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"No one to consult! That is the hardest part" Choice-making experiences for prenatal screening tests among Japanese women and their spouses in Austria - a qualitative interview study

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Abstract

Objective

Japan is the only country in the world that allows abortions due to economic reasons but illegalise them due to foetal anomaly. The objective of this study was to explore the choice-making experiences for prenatal screening among Japanese women and their spouses in Austria.

Methods

We conducted a qualitative study using semi-structured face-to-face interviews with Japanese women and their spouses in Austria. Data were analysed using thematic analysis.

Results

Twenty-five participants (14 women and 11 men) took part in the interviews. Four themes were identified: 1) Knowledge, information and memory; 2) Communication and interactions with health professionals; 3) Reasons for choice; and 4) Emotional support. Participants had limited knowledge and experienced directive counselling. Women expressed negative emotions in the choice-making processes, did not perceive husbands as a source of support and lacked a person to consult.

Conclusion

There are common characteristics among East Asian population despite different context and differences found between our Japanese participants and women in other European countries.

Practice implication

Proactive interventions aimed at increasing knowledge that help women to develop their preferences and reflect on their values could be further promoted among women of all socio-cultural backgrounds in Austria.

Keywords: prenatal genetic screening, Japanese, Austria, informed decision, directive counselling

1. Introduction

The risk of having a child with autosomal trisomies (21, 18, and 13) increases with age [1]. With rising maternal age [2], non-invasive prenatal screenings are routinely offered to pregnant women in many Western European countries. Informed choice based on adequate knowledge and a decision which is in accordance with the preference and values of a woman is the guiding principal in implementing any prenatal screening and diagnostic tests [1]. Nevertheless, in recent years the non-invasive nature and the lower risk possibilities of miscarriage in implementing prenatal screening tests have led some health professionals to neglect the patients' informed choice-making process and to carry out such tests in a routine manner [3, 4].

Little is known about the experiences and the factors that influence choice-making for prenatal screening among the East Asian women in Western European countries. A literature review indicates poorer knowledge and lower likeliness of making informed choice for prenatal genetic screenings among the women of Asian origins compared to the host populations in Western countries [5]. Other studies suggest cultural and familial values, such as respecting the feeling of family members [6], valuing the views of 'significant others' [7], considering societal values [8], or unfamiliarity with the concept of autonomous choice [9] to have strong influences on choice-making for prenatal screening among the East and South East Asian women and their spouses.

Japan is a unique country in Asia as it is the only country in the world that allows abortion due to economic reasons but illegalise them due to foetal 'anomaly' or 'impairment' [10]. National guidelines in Japan recommend prenatal screenings to be performed on a request-base accompanied by genetic pre-counselling for all types of prenatal screening aimed at detecting foetal anomalies [11]. Thus many obstetric-gynaecologists are generally reluctant to offer the

screening tests [12, 13]. The system for conducting prenatal screening is underdeveloped [14], supply is limited [11] and thus uptakes for prenatal aneuploidy screening are extremely low − remaining under 5% in 2012 [13, 15].

The actual uptakes rates in other East or South East Asian countries in which abortion is legal are unknown. Nevertheless, we assume them to be higher than in Japan especially in countries where prenatal genetic screening is promoted by the government (China) [16], recommended routinely to all pregnant women regardless of age (Singapore) [17] or has long been incorporated into routine prenatal examinations (Taiwan) [18]. Exception could be South Korea where many physicians are found to be reluctant to offer prenatal genetic screening to all pregnant women despite abortion due to foetal impairment being legal [10, 19].

In Austria, abortion due to foetal anomaly is legal [10, 20]. Prenatal examinations are free of charge but prenatal screenings to detect foetal anomalies are not. Types and frequencies of prenatal examinations are guided by the Mother-Child-Pass programme. Taking these required examinations are not obligatory but are stipulations to receiving childcare benefit [21, 22]. Prenatal screenings, however, are not part of the programme and pregnant women willing to undertake prenatal screening tests such as the nuchal translucency (NT) test, organ screening, second trimester combined tests or the non-invasive cell-free DNA testing (known as NIPT) need to pay the extra cost themselves [23, 24]. Costs would be paid by the social insurance when valid reasons for testing are provided by the physicians [24, 25, 26]. For details of the major types of screening tests offered in Austria and their price, see Appendix A.

Although it is not part of the social insurance scheme, prenatal genetic screening is considered as one of the important elements of the Austrian public health policy [25]. There are, however, no

national guidelines or policies in Austria that stipulate how and to what extent health professionals should offer prenatal screening tests that can detect foetal anomalies to pregnant women [27, 28] except for some recommendation papers developed out of individual initiatives [29, 30]. There are also no centrally collected statistics on the uptake rates for prenatal screening and diagnostic tests in Austria either. Each hospital and screening centre collects own data. These data are rarely linked with demographic data such as ethnicity, education or socio-economic status [28]. A recent report, however, indicates relatively high public acceptance and uptakes of prenatal genetic screening among the Austrian population [31]. The Austrian Social Insurance Association estimated the uptake rate of any prenatal screening to detect foetal anomalies to be as high as 90% among all pregnant women over the age of 35 in 2017 [23]. This is equivalent to the organ screening rate among the pregnant women in the Netherlands [32].

There are around 25,000 East Asians (defined as those born in China, Hong Kong, Japan, Macau, Mongolia and South and North Korea) in Austria making up 1% of the entire non-national-born population. There are more female (60%) than male and 66% (16,400) are between the age of 18 and 49 [33]. 68% of the East Asian-born population in Austria are from China, followed by the Japanese (15%). In 2017, there were 2,875 Japanese registered in Austria. 70% (or 2,013) were female of which 86% (or 1,610) were in their reproductive age between 18 and 49 years old. 67% of the Japanese live in Vienna (1,926) [33]. Being one of the extreme minority ethnic groups, there have been hardly any studies on Japanese immigrants' health in Austria. It is important to make the voices of ethnic minority population heard in order to ensure informed and ethical choice for prenatal screening among women of all backgrounds.

Therefore, the aims of this study were to: (i) explore the choice-making experiences of Japanese women and their spouses for prenatal screening tests to detect foetal anomalies in Austria and (ii) identify factors that could influence informed choice-making among this ethnic minority group.

2. Methods

We conducted a qualitative interview study on knowledge, perspectives and experiences regarding prenatal screening and on the choice-making factors among Japanese women and their spouses in Vienna, Austria.

2.1. Sampling and recruitment

Our sample included 25 participants (14 female and 11 males) from which 14 sets of interviews were collected (11 couple and three female-only interviews). Participants were recruited through purposeful, snowball and maximum variation sampling [34]. The first author (Y.S.) contacted two active members of a Japanese mothers' community network and asked them to introduce her to the others. We invited all spouses to participate through their wives. Inclusion criteria for women were: 1) Japanese national born and grew up in Japan; 2) over the age of 18; 3) gave birth in Austria between 2013 and 2016; 4) have gone through prenatal examinations in Vienna; 4) able to hold an interview in Japanese, German or English; and 5) not pregnant at the time of interview. Inclusion criteria for spouses were 2) and 4). We did not interview pregnant women to avoid the situation in which the participants became aware of some procedures during the interview when it was too late to carry out such tests. No women declined but three husbands refused to participate in the interview due to time constraints. We asked all couples to be interviewed separately but only one out of eleven couples agreed. Time and convenience were given as reasons. The transcripts of the separately conducted couple interviews were combined

into one. This study was approved by the Ethics Committee of the Medical University of Vienna (1622/2014). All 25 participants gave individual written consent to take part in the study.

2.2. Data collection

Semi-structured interviews were conducted with all participants. The interview schedule was developed, pilot-tested and translated. The English interview guide can be found in Appendix C. Y.S. who is an experienced interviewer conducted all interviews between June and October 2016. Interviews were all done face-to-face in Japanese, English and/or German, or in the mix of two of these languages according to the preferences of the study participants. Languages used in the interviews were 83% Japanese, 9% German and 8% English (see Appendix D for detail). When participants had limited knowledge about prenatal screening tests, the interviewer prompted questions on specific types of screening as outlined in Appendix A. Basic demographic and background data of the participants were collected through a one-page questionnaire prior to the interview. Y.S. transcribed all interviews verbatim and translated the non-English texts into English. The accuracy of the translation was verified by an external professional trilingual translator. Y.S. is bilingual in Japanese and English with an advanced knowledge of German. The second author E.M. is a native German speaker with an advanced knowledge of English.

2.3. Data analysis

The unit of analysis is 14 interviews composed of eleven couple-interviews (one being conducted separately) and three interviews with women only. We used thematic analysis following Braun and Clarke's 'six phases of analyses' [35]. Two coders (Y.S. and E.M.) read the first three transcripts to familiarise themselves with data, took notes and exchanged preliminary ideas. The transcripts were then coded independently line-by-line. We ensured the accuracy of

translation by Y.S. coding the transcripts in the original languages of the interviews and E.M. coding the translated English transcripts. Coders met after coding each transcript and compared the results. We considered the quality of translation to be high when two coders designated similar or same meanings to the same quotes. When there were discrepancies, we checked if these were due to inaccurate translation or due to differences in the interpretation of the data. Subtle nuances and unclear meanings of the translations were discussed and clarified. Discrepancies were discussed and solved by consensus.

Initial codes were re-grouped and formulated into potential themes. Based on these themes, new participants were recruited, interviewed, and their interview transcripts added to the dataset. Themes were further revised to ensure good 'fit' with newly identified codes. Additional recruitment stopped when saturation was met. We considered the data reaching saturation when the analysis of three consecutive sets of interview did not reveal additional codes nor themes. The process of sampling and saturation can be found in Appendix B. The sample size of 14 fulfils the indicative recommended sample size for a rigorously conducted thematic analysis [36, 37]. Definitions of each overarching theme, higher-level theme and code, were discussed and finalised with a senior researcher (T.S.) who had not been involved in the analysis of the data. Atlas.ti software [38] was used in coding, managing and re-organising the data. As a final step, a professional Japanese-English-German translator who was not involved in the study verified the accuracy of the translation and validated their 'fit' to each theme and sub-theme [39].

3. Results

3.1. Participants

Demographic characteristics of the participants including spouses' nationalities and the actual screening tests undertaken are depicted in Table 1.

Table 1. Descriptive statistics of the study participants (N=25)

	Women: n = 14	**Spouses: n = 11**
Age in years at the time of interview		
Median	38.5	42.0
Range	29-43	28-51
Age in years at first birth n (%)		
≥ 35	6 (43)	3 (27)
< 35	8 (57)	8 (73)
Numbers of multipara mothers and age (%)	9 (64)	
Age in years at second birth		
≥ 35 and < 40	2 (22)	
< 35	4 (44)	
≥ 40	3 (34)	
Number of years living in Austria prior to birth		
Median	2.5	
Range	0-9	
Employment status in Austria (%)		
Employed	3 (21)	11 (100)
Unemployed	11 (79)	0 (0)
Education (%)		
High-school/College	2 (14)	1 (9)
Bachelor	8 (57)	5 (46)
Post-graduate degree	4 (29)	5 (46)
Nationalities (%)		
Japanese	14 (100)	4 (36)
Austrian	0 (0)	4 (36)
Others (Asian, European, North American)	0 (0)	3 (27)
Screening tests undertaken (%)		
Organ screening	14 (100)	-
Combined test (NT+serum test)	6 (43)	-
NT only (without serum test)	1 (7)	-
NIPT	1 (7)	-
Not sure if serum test was done	4 (29)	

All couples were married and had health insurance. More than half of the women were over the age of 35 at first birth reflecting the demographic characteristics of Japanese female population in Austria. Eleven women (79%) had lived in Austria less than 3 years prior to giving birth. At least one of the four screening tests was offered to every woman. Two women had a prior wish

to undertake the combined test before it was offered to them (interview 3 and 13 for her second child only). All other women were either unaware, undecided or have not yet thought about their options until the screening tests were offered. In eight out of the eleven couple-interviews, women talked much more than men, two couples talked the same amount and in one couple-interview the man did more talking (see Appendix D. for detail). One male had hardly anything to say about the topic.

3.2. Results of the qualitative analysis

We identified 51 codes and grouped them under 14 higher-level themes and finally under four overarching themes: 1) Knowledge, information and memory; 2) Communication and interactions with health professionals; 3) Reasons for choice; and 4) Emotional support. The analysis of 14 sets of interviews revealed differences between female and male as well as between first and second pregnancy . The overarching themes, higher-level themes and original quotes are summarised in Table 2.

3.2.1 Knowledge, information and memory

Ten interviews revealed very limited pre-knowledge on the types, purposes, timings of the tests and how they were organised in Austria. Lack of knowledge led to being surprised and feeling unprepared to make a choice. In most cases, spouses expressed similar levels of knowledge regarding prenatal tests as their wives except two couples whose women clearly had more knowledge than their Japanese husbands (interview 3 and 7). Multiparous couples had increased knowledge about the Austrian healthcare system and understood better what the health professionals were talking about.

Eight interviews showed that women and their Japanese spouses collected information in Japanese and from Japanese sources. They tended to assume that screening tests were organised in a similar way in Austria. More than half of the interviews revealed memory confusions due to too much new information given in a short time and lack of understanding to what kind of tests were actually undertaken. Memories and understanding were only slightly clearer with the second child. Some participants referred to their Mother-Child-Pass but they did not found it useful in keeping records and tracing memories related to prenatal screenings.

3.2.2 Communication and interactions with health professionals

Ten interviews revealed negative experiences with health professionals. Participants often felt pressured or directed by the health professionals to undergo the screening tests. They were shocked and surprised with health professionals' casual attitudes towards the tests. Multiparous couples were less shocked the second time, but some felt more pressured to take the test because of their age. Five interviews revealed positive experiences with their physicians such as feeling of being provided with an option or feeling supported. This was expressed by two women and three non-Japanese male.

Half of the interviews revealed passivity in communication with health professionals. The passive attitude in communication did not change with the second pregnancy. Three interviews revealed language difficulties due to technical terms used in prenatal screening. in Only one non-Japanese male and one woman said they actively asked questions to their physicians. Midwives were not considered as health professionals to consult by any of the participants in the study.

3.2.3 Reasons for choice

Factors influencing the choice for taking or not taking the tests were manifold but clustered around three higher-level themes: following health professionals' advice and going with the flow; accessibility, availability and cost; and age. Ten interviews showed the screening uptake or non-uptake being highly influenced by doctors' advice. Two couples said they thought that the prenatal screening test was compulsory. While similar reasons were given for the second pregnancy, some women became more proactive in their choice or gave more deep thoughts about their choice. All multiparous women went through the same or more types of screening tests for their second pregnancy (see Annex B). Seven interviews revealed accessibility, availability and costs to be important factors for both the first and the second pregnancy. Some women and couples felt barriers to uptake much lower in Austria than in Japan. Age was mentioned in six interviews in which four women specifically referred to the age above 35 as being a risk factor. Other choice-making factors included 'wanting to feel relieved or better to know than not to know' (n=3); risk to the foetus is high or low (n=2); prioritising husband's wish (n=1); consideration to the first child (n=1); it was too late (n=1); curiosity (n=1); and genetic risk in the family (n=1).

While the couples mostly agreed on the reasons influencing their choices, in three couple interviews, males and female stated different reasons. One Japanese husband thought they 'went with the flow' but his wife expressed 'conscious choice' (interview 3). An Austrian husband stated his clear preference for not taking the test while his wife expressed much more ambivalent feelings of 'wanting to just feel relieved' (interview 6).

3.2.4 Emotional support

Ten interviews revealed that talks about the prenatal screening were consciously held between couples and with family and friends. Eight out of these ten interviews showed that couples talked

about the tests but avoided having deep and open conversations and making concrete joint decisions before the test. While three women expressed doubts about this avoidance strategy, one husband thought it was 'good to forget'. Four women expressed frustrations that they did not have any deep conversations with their husbands. They felt their complex emotions could not be shared with their husbands. Male expressed more ease in making choice and sticking to it while this was difficult for women. Women tend to speak more openly about these issues when they were interviewed alone or separately from their husbands. An exception was one highly acculturated and working woman who expressed that the choices were mainly made by her with equal emotional involvement from her husband (interview 4).

Four women said they talked about the prenatal screening with their female Japanese family members or friends. Being able to talk gave them a sense of relief as they felt that it was a topic that could not be openly shared with everyone. One woman said despite talking with her friends she had no one to consult. Talking with relatives in Japan made two women become aware of the differences in Japan and Austria. Austrian friends and colleagues were also consulted but only through non-Japanese spouses.

Table 2. Overarching themes, higher-level themes and quotes related to choice-making experiences (n=14 transcripts)

Overarching and higher-level themes	Experience with first birth (n=14)	Experience with second birth (n=9)
Theme 1. Knowledge, information and memory (n=11)		
1.1. About prenatal screening tests and the related system in Austria (n=11)	n=10 *"I guess it was a requirement for the child benefit, right? Those required check-ups are listed in the Mother-Child-Pass and [they said] we have to be quick because it has to be done in a certain period" (interview 1, female).*	n=6 *"The doctor introduced the test the way he did it with the first child. The difference was that I could understand better what he was talking about" (interview 2, female).*
1.2. Collecting information in	n=6 *"I think I got most information from*	n=2 *"At that time, as far as I knew from the*

Japanese (n=8)	*Japan. And most of it, I guess, found on the internet" (interview 8, female)* *"I'm not even sure if it's a screening test, but I read in a [Japanese] book that doing the test can possibly lead to miscarriage" (interview 7, male).*	*people around me and what I read [in Japanese] was that such new test [NIPT] has started in the US and China. But in Japan the access was limited. I did not even know if such test was available here [in Austria] so I assumed that it would probably not be possible to go through such a test here either" (interview 2, female)*
1.3. Memory and records (n=8)	Uncertain memories/understanding: n=3 *"At the interview I said I didn't remember taking up the combined test but I had taken it" (post-interview E-mail communication 8, female)*	Uncertain memories/understanding: n=3 *So did you do the NT?(interviewer)* *What is NT? Oh yeah that one. The doctor just checked with the ultrasound, I guess (interview 5, female).*
	Reliance on written records: n=5 *"It must be written somewhere here [searching through the Mother-Child Pass]. It can't be that nothing is recorded in the Pass about the screening, right?" (interview 1, male).*	Reliance on written records: n=1 *"For the second child, I thought we went through some blood tests in addition to the NT but on the test-centre's document, none of those items were ticked (post-interview E-mail communication 1, male).*
Theme 2. Communication and interactions with health professionals (n=14)		
2.1. Negative experience (n=10)	Feeling pressured/directed: n=10 *"Well the doctor took it for granted that I do the combined test like 'you goanna do it, right?'" (interview 10, female).* *"We said 'we are also doing NIPT' and I remember the doctor was like 'Why would you do that?' I thought it was a bit you know, not exactly objective as far as a doctor" (interview 11, male).*	Feeling pressured/directed: n=4 *"Because of my age [=39] (female)* *They scared us, right?" (male)* *(interview 1, female and male).* *"The doctor wanted me to do at least the organ screening. He asked me several times – 'have you already done it?' have you done it?'" (interview 6, female).*
	Surprised, shocked or irritated: n=4 *"The doctor talked in a normal ordinary way and I asked 'what kind of thing is that?' and he casually said 'It's a screening test'" (interview 3, female).*	Surprised, shocked or irritated: n=2 *"It was rather a shocking way of communicating, right? (interview 1, female)* *Yes, right (interview 1, male)* *Oh yes, I was a little shocked" (interview 1, female)*
2.2. Positive experience (n=5)	*Felt being provided with an option: n=4* *"The combined test was optional. We asked ourselves if we wanted it or not. Before that we just had some leaflets, right?" (interview 8, male).* Felt supported in the choice making process: n=1 *"Our doctor was very kind. She called us and offered support in case of an unfavourable result, right? She wanted to mentally support us (interview 9, male)"*	Felt being provided with an option: n=1 *"They explained to us different types and timings of the test and said 'they are only for those who want to do it. Do you want to do it? There is this and that kind of risk…'. That kind of general explanation was given to us and we said 'Yes'" (interview 4, female).* Felt supported in the choice making process: n=0
2.3. Way of communication:	Passive communication: n=6 *"I guess the doctor would have had answered if we had asked, but we did not*	Passive communication: n=4 *"To tell you the truth, for the second child, I did not meet the midwife at all before birth.*

Passive (n=7) Active (n=2)	*ask anything" (interview 14, female).* <u>Actively inquired: n=1</u> *"I think we asked about the NIPT to our doctor because it was something that we had researched about and we knew that 'OK we probably want to do this' so we asked her" (interview 11, male).*	*We talked only on the phone" (interview 2, female).* <u>Actively inquired: n=1</u> *"I wanted to do OSCAR here in Austria so we returned from Japan with that timing and I consulted my obstetrician immediately. I also told him that I am concerned with my age" (interview 3, female).*
2.4. Language barrier (n=3):	<u>n=2</u> *"I usually do not bother reading my examination results but when I got the prenatal testing result I checked the words in my electronic dictionary, did research on Japanese internet sites and tried to interpret it but I could not really understand what it meant" (interview 14, female).*	<u>n=1</u> *"For that follow-up examinations in the hospital, I could not follow the medical jargons so I hired a Japanese doctor as an interpreter" (interview 12, female).*
Theme 3. Reasons for choice (n=14)		
3.1. Following health professionals' advice and going with the flow (n=9)	<u>n=8</u> *"For the first child, I did not know anything so without thinking too much. Going with the flow as the doctor says, yes, right" (interview 2, female)* *"Requested it? No, no rather going with the flow" (interview 3, male)*	<u>n=4</u> *I thought it is something that everyone does it so I just did it [NT & OS] (interview 12, female).* <u>Thought and acted more proactively: n=5</u> *"I decided for myself [to do the CT after talking to a Japanese female friend] (female). My wife decided (male)" – interview 9, interviewed together.*
3.2. Access, availability and cost (n=7)	<u>Access, availability and cost: n=6</u> *"We said 'we would like to try NIPT' and we were allowed to do it on that day on the spot. We had no appointment. I thought I would have to come again on another day but on that day they said 'OK, we got it'! (interview 11, female).*	<u>Access, availability and cost: n=5</u> *"For the first child it was too expensive for us. We had a private doctor and an additional cost of 350 Euro would have been too much. For the second child [we changed to a public doctor] and thought we should do it also out of consideration for the other child" (interview 13, female).*
3.3. Age (n=6)	<u>n=4</u> *"Because I was 35. I belonged to the so-called age-group of 'elderly birth'" (interview 8, female).* *"Just because we were both a bit older and you know that the chances of some sort of genetic disorder is a bit higher, so I thought it was worth checking" (interview 11, male).*	<u>n=4</u> *"For the second child I got pregnant at the age of 38 and gave birth at 39. So that time, on the contrary [to the first experience], I thought about lots of things like considering amniocentesis in case of a unfavourable outcome, things like that (interview 2, female).*
3.4. Different reasons within the couple (n=3)	<u>n=2</u> <u>*Interview 3, couple interviewed separately*</u> *"They had more advanced test methods here than in Japan. They also said, it is a kind of test that does not affect the foetus,*	<u>n=1</u> <u>*Interview6, couple interviewed together*</u> *"Every time I went for a check-up, I wanted to feel relieved knowing everything was OK" (female)* *I asked her "What if we found trisomy?*

	and in case the baby should have a problem they could be prepared for treatment right after the birth. I thought of my age [too] and decided to do it." (female) <u>versus</u> *"Went with the flow" (male)*	*Would you like to terminate pregnancy? No. Then it's the same. We do not do it" (male)*
Theme 4. Emotional support (n=10)		
4.1. Avoidance strategy (n=8)	<u>Avoiding discussing and thinking hard: n=3</u> *"So if there were some problems what shall we do? We did not give a concrete answer to that question. We do the test, see the result and then think about it" (interview 8, female).*	<u>Avoiding discussing and thinking hard: n=5</u> *"If the result were so-and-so what would we do? That level of discussion we were not able to have" (interview 5, female).*
4.2. Reflection on avoidance strategy and perception gaps (n=8)	<u>Reflecting on avoidance strategy: n=2</u> *"When I think about it now, I don't know what we would have had done if we got an unfavourable result" (interview 8, female).*	<u>Reflecting on avoidance strategy: n=2</u> *"I am astonished how vague our memories are. On the other hand, we forget good things as well as bad things and that allows us to continue living taking things easy like this" (E-mail communication 1, male).*
	<u>Reflecting on perception gap with spouse: n=4</u> *"He [my husband] said "we will do it". Well [different from my husband] I was a bit calmer and was contemplating if I should really take the test [NIPT], also because it was quite expensive. Well, it costs much less than in Japan but if you think calmly for a while.. For him [in a small voice] it was like, if the result was unfavourable….then we had to give… give up" (interview 11, female, interviewed with husband).*	<u>Reflecting on perception gap with spouse: n=3</u> *My husband's honest opinion was that we have to take into consideration the option of giving up. Otherwise, there is no point doing the test, according to him. That is logical and I very much agreed with him, but as my belly grew bigger and bigger, I was not sure if I could stick to such a thought and I was increasingly becoming uncomfortable with my decision [of doing the test]. So, I emotionally struggled but not my husband (interview 2, female interviewed alone).*
4.3. Talking to friends and families (n=7)	<u>Talking to relative and friends in Japan: n=2</u> *"By coincidence my cousin [in Japan] was also at a similar stage of pregnancy and we always told each other over the phone what kind of prenatal check-ups we did and she said 'What? We don't have that kind of prenatal screening tests here!' She said they didn't even mention it. I told her it was compulsory in Austria" (interview 14, female).*	<u>Talking to relative and friends in Japan: n=3</u> *"That's why I kept this topic only to my very close friends. The waiting time felt really long. When I got the [negative] result I could finally tell my Japanese friend" (interview 2, female).* *"I consulted my friend in Japan but having no one here to consult, that was <u>really</u> the hard part!" (interview 13, female).*
	<u>Consulting Austrian friends: n=3</u> *"My male Austrian friend who is also a doctor said 'no, no, it's not necessary to do the test'. We were relieved to hear that, right? (interview 6, Austrian male)* *"I asked some of my female co-workers who were pregnant at that time" (interview 11, North American male).*	<u>n=0</u>

4. Discussion and conclusion

4.1. Discussion

To our knowledge, this is the first study that investigated the prenatal screening experiences of a specific sub-group of East Asian women and their spouses in Austria. In line with previous findings on studies among Asian women in Western countries [5, 6, 8, 9, 40], we observed low literacy on prenatal screening tests, unfamiliarity with the concept of informed-choice or 'patient autonomy' and the strong influence of familial factors in the choice-making experiences of our Japanese participants. This indicates some common cultural features among this ethnic group, especially among the East Asians [41]. In terms of gender roles, we observed striking similarities between our Japanese female participants and the South Korean women interviewed in the US. Jun et. al. [9] found that less acculturated South Korean women tend not to directly communicate their emotions with their husbands and felt frustrated with their husbands' passive attitudes in joint-decision making. At the same time, a possible heterogeneity within the East Asian population are highlighted. For example, Chinese Americans seem to have favourable attitudes towards routinised prenatal genetic screening in the US [42, 43]. In contrast, our Japanese participants were rather sceptical or surprised with the routinisation.

Our study indicates overall passivity in making choice and a tendency in delaying concrete choices. Although these are in line with findings among women in other European countries [44, 45], we observed a strong contrasts in many other aspects. For example, Chen et al. [44] and Aune [45] found that Finnish and Norwegian women felt well supported by their husbands and health professionals in their choice-making process. Crombag et al. [46] made similar observation among Dutch women regarding support from midwives in the Netherlands. Although women in our study perceived husbands to be an important person to talk, none of

them explicitly stated feeling emotionally supported. Few women perceived health professionals as a source of emotional support. According to Chen et. al [44], a majority of Finnish women in their study reported having positive experiences when making choice, feeling well informed and confident, and not feeling pressured to take the tests. Many of our participants stated negative experiences with health professionals, did not feel sufficiently informed, were insecure with their choice, and felt pressured to take the test. While Finnish women seem to expect 'easy and quick' choice [44], female Japanese participants in our study anticipated pre-counselling and more time to contemplate. In regards to parity, literature suggests more knowledge, less information needs and less screening uptakes among multiparous women compared to nulliparous women [32,47]. Among our multiparous women, knowledge regarding prenatal screening tests did not substantially increase, we observed increase in uptakes and increased suffering for not being able talk to someone about their choices and the tests.

One of the strengths of our study was keeping high standard translation of different languages so that original meanings and nuances were not lost. Another strength was to include males' perspectives and also compare between nationalities. Japanese spouses talked very little about issues related to prenatal screening tests. Non-Japanese male participants tend to express more explicitly the feeling of being supported by health professionals. This could be related to language and cultural barrier and requires further investigation. Men tended to accept the avoidance strategy more than the women and expressed more ease in making choices. Women interviewed alone tended to speak more openly about the perception gaps with their husbands. The researchers were aware that interviewing couples together could have had limited individuals to talk more freely and this is one of the limitations of our study. Nevertheless, guided by rigour of analysis, we are confident to state that code and theme saturation have been

met allowing us to identify the main thematic issues of concern among our specific sample of population [48]. In our study, only three women had paid jobs. This could have influenced our findings especially in regards to acculturation, access to local social networks and information. Future study could compare experiences of women interviewed alone to those interviewed with their spouses. Furthermore, comparison could be made between employed and non-employed immigrant women. Males' perspectives on prenatal screening could also be investigated further.

A limitation of our study is that we could not compare our participants' experience with that of the Austrian women since we did not find any published studies on this topic. Instead, we compared with studies from other European countries. The fact that prenatal screenings to detect foetal anomalies are not free of charge in Austria could have had influenced the experience of our participants. We recommend further studies in Austria with Austrian women and with other immigrant population, or comparative studies with Japanese women in other Western European where screenings are free of charge or where screenings are offered together with pre-counselling and information session by midwives [32].

4.2. Conclusion

This study is the first-of-its-kind study conducted in Austria as well as in a non-English European country context. We found similarities among the East Asian population despite different context and differences in experiences between our Japanese participants and women in other European countries. Furthermore, our study contributes to the body of knowledge on East Asian women's and their partners' choice-making experiences of prenatal screening that can detect foetal anomalies in Western countries and especially in Western Europe. We found

common issues as well as a range of diverse socio-political, cultural and gender factors that affected informed choice-making for prenatal screening among this ethnic group.

4.3 Practice Implications

Our study indicates that the principal of informed choice for prenatal screening is not fully realised under the current system in Austria. Lack of information and knowledge, the value gap between Japan and Austria, the perception gap with their husbands and lack of proactive and emotional support led to difficulties in determining preferences among our female participants. Information is a key in developing one's preference. Our participants sought information but it was not comprehensive, and was provided in a rushed, ad-hoc and directed way. Additional support and proactive interventions to increase knowledge on prenatal screening are known to significantly contribute to informed-choice making among women of all education levels and especially among the non-Western ethnic minority groups [49, 50]. Such approach, taking into consideration the various factors identified in this study, could be further promoted in Austria as well as in other Western European countries to ensure informed choice which is in accordance with the preference and values of women of all socio-economic and cultural backgrounds.

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Conflicts of interest

No conflict of interests.

Author contributions

Y.S. conceived and designed the study and oversaw its completion to the end. Y.S. also conducted all interviews with study participants and transcribed and translated them. Y.S. and E.M. coded and analysed the data and T.S. provided input to the analysis and process. Y.S. drafted the manuscript, with input from all other authors. All authors read and approved the final manuscript. I confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

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Appendix A.

Non-invasive Prenatal Screening Tests for Detecting Foetal Anomalies Commonly Available in Austria

Genetic or non-genetic	Name of screening	Description	Timing, method and price
Non-genetic screening	**Organ screening**	Detects the malformation of the foetus's organs (and prepare for treatment)	18-22 weeks: Ultrasound Approx. 150 EUR
Genetic screening for detecting chromosomal anomalies (a pre-step to diagnostic tests)	**Nuchal translucency (NT) screening**	Detects chromosomal anomalies –Trisomy 21 (Down syndrome); Trisomy 18 and 13. Measures the thickness of a space at the back of the foetus's neck. An abnormal measurement means there is an increased risk that the foetus has Down syndrome or another type of aneuploidy. It is also linked to physical defects of the heart, abdominal wall, and skeleton. The special ultrasound method can also detect heart failure or other organ malformation.	11-14 weeks: Special ultrasound Approx. 100 EUR
	Combined test/OSCAR (One Stop Clinic for Assessment of Risk)	Calculates the risks of chromosomal anomalies of Trisomy 13, 18 und 21 from the combination of: NT screening; Crown-rump length measurement; Alpha-fetoprotein screening (AFP): serum test from mother's blood (Beta-HCG und PAPP-A); and Maternal age AFP test can also detect the possibility of neural tube defect (spina bifida) which is not caused by chromosomal anomalies.	11-14 wks: Ultrasound and blood test Approx. 150 – 230 EUR
	NIPT (non-invasive prenatal test) cell-free DNA testing	Screens the cell-free DNA that is released from the placenta into a pregnant woman's bloodstream. Screens trisomy 13, trisomy 18, trisomy 21 and problems with the number of sex chromosomes (that determines sex). Offered in Austria since Autumn 2012.	From 10 weeks onward Approx. 600 – 800 EUR

Source: L. Glöckner, J. Haas, Pränatales Screening in Österreich : Combined Test versus zellfreier DNA-Test, Bericht - Hauptverband der Österreichischen Sozialversicherung. August (2017). In German. [Prenatal screening in Austria: combined test versus cell-free DNA-test, Report from Austrian Social Insurance Association] in German (Available from http://www.hauptverband.at/cdscontent/load?contentid=10008.644578&version=1505401403 Accessed August 30, 2018); Vienna Women's Health Programme, Pränatal-Diagnostik Untersuchungen in der Schwangerschaft [Prenatal-diagnostic tests during pregnancy] (2018) in German (Available from https://www.wien.gv.at/gesundheit/beratung-vorsorge/frauen/frauengesundheit/pdf/praenatal-diagnostik.pdf Accessed August 30, 2018).

Appendix B: Maximum variation sampling and the data saturation process

Participants	# of new codes identified	Spouse nationality	Maternal age at birth	Contact with a midwife**	Women's years in Austria before birth	Women's self-rated German skill	Women's Education	Women's employment status	Type of screening tests taken based on memory and written documents	
									1st pregnancy	2nd pregnancy
Interview 1 couple together	21	Japanese	35, 40	No	4	Basic	Bachelor	No	NT & OS***	NT & OS (thought she did CT)
Interview 2 woman only	9	Japanese	35, 39	No	3	Basic	Bachelor	No	CT & OS	CT & OS
Interview 3 couple separate	7	Japanese	37, 40	No	2	Basic	Bachelor	No	CT & OS	CT & OS
Interview 4 couple together	2	Austrian	33, 36	Yes	7	Interm.	Master	Yes	NT & OS (possible CT)	NT & OS (possible CT)
Interview 5 couple together	2	East Asian	34, 38	No	0	Basic	Bachelor	No	No screening test	Detail ultrasound (possible NT)
Interview 6 couple together	4	Austrian	38, 40	Yes	1	Intermediate	Master	No	OS only	OS only
Interview 7 couple together	1	Japanese	42	No	0	Very basic	Bachelor	No	OS only	-
Interview 8 couple together	0	European	35	Yes	9	Interm.	Master	Yes	CT & OS (assumed she did not do CT)	-
Interview 9 couple together	1	Austrian	33, 36	No	1	Basic	Bachelor	No	NT & OS	CT & OS
Interview 10 woman only	1	Japanese	38	No	1	Basic	Master	No	CT & OS	-
Interview 11 couple together	3	North American	37	Yes	1	Basic	Bachelor	No	OS & NIPT	
Interview 12 woman only	0	Japanese	28*, 33	No	3	None	Bachelor	No	OS only in Japan	OS & NT in Austria
Interview 13 couple together	0	Austrian	31, 33	Yes	0	Interm.	College	Yes	OS & NT for first child	CT & OS
Interview 14 Couple together	0	Japanese	28	No	3	Basic	College	No	OS & NT (possible CT)	-
Total number of codes	51									

* First child in Japan. ** Excludes contacts during and right after birth as most births in Austria are automatically assisted by midwives .
*** OS: Organ screening or fetal anomaly scan

Appendix C: Interview guide

May I ask you (and your husband) about prenatal screening and diagnostic testing?

Could you tell me about your experiences going through these tests?

How did you decide to undertake the test or not take it?

How did you collect information regarding prenatal testing?

What kind of discussion took place between you and your husband?

What kind of questions did you ask your obstetric-gynaecologists or midwives regarding prenatal testing?

Note: When participants had limited knowledge about prenatal screening tests, the interviewer prompted questions on specific types of screening as outlined in Appendix A.

Appendix D: Languages used and proportion of talks done by each partner in one interview

No.	Interview type	Spouses' mother-tongue**	Word counts and % of talk done by each participant in one interview transcript				Word counts and percentage of each language used in one interview transcript						Total word counts per interview transcript (100%)
			Female		Male		Japanese		German		English		
			Count	%	Count	%	Count	%	Count	%	Count	%	
01	couple together	Japanese	324	23	1,071	77	1,071	100	0	0	0	0	1,395
02	female only	Japanese	1,396	100	-	-	1,396	100	0	0	0	0	1,396
03	couple separate*	Japanese	1,141	70	499	30	1,141	100	0	0	0	0	1,640
04	couple together	German	1,194	83	236	17	1,430	100	0	0	0	0	1,430
05	couple together	East Asian language	617	98	10	2	627	100	0	0	0	0	627
06	couple together	German	691	57	518	43	365	30	844	70	0	0	1,209
07	couple together	Japanese	434	72	168	28	602	100	0	0	0	0	602
08	couple together	Northern European language	477	74	167	26	424	66	220	34	0	0	644
09	couple together	German	352	66	182	34	393	74	141	26	0	0	534
10	female only	Japanese	814	100	-	-	814	100	0	0	0	0	814
11	couple together	English	1,010	49	1,065	51	987	48	0	0	1,088	52	2,075
12	female only	Japanese	715	100	-	-	715	100	0	0	0	0	715
13	couple together	German	533	85	91	15	512	82	96	15	16	3	624
14	couple together	Japanese	692	83	142	17	692	100	0	0	0	0	834
Total			**10,390**	**71%**	**4,149**	**29%**	**12,134**	**83%**	**1,301**	**9%**	**1,104**	**8%**	**14,539**

*Two transcripts are combined into one and are treated as one transcript.

**To ensure the anonymity of the participants, some languages are not specified