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Murakami, K

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## Research Article

## Experiences regarding maternal age-specific risks and prenatal testing of women of advanced maternal age in Japan

Kyoko Murakami, RN, RM, MSN,<sup>1</sup> Sue Turale, RN, DED, FACN, FACMHN,<sup>1,2</sup>Heather Skirton, PhD, RGN, RGC, QMW, PGCAP,<sup>3</sup> Faye Doris, RM, MSc,<sup>3</sup> Kumiko Tsujino, RN, PhD,<sup>4</sup>Misae Ito, RN, RM, PhD<sup>5</sup> and Saeko Kutsunugi, RN MHSc<sup>1</sup><sup>1</sup>Faculty of Health Sciences, Yamaguchi University Graduate School of Medicine, Ube, Japan <sup>2</sup>Department of Global Health and Nursing, Division of Nursing Science, College of Health Sciences, Ewha Womans University, Seoul, South Korea <sup>3</sup>Faculty of Health and Human Sciences, Plymouth University, Plymouth, UK <sup>4</sup>Faculty of Health Sciences, University of Ryukus, Urasoe, Okinawa, Japan and <sup>5</sup>Faculty of Health & Welfare, Kawasaki University of Medical Welfare, Kurashiki, Japan

## Abstract

The number of pregnant women of advanced maternal age has increased worldwide. Women in this group have an increased chance of fetal abnormality. To explore Japanese women's experiences regarding maternal age-specific risks and prenatal testing, we conducted a descriptive qualitative study. Semi-structured interviews were conducted with 16 women aged 35 years or over who had given birth within the previous three months to a healthy, term infant. Thematic analysis of transcribed interview data was performed and three major themes were identified: inadequate understanding of genetic risks; insufficiently informed choice regarding prenatal testing; and need for more information from health professionals. Some participants were not aware of maternal age-specific risks to the fetus. Many took their cues from health professionals and did not raise the topic themselves, but would have considered prenatal testing if made aware of the risks. Nurses, midwives and other health professionals need to adequately inform pregnant women about the genetic risks to the fetus and offer testing at an appropriate stage early in the pregnancy.

## Key words

advanced maternal age, informed choice, prenatal testing, qualitative study, risk perception, thematic analysis, fetal abnormality.

## INTRODUCTION

Advanced maternal age (AMA) is defined as 35 years or over for primipara and 40 years or over for multiparous women at the time of delivery (International Federation of Gynecology and Obstetrics, 2014). The number of pregnant women of AMA has increased worldwide (Laopaiboon *et al.*, 2014). For example, the proportion of births to women  $\geq 35$  years in Japan increased from 8.6% in 1990 to 25.9% in 2012 (Ministry of Health, Labor and Welfare, 2013). This is mainly attributed to women marrying at an older age than previously, and advancements in the use of fertility treatments, including assisted reproductive technology (ART) (Billal *et al.*, 2011; Ooki, 2013).

Increasing maternal age is associated with a raised incidence of adverse maternal outcomes (Khalil *et al.*, 2013; Laopaiboon *et al.*, 2014), and women of any parity have an

increased chance of having a baby with a chromosomal abnormality as they age (Nakata *et al.*, 2010; Savva *et al.*, 2010). Technical progress has brought greater opportunities for antenatal screening and testing to detect whether the fetus has an abnormality (Nakata *et al.*, 2010; Hagen *et al.*, 2011). For five decades, amniocentesis has been offered, often on the basis of a woman's age. In more recent decades, women  $\geq 35$  years have had access to antenatal fetal screening using maternal serum tests and ultrasound before making a decision about an invasive test (Nakata *et al.*, 2010; Chitty & Bianchi, 2013). Despite the fact that screening and testing should be offered as options rather than routine tests, and that counselling and information affect the uptake of testing (Godino *et al.*, 2013), there is still evidence that women and their partners do not make informed choices (Barr & Skirton, 2013).

In Japan, women concerned about the risks of fetal abnormalities can choose non-invasive screening at 10–13 gestational weeks. In the second trimester, amniocentesis is offered to women at increased risk of fetal chromosomal abnormality, that is, women  $\geq 35$  years at time of delivery (Genetic-Medicine-Related Societies, 2003). Recently, the

Correspondence address: Sue Turale, Department of Global Health & Nursing, Division of Nursing Science, Ewha Womans University, 52 Ewhayeodae-gil, Seodaemun-gu, Seoul, 120-750, Korea. e-mail: turale@ewha.ac.kr

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obstetric clinical setting has changed rapidly as a result of a obstetrician shortages (Ministry of Health, Labor and Welfare, 2013) and expanding options for prenatal testing (Suzumori *et al.*, 2014).

Bayrampour *et al.* (2012a,b) conducted a qualitative study of 15 primiparous women of AMA, and identified four themes related to perception of pregnancy risk: definition of pregnancy risk; factors influencing risk perception; risk alleviation strategies; and risk communication with health professionals. Yang *et al.* (2007) studied experiences of primiparous women in Asian countries and reported that their reactions included surprise and worry about childbirth outcomes, and embarrassment and ambivalence regarding lifestyle changes. In a quantitative study, Yotsumoto *et al.* (2012) reported that pregnant women with less knowledge of non-invasive prenatal testing had a more positive attitude toward it. However, there are few studies reporting the perceptions of women of AMA regarding risks related to their age.

In this study, we focused on a particular subset of women who are at increased risk of bearing a child with a congenital abnormality.

### Study aim

The purpose of this study was to explore the experiences of mothers regarding maternal age-specific risks and prenatal testing, within the context of their AMA.

## METHODS

### Design

This was a descriptive qualitative study using semi-structured interviews.

### Participants

Participants were eligible for inclusion if they were aged 35 years or older and had given birth within the last three months to a healthy term infant. Purposive sampling was carried out in order to achieve a maximum variation sample (Coyne, 1997). An effort was made to recruit women across the age range of 35–50 years, women who had invasive testing, as well as those who had not, and women with uncomplicated and complicated pregnancies or births. Women were excluded if: they or their infants had an existing medical problem after delivery; their infant had been diagnosed with or was suspected of having a congenital abnormality; or if they were health professionals.

### Data collection

Data were collected using semi-structured interviews, which is a suitable method for exploratory studies (Polgar & Thomas, 2008). Prior to the interview, participants' demographic information was collected using a short questionnaire. Interviews were then undertaken using a set of open questions focused on the woman's pregnancy experience. The researchers, all of whom have midwifery experience,

designed the interview guide. The major foci of the interview questions were: (i) given your age when you were pregnant, did you have any specific concerns about the baby's health? and (ii) what information were you given about the chances that the baby might have Down syndrome or other similar conditions? Who discussed it with you?

Potential participants were invited to be involved in the study when they attended a Japanese university hospital for a routine postnatal check-up one month after birth. The mother was asked for her permission to be contacted by the researcher and to have an interview two months after birth. Sixteen interviews were conducted over nine months during 2011–2012 in quiet, private locations convenient to participants. Interviews lasted 40–60 mins and 15 interviews were digitally audio-recorded with the consent of the participant, with the interviewer taking notes. One interview was not audio-recorded according to the participant's wishes. However, detailed handwritten notes were taken and transcribed almost verbatim immediately after the interview. The interviewee performed verification of the transcript. We conducted two practice interviews with mothers in the outpatient clinic to test the interview questions. After these practice interviews, a question on the information needs of women of AMA was added because we had obtained little information on this topic. Interviews ceased when data saturation occurred.

### Data analysis

Interviews were transcribed verbatim, and translated from Japanese to English by a bilingual researcher, then translated back into Japanese by another researcher to check that the translation was correct. Data were analyzed using thematic analysis described by Braun and Clarke (2006). This inductive approach enabled identified themes to emerge from the raw data. First, three researchers independently read the interview transcripts several times to obtain overall impressions. Second, we generated initial codes, which refer to the most basic elements of the raw data that can be assessed in a meaningful way. We paid attention to ensure that repeated patterns within the data were noted for later phases. Third, we identified a set of subthemes and organized these under major themes. We then reviewed the themes, identified the essence of each theme, and named each accordingly. Lastly, we made a final analysis and selected examples of data to underpin each theme from the transcripts.

### Rigor

Regarding trustworthiness, the interviewer asked participants questions during and after the interviews to clarify their perceptions and validate the interpretations of their intended meanings. To enhance credibility, two experts checked the two practice interviews. After interviewing, member checking was performed to confirm the credibility of the data. One Japanese researcher and two English-speaking researchers independently analyzed the data at each stage using the same analysis method. Emergent themes were then compared. University faculty members and a peer debriefer

**Table 1.** Demographic characteristics of the women in the study

Participant no.	Age (years)	Parity	Using ART	Desire for another child	Return to full-time work	Pregnancy complication
1	38	3	–	No	No	–
2	37	1	ICSI	Yes	Yes	PIH
3	37	1	ICSI	Yes	No	–
4	36	4	–	No	No	Threatened miscarriage
5	40	2	IVF	No	No	–
6	37	1	ICSI	Yes	Yes	Threatened miscarriage
7	39	1	–	Yes	Yes	Threatened miscarriage & had amniocentesis
8	43	2	–	No	No	–
9	39	1	–	No	No	PIH, asthma, threatened premature labor
10	39	1	ICSI	Yes	No	Myoma
11	36	2	AIH	No	No	Threatened miscarriage
12	41	1	–	Yes	Yes	–
13	39	1	–	Yes	Yes	–
14	37	1	–	Yes	Yes	Placenta praevia
15	35	2	AIH	Yes	No	–
16	36	3	–	No	No	Threatened premature labor

AIH, artificial insemination with husband's sperm; ART, assisted reproductive technology; ICSI, intracytoplasmic sperm injection; IVF, in vitro fertilization; PIH, pregnancy-induced hypertension.

established transferability. Discussion continued until consensus on themes and subthemes was reached and confirmed by member checking (Holloway & Wheeler, 2009).

### Ethical considerations

Ethical approval was obtained from the Institutional Review Boards of Yamaguchi University Hospital and Yamaguchi University. Prior to the study, participants were informed of the study purpose and processes, guaranteed anonymity and confidentiality by oral and written information, and gave written informed consent.

### RESULTS

The 16 participants had a mean age of 38.1 years (range, 35–43); nine were primiparous and seven were multiparous. All were married, and six were employed. Of the 11 participants who considered their pregnancy to be planned, seven became pregnant using ART. Nine wished to have another child. One primiparous mother had undergone amniocentesis during pregnancy, and one multiparous mother had undergone amniocentesis in a previous pregnancy (Table 1). The three emergent themes are described below.

#### Theme 1: Inadequate understanding of genetic risks

Most participants were aware that the risk of fetal congenital anomaly increased with maternal age; however, many did not understand the risks in detail:

It may have been due to my age, but I had two concerns, one is my physical matters (sic) and the other is whether my baby would be born with a handicap or not in this

second pregnancy . . . I was most worried about if my baby has normal fingers and feet or no heart problem because I had got a lot of information about risk to the fetus with advanced maternal age from elsewhere. (Participant 5)

Participants recognized the connection between their age and pregnancy risks by hearing the word *kourei ninshin*, referring to a woman who gives birth at  $\geq 35$  years. This label triggered women's anxiety about the risks. Some participants felt that they might have additional risks if they were  $> 40$  years. Additionally, some participants who had conceived using ART were worried about additional genetic risk to the fetus because of the use of this method. However, some were surprised at their high-risk status:

I think that micro-insemination is done by hand using an injection needle. I am not an expert in this area so I was really worried that there was some risk involved, or that there might be some problems with the baby . . . (Participant 3)

When I was first examined at a clinic, I was told to go to the university hospital because I was a primiparous advanced maternal age woman . . . I didn't even go into the exam room. I was very shocked. (Participant 12)

However, a few participants did not know that the risk to the fetus increased with maternal age. Two multiparous mothers believed the risks of AMA were only associated with primiparous pregnancies and many multiparous women mentioned that they were not given information during this pregnancy:

I only heard that Down syndrome [is] caused by increased maternal age after delivery of this child [third

child]. I had never heard of it before then. When [I transferred to a university hospital, and] I gave birth and heard about it for the first time, and was like, what is all this about? (Participant 1)

I do not know how being old is increases the risk to the baby. I think it also depends on whether or not it's your first child. I think whether or not you've had a miscarriage before . . . but I don't really know for sure. (Participant 2)

## **Theme 2: Insufficiently informed choice for prenatal testing**

### *Subtheme 1: Recognition for invasive testing*

Regarding testing, some participants were aware of the miscarriage risk associated with amniocentesis and believed testing did not provide a definite result. On the other hand, some participants knew nothing about testing and some were given information about testing or obtained it too late for termination of pregnancy:

I didn't know that there are many tests of genetic screening before I watched it on the TV. Unless I had said something, the doctor probably wouldn't say anything, would they? . . . When I found out on TV that amniocentesis was possible, it was too late. On the other hand, without TV, I would probably have never known. (Participant 5)

### *Subtheme 2: Ambivalent feelings and inferring risks to the fetus*

Many participants would have continued with the pregnancy even if the fetus had an abnormality and were, thus, dissuaded from testing. While many women were ambivalent about testing, they were reassured and/or made their own calculations of risk, based on ultrasound screening:

When thinking of having a test, if I found my baby was abnormal from the test . . . when I think about what I would have done with the baby, then I think "I would rather not know" . . . I'm not sure if I could raise the child even if it is born, but what is most difficult is being asked to choose. (Participant 5)

I could guess the risks of my pregnancy personally, and asked my doctor "Isn't my baby pretty small?" because my first baby was stillborn and I was quite nervous. But the doctor didn't worry about my baby. . . . In the ultrasound up until the amniocentesis there was no abnormality with the size, and all I could do was believe in the child. (Participant 10)

### *Subtheme 3: Couples' decision-making process*

In the decision-making process, some participants discussed testing with their husband. Some then had an amniocentesis because they wanted to know as much as possible and do what was best for the baby:

While reading the book, it mentioned lots of different things. I realized it would be a problem if the baby had a disability, so I discussed it with my husband. I was concerned about a disability with my baby, but really the only thing we could do was amniocentesis, but . . . we decided to do whatever we could, and I had the test. The test didn't show any abnormalities, so I was able to be reassured about those aspects . . . I think that helped me through my pregnancy. (Participant 7)

However, some made individual choices and/or withheld information from their husbands:

My husband seemed to want to do the testing for congenital abnormalities, but didn't know what it involved in detail. When he came to the check-up with me, he asked the doctor about it directly, but we were told that it was already "too late." Although I already knew, I didn't say anything because I felt sorry for the baby. Either way, I would have wanted to have the baby if the baby was disabled. (Participant 9)

## **Theme 3: Need for more information from health professionals**

### *Subtheme 1: Interaction with health professionals*

Many participants reported they had received no information from health professionals. In some cases, information was only given by a health professional if the mother asked a direct question:

I wondered if I would have explanations of the risks and tests. I thought I shouldn't worry since I was told no problem of my pregnancy. But, I did wonder if there would be any explanations. (Participant 13)

Many participants appear to have been reassured by doctors telling them that the baby was healthy. They believed that if an abnormality were suspected, their doctor would mention it. They were, therefore, reassured by the lack of information provided about risks or tests:

I just have read about it [amniocentesis] through books and the Internet . . . I thought maybe I would be told to have the test, but I was not. So I thought I must be OK. (Participant 14)

Doctors sometimes actively discouraged women to have testing, such as amniocentesis:

When I said that, my doctor told me "Everyone asks about the tests hoping that their own child won't have any problems, but if they did, have you thought about what you would do?" and "If there was a problem, would you terminate the pregnancy?" So I was a bit startled by that. After that, the reaction from the hospital was like "Well, we don't really support terminating a pregnancy for that reason." I thought a lot about it but decided that

maybe it was better not to know, and in the end I didn't do the testing. (Participant 2)

### *Subtheme 2: Information needs*

Many participants reported ambivalence about obtaining information, because too much information might increase worry. In fact, some participants consciously resisted obtaining information. Furthermore, some women appeared to feel obliged to have tests performed if the doctor actively mentioned it:

Well, if my doctor had told me about the test maybe that would have caused me to be anxious anyway, so I think for me it was better that they didn't talk to me about it. . . . but I do wish a little bit that the doctor had spoken to me about amniocentesis. (Participant 3)

. . . I know a mother who was still thinking of having the test, so if the doctor explains about the test, she would decide to have it . . . They may think it is kind of obligatory. If the doctor said so, I had better [do it] . . . (Participant 15)

Mothers stressed that the decision should be made without any type of coercion. However, they wished to obtain at least minimal information about testing because without this they would not know what to question. Therefore, they wished to have written information, such as pamphlets or books to read, and, subsequently, raise the issue with health professionals themselves if they wished:

Even if I was told to ask, I think that some people who would not know how to ask. I think that if at [the] least information is provided, then anxiety would be eased. I think that depending on the person, as expected there are people who obtain information and those who don't know how to ask . . . I think if we got told a little then it would be helpful for pregnant women. (Participant 11)

In addition, women wished to talk about the risk of the pregnancy and/or testing with their "own" doctors and midwives. A lack of opportunity for discussion with their midwife or doctor often led to an inability to make an informed choice:

If I need to know something, I'd rather hear it from a specialist doctor than from the Internet or the TV, so I'd like the doctor to tell me everything I need to know . . . Rather than worrying myself with the talk of people who don't know anything about it, I'd rather worry myself with what I have been told directly by a specialist. My baby is healthy now, so I think maybe it was OK that I didn't ask, but if things hadn't gone well then I'd probably wish I'd asked about it. (Participant 3)

## **DISCUSSION**

Our findings highlight the experiences of women of AMA in relation to risks to the fetus and prenatal testing. These

experiences are important because they affect prenatal care use, information seeking and decision-making about prenatal testing.

### **Risk perception of women of advanced medical age**

Many participants recognized that there were risks of having a baby with a congenital anomaly, such as Down syndrome, that were connected with maternal age; this finding reflected those of previous studies (Maheshwari *et al.*, 2008; Bayrampour *et al.*, 2012a,b). On the other hand, some women did not fully recognize the extent of the risk – this was especially true of multiparous women. This might be because women who conceive at an older age may feel fortunate to conceive and are, thus, unwilling to consider testing or termination. It has been shown that information about risk may increase anxiety rather than alleviate concerns (Carolan & Nelson, 2007), and this may lead women to limit information-seeking to avoid such anxiety (Bayrampour *et al.*, 2012a,b). Furthermore, some women were worried about additional risks to the fetus if they conceived using ART. Misperception of the risks may either lead women to seek higher levels of medical intervention because they incorrectly perceive themselves as being high risk, based on their age alone (Cooke *et al.*, 2010), or to be ignorant of their high-risk status (Carolan & Nelson, 2007; Carolan & Frankowska, 2011). To promote the empowerment of women, health professionals should be sensitive to the fact that women may not be aware of all of the risks associated with maternal age, and provide appropriate information, such as the fact that maternal age itself does not involve noticeable extra risk for non-chromosomal birth defects (Ooki, 2013). Pre-conception education and risk communication will benefit women, as suggested in a previous study (Cooke *et al.*, 2010).

### **Informed choice and decision-making**

Our findings support the idea that women of AMA have ambivalent feelings about seeking information since they might be aware of pregnancy risks. Similar to previous findings (Cooke *et al.*, 2012), some of the women in our study would have liked to have known the status of their fetus, but would have continued the pregnancy even if the fetus was affected by a condition; thus, they were dissuaded from testing.

On the other hand, many participants were given little information by health professionals and in many cases were only provided with information once they had asked for it. Women expressed a wish for individual face-to-face discussions with their health professionals about "their own" risks, but this may not have been offered because of limitations on pregnancy termination and restrictions on discussion of screening in the past. In Japan, the guideline for screening using serum markers (Ministry of Health, Labor and Welfare, 1999) recommends that doctors need not actively explain this and should not actively recommend it to pregnant women. Termination may be conducted only before the gestation age at which the fetus would be viable outside the womb. This is usually prior to 22 weeks gestation (JAOG, 1990). However, it is not legal to terminate a pregnancy at any time because of

fetal abnormalities. Therefore, doctors may refrain from explaining prenatal testing because, if they find a fetal abnormality, they cannot terminate pregnancy for that reason. As a result of the expansion of genetic counselling services in 2011, the national guideline now requires those considering the maternal serum marker test to have adequate and sufficient genetic counselling (Guideline for NIPT, 2013). While technical progress has brought greater opportunities, the legal and social systems continue to present challenges, which need to be discussed nationally.

In addition, culture may influence the discussion of topics such as disability. In Japan, serious illness is still not always discussed between care provider and patient, and some patients prefer not to know if their illness is life threatening or incurable (Turale & Ito, 2008). Moreover, some women in our study believed that the baby was a blessing and that parents have the potential to look after a child if he/she is born with a disability. While some participants preferred not to have an amniocentesis, they wanted ultrasound screening. However, they may have been unaware that soft markers (minor anatomical variants detected on ultrasound) can indicate a risk that the fetus has a chromosomal abnormality, such as Down syndrome (Holmgren & Lacoursiere, 2008). Furthermore, many of our participants believed that if the fetus had a suspected abnormality, the doctor would have mentioned it and recommended prenatal testing. These misunderstandings might hinder accurate informed consent for prenatal testing. Health professionals should pay attention to these aspects of prenatal testing and informed consent.

While some participants discussed prenatal testing with their husbands, many participants made their own choices. Sharing the decision-making process represents a possible cause of conflict between the woman and her husband (Arimori, 2006; Durand *et al.*, 2010). Therefore, women might take responsibility for their own decisions during pregnancy. In Japan, some women and their partners believe in traditional gender role ideology, that is, “a man’s job is to earn money and a woman’s job is to look after the home and family” (Cooke *et al.*, 2012). However, work by Barr and Skirton (2013) in the United Kingdom has shown that while fathers wish to be involved in decision-making, nurses/midwives make little effort to include partners in discussions about prenatal screening (Suplee *et al.*, 2007). Further research is needed on the role of the partner in the decision-making process in Japan and other countries.

### Information needs and nursing care

Although they expressed a need for “adequate” information, many participants felt they had been over-informed regarding the pregnancy, which reflects findings of previous studies (Carolan, 2007). Therefore, most participants sought useful information, given sensitively and unobtrusively. This finding is consistent with studies of women in the UK (Barr & Skirton, 2013). Both the volume and method in which information is delivered influences the decisions of a woman and her partner.

### Limitations

In this study, participants were sampled from only one hospital; therefore, it is not clear if the findings are transferable to other settings. However, the experiences and beliefs of women from an eastern country such as Japan may be important not only in the East, but in Western countries with multicultural populations. Future research is needed using triangulation methods, such as collecting data from partners or health professionals, to obtain more data across a wider population.

### CONCLUSION

While some of our participants recognized maternal age-specific risks to the fetus, others were unaware of such risks. A lack of awareness of these risks could result in uninformed decision-making and decisional conflicts between women and healthcare providers. It is important that health professionals consider women’s informational needs, taking into account cultural and religious influences. Nurses, midwives, and doctors, in particular, must take more responsibility for providing adequate information and access to appropriate counselling regarding possible genetic issues. Further research to explore the most effective way of sensitively providing adequate information is required.

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### CONTRIBUTIONS

Study Design: KM, ST, HS, FD, KT, MI, SK.

Data Collection: KM.

Data Analysis: KM, ST, HS.

Manuscript Writing: KM, ST, HS, FD, KT, MI, SK.

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