foetus. For pregnant women, as Hong-Lan Din described it in her drawing, it is like experiencing a rainy day.

Hong-Lan has a very creative reflection on her experience of undergoing PST. She drew a woman standing in both a sunny day and a rainy day (Fig. 5.2). When we afterwards talked about her drawing, she explained:

> In general, having PST for me is always full of happiness and fears. It is sometimes like a rainy day, but also sometimes like a sunny day. As a pregnant woman, the feelings are always very complicated, because you expect to have a check [ultrasound scan] to see the baby, but you also worry about hearing bad news. So it is always like that (Hong-Lan Din, 29 years old, first pregnancy).

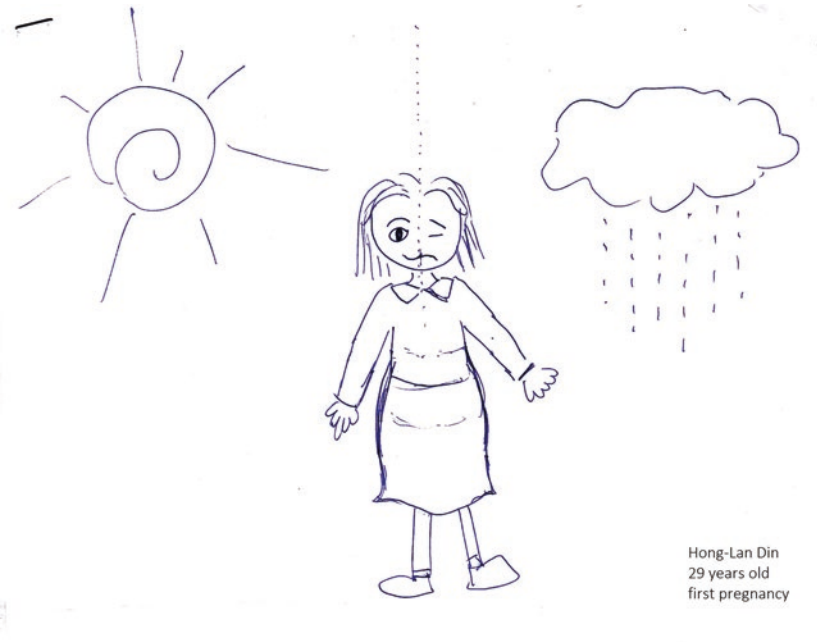

Fig. 5.2 Hong-Lan Din's drawing: Sunny days and rainy days

Having PST enables women to see the foetus on the ultrasound monitor and to know its health condition. That pleases them, but it also makes them anxious, as most of my participants' narratives suggest. Hong-Lan's drawing and description illustrates both her pleasure and anxiety in PST. She drew a woman who has two different faces and stands in two different weathers because she is not sure which one she is going to have; but these feelings are not opposite to each other, they always come together as her drawing shows. This kind of uncertainty, as another of my informants Mu-En Yo describes, is like a lucky dip.

A Lucky Dip

Mu-En drew a lucky dip (Fig. 5.3) to describe how PST makes her feel uncertain and anxious. She told me:

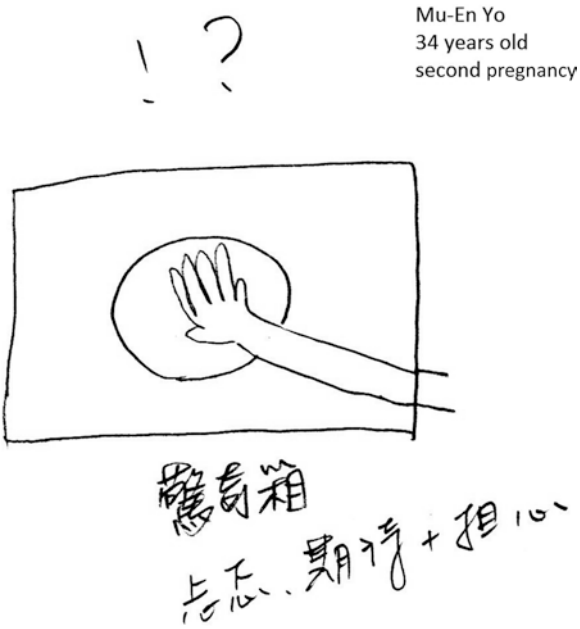

Fig. 5.3 Mu-En Yo's drawing: A lucky dip

> It is as if you put your hand into a lucky dip. And you will never know what you are going to get from the black box. So for me having PST is full of anxiety, expectation and worries. Because during each visit you don't know what your obstetrician is going to tell you. … Therefore you are full of anxiety when you go into the clinic. I always look forward to visiting the clinic, but I also worry a lot (Mu-En Yo, 34 years old, second pregnancy).

The word in Chinese 驚奇箱 (*jing chí xiang*) that Yo puts on the top of the drawing means "surprise box" and translates into "lucky dip" in English. Lucky dip is "a game in which people choose a present from a container of presents without knowing what it is going to be" (Oxford Advanced Learner's Dictionary 2000: 800). This opacity brings uncertainty; it is unpredictable. To express her complicated feelings towards having PST Mu-En Yo uses three words: "tan te" (忐忑, anxieties), "qi dai" (期待, expectations) and "dan xin" (擔心, worries). In this way, Mu-En's experience of ambivalence corresponds to Hong-Lan's sunny and rainy days. But what is it that triggers women's anxiety? According to Mu-En "You will start to worry whether or not you will pass the prenatal screening and testing after you received the Maternal Health Handbook." Mu-En started to worry after receiving the handbook, not when she discovered she was pregnant. For Mu-En, the handbook stirred her anxiety. Two of my other study participants, Yi-Zheng Hsu and Hsiao-Huei Chen, also shared this experience: "the more I know the more anxious I am" (Hsiao-Huei Chen, 33 years old, second pregnancy). Knowing more information may trigger women's anxiety but taking part in testing maintains this constant disquiet. It is as if women are carrying a heavy basket of eggs, as Wan-Ni Lee's drawing (Fig. 5.4) illustrates.

A Heavy Basket of Eggs

To explain her drawing, Wan-Ni said:

> For me, having PST feels like I am caring for these eggs. It is like caring for this basket of eggs, and it is not easy. […] When undergoing the procedure, I feel lots of expectations and anxieties. I worry I won't be able to hold the basket well, or that maybe there is a problem with the basket, and the eggs will fall out. I mean if there is any problem with it. My feeling is totally like that.

Fig. 5.4 Wan-Ni Lee's drawing: Holding a basket of eggs

> Because I think what makes pregnant women worry is that there might be some problems detected with the baby. Therefore I felt cold during every PST, especially around my feet and hands because I was so afraid that the obstetrician would tell me there is any problem with my baby (Wan-Ni Lee, 32 years old, second pregnancy).

At first glance, Wan-Ni's drawing looks like a happy woman who is holding a basket of eggs. However, after hearing Wan-Ni's description, this does not seem to be the case. During our conversation, I could see from her body language that she was very worried and anxious about the health of the foetus. Wan-Ni described her anxiety as stemming from her own uncertainty about her capacity to hold and protect the basket.

When I asked further about what makes her feel so nervous during PST, she explained:

> Sometimes I think about …hmm…what would I do if anything happened to baby or if the baby was detected with some defect? […] Many friends told me that I was thinking too much. I understand that many things are not controllable so I feel anxious and helpless in every PST ….Therefore every time when I look at the monitor, I always just do a quick scan of the image of the foetus. Then I turned my head and tried to avoid seeing more of it. So when the obstetrician was showing the foetus, I always did a quick scan only. So for me, PST is like having to care for this basket of eggs, but it is actually not easy (Wan-Ni Lee, 32 years old, second pregnancy).

Even though Wan-Ni successfully gave birth to a child in her last pregnancy, she still experienced a lot of anxiety. When talking about her fear and uncertainty in PST her eyes welled with tears. It is clear that her anxiety is associated with uncertainty and lack of control concerning the health of her foetus: "I understand that many things are not controllable so I feel anxious and helpless in every PST." This triggers her anxiety because she is afraid of having to decide between a termination or having a disabled child. Whilst she agrees with her friends that she is overthinking the risks, this doesn't allay her fears. As Wan-Ni points out "once it happens to you, it is something that can't be changed back for the rest of your life".

In contrast to Wan-Ni's anxiety, her husband Chi-Jie Shih sees PST as a "good thing":

> I don't feel that PST is very troublesome. I do think it is necessary to have. It is good for the baby. If the result of PST shows abnormality, if the baby is anomalous, we would know earlier and therefore make the decision earlier (Chi-Jie Shih, 31 years old).

I interviewed the couple separately, Chi-Jie first, then Wan-Ni. When interviewing Chi-Jie, his positive attitude towards PST was clear; he saw it as a helping hand. He did not appear to be emotionally burdened by the experience, taking a more practical perspective: for Chi-Jie, PST could help him to make a decision earlier if the foetus is "anomalous".

The decision-making that Chi-Jie talked about is the same thing that concerned Wan-Ni: "what would I do if anything happened to the baby or if the baby was detected with some defect?" However, imagining making this decision upsets Wan-Ni a great deal, whereas Chi-Jie seems to remain calm.

To understand how Chi-Jie experienced PST, I also asked him to draw a picture that answered the question: "What is PST for you?" Chi-Jie drew a pregnant woman undergoing an ultrasound scan done by one obstetrician (Fig. 5.5). He did not put himself in the drawing. Interestingly, I found that almost all my male participants drew only the PST technology, the obstetrician and the woman. They position themselves as outsiders in the course of PST. This echoes other studies which show that women usually do more and take more responsibility than men when engaging in reproductive technologies (Wu 2000, 2001; Franklin and Roberts 2006; Throsby 2004; Rapp 2000). This means women experience more

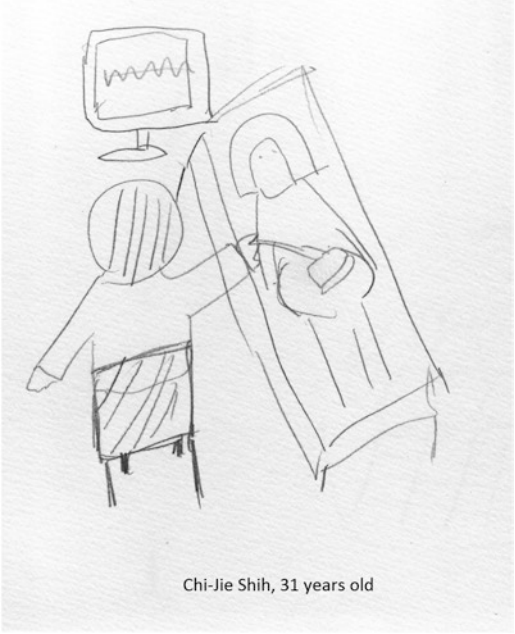

Fig. 5.5 Chi-Jie Shih's drawing: A woman with an ultrasound scan

pressure than men, as shown by studies in both the USA and Taiwan (Rapp 2000; Wu 2000, 2001). As Rapp (2000: 127) explains:

> Most of the technological augmentation of anxiety is expressed by women, not only because pregnancies happen inside of women's bodies, but because most (perhaps all) cultural constituencies in contemporary America assign the benefits and burdens of making and raising babies to women.

Rapp suggests that the American women in her study are often the ones who disproportionately bear the burden of rearing children. Even though men's involvement in childrearing may be a social goal, women do the hard work of living with pregnancy and facing PST. She sees this as an instance of "male privilege" (Rapp 2000: 182). In a similar vein, Celia Roberts (2006) suggests that men's role in reproductive process is gendered through social and medical practices which constitute women within an uneven distribution of responsibility for decision-making. In Vietnam, decisions arising from PST are often taken not by women alone, rather following consultations with extended family members. Yet, even in such situations of collective decision-making, Gammeltoft has argued that it was the women who alone struggled with the "dilemmas of conscience" surrounding selective abortion (Gammeltoft 2014: 223). In my study, the main reason that makes Hong-Lan, Mu-En and Wan-Ni worry is not only the burden that they bear, but also the moral decisions they may have to make. As Wan-Ni asks, "what should I do if anything happened to the baby or if the baby is detected with some defect?" This difficult question positions them as "moral pioneers", yet as we will see, not necessarily in the same manner as women in America or Europe might be.

Amniocentesis: Accounting for PST

According to a national survey from 2008, there were 330,000 pregnant women who underwent amniocentesis, an increase of 95.9% from 1998 (National Statistic ROC, Taiwan 2009: 49). However, this number represents pregnant women who were sponsored by NHI only. If counting those paying the examination fees themselves, the number would

be higher. While conducting my fieldwork, I found that many young women requested to have amniocentesis. Many of them were less than 30 years old, and thus not within established risk categories, and therefore had to pay the examination fee of 8000 NT dollars (around 170 British pounds). Without clinical indication, some women still decided to have amniocentesis even if it is one of the more expensive self-pay medical examinations in Taiwan and increases the risk of miscarriage.

Shu-Lan Hua told me the reason that she engaged with amniocentesis:

> The purpose of amniocentesis is to see if the baby carries some possible disease. And the accuracy for maternal serum screening is only 50–60% reliable for seeing if the baby has the problem. However, amniocentesis is 99% reliable for seeing if the baby carries Down's syndrome. Therefore we of course chose the latter one even if it is a bit scary. I heard that most Down's syndrome children were born by young women. Especially when I heard a story from one of my friend's wife, I had decided to have amniocentesis. She gave birth to a Down's syndrome child when she was 22. Her maternal blood screening is very low, so she didn't have further testing. After hearing this, I wanted to have amniocentesis straight away. I had it in my last pregnancy, so I did it again this time (Shu-Lan Hua, 26 years old, second pregnancy).

Learning from a friend's experience and other sources of information, Shu-Lan was convinced that MSS is not reliable enough, so she decided to have amniocentesis in her first pregnancy even though she was only 23 years old and had no family history of Down's syndrome or any genetic diseases. As she emphasised, the reliability of MSS is about 50–60% compared to 99% in amniocentesis. For Shu-Lan, MSS does not provide a certain answer. In contrast, she thinks that amniocentesis does. This "technological accountability" implies a certain kind of purpose (Franklin and Roberts 2006: 228). Clearly for her it is important to know whether the foetus has Down's syndrome or not, as she does not want a Down's syndrome baby, as she told me, "we can make the decision earlier if we know the result earlier", which was similar to Chi-Jie's ideas. Like some of my other participants, Shu-Lan explains why she made the decision to have amniocentesis: to know for certain whether the foetus has Down's syndrome (and other genetic defects) or not.

Many of my participants were keen to know the health condition of the foetus. To ascertain a definite answer, they all chose to have amniocentesis, as Yi-Ling Sue suggested, "PST can ease your anxiety" (Sue, 29 years old, first pregnancy). However, although some women think that PST can ease their worries about the health of the foetus, at the same time, it can also produce more anxiety as I learnt from Wan-Ni's and Hong-Lan's experience.[4] In the next section, I use Hsue-Juan Zhang's description of PST to illustrate how decision-making about whether or not to have amniocentesis is an anxious process.

To Do or Not to Do: Visiting Four Obstetricians in Five Days

As already noted, within Taiwan's health care system, pregnant women are entitled to have ten free sessions of PST, and they can choose to visit any clinic or obstetrician for these. During my fieldwork, I found that many of the participants in my study engaged with a form of prenatal care "shopping" when they were anxious and seeking a second opinion.

> They told me it [the white spot] could be detected as Down's syndrome because my baby is big enough that time, so they could find it through ultrasound screening. I think the obstetrician checked very carefully. I didn't know that the cyst in the brain could cause Down's syndrome. Through last Friday, Saturday, and Sunday, I suffered a lot. It was really difficult for me because every obstetrician had a different opinion. It was the holidays and we went back to our home town of Yi-Lan. On the Friday night, we went back to Yi-Lan after visiting Wu's clinic, and we discussed with in-laws. All the family came and discussed about how to sort it out together. My in-laws worried a lot. […] They suggested I visit an obstetrician in Yi-Lan. The obstetrician thought that it is alright and I shouldn't worry so much. […] After I visited that obstetrician, they worried a lot. They worried if having amniocentesis would hurt the baby. They decided that I should have a maternal blood test first. Therefore we decided to have a maternal blood test (Hsue-Juan Zhang, 30 years old, second pregnancy).

Hsue-Juan recalled the days when the obstetrician revealed a cyst in the brain of her foetus, and how it worried her and her family. To get a second opinion, she was advised to visit another obstetrician. To avoid miscarriage, she was advised by her in-laws to have a MSS. In Hsue-Juan's case, her family was involved with the decision-making.[5] However, Hsue-Juan was so upset that she fainted after the blood sampling. She told me "I worry it [amniocentesis] might hurt the baby or cause a miscarriage. I also worried about if the result is positive."

Hsue-Juan's anxiety is twofold: firstly, the foetus may have Down's syndrome; secondly, amniocentesis may cause a miscarriage. Even though the obstetrician in Yi-Lan city advised her not to worry too much, she was still anxious. Two previous obstetricians had advised MSS, but it seems their efforts did not comfort her. However, she made her mind up after consulting a third one.

> So after two days, on the morning of 6th of April, we went to visit Wu's clinic again, to visit another obstetrician, Dr. Wu, to have another check again. During the course, he knew my situation and asked us what we want to know. He said 'Do you want to know if the risk [of having a Down's syndrome child] is high or low? Or do you prefer to know if you can pass this test?' In other words, he meant that having amniocentesis is very common nowadays. So his suggestion was we could go straight to have an amniocentesis. That's the reason we visited Ke clinic after seeing him at the same day.
>
> (Interviewer: Really? Did he say having amniocentesis nowadays is very common?)
>
> Yes. He said it is very common, and it is not a big deal. He told us that his wife and many nurses in his clinic, who are under 30 years old, all had amniocentesis. He thought it was absolutely fine. He also thought that miscarriage is rarely caused by it. He meant that the percentage of miscarriage after having amniocentesis is not high. He also told me that he has nothing to do with it if finally the result of amniocentesis is positive. He meant that it is not his responsibility if it does happen like that (Hsue-Juan Zhang, 30 years old, second pregnancy).

Hsue-Juan finally decided to have amniocentesis after visiting Dr Wu, the third obstetrician. She seemed to be convinced because the obstetrician

gave her direct advice. What is more, Dr Wu spoke to Hsue-Juan's anxiety more directly and asked her what she was actually looking for: "Do you want to know if the risk [of having a Down's syndrome child] is high or low? Or do you prefer to know if you can pass this test?" It is clear that Hsue-Juan seeks the latter but that this is also what triggers her anxiety because this "test" embodies both medical and social discourses. Dr. Wu's emphasis on Hsue-Juan's responsibility if an undesired result were to occur raises a question: what kind of responsibility is this? I would argue that Dr. Wu's account of responsibility is misleading, and that in fact this responsibility is unevenly distributed to Hsue-Juan. When Dr. Wu told Hsue-Juan about the health of the foetus, he participated in a moral judgment about it. Dr. Wu told Hsue-Juan that "it is common to have amniocentesis" which implies selection and termination, but he deflects the responsibility for this onto Hsue-Juan. This is what triggers Hsue-Juan's anxiety; she is made to feel responsible for the result whatever it is.

Moreover, I also want to argue that women's anxiety and decision-making imply their responsibility for *you sheng*. The women I interviewed are influenced by *you sheng*, a discourse and policy which places emphasis on having a healthy child, and this involves women's responsibility for having further genetic testing, even though this includes judging the quality of their own foetus and the possibility of termination. This is what puts women at a moral threshold as all the women in my study made their decision by referring to *you sheng*.[6] As such, I use the term "moral bearing" to indicate that Taiwanese pregnant women are positioned in ways unique to Taiwan especially as a result of the wide acceptance of the idea of *you sheng*—an idea that contributes to Taiwanese pregnant women constantly imagining and worrying about their child becoming a burden to society. In addition, as I will argue, in the Taiwanese context PST places pregnant women in a paradoxical position.

Paradox: The Responsibility and the Choice

In Hsue-Juan's story, Dr. Wu sees PST as an examination of a pregnant woman. So his directive suggestion is to have amniocentesis to see whether Hsue-Juan will pass or not. This conceptualisation is also

expressed by Mu-En, Hsiao-Huei and Pei-Yian. As Pei-Yian said, "PST is like an exam, and it matters whether you pass it or not" (Pei-Yian Tsai, 31 years old, second pregnancy). Seeing PST as an exam could certainly trigger anxiety in women because no one likes to fail an exam. For me, this "exam" implies a negative attitude towards the foetus and the woman. So, what if they fail it? When I asked Pei-Yian about this, she said:

> If it is confirmed that it [the foetus] does not develop well [with Down's syndrome], it is better to terminate within 24 weeks. So it is very difficult for women (Pei-Yian Tzai, 31 years old, second pregnancy).

Pei-Yian's suggestion that when the foetus is confirmed with high risk of Down's syndrome, "it is better to terminate within 24 weeks" is based on termination law in Taiwan. According to Article 9 of the "Eugenic Protection Law", women are allowed to terminate a pregnancy when the foetus is diagnosed with a malformation based on medical evidence; or when women are mentally or physically affected by the pregnancy in a negative manner. However, in Pei-Yian's statement, what "is very difficult for women" is their failure of the "exam", imagining having a disabled child and undergoing a termination.

> I worried about my baby with Down's syndrome; of course I worried about it. I was afraid of having a kid with Down's syndrome since it will bring more burdens for our country (Hsue-Juan Zhang, 30 years old, the second pregnancy).

Seeing one's own child as a burden to society could be difficult. Hsue-Juan is not alone in conceiving of disabled children as a burden to society. Other participants, like Chi-Jie, Wan-Ni, Hong-Lan and Chiao-Wong Lian, also expressed this to me during interviews:

> [Chiao-Wong Lian:]Once you give birth to him/her, you need to take the responsibility. You need to take care of him/her through your whole life. This is your responsibility, and you can't abandon him/her. […] But people will ask why you gave birth to this kind of child and they probably will discriminate against the child.

> The earlier you undergo the test the better decision you can make about the foetus. My obstetrician also suggested we engage with CVS [chorionic villus sampling] since it is the part of the prenatal checks we can have in the early stage. Then we can make a decision if there is a problem with the foetus. [What decision?] I meant terminating the pregnancy. You know, I shouldn't deliver it if my baby carries thalassemia. It will bring lots of social costs and be a burden to the whole society (Yi-Zheng Hsu, 31 years old, first pregnancy).

When seeing disabled children as a burden to society, my participants' attitude towards termination is clear. It seems as if they are not concerned about disability rights or abortion. As I will discuss later, this kind of impression could mislead us when probing the paradox of PST.

Only 2 out of 35 participants who participated in my research said that they would not terminate the pregnancy if the foetus was detected with Down's syndrome. The rest all said that "the earlier you make the decision the better it is" (Tzi-Xing Huang, 34 years old, second pregnancy). Wen-Feng Tu was one of the outliers in the group, she described her determination not to terminate her pregnancy:

> I had maternal blood testing, and the data was higher than average. So my obstetrician suggested I have amniocentesis….I asked my obstetrician what is the purpose of doing this. My obstetrician answered that it is a kind of testing which has higher accuracy to detect if the foetus has Down syndrome. He said that we [my husband and I] can consider terminating the pregnancy if the result of amniocentesis is positive. I told my obstetrician that there is no difference for me because my decision will never change no matter whether the foetus has Down syndrome or not (Wen-Feng Tu, 32 years old, first pregnancy).

Wen-Feng told me that she saw many friends and colleagues experience anxiety and pressure "because they all want to avoid having a disabled child". As she suggests:

> This kind of decision is the result of bringing hospitals and pregnancy together. It is also because of *you sheng* expectation of pregnant women and their family, they together construct this kind of idea (Wen-Feng Tu, 32 years old, first pregnancy).

As Taiwanese scholars Chiang et al. (2005, 2006) suggest, the routine checks of PST help to construct a specific life attitude of *you sheng* (some women they interviewed explicitly emphasised *you sheng*). As they argue, not only does this kind of routine check shape ordinary people's attitude to disability, the idea of *you sheng* is also implicit in the *Maternal Health Handbook* (Chiang et al. 2005). "When women are encouraged to have amniocentesis, they also internalize discriminatory beliefs concerning disabled people" (Chiang et al. 2005: 74). What is more, because of this *you sheng* attitude, most women see disabled children as a burden to society. When women are imagining disability and facing reproductive decisions, they found that *you sheng* becomes one of the important factors that helps them to make their decision (Chiang et al. 2005). Chiang et al.'s research resonates with my observation that most of my participants use *you sheng* to justify their decision as morally sound. As Mei-Hua Lee suggested to me, "[a]s you know about *you sheng*, we shouldn't give birth that is not *you sheng*" (Mei-Hua Lee, 34 years old, first pregnancy).

From Wen-Feng's and Hsue-Juan's experience of PST, it is clear that their obstetricians delineated their choices; obstetricians are actively involved in pregnant women's decisions during the course of their prenatal testing. In this case, the choices available to pregnant women are not as free and open as the medical establishment suggests. Tom Shakespeare (1998: 676) contends that genetic testing technologies are never neutral "because the possibility of obtaining prenatal genetic information inevitably creates new problems and dilemmas". Testing and selection are made desirable through PST.

Although PST makes women anxious, they still rely on it. "PST is one of the things I like the most in my pregnancy, but it is also the one I am most scared about" (Wan-Ni Lee, 32 years old, second pregnancy). This paradox corresponds to Hong-Lan's drawing; it is like sunny days and rainy days coming to women together. This paradox demonstrates the complex intertwinements of *you sheng*, morality, technoscience and women's reproductive choice. It also illustrates how women, as moral bearers, are constituted in morality and choice in Taiwan. Another paradox, as I have argued earlier, is that having PST appears to be an individual choice where women are themselves responsible for their decision-making; however, this idea of PST is in fact socio-technically

constructed through *you sheng*, medical professionals and technological practice, and it can therefore be questioned to what extent we are actually dealing with individual choices.

Conclusion

The choices of the pregnant women who participated in my study are shaped by the medical, social and moral terrains within which they are situated. However, once made, these decisions, in turn, reshape the social and moral terrain. What is more, participants' decisions are informed by moral debates concerning the health of the foetus and avoiding bearing a child who will burden society. Their anxiety indicates that making this decision is difficult because it involves collective values. Rapp uses the term "moral pioneers" to indicate that both accepting or resisting having testing involves participating in a set of values and reshaping the social and moral terrain. I found this to be the same in my research. Yet, by extending Rapp's discussion on moral pioneers, I use the term moral bearing to identify the difference between the women in Rapp's study and my work. Almost all my participants participate in articulating the moral value that a disabled child is a burden to society, and in return, their decision helps to confirm that value. Prenatal decision-making embodies those distributed actions and enacts biomedical and social values. My participants' decision-making and also their anxieties demonstrate the context of moral bearing that they are constituted in. Most women in my research chose to have further testing and indicated that they might terminate the foetus if the result is positive, but this attitude is not only an expression of individual moral, it is interwoven with the idea of *you sheng*, medical practices and family relations (particularly important is pressure from in-laws). All of those factors together push women to the intersection of a moral frontier to judge their unborn foetus during PST. More specifically, women act as moral bearers, their decision-making does not only intertwine with medical professionals, technoscientific practices and social values, but also enact moral judgements of women's reproduction.

However, as we have learnt from these women, their choices usually also reflect their individual experiences and religion. As Wen-Feng

suggests, having a disabled child is a challenge for parents. To some extent, Taiwanese women's attitude to terminating the pregnancy seems to stem from a practical approach which is similar to that Gammeltoft found in Vietnam and different from the women in Rapp's study who seem to be pushed at the intersection of abortion and disability rights. Women's choices may be constituted in social and biomedical practices, but women are not passively participating in the process. Instead, their choices and positions as moral pioneers indicate the material-semiotic relations in which they are embedded in. One significant paradox in my findings is that Taiwanese women seem to rely more on technologies and medical professionals to ease their anxieties even as their anxieties are triggered by these same practices. It seems as if women's anxieties cannot be stopped once they are constituted in Taiwan's routinised PST programme.

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Notes

1. This chapter is part of my PhD thesis. A version of it appeared in Chinese in the Taiwanese Journal: *Taiwanese Journal for Studies of Science, Technology and Medicine* 21: 77–134.
2. Please see the website: http://www.merriam-webster.com/dictionary/bearing (last accessed 15/9/2016).
3. Please see Bureau of Health Promotion, Department of Health (2008).
4. This is similar to what Gammeltoft found in her study in Vietnam: "Although many women said that they found ultrasounds anxiety-relieving, their stories indicated that fetal images were also anxiety-producing" (Gammeltoft 2014: 90).
5. As some studies show, a woman's pregnancy is not just a personal issue in Taiwan, particularly because it embodies patrilineal reproduction (Stafford

1992; Chen 1990; see also Gammeltoft 2014 on Vietnam). It is a family issue. The sex of the foetus concerns the family, so does its health. This imposed lots of pressure on women in my study. In particular, when the in-laws participated in decision-making, it both made women stressed and made them feel like the foetus was more important than them. For example, Wei-Lun Wu (33 years old, first pregnancy) said that "they only care about the foetus not me".

6. See Zhu (2013) for a discussion of how maternal serum screening has become a part of a "quality assurance regime" which enlists pregnant women to take active measures of self-assurance in the People's Republic of China, not least with direct reference to *you sheng* discourses.

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