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## Young women's opinions on the use of a blood test to predict the possibility of premature ovarian failure: a qualitative study

Anouk Grootenhuis<sup>a</sup>, Agnes van den Hoogen<sup>b</sup>, Frank Broekmans<sup>b</sup>, Helen Torrance<sup>b</sup>, Harmieke van Os-Medendorp<sup>b</sup> and Henrietta Ockhuijsen<sup>b</sup>

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### ABSTRACT

The anti-Müllerian hormone (AMH) test is increasingly being used to predict the age when women will enter menopause, signalling the end of their reproductive life. However, the accuracy of the AMH test varies widely. In this qualitative study, we asked young women of three differing education levels about the possibility of predicting premature ovarian failure (POF), defined as menopause that occurs before the age of 40. A total of 15 face-to-face semi-structured interviews were conducted. The overarching theme was 'considering the possibility of predicting POF', and the three interpretive themes were (i) limited fertility knowledge, (ii) preconditions for pregnancy and (iii) desire to have children. The interview was their first awareness of the concept of POF. All the women who participated in this study wished to have children at some point later in life and tended to think more about fulfilling preconditions before getting pregnant than about their actual fertility. Most participants ( $n=8$ ) were interested in the AMH test regardless of their education level. Five participants wanted to take the test in the future. This research provides some insight into young women's current thoughts about the possibility of predicting POF with an AMH test.

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### Introduction

Worldwide, the average prevalence of infertility among women is 9.0%. Prevalence rates range from 3.5 to 16.7% in more developed countries and from 6.9 to 9.3% in less developed countries (Boivin, Bunting, Collins, & Nygren, 2007). Infertility is defined as the inability to conceive after 12 months of regular unprotected sexual intercourse (Daibes, Safadi, Athamneh, Anees, & Constantino, 2017). Infertility is a known health problem that influences the quality of life through physical, psychological and social effects (Daibes et al., 2017).

Every woman is born with a finite number of oocytes (around 1 million follicles/oocytes) (Gleicher, Kushnir, & Barad, 2015), and each month, the number decreases. At some point, when the number of oocytes is too low, the woman stops menstruating. A woman is considered to be menopausal when no menstrual periods have occurred for 12 consecutive months is defined as the start of the menopause

(Gleicher, Weghofer, Oktay, & Barad, 2009; National Institutes of Health, 2005). Worldwide, the average age at which menopause occurs is around 51 years, with a broad range of 40–60 years (Bouma et al., 2001; Gleicher et al., 2015; Pal & Santoro, 2002; Treloar, 1981). When menstruation stops before the age of 40 years, it is called premature ovarian failure (POF). Worldwide, POF affects 1 in every 1000 women between the ages of 15 and 29, and 1 in every 100 women between the ages of 30 and 39 (Goswami & Conway, 2005; Pal & Santoro, 2002; Shuster, Rhodes, Gostout, Grossardt, & Rocca, 2010). POF can be described as a decline in both ovarian function and the ovarian response to follicle-stimulating hormone (FSH) and as a reduction of oestrogen levels (Alipour, Rasekhjahromi, Maalagh, Sobhanian, & Hosseinpoor, 2015). Risk factors for POF include hereditary diseases, enzyme shortage (decreased oestrogen production), smoking, alcohol use and autoimmune diseases as well as damage to the ovaries as a result of chemotherapy and radiation therapy (Gleicher et al., 2015).

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The anti-Müllerian hormone (AMH) is one of several hormones involved in the regulation of the early stages of follicle development (De Vet, Laven, Temmen, de Jong, & Fauser, 2002; Thomas, Telfer, & Fraser, 2007). It is used as a marker for estimating the number of growing follicles in an ovarian cycle. The amount of AMH in serum declines due to the depletion of the ovarian primordial follicle pool (Alipour et al., 2015; Visser, De Jong, Laven, & Themmen, 2006; Weenen et al., 2004).

Many studies on the predictive value of the AMH for POF have been published (Alipour et al., 2015; Gleicher et al., 2015; Kelsey, Wright, Nelson, Anderson, & Wallace, 2011; Pal & Santoro, 2002; Thomas et al., 2007). A meta-analysis investigated 3260 samples of serum AMH to calculate the normal range of the AMH for different age classes of women (Kelsey et al., 2011). It was found that the AMH level of growing follicles rises from birth up to the age of puberty, reaching a peak at around 24–25 years (0.8 ng/ml), whereas after menopause this value is lower (0.1 ng/ml) (De Vet et al., 2002; Kelsey et al., 2011). The occurrence of consistently low levels of AMH is a marker for POF (Alipour et al., 2015; Gleicher et al., 2015; Thomas et al., 2007). Thus, a validated model to calculate expected menopause onset was developed (Kelsey et al., 2011), but the accuracy of the prediction varies widely (95% CI 0.01–0.22) (Broer, Broekmans, Laven, & Fauser, 2014; Depmann, 2016; Stoop, 2018). Multiple blood samples over a longer period are needed to increase the reliability of the AMH test (Tehrani, Solaymani-Dodaran, Tohidi, Gohari, & Azizi, 2013).

Women with POF have difficulties coping not only with the inability to become pregnant but also with mood swings, sweating, weight gain and loss of sexual desire (Singer, Mann, Hunter, Pitkin, & Panay, 2011). Additionally, women experience POF as something very painful and hard to accept, both physically and psychologically (Singer et al., 2011). It has been proposed that the possibility of predicting POF may help some women prepare for it and take preventive actions such as egg freezing (Cartwright, Grace, & Rymer, 2010; Chirwa, Ma, Guallar, & Tariq, 2017; Parton, Ussher, & Perz, 2017).

It is expected that higher-educated women would be more interested in the possibility of predicting POF than lower-educated women. Highly educated women are more likely to seek medical help for infertility (Moreau, Bouyer, Ducot, Spira, & Slama, 2010). Fertility awareness is significantly associated with level of education ( $p=0.007$ ), and it increases linearly with a higher level of education ( $p < 0.001$ ) (Swift & Liu, 2014).

Currently, little is known in the Netherlands about women's opinions on the AMH test for predicting POF

and fertility preservation. The aim of this research is therefore to gain an understanding of whether women want to know when their menopause will start. More specifically, the study can shed light on the opinions of women with different education backgrounds on fertility, fertility preservation and the possibility of predicting POF.

## Materials and methods

A generic qualitative design involving semi-structured interviews was used to establish how women perceive the possibility of predicting POF (Baarda et al., 2013; Creswell, 2003; Kahlke & Hon, 2014). A qualitative design is an inductive approach that can provide insight into the essential meaning of participants' experiences and perspectives (Lim, 2011). This approach was chosen because the research question for this study did not require a design guided by a special set of philosophical assumptions (Cooper & Endacott, 2007; Percy, Kostere, & Kostere, 2015). The strength of this design was that the participants' subjective opinions, beliefs and experiences could be investigated without the limitations of approaches such as grounded theory and phenomenology (Baarda et al., 2013; Creswell, 2003; Kahlke & Hon, 2014).

## Participants

The participants consisted of women in the Netherlands aged 18–30 years of three education levels: (i) university (U); (ii) higher professional school (HPS); and (iii) medium professional school (MPS). Purposeful sampling was used to reach maximum variation in education level and age (Polit & Beck, 2012). The age range of 18–30 was chosen because the treatment of POF is most effective before the age of 30 (NVOG, 2010).

## Data collection

The semi-structured interviews were conducted by the first author using the interview guide in Table 1. The topics covered in the face-to-face interviews included fertility, fertility preservation and the possibility of predicting POF. The interview guide was based on the literature and the knowledge of the researchers (HO and HT). Open questions using prompts and probes were used to elicit more detailed information (Boeije, 2010). To increase the credibility of the findings, AG had completed the interview training provided by Utrecht University to strengthen her skills (Boeije, 2010; Maso & Smaling, 1998).

**Table 1.** Interview guide.

Main concepts	Questions
Introductory remarks about this research project	<ul style="list-style-type: none"> <li>• Thank you for taking part in the survey. All feedback will be anonymous.</li> <li>• I am curious about your experiences, opinions and ideas. That way I can gather a significant amount of information for this study. Your story is important to me.</li> <li>• Do you give permission for the interview to be recorded?</li> <li>• Do you have an hour for this interview?</li> <li>• (The researcher introduces herself)</li> <li>• (The interviewer explains the reasons for this research.)</li> </ul>
Fertility	<ul style="list-style-type: none"> <li>• Do you think about fertility?</li> <li>• What is the reason you are thinking about this subject?</li> <li>• What do you know about fertility/infertility?</li> <li>• How is your situation at home? What is your marital status? (Cohabiting, single, long-distance relationship)</li> <li>• How important is fertility for you?</li> <li>• Would you like to have children? Why/why not?</li> <li>• Which barriers and facilitators play a role in your decision? (Age/career/partner/finances/religion)</li> <li>• Do your friends or family suffer from fertility problems? (Friends/parents/aunts)</li> <li>• Does this affect your way of thinking about fertility or infertility?</li> </ul>
Fertility preservation	<ul style="list-style-type: none"> <li>• What do you know about fertility preservation?</li> <li>• Do you know which fertility treatments there are?</li> <li>• What do you think of these fertility treatments?</li> <li>• What are the benefits of these fertility treatments?</li> <li>• What are the disadvantages of these fertility treatments?</li> <li>• When there are costs involved with the treatment, what do you think?</li> <li>• Would you mind that?</li> </ul>
Considering the possibility of predicting POF	<ul style="list-style-type: none"> <li>• What do you know about premature ovarian failure (premature menopause, when the final menstrual period occurs before the age of 40)?</li> <li>• What do you think about that?</li> <li>• What are the consequences of premature ovarian failure?</li> <li>• Do you know people who have premature ovarian failure?</li> <li>• How do you view fertility treatments such as storing egg cells, ovarian tissue or embryos?</li> <li>• Suppose that in the future it will be possible, with a simple blood test, to predict premature ovarian failure. Are you then willing to use the AMH test to predict POF?</li> <li>• At what age would you like to do this test?</li> <li>• What would you do with the result of the test?</li> </ul>
Concluding remarks	<ul style="list-style-type: none"> <li>• This concludes this interview. Do you have any questions?</li> <li>• If you have any questions later on, you can always contact me.</li> </ul>

At the beginning of the interview, several demographic characteristics were collected such as age, education level, marital status, sexual orientation and religion. All these characteristics play an influential role in fertility awareness (McQuillan, 2004; Pyper, 1997; Stacey & Biblarz, 2001). At the end of the interview, a summary of the main topics was provided to the participant to check whether the received information was correct.

To increase reliability and validity, peer debriefing was conducted between the researchers throughout the interviewing period (Boeije, 2010; Maso & Smaling, 1998). Interviews were conducted until data saturation was reached (Boeije, 2010). To determine if saturation had occurred, one extra interview was conducted at every education level. All the interviews were audio-taped and fully verbatim transcribed to ensure the reliability of the findings (Holloway & Wheeler, 2015).

### Procedure

Permission was sought to recruit students from different educational levels 'Us, HPSs and MPSs' at their institutions to participate in the study. Three

educational institutions granted permission to place an advertisement on their websites-inviting volunteers to participate in the study. The students were asked to send an email to the research team if they were interested in participating. All the selected participants were then emailed an information letter and one week later, the researcher contacted them by telephone to ask if they had any questions and to schedule their interviews. Written informed consent was obtained from each participant before her interview. None of the participants withdrew. The interviews were conducted at the participants' preferred location, at home or at school. The interviewer devoted attention to building a good, empathetic yet professional relationship with them (Pitts & Miller-Day, 2007).

### Quality measures

The analysis was guided by the Qualitative Analysis Guide of Leuven (QUAGOL), as shown in Table 2 (Dierckx de Casterlé, Gastmans, Bryon, & Denier, 2012; Tong, Sainsbury, & Craig, 2007). This guide was used because it included a spiral of analysis, which results in a forward-backward movement between within-

**Table 2.** COREQ checklist qualitative research reporting.

Domain 1: Research team and reflexivity	
Personal characteristics	
1. Interviewer	AG conducted the face-to-face interview
2. Credentials	AG: MSc. HO: Dr, PhD, RN
3. Occupation	AG: Team manager children department/Nurse HO: Nursing scientist
4. Gender	Female: AG, HO
5. Experience and training	The researchers (AG, HO) had experience with qualitative research methods based on previous research projects. Good clinical practice training.
Relationship with participants	
6. Relationship established	No established relationship with the participants.
7. Participant knowledge of the interviewer	No known previous knowledge of the interviewer
8. Interviewer characteristics	No characteristics reported.
Domain 2: Study design	
Theoretical framework	
9. Methodological orientation and theory	Qualitative analysis was guided by the Qualitative Analysis Guide of Leuven (QUAGOL). MAXQDA 12 Standard (Berlin, Germany) program was used to organise and analyse the data.
Participant selection	
10. Sampling	Purposeful sampling
11. Method of approach	The participants were approached by email and phone
12. Sample size	15 participants were interviewed, $N = 15$
13. Non-participation	Inapplicable
Setting	
14. Setting of data collection	The interviews took place at school or home setting.
15. Presence of non-participants	No
16. Description of sample	Age, educational level, sexual orientation, marital status, religious. See Tables 3 and 4.
Data collection	
17. Interview guide	The questions were based on the literature and the knowledge of the researcher (AG), fertility doctor (HT), and supervisor (HO). The interview guide is enclosed with this article.
18. Repeat interviews	No
19. Audio/visual recording	The interviews were audiotaped.
20. Field notes	Yes, short field notes were made.
21. Duration	The duration of the interviews was ~40 min.
22. Data saturation	Yes, data saturation was discussed and considered sufficient to perform the analysis.
23. Transcripts returned	No
Domain 3: Analysis and findings	
24. Number of data coders	Two researchers (AG and HO) coded the data.
25. Descriptions of the coding tree	The process of analysis consisted of two parts: (1) Preparation of the coding process (five stages). (2) The actual coding process (five stages).
26. Derivation of themes	Themes were derived from the data
27. Software	MAXQDA-12
28. Participant checking	During and at the end of the interview a summary was provided on the main topics, to check if the received information was well interpreted by AG.
Reporting	
29. Quotations presented	Yes, age and education identified the participants.
30. Data and findings consistent	Yes
31. Clarity of major themes	Major themes are presented.
32. Clarity of minor themes	Themes are categorised.

case and across-case analysis (Dierckx de Casterlé et al., 2012). The MAXQDA 12 Standard (Berlin, Germany) program was used to support the data processing (Anonymous, n.d.). MAXQDA is a software program that collects, organizes, analyzes, visualizes qualitative and mixed-methods data.

### Data analysis

The process of analysis consisted of two parts, namely, 'preparation for the coding process' and 'the actual coding process' (Dierckx de Casterlé et al., 2012).

In the first part, as soon as possible after each interview, AG coded the transcripts. Based on observational memos, theoretical memos and recordings to ensure

the highest possible reliability of the data (Mays & Pope, 1995; Maso & Smaling, 1998; Polit & Beck, 2012). This preparatory work was crucial to developing a useful and empirical framework for the coding process (Polit & Beck, 2012). A forward-backward movement was utilized between within-case and across-case analysis. This was done by AG and HO independently of each other. Next, the essence of the participants' responses to the research question was analyzed by means of constant comparison. All the information was categorized into themes before inputting it into the software.

In the second part, the list of concepts was converted to MAXQDA (Connelly & Peltzer, 2016; Creswell, 2003). Based on the previous stages, a list of

contextual and analytical concepts was drafted. This part ended with a description of the findings. During this iterative process, the data analysis was alternated with data collection. After every three interviews, the researchers AG and HO discussed their differences and similarities to reach a consensus on the coding process (Maso & Smaling, 1998). When presenting the findings, each participant quotation was followed by the participant's age and education level.

### Ethics

The study was conducted according to the World Medical Association Declaration of Helsinki (World Medical Association, 2013). The Medical Research Ethics Committee has stated that this study did not fall within the scope of the Dutch Medical Research Involving Human Subjects Act (WMO) (Protocol ID: 17-834/C). All data were handled confidentially and anonymously. The names of the participants are fictitious. The handling of personal data complied with the European Commission's laws on the protection of personal data (European Commission, 2012).

### Results

Fifteen interviews were conducted, and saturation was reached after 12 interviews. Three extra interviews (one per education level) were conducted to confirm saturation. The duration of the interviews ranged from 23 to 57 min (mean 40 min). The mean age of the participants was 24 years (min 19 to max 28) (Tables 3 and 4).

The overarching theme was 'considering the possibility of predicting POF', and the three interpretive themes were (i) limited fertility knowledge, (ii) preconditions for pregnancy and (iii) desire to have children. The participant's perceptions of possibly predicting POF emerged from the different views that

participants had when they imagined having POF: they were thinking about how they would respond. This overarching theme links the three interpretive themes. The theme of 'limited fertility knowledge' emerged from the fact that none of the participants, independent of education level, had prior knowledge of fertility, fertility preservation or POF: the interview was the first awareness with the concept of POF. 'Preconditions for pregnancy', such as adequate housing and economic certainty, needed to be fulfilled before participants would consider having children and therefore think about fertility. Accordingly, most of the participants indicated a preference to settle these matters before considering the AMH test. The theme of a 'desire to have children' emerged because none of the participants had already decided on having children, so they did not have this desire at the time. Should the participants wish to have children in the future and want to know if their attempts will be successful, the AMH test might be a facilitator. Each theme is described in detail below with representative quotes given in italics. In addition, an overview of the themes and the relation between them is shown in Figure 1.

### Considering the possibility of predicting POF

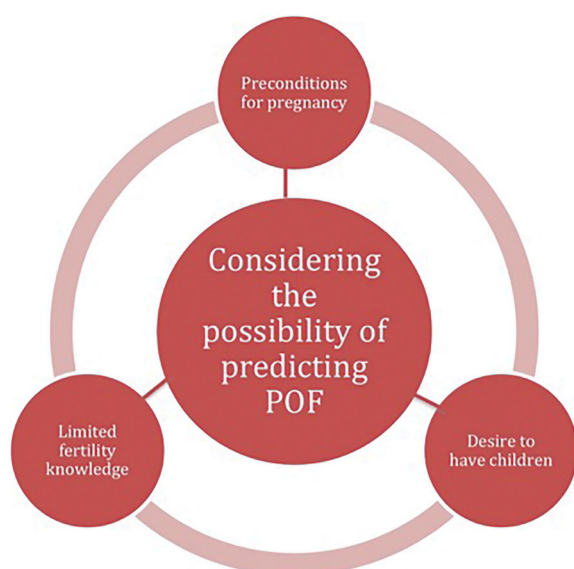
Most ( $n = 8$ ) participants said that they would take the AMH test if it was easy to do in a comfortable place, preferably without a hospital visit, and not too expensive. The possibility of predicting POF was perceived differently by the participants. During the interview, participants were asked if they would take the AMH

**Table 3.** Demographic characteristics of participants ( $n = 15$ ).

Name	Age (years)	Education level	Sexual orientation	Marital status	Religion
Anne	24	University	Heterosexual	Cohabiting	Catholic
Birgitte	25	University	Heterosexual	Single	None
Christel	24	University	Heterosexual	Single	None
Denise	28	University	Heterosexual	Long-distance relationship	None
Evelien	26	University	Heterosexual	Single	Catholic
Femke	23	Higher professional school	Heterosexual	Cohabiting	Catholic
Frederike	25	Higher professional school	Heterosexual	Long-distance relationship	Catholic
Karlijn	24	Higher professional school	Heterosexual	Single	Catholic
Katie	26	Higher professional school	Heterosexual	Cohabiting	None
Lenne	27	Higher professional school	Homosexual	Cohabiting	None
Amira	19	Medium professional school	Heterosexual	Long-distance relationship	Muslim
Marja	21	Medium professional school	Heterosexual	Long-distance relationship	None
Monique	21	Medium professional school	Heterosexual	Single	None
Elif	22	Medium professional school	Heterosexual	Long-distance relationship	Muslim
Sanne	23	Medium professional school	Heterosexual	Single	None

**Table 4.** Characteristics of the participants ( $n = 15$ ).

Characteristics	<i>N</i>
Weekly smoking use >10 cigarettes	3
Weekly alcohol use >4 glasses	8
Family history with fertility problems	0
Employment full-time	10



**Figure 1.** The overarching theme was ‘considering the possibility of predicting POF’ and the three interpretive themes were ‘limited fertility knowledge,’ ‘preconditions for pregnancy’ and ‘desire to have children’.

test. Most of the participants ( $n=8$ ) were positive about the AMH test believing that it would give them more certainty about their future fertility:

If the AMH test were just as easy as a pregnancy test and low in costs, then it would be easier to choose it. (Femke 23-HPS)

Yes, I would definitely do the test. Then I would know what I could expect. Because I am someone who would like to know. (Elif 22-MPS)

The desire to become a mother was high among these participants. Some ( $n=5$ ) said that they would take the test in the future but would postpone it for the moment. Others said that they would like to be older before taking the AMH test and that they would like to have more information about the invasiveness of it:

Not at this moment. I would first want to read more about how invasive the test will be and get some information from my family and my boyfriend. Then I would write down advantages and disadvantages and then make a well-considered choice. But I am certainly not negative about it. (Katie 26-HPS)

Two participants reported that they were against the AMH test because it would provide disturbing information and would affect their day-to-day life. Examples of such disruptions were the regular blood collections and the constant thinking about the ability to have children and/or the consequences of being single.

I would not do the test. I live in the moment. In addition, I find it inconvenient that you have to go to the hospital. If you could buy something from a drug store, like a pregnancy test, it would be less inconvenient but this is really an investigation. (Femke 23-HPS)

Two participants gave two clear examples of situations in which the AMH test may be useful: in the case of serious illness (e.g. cancer) and in the case of POF occurring in the family. One thing was certain: if POF occurred in the family, all the participants in this study said they would take the AMH test to decrease their uncertainty about their fertility. One participant mentioned her boyfriend’s Muslim religion as a factor influencing her thinking about the AMH test. She said that he would probably not want her to take the AMH test or fertility preservation measures:

I think my boyfriend thinks differently about fertility preservation (for example IVF). That is because he is Muslim. According to him, it has to be in a natural way: otherwise, it is not allowed. (Frederike 25-HPS)

### Limited fertility knowledge

This theme emerged from the interviews because the participants’ knowledge of (in)fertility was based on their experiences within their social network (friends and family) rather than the existing literature. Most participants described a lack of knowledge regarding fertility, fertility preservation and POF. None of the participants, irrespective of their level of education, demonstrated any or very little prior knowledge of the interview topics. Twelve participants said that becoming pregnant is not self-evident: they had heard this from family and friends who had experienced miscarriages and infertility. One participant expressed that she was uncertain about her fertility because of her unhealthy lifestyle as a smoker and being overweight. The participants also had limited knowledge of fertility preservation. They were not aware of or had only basic knowledge of, treatments for fertility preservation, such as *in vitro* fertilization (IVF) and intracytoplasmic sperm injection (ICSI).

You cannot think, ‘I want to get pregnant, and I will succeed’. You do not know that at all. A girlfriend of mine had a few miscarriages. (Katie 26-HPS)

That you ... freeze the sperm? But for the rest, I have no idea. (Sanne 23-MPS)

The researcher provided information about fertility preservation options and asked the participants what they would do in the case of being able to predict

infertility. Most of the participants considered preventive measures, such as freezing oocytes or embryos. Some said that they would fulfil their wish for children earlier. The interviews also revealed that the participants had little knowledge of the transition to menopause and especially limited knowledge of POF. The main reason was that few people in the participants' surroundings had to deal with POF. Participants noted examples of a mother or aunt who was in transition, but the interviewees were not aware that POF was also possible. Fourteen participants said that they had never heard of POF or that they had no idea at what age menopause could occur:

I have never heard of it. Can you explain it to me? (Marja 21-MPS)

Early menopause? I have never heard of this. There is less information about it. Unless you are looking for it: then there is plenty to find. I think women could learn about this through, for example, brochures and advertisements. (Lenne 27-HPS)

I have no idea what premature ovarian failure or early transition means. (Denise 28-U)

One participant had more knowledge of POF because a colleague suffered from it:

One colleague is 31 years old and she is already in transition. She has endometriosis. She had a desire for a child but is already in the transition. (Karlijn 24-HPS)

### **Preconditions for pregnancy**

Most participants mentioned that they did not yet want to get pregnant. They wanted to arrange better preconditions first, such as adequate housing, economic certainty, a stable relationship or a partner in the case of single participants:

Hmm, I would rather do as my parents did. That is, you spend a lot of time together with your partner, such as travelling. And then preferably the perfect picture of getting married, a house, and then children. All the conditions must be met, and as far as my career is concerned, I must first have a permanent job before I start with children. In short, I would like stability first before I have children. (Birgitte 25-U)

Most of the participants found education to provide stability and a full-time job to be an important precondition. One participant said that she had had an abortion. It had been clear to her that her situation had to be better before having a child because she had had no job or boyfriend. Participants stated that having a partner is a precondition for having a child:

I wanted to have my own place, have a good job and have certainty that I could give the baby what she deserved. I did not have that when I was pregnant. That is why I chose an abortion. (Sanne 23-MPS)

Yes, I really want children, but I have no idea when. I am not thinking about that, because I do not have a boyfriend. (Evelien 26-U)

### **Desire to have children**

None of the participants had already decided on having children. However, becoming pregnant and having biological children was a future wish for all the interviewed participants:

Yes, I really want children, but later because I am now 26 years old. At this moment, I find myself too young. (Katie 26-HPS)

I am still quite young, but I would like to have children later. (Christel 24-U)

If POF occurred and it was not possible to become pregnant in a natural way or through a reproductive technique, all the participants would certainly consider adoption. Most of the participants claimed to have a strong desire to have children; however, they had never thought about reproductive techniques and adoption because they were not thinking about getting pregnant yet:

I would love to have children, and I have thought about adoption, but I would really like to have my own biological children. But I am open to adoption. (Amira 19-MPS)

I have never heard of ICSI, but I will do everything to become pregnant in a natural way. (Denise 28-U)

### **Discussion**

This is the first study in the Netherlands that explored the opinions of young women with different education levels on predicting POF. One overarching theme 'considering the possibility of predicting POF' and three interpretive themes 'limited fertility knowledge', 'preconditions for pregnancy' and 'desire to have children' emerged. Limited knowledge of fertility and fertility preservation measures seemed to influence whether women would take the AMH test. Women tended to think more about fulfilling preconditions (e.g. housing, work) before getting pregnant than about their actual fertility. All of the interviewed women had a desire to have children: this might have had a positive influence on their perceptions of taking



the AMH test to predict POF. Overall, our study showed that regardless of their education levels, most participants would take the AMH test to predict POF. This study is a first step towards gaining more knowledge about women's opinions on the possibility of predicting POF. There is a lack of previous qualitative studies about the possibility of predicting POF. However, studies on menopause emphasise the importance of early detection. A qualitative systematic review showed that women should be prepared for menopause, and that the AMH test could help (Hoga, Rodolpho, Goncalves, & Quirino, 2015). A narrative review described several consequences of premature menopause, such as effects on cognition, mood, the cardiovascular system, bones and sexual health (Faubion, Kuhle, Shuster, & Rocca, 2015). It is important to address the psychological impact of early menopause as early as possible. The AMH test would make it possible to know about these consequences early on and act accordingly.

One of the interpretive themes that emerged from the data was 'limited fertility knowledge'. This is in line with previous studies that stated that the participants' knowledge of (in)fertility was rather based on their experiences within their social network (friends and family) than on the existing literature (Bunting, Tsubulsky, & Boivin, 2013; Hickman, Fortin, Goodman, Liu, & Flyckt, 2018). More education is needed about chances for early menopause to improve decision-making about POF.

The theme 'preconditions for pregnancy' provided insight into several central elements, such as adequate housing, economic certainty and a stable relationship. This is in line with a review, which revealed that sub-optimal housing conditions or financial status are the primary reasons for delaying childbearing (Rindfoss & Brauner-Otto, 2008). As well as the wish for further education (Ekert-Jaffé et al., 2002; Kravdal & Rindfuss, 2008; Mills, Rindfuss, McDonald, Te Velde, ESHRE Reproduction and Society Task Force, 2011). Most of our participants found education important in providing stability to ultimately offer children the best conditions. The findings presented under the theme 'desire to have children' indicate that during the interviews, all had a desire to have children and were therefore interested in their future fertility. Worldwide, the average age of women at childbirth was 30 years in 2015 (Organisation for Economic Co-operation and Development, 2016). The mean age of the participants in this study was 24 years, which may explain the fact that these women were not concerned with fertility, fertility preservation or POF. Other studies have shown

that women have a strong desire to bear biological children, which is in line with the responses of the participants in this study (Hodes-Wertz, Druckenmiller, Smith, & Noyes, 2013; Virtala, Vilkska, Huttunen, & Kunttu, 2011).

While previous research has suggested that level of education is a strong predictor of women's fertility awareness and willingness to seek medical help when faced with infertility, our study found no association between participants' level of education and knowledge of fertility (Hampton & Mazza, 2015; Hampton, Mazza, & Newton, 2013; Moreau et al., 2010). A possible explanation is that in the Netherlands, MPSs can be differentiated into level 1 (lowest) up to level 4 (highest) (Gelderblom, Gravesteijn, de Vleeschouwer, & Stegehuis, 2016; Hofland & Westershuis, 2017; van Eck & Glaude, 2016). In this study, by chance, only women with MPS level 4 were interviewed. This may have affected the findings of this study.

The strength of this study is that the coding process and identification of themes were based on the consensus between both authors; this makes the reliability of this study high. In addition, to improve the reliability and validity, several methods were used like writing memos, conducting a pilot interview, audio recording, verbatim transcribing of the interviews, providing summaries during the interviews and using a Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Mays & Pope, 1995; Tobin & Begley, 2004; Tong et al., 2007). Another strength was the maximum variation approach, which was achieved for education level and age (Maso & Smaling, 1998). The variation in age (19–28) could have influenced the findings regarding the relevance of the subject under discussion. Most women were under the age of 24 and were not ready to think about getting pregnant or having children. This may have affected their opinions about predicting POF.

However, this study also had some limitations. The participants had limited knowledge of the various themes during the interviews (fertility, fertility preservation and POF), and they had limited time to think about the consequences of POF for their situation and how to cope. A weakness of this study could be the chosen design of a generic qualitative study. All of these critiques have in common a concern about ensuring the congruence of the epistemological, theoretical, methodological and technical levels of the research framework (Cooper & Endacott, 2007). Therefore, most participants considered many kinds of dilemmas during the interview regarding fertility. One of these dilemmas was that the accuracy of the AMH

test varies widely and that several tests are needed for a more accurate prediction. This made the question 'Would you be willing to use the AMH test to predict POF?' even more difficult than it already was. The participants not only had to think about POF but also had to consider the invasiveness of the AMH test. Participants should have more information to make an informed choice.

Recommendations from this study include better education of young women on fertility, fertility preservation and POF, especially if there is an increased risk of fertility issues (e.g. if there is a family history or after chemo/radiotherapy). A recommendation for future research is to interview women who are older: 25–40 years, with and without fertility issues. Older participants would probably be more concerned with a desire to have children, would be more informed about (in)fertility and able to make other choices.

In conclusion, this research provides some insight into young women's thoughts about the possibility of predicting POF with the AMH test. Most participants ( $n=8$ ) were interested in the AMH test regardless of their education level. Five participants said that they would take the test in the future but would postpone it for the moment. All participants said that they would take the AMH test if POF had occurred in their family.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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