human reproduction

#### **ORIGINAL ARTICLE**

# Women's perceptions of fertility assessment and counselling 6 years after attending a Fertility Assessment and Counselling clinic in Denmark

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**STUDY QUESTION:** What are women's perceptions and experience of fertility assessment and counselling 6 years after attending a Fertility Assessment and Counselling (FAC) clinic in Denmark?

**SUMMARY ANSWER:** Women viewed the personalized fertility knowledge and advice they received as important aids to decision-making and they felt the benefits outweighed the risks of receiving personalized fertility information.

**WHAT IS KNOWN ALREADY:** Many young people wish to become parents in the future. However, research demonstrates there is a gap in women's and men's knowledge of fertility and suggests they may be making fertility decisions based on inaccurate information. Experts have called for the development of interventions to increase fertility awareness so that men and women can make informed fertility decisions and achieve their family-building goals. Since 2011, the FAC clinic in Copenhagen, Denmark has provided personalized fertility assessment and guidance based on clinical examination and evaluation of individual risk factors. Available qualitative research showed that attending the FAC clinic increased fertility awareness and knowledge and was experienced as a catalyst for change (e.g. starting to conceive, pursuing fertility treatment, ending a relationship) in women 1-year post-consultation.

**STUDY DESIGN, SIZE, DURATION:** The study was a 6-year follow-up qualitative study of 24 women who attended the FAC clinic between January and June 2012. All women were interviewed during a 2-month period from February to March 2018 at Rigshospitalet, their home or office, in Copenhagen, Denmark. Interviews were held in English and ranged between 60 and 94 min (mean 73 min).

**PARTICIPANTS/MATERIALS, SETTING, METHODS:** Invitations to participate in an interview-based follow-up study were sent to 141 women who attended the FAC clinic in 2012. In total, 95 women read the invitation, 35 confirmed interest in participating and 16 declined to participate. Twenty-five interviews were booked and 24 interviews held. Interviews followed a semi-structured format regarding reasons for attending the FAC clinic, if/how their needs were met, and perceptions of fertility assessment and counselling. Data were analysed using thematic analysis.

MAIN RESULTS AND THE ROLE OF CHANCE: At the follow-up interview, women were on average 39.5 years old. Ten were currently single or dating and 14 were married/cohabiting. All were childless when they attended the FAC clinic. At the follow-up interview, 21 women were parents (14 women with one child; 6 with two children; 1 with three children) and the remaining three women intended to have children in the future. The most common reason for originally attending the FAC clinic was to determine how long they could delay childbearing. Most of the women now believed their needs for attending had been met. Those who were dissatisfied cited a desire for more exact ('concrete') information as to their remaining years of fertility, although acknowledged that this was likely not realistic. Women stated that they had felt reassured as to their fertility status after attending the FAC clinic whilst receiving the message that they could not delay childbearing 'too long'. Women viewed personalized fertility knowledge as an important aid to decision-making but cautioned about

developing a false sense of security about their fertility and chance of conceiving in the future based on the results. Although women were generally satisfied with their experience, they wished for more time to discuss options and to receive additional guidance after their initial meeting at the FAC clinic.

**LIMITATIONS, REASONS FOR CAUTION:** Participants were from a group of Danish women attending the FAC clinic and interviews were conducted in English, which means they are not representative of all reproductive-aged women. Nevertheless, the study group included a broad spectrum of women who achieved parenthood through different means (heterosexual/lesbian relationship, single parent with donor, co-parent) with various family sizes, and women who were currently childless.

**WIDER IMPLICATIONS OF THE FINDINGS:** Our study provides support for an individualized approach to fertility education, assessment and counselling provided at a time when the information is relevant to the individual and their current fertility decision-making. The findings suggest that although satisfied with their visit to the FAC clinic, the women wished for more information and guidance after this visit, suggesting that the current intervention may need to be expanded or new interventions developed to meet these additional needs.

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Key words: counselling / qualitative research / reproductive decision-making / fertility assessment / fertility education

## WHAT DOES THIS MEAN FOR PATIENTS?

In this study, 24 women were interviewed 6 years after they had attended the Fertility Assessment and Counselling (FAC) clinic in 2012. The FAC clinic was started in Copenhagen, Denmark as a fertility awareness intervention to give men and women who are considering having children in the future the opportunity to learn about their current fertility and identify any risk factors that might make it difficult to become pregnant/father a child in the future. The goal of the FAC clinic is to give men and women the information they need to make informed choices about their fertility and to achieve their family plans.

Our findings showed that women attended the FAC clinic because they wanted to know how long they could safely wait to have a child because they wanted to postpone their family plans. Most felt satisfied with the FAC clinic visit and believed their needs had been met. Women said they felt reassured about their fertility and chance of having a child in the future but also said they understood they should not wait 'too long' to have children. Women believed the information they received at the FAC clinic helped with their decision-making, but warned against developing a false sense of security about their chances of becoming pregnant in the future based on the information provided. Overall, the women felt the benefits (e.g. facilitates informed decision-making) outweighed the risks (e.g. information may influence behaviour) of receiving individual fertility information. Our study provides support for fertility awareness efforts in women to include interventions that are personalized, timely and relevant to the person's stage of life and current fertility decision-making.

# Introduction

Women and men in high-resource countries are delaying parenthood and the average age at first birth has steadily increased over the last 40 years in Western Europe and North America, and the last 25 years in Eastern European countries (Schmidt et al., 2012). The current average age at first birth for women in Denmark is 29.3 years (Statistics Denmark, 2018). Whilst there are benefits of delaying parenthood (e.g. career stability, financial stability, emotional readiness; Mills et al., 2011), there are also consequences such as increases in age-related infertility, not achieving desired family size and unintentional childlessness (Leridon and Slama, 2008; Habbema et al., 2015). Research highlighting the gaps in men and women's fertility knowledge suggests that they may be making decisions to delay parenthood based on misinformation and inaccurate assumptions about fertility. A recent systematic review on 71 articles assessing fertility awareness confirmed the gaps in

men and women's knowledge and called for interventions to increase fertility awareness (Pedro et al., 2018). Current efforts have been two-pronged: the development of broad fertility educational strategies (e.g. brochure, video, website) aimed at increasing knowledge and influencing fertility intentions across different age groups (e.g. Williamson et al., 2014; Daniluk and Koert, 2015; Garcia et al., 2016; Maeda et al., 2016; Conceição et al., 2017; Hammarberg et al., 2017; Boivin et al., 2018a,b), and the development of personalized fertility assessments and guidance that are tailored to each individual (e.g. Bunting and Boivin, 2010; Stern et al., 2013; Hvidman et al., 2015), with the majority of efforts focused on the former.

The Fertility Assessment and Counselling (FAC) clinic was opened in Copenhagen University Hospital, Rigshospitalet, in Copenhagen, Denmark at the end of 2011. The overall goal of the clinic is to increase women's and men's fertility awareness in terms of general knowledge on fertility and to provide a guide to their own status and

help them fulfil their family-building goals (i.e., timing of children, desired family size; Hvidman et al., 2015). Men and women with no known fertility problems can make an appointment to attend the FAC clinic without referral. Free-of-charge consultations are provided by a specialist in reproductive medicine and include a risk assessment (based on personal medical and reproductive history and lifestyle factors) and a clinical evaluation (women: antral follicle count (AFC), anti-Müllerian hormone (AMH) test; men: semen analysis). Men and women are provided with an estimate of their reproductive potential and offered advice based on their personal risk profile along with general information about age-related fertility decline and risk factors for fertility problems (Hvidman et al., 2015).

In earlier studies from the FAC clinic, Hvidman et al. (2015) outlined the creation of the concept, presented data on the first 916 women seen at the FAC clinic and showed that 70% of women stated that the reason for making an appointment was a wish for an estimate of how long they could safely delay childbearing. A study examining an older cohort of women attending the FAC clinic (aged 35–43 years) found similar reasons cited (Birch Petersen et al., 2015), which may also be due to overlap in this study population and Hvidman's et al.'s (2015) sample (i.e., inclusion of same participants). Concern about their fertility was also an often cited reason for attending (Birch Petersen et al., 2015; Hvidman et al., 2015). A qualitative study involving interviews with 20 cohabiting or single women (age 34–39 years) before their FAC clinic visit provided further insight into women's concerns, with women sharing their fears about infertility and describing how their 'biological clock was ticking' and they wished to 'buy more time' (Birch Petersen et al., 2016).

Sylvest and colleagues (2018) conducted a 1-year follow-up study with the 20 single or cohabiting women in Birch Petersen et al.'s (2016) study whom had been interviewed before attending the FAC clinic. Findings showed that attending the FAC clinic increased women's fertility awareness and was experienced as a catalyst for behaviour change and action (e.g. starting to try to conceive, seeking fertility treatment, ending relationship). Those who took action did not experience any regrets. Some of the women identified that they were still in 'limbo' and had not started to try to become pregnant at the I-year mark. There is growing support for the inclusion of qualitative methods in assessing the acceptability and usefulness of an intervention, including examining participants' experiences with and perceptions of the intervention (Bowen et al., 2009). Qualitative methods allow for an in-depth exploration of a complex experience about which we know little (Patton, 2014). There have been no long-term qualitative follow-up studies conducted on FAC attendees beyond the I-year mark. As such, we know less about the long-term experience and impact of attending the FAC clinic. The purpose of this study was to examine women's perceptions and experience of fertility assessment and counselling 6 years after attending the FAC clinic. This knowledge could help us understand whether women's needs are being met by attending the FAC clinic and how to adapt the intervention to better meet their needs.

# Materials and methods

# Ethical approval

According to Danish law, interview studies do not require permission from a scientific ethics committee. The research was approved by the

Danish Data Protection Agency. Participants provided consent to participate in the study.

# Study design

This was a qualitative follow-up study of 24 women who had attended the FAC clinic 6 years prior to the current data collection. The 6-year criteria were selected given that this was the longest follow-up period available since the first year of operation. To participate, women needed to have attended the FAC clinic alone or with a partner between January and June 2012 and be willing to be interviewed in person and in English. There were no restrictions based on parenthood status. The FAC clinic has been open for all women, men and couples who wish to attend and make an appointment except those that already had known infertility (Hvidman et al., 2015). For the women, there have been no criteria in terms of parity, but in practice the large majority of the women have been nulliparous, and in the present sample none of the women who participated had a child at the time they attended the FAC clinic.

#### **Data collection**

The names and Danish Personal Identification (CPR) number of the women who had attended the FAC clinic in the first year of operating (January to June 2012) were extracted from a database of women who agreed to be contacted for future research. We sorted participants according to their date of attendance starting from January 2012. Potential participants were selected consecutively in batches of ~40 women until data collection was completed. Recruitment notices were sent using the national Health Care electronic system linked to the CPR number. This system sends an email alert to citizens when new information has been added to their account (e.g. medical test results, referral to specialist). They must log in to access the information. The recruitment notice included a brief introduction to the study and a link to an online survey where they could register their response: Yes, interested in participating; Yes interested and wished for more information or Not interested. No reimbursement for participating was provided. In total, 141 notices were sent, with 95 women opening the notice and 51 entering a response (35 interested and 16 not interested). Ultimately, 24 interviews were held due to scheduling or other issues (e.g. cancelled due to illness, not available during interview period). In qualitative research, a specific sample size is not predetermined, rather it is necessary to collect enough data to yield rich and detailed information regarding the phenomenon under study (Morse, 2000; Braun and Clarke, 2016). As such, recruitment, data collection and data analysis occur concurrently. Saturation of data, wherein no new themes or information emerge from each subsequent interview, is used as a criterion for how much data should be collected and to ensure trustworthiness of the study's findings (Saunders et al., 2018). Researchers have found that data saturation often occurs after  $\sim\!12$  interviews but underscore that there is variability across studies (Guest et al., 2006). The concept of information power has also been used to determine a suitable sample size in qualitative research, which suggests that the more information that the sample holds that is relevant for the study, the lower the number of participants needed (Malterud et al., 2016). In this study, conducting over 20 interviews allowed us to gain an in-depth, nuanced understanding of the experience and perceptions of the FAC clinic from a wide range of personal

trajectories (e.g. relationship status, sexual orientation, parenthood status) and to ensure the data saturation criterion was met and there was ample information power.

Interviews were held in person at the location of the woman's choice in Copenhagen (work place, home, Rigshospitalet) over a 2month period in 2018 (February to March). Interviews ranged from 60 to 94 min (average 73 min). Interviews were conducted by the first author, an experienced psychologist and qualitative interviewer/researcher. The interviews were in-depth and semi-structured. The interview guide included questions to explore the following topics: reasons for attending, if/how their needs had been met, their understanding of the information provided, and general perceptions of the FAC clinic and fertility assessment and counselling, along with questions about their fertility decision-making after the FAC clinic visit. Follow-up questions were used to probe for in-depth accounts. Interviews were transcribed verbatim by the first author. The data specific to the topics of reasons for attending, needs, their understanding of the information provided, and general perceptions of FAC/fertility assessment and counselling are included in this article. Each topic is identified by a broad title and number, and the themes and subthemes within each topic are described in detail.

## Data analysis

The transcript data were analysed using an iterative process and guided by Braun and Clarke's (2006) phases of thematic analysis: familiarizing self with the data (transcribing, reading and re-reading transcripts); developing initial codes (coding small sections (quotations) in a systematic fashion across the data set, combining data relevant to each code); developing initial themes (grouping codes into potential themes, gathering all data relevant to themes); reviewing themes (checking themes in relation to the coded quotations and entire data set); defining and renaming themes (ongoing analysis and revision of themes through discussion and reflection); and producing the report (selection of vivid examples and finalizing analysis). To maintain trustworthiness of the analytic process, at each stage two or more co-authors read the first author's initial analysis and provided feedback, which was discussed in detail and integrated into the next phase of analysis.

#### Results

Demographic information and fertility details are provided in Table I. All women were childless when attending the FAC clinic in 2012. Most (21 women, 88%) reported they had tried to become pregnant in the 6 years after attending the FAC clinic, with almost half (9 women, 43%) starting to try in the first year. Of those who tried to have a child, all (n=21) had become parents to at least one child (14 women with one child; 6 with two children; 1 with three children). The three remaining women reported they intended to have children in the future (age range 37–42 years). A description of the themes and subthemes under the four broad topic areas is provided. The topic areas, presented below, include: Reasons for attending; If and how their needs were met; Interpretations and understanding of information received; and Perceptions of the FAC clinic and fertility assessment and counselling. See Fig. I for a Thematic Map of the four topic areas, themes and subthemes and Tables II–V for illustrative quotations.

**Table I Participant demographics, parental status and fertility details.** 

	N (%)
Demographics	•••••
Age at intervention (years M (SD))	33.5 (3.4)
Age (current) (years M (SD))	39.5 (3.4
Marital status at intervention	
Married/cohabiting	9 (38%)
Single	15 (63%)
Marital status (current)	
Married/cohabiting	14 (58%)
Single	10 (42%)
Education level (after high school)	
Low (<3 years)	I (4%)
Medium (3–4 years)	13 (54%)
High (+4 years)	10 (42%)
Parental status and fertility details	
Parental status at intervention	
No children	24 (100%
Parental status (current)	
No children	3 (13%)
Parents	21 (88%)
Partnered	14 (67%)
Solo mother	7 (33%)
Year tried to become pregnant $\left(n=2I\right)^{a}$	
Before FAC clinic	I (5%)
First year after attending	9 (43%)
Second year	I (5%)
Third year	4 (19%)
Fourth year	5 (24%)
Pregnant without trying	I (5%)
Number of children (n $= 21$ )	
I child <sup>b</sup>	14 (67%)
2 children	6 (29%)
3 children	I (5%)
Number of deliveries and type of conception	
Partnered women	
Deliveries	20
Natural conception	15 (75%)
MAR <sup>c</sup>	5 (25%)
Solo mothers	
Deliveries	9
MAR	9 (100%)
Wished for more children $(n = 21)$	
No (all had 2–3 children or currently pregnant)	8 (38%)
Yes	13 (62%

All details are at follow-up interview (current) unless indicated.

 $\label{eq:local_local_local} Intervention = attending Fertility Assessment and Counselling (FAC) clinic in 2012. \\ Cohabiting = living together.$ 

MAR= medically assisted reproduction (including any form of fertility treatment).

<sup>&</sup>lt;sup>a</sup>Does not include three women with no attempts to become pregnant and no children.

<sup>&</sup>lt;sup>b</sup>Two women were currently pregnant with second child.

<sup>&</sup>lt;sup>c</sup>Includes two deliveries conceived with donor insemination from lesbian couple.

#### 1. REASONS FOR ATTENDING

Seeking Information and reassurance a) Wish for information and knowledge

- b) Confirmation and reassurance regarding delay and future
- pregnancy c) Concern about fertility
- d) Aid for decision-making

#### 2. IF AND HOW THEIR NEEDS WERE MET

Needs met

- a) Increased knowledge
- b) Sense of reassurance
- c) "Kick in the butt" Motivation to decide and act

#### Unmet needs

- a) Wish for concrete, simple answer
- b) Sense of uncertainty perceived conflicting information c) Wish for more information and/or discussion of options

Women's perceptions and experience of fertility assessment and counselling 6 years after attending the FAC Clinic

#### 3. INTERPRETATIONS AND UNDERSTANDING OF INFORMATION RECEIVED

There's no problem

- a) Everything looks "fine"
- b) "Good" results equal certainty of pregnancy in
- c) Focus on confirmatory information it's OK or safe
- d) But don't wait too long

There's a problem

a) Need to act now or in near future

There could be a problem

a) No guarantees

#### 4. PERCEPTIONS OF THE FAC CLINIC AND FERTILITY ASSESSMENT AND COUNSELLING

Need for caution when providing high stakes information a) Must manage expectations of information provided

- b) Risk of misinterpretation of information
- c) Possibility of creating false security
- d) May cause distress
- e) Risk of information influencing behaviour
- f) Information provided may not be sufficient

Benefits of receiving information outweigh costs

- a) Value of increased awareness and knowledge
- b) Facilitates informed decision-making
- c) Builds sense of control and empowerment
- d) Provides sense of reassurance regarding delay of pregnancy
- e) Use as a preventative tool

Figure 1. Thematic map of the four topic areas, themes and subthemes. Numbered items are broad labels for topic areas. Themes are centred and subthemes are listed by lowercase letters. FAC, Fertility Assessment and Counselling.

# Table II Illustrative themes, subthemes and quotations: Reasons for attending.

#### Seeking information and reassurance

#### (a) Wish for information and knowledge

I came in to know my fertility and I went out knowing my fertility. Like knowing there shouldn't be a problem'.

#### (b) Confirmation and reassurance regarding delay and future pregnancy

'It was important to find out that I could wait to be honest. . . because I wasn't ready at that time to get pregnant'.

#### (c) Concern about fertility

'I realized that some have problems when they are 32 so I wanted to have a check of my chances and I was also a little bit nervous when you are there'.

#### (d) Aid for decision-making

1 was getting older and older . . . and I wanted to go and have it checked out to see can I stay with him and wait or should I just say you know what I have to leave you and have a child with a donor'.

#### Table III Illustrative themes, subthemes and quotations: If and how their needs were met.

#### **Needs** met

#### (a) Increased knowledge

'I found out if I was fertile and that was the goal. It did what it should for me'.

#### (b) Sense of reassurance

'I think it made me relax a bit... we will still [try to conceive] in another two years - it's going to be OK'.

#### (c) 'Kick in the butt' - Motivation to decide and act

'For me it was good. You know to get that kick in the butt'.

'It was really, really good that we answered the study because otherwise we would have just taken it slow and not worried about it and it probably wouldn't have happened'. [had a child]

#### **Unmet needs**

#### (a) Wish for a concrete, simple answer

'It's difficult because basically you want to know should you start having children now or can you wait. And I guess you can't tell us that because no one knows'.

'I understand why it's just as part of the project it's frustrating. I: What does the frustrating refer to? P: That I couldn't have a yes no should I have children now or in the X amount of years'.

#### (b) Sense of uncertainty - perceived conflicting information

'I mean in one way it was very helpful but the results I received were also quite confusing because there was sort of a gap between the visual count of the eggs that I had in my ovaries and what the blood work told'.

#### (c) Wish for more information and/or discussion of options

'It would have been helpful to know you have a year. Do you want to get pregnant? If yes, ok you have these options, you can do this and this and maybe you can improve your fertility by doing this and at least OK if you want to get inseminated OK go this way and what could be done to become pregnant'.

#### Table IV Illustrative themes, subthemes and quotations: Interpretations and understanding of information received.

#### There's no problem

#### (a) Everything looks 'fine'

'I had that test and nothing was wrong. And he said oh nothing is wrong'.

#### (b) 'Good' results equal certainty of pregnancy in future

'I just had an idea that I would get pregnant fast and because I think I just interpreted, the "everything is good" with these results especially for your age and for my mind it just meant "oh I have a ton of eggs I'll just get pregnant". And it's not something that they said to me so it is not like I was misled it was just something in something I thought'.

#### (c) Focus on confirmatory information—it's OK or safe to wait

'Maybe I over-interpreted the results like I wanted to hear that I could wait so maybe I took it like for like a guarantee that sure you can wait but I do remember the doctor telling me that you have a couple of good years left'.

#### (d) But don't wait too long

'Basically I was told that I was pretty fertile so that was great. But I shouldn't wait too long'.

#### There's a problem

#### (a) Need to act now or in near future

'So they said within the year you need to get pregnant because your chances are very poor'.

#### There could be a problem

#### (a) No guarantees

'I completely understood that it was not a guarantee but an estimate but even though it made me feel very happy and relaxed'.

# Reasons for attending

Women's perceptions of their reasons for attending the FAC clinic were grouped under the theme: Seeking information and reassurance. Subthemes are presented under the theme. See Table II for themes and illustrative quotations.

Seeking information and reassurance.

Wish for information and knowledge. All women stated they attended the FAC because they wanted new information including their chances of conceiving in the future, how many years of 'good fertility' they had left (including actual number of years or number of eggs remaining) or their overall fertility status.

# Table V Illustrative themes, subthemes and quotations: Perceptions of the FAC clinic and fertility assessment and counselling.

#### Need for caution when providing high stakes information

#### (a) Must manage expectations of information provided

'I think it's very important to keep that it is a chance that it's no guarantee. To make it very, very clear even for people who don't understand anything at all if that's all they get from that consultation it should be that this is not a guarantee'.

#### (b) Risk of misinterpretation of information

1 just think that maybe it should be stressed more when you have the counselling that even though your results look good or if they are good that it doesn't necessarily mean that you will get easily pregnant, that you will have an easy time conceiving'.

#### (c) Possibility of creating false security

'I think it is more difficult when you are told "this is good" because maybe it is almost like a false sense of security for a lot of, well for me and maybe for a lot of other people. I think it's dangerous, you never know, I mean what difficulties you will have when you try and start to conceive'.

#### (d) May cause distress

'Well some people can get stressed about it [information provided] but . . . I think I would prefer to know what are the challenges instead of trying and trying and

#### (e) Risk of information influencing behaviour

'I think maybe it could potentially push you in a direction that you were not supposed to follow. Because you have this knowledge'.

#### (f) Information provided may not be sufficient

'So I think it's important to highlight . . . all the consequences of waiting. Not only reduced chance of getting pregnant and increased risk of diseases, Downs [syndrome] and stuff like that, but also the fact that the new technologies the chance of success are not that good and to highlight how many women who get pregnant with the eggs or insemination or intervention'.

#### Benefits of receiving information outweigh costs

#### (a) Value of increased awareness and knowledge

'Sometimes when truth is in your face it helps you act like it makes you act ...the fact that she said... if you don't act you might not have kids and of course I was grateful for that because that would have been for me devastating. So I was grateful'.

'I think you can become a bitter person if you, it gives you more force, more power to actually make your own choices and to know that you did something. Maybe it won't end up the way you thought but at least you did something'.

#### (b) Facilitates informed decision-making

'It will also help you to move on in the right direction instead of maybe struggling or hoping for years and putting your power into something that isn't possible when you could take another decision you may take adoption or another type of life that would be right for that person'.

#### (c) Builds sense of control and empowerment

'I think for me it was a great thing and for most people it would be a great thing because it gives the more information about their own body that they don't have. Nobody knows those kind of things so I think it's a great thing'.

'But I think it just gave a sense of control... it just gave us a few more years (laugh) to do fun stuff'.

#### (d) Provides sense of reassurance regarding delay of pregnancy

'But we were sort of, we were shown that yes everything is good and when you start it shouldn't be a problem from both of you so for us we knew OK we can take a breather for a year or two'.

## $\left( \mathbf{e}\right)$ Use as a preventative tool

'I said before it is especially good if it shows that maybe you're nearing early menopause or whatever problems you could have, maybe you have a blocked ovary or something else you were unaware of then you have something you can say "OK I need to get this going, it can't wait. I need to start now".

'Just imagine if people went through and they could make a choice and didn't have to experience going to the fertility clinic. It could save people from the disappointment basically'.

Confirmation and reassurance regarding delay and future pregnancy. Women described their desire for reassurance from a medical professional that they could safely wait to have a child until some point in the future and would be able to conceive when they tried. They wished for an answer that confirmed their current fertility decisions.

Concern about fertility. Women reported that their fertility was on their mind before attending the FAC clinic. Women shared their experience of distress, concern and anxiety about their fertility 'running out' and not being able to conceive in the future.

Aid for decision-making. The women wished for information that could help them make decisions regarding their fertility.

#### If and how their needs were met

Women's perceptions and experiences regarding if and how their needs had been met were grouped under two themes: Needs met and Unmet needs. Subthemes are included under each theme. See Table III for themes and illustrative quotations.

#### Needs met.

*Increased knowledge.* Many women stated that they left the FAC clinic with the information that they were seeking that helped them feel equipped to make informed choices.

Sense of reassurance. Women described the feeling of relief and reassurance about being told they should not worry about their fertility and had more time to wait to conceive.

'Kick in the butt'—motivation to decide and act. Some women felt attending the FAC clinic gave them a 'kick in the butt' to make decisions and take actions regarding their fertility and if they wanted to become parents in the future (e.g. initiating a conversation about parenthood with their partner, starting to try to conceive, seeking fertility treatment, ending a relationship or becoming a sole support mother). In 'acting' sooner, women believed that they had avoided potential infertility or unintentional childlessness.

#### Unmet needs.

Those women who perceived that their needs had not been met by attending the FAC clinic also acknowledged that their expectations for the intervention were 'likely not realistic'.

Wish for a concrete, simple answer. A few participants stated that they did not receive a concrete answer regarding their fertility potential and how many years they could wait to have a child.

Sense of uncertainty—perceived conflicting information. Some women perceived that the information provided was ambiguous or conflicting. For example, perceiving conflicting results from the clinical evaluation (AMH test and AFC) and the advice provided by the consultant.

Wish for more information and/or discussion of options. Several women wished for more time to discuss options and to receive additional information and guidance in a subsequent meeting after the session (e.g. what are your options if your fertility is declining, how do I know I am still fertile after having my first child?).

# Interpretations and understanding of information received

In general, women recalled receiving information related to their personal fertility levels and general information about fertility. The women's subjective understanding of the information they received was grouped into three themes: There's no problem, There's a problem and There could be a problem. Subthemes are included under each theme. See Table IV for themes and illustrative quotations.

#### There's no problem.

Everything looks 'fine'. The women remembered being told that 'everything looks fine' or 'normal' regarding their fertility, which they interpreted to mean there were no problems identified.

'Good' results equal certainty of pregnancy in future. By extension, most of the women who recalled being told their fertility was 'fine' also noted that they believed this result was confirmation of their concrete chances of becoming pregnant in the future. Some women shared their awareness they had 'over-interpreted' the information provided to confirm certainty of pregnancy in the future, in hindsight.

Focus on confirmatory information—it's OK or safe to wait. Women attended the FAC clinic seeking reassurance that they could wait to conceive and would be able to become pregnant in the future when they were ready. As such, they described a tendency to focus on the FAC clinic information that confirmed this option and did not focus on other information provided (e.g. age and fertility decline).

But don't wait too long. Women spoke of understanding that regardless of their personal fertility potential, they should not 'wait too long' to have children.

#### There's a problem.

Need to act now or in near future. In a few cases, women understood there was a problem with their fertility, or their advanced age may be an issue. The women interpreted this to mean that they must 'hurry up' or 'start now' if they wanted to have a child because their fertility might be compromised. Overall, women expressed their gratitude that the problem was identified and they avoided unintentional childlessness.

#### There could be a problem.

No guarantees. In a few cases, women understood that there could be a problem with their fertility even if not identified in the tests, thus there were 'no guarantees' they would become pregnant if they waited too long before trying to become pregnant.

# Perceptions of the FAC clinic and fertility assessment and counselling

Women's perceptions were based on their personal experience of attending the FAC clinic and included their advice for those providing and accessing this type of intervention in the future. All participants agreed that there is value in this service, but that it must be offered with caution because it provides 'high stakes' information that has significant implications for people's subsequent decisions. The women's responses were categorized into two themes: Need for caution when providing high stakes information and Benefits of receiving information outweigh costs. Subthemes are included under each theme. See Table V for themes and illustrative quotations.

Need for caution when providing high stakes information.

Must manage expectations of information provided. Women suggested that before attending the FAC clinic individuals must: be clear on what they want out of the test and realistic about what the test can tell them; be open minded and prepared for any answer; consider options and actions based on potential answers; and be aware of the consequences of receiving information and that decisions could be made based on the information provided.

Risk of misinterpretation of information. Women stressed that the FAC clinic's 'message' should include the qualification that the information provided does not guarantee a pregnancy in the future. They suggested that to avoid 'over-interpreting the results' attendees should be told that even if their fertility 'looks good' they 'shouldn't wait too long'.

Possibility of creating false security. Many of the women spoke generally about the possibility that those attending the FAC clinic may develop a false sense of security that their fertility is currently 'good' and they can delay parenthood indefinitely but be unable to achieve a pregnancy in the future after waiting too long. This was described as the worst-case scenario rather than based on their personal experience.

May cause distress. Like the previous concern about 'False security', some women highlighted their general concern about how others might react to 'bad results'. They believed that the information may come as a shock if it is not expected. That said, those women who

received what they perceived as 'bad results' spoke of being grateful that they knew there was a problem so that they could take action before time ran out.

Risk of information influencing behaviour. As with the previous subthemes, women stated a general concern that knowledge may 'push' people to act before thinking, such as rushing to become pregnant or to end a relationship with a partner who is not ready to become a parent.

Information provided may not be sufficient. A few women mentioned that more information is needed than is provided in the intervention in order to make informed decisions about their fertility, including more comprehensive testing and opportunities for questions and additional follow-up.

Benefits of receiving information outweigh costs.

Value of increased awareness and knowledge. Despite highlighting the cautions or concerns regarding this type of intervention, all of the participants believed that the benefits of receiving information and being able to make informed decisions outweighed the potential costs. As such, they believed that regardless of the result, knowledge is important as it increases awareness, provides new insights into personal and general fertility and reduces uncertainty. Benefits were described on a personal level (i.e. made them realize they had to start trying to conceive very soon or risk infertility and childlessness) and the potential societal level (e.g. reducing the need for fertility treatment).

Facilitates informed decision-making. The most significant and often cited benefit of the FAC clinic was that it facilitates informed decision-making. The women wanted to make conscious decisions based on information rather than deciding by default. They stressed that it was easier to make decisions when they 'know the facts'. Based on their experience, women argued that people should be provided with 'straight answers' about the reality of age and fertility decline regardless of their personal fertility levels, even if it causes initial distress.

Builds sense of control and empowerment. The participants highlighted how attending the FAC clinic provided them with a sense of control or empowerment to make informed decisions and actions. Many of the participants mentioned that they had recommended the FAC clinic to their friends, that they would encourage their children to attend as young adults, and/or that everyone should have access to this service.

Provides sense of reassurance regarding delay of pregnancy. The participants spoke personally and more generally about the sense of reassurance provided through this type of intervention that they had 'more time' before trying to become pregnant. As such, the stress of the 'ticking clock' was reduced for a limited amount of time.

Use as a preventative tool. The women believed that, particularly in the case of an identified or possible problem with fertility, potential fertility problems could be subverted by trying to become pregnant sooner or seeking fertility treatment before it was too late. As such, it was 'good to know problems' before it was too late to do anything about it.

# **Discussion**

The most common reason that women attended the FAC clinic was to seek information and determine how long they could delay

childbearing. Similar to Sylvest's et al.'s (2018) 1-year follow-up study of 20 women attending the FAC clinic, most of the women in the present 6-year follow-up study (no overlapping participants) believed their needs had been met by attending the FAC clinic. Those who were dissatisfied cited a desire for exact, concrete information as to their remaining years of fertility, although acknowledged that this was likely not realistic. In this study, women viewed personalized fertility knowledge as an important aid to decision-making but cautioned about developing a false sense of security based on the results. Women stated they felt reassured about their fertility status after attending the FAC clinic whilst understanding that they should not wait 'too long' before trying to become pregnant. Despite different samples and follow-up time points, the similarity between the Sylvest et al. (2018) study and the present study findings emphasizes consistencies in women's experiences and supports the trustworthiness of both study's findings on the benefits of attending the FAC clinic.

The women's accounts highlight the value of the FAC clinic as a screening tool and support the basic principle of screening—'don't guess, assess'—that is, to provide personal health information to help individuals make informed decisions about their health. The FAC clinic intervention meets one of the World Health Organization's (Wilson and lungner, 1968) general screening criteria, which includes the selection of a condition that can be detected at an early stage (i.e. infertility or fertility problems) and the availability of acceptable treatment for the condition (i.e. fertility treatment) or the possibility of preventing the condition (e.g. advanced decision to conceive thus preventing agerelated infertility). When asked about their perception of the FAC clinic and fertility assessment and counselling more broadly, women in the study expressed some concerns or risks about providing this type of service (e.g. developing a false sense of security of one's fertility and waiting 'too long'), but all women acknowledged that the benefits of receiving information and being able to make an informed decisions outweighed any concerns. This was particularly the case of when a problem was identified, providing women with the opportunity to make informed decisions and seek assistance to increase the likelihood of becoming pregnant and having a family.

The women's accounts highlight their desire for an exact, concrete answer as to their fertility potential and their tendency to overinterpret the information provided (i.e., 'no problems' identified) to indicate the certainty of becoming pregnant in the future. This is consistent with the findings of a systematic review of attitudes towards health-based screening that showed that people generally overestimate the benefits of health-based screening, underscoring their wish for concrete answers regarding one's body (Hoffman and Del Mar, 2015). In the current study, some of the women recognized their tendency to over-interpret the information, however, others were unaware. The women's tendency to focus on confirmatory information (i.e. that they could wait) highlights the need to provide accurate and balanced information about a screening intervention's benefits, to contextualize and qualify the information provided including examples where 'good news' did not lead to a pregnancy (i.e. 'no guarantee' of future pregnancy), and to be cautious of language which could be overinterpreted (Hoffman and Del Mar, 2015).

This study highlights that fertility is indeed a highly emotional issue, with many women reporting that their fertility was on their minds before they attended the FAC clinic, often causing worry and distress. Consistent with previous research on attitudes towards fertility

education (e.g. Boivin et al., 2018b), when speaking about fertility education more broadly the participants cautioned that receiving fertility-related information may increase individuals' distress. The few studies that have examined this specifically provide some preliminary support for an increase in subjective anxiety or worry after exposure to a fertility education intervention without personalized information (e.g. Maeda et al., 2016; Boivin et al., 2018a,b). Boivin et al. (2018b) suggested distress may increase when fertility information feels threatening to other goals (e.g. career).

In our study, whilst some women experienced dissatisfaction with residual uncertainty because they wished for an exact or 'concrete' answer regarding their fertility, ultimately all felt that the benefits of receiving personalized fertility information outweighed the risks. Most of the women felt reassured given they had the information they needed to make an informed decision about their fertility. That said, our participants may be unique because they actively sought advice at the FAC clinic—in many cases because they already felt worried or concerned about their fertility—and they received reassurance, which itself felt empowering rather than distressing. For example, those who were told they might have a problem with their fertility felt reassured that they could now take action and avoid unintentional childlessness.

It may be that in our study women's distress and uncertainty was reduced because they were provided with personalized fertility information in a highly supported environment. As such, these women did not only receive fertility education, they were offered personalized, fertility assessment and guidance tailored to each individual, and supported in the information they received. There may also be some positive recall bias in those for whom the anticipated harm (i.e. not being able to become pregnant) did not come to pass and a resolution of decisional anxiety regarding fertility and competing life plans. In other studies testing fertility education interventions, participants could have been taken by surprise if they did not actively seek out the fertility information or they may not have been at the stage in their lives where their fertility was relevant, and importantly the information was not personalized or provided in a highly supported environment as is the case in the FAC clinic (e.g. Maeda et al., 2016; Boivin et al., 2018a,b).

Our findings show those who expressed some distress were those who described uncertainty in their fertility potential due to perceived conflicting results of clinical examination (e.g. AMH and AFC) or conflicting messages between tests and advice. Some of this uncertainty might have been a function of the FAC clinic procedure, as originally the AMH test results were provided 2 weeks after the visit by email. Currently, FAC clinic attendees have their blood taken and AMH tested before the clinic visit so that the results of all tests can be integrated into the information and guidance provided in the in-person meeting, ensuring that attendees are not left confused or having to interpret results on their own. This may resolve some of the uncertainty described by the participants. In addition, women highlighted their wish for more time to discuss options and to receive additional information and guidance after attending the FAC clinic. Additional support and follow-up may be a way to fulfil the unmet needs stated by the participants and reduce any remaining uncertainty and distress.

Previous research supports the increase in fertility knowledge after exposure to fertility education interventions (e.g. Williamson et al., 2014; Garcia et al., 2016; Maeda et al., 2016; Conceição et al., 2017; Hammarberg et al., 2017; Boivin et al., 2018a). There are mixed findings in the few studies measuring long-term retention with some

showing knowledge maintained at follow-up (e.g. Maeda et al., 2018) and others showing it is not (e.g. Daniluk and Koert, 2015). In our study, 6 years after attending the FAC clinic, women were still able to recall very clearly the information received, most commonly the age and fertility decline graph shown by the consultant. Taken together, these findings support the value of including interventions that are personalized, timely, and relevant to the individual's stage of life and current fertility decision-making as part of a two-pronged approach to fertility education and awareness.

Finally, the findings highlight that attending the FAC clinic might be an important first step or action in women's fertility decision-making process and/or becoming ready for parenthood. The participants shared how the FAC clinic was a 'kick in the butt' and motivated them to decide and act, similar to the women in Sylvest et al.'s (2018) I-year follow-up study, suggesting that attending the FAC clinic acted as a cue to action as outlined in the Health Belief Model (Rosenstock, 1990; Glanz and Bishop, 2010) and provides support for the FAC clinic's acceptability and usefulness as an intervention. Finally, it should be stressed that the true effectiveness of the FAC clinic's activity in terms of predicting long-term fertility remains to be investigated with follow-up studies on total delivery rates at the end of their reproductive age.

#### **Limitations**

The participants were volunteers from a sample of Danish women who previously attended the FAC clinic in its first year of operation. Whilst 141 women were invited to participate, ~25% expressed interest in participating. That said, in a qualitative study, diversity of opinions is more important than representativeness. The study group included a broad spectrum of women with variability in experiences at the FAC clinic (i.e. interpretation of information received) and fertility trajectories (e.g. parental status, number of children, sexual orientation, single/partnered parenthood). However, we do not know the experiences of those who did not participate. The current study group is on average older than the current average age at first child in Denmark (33.5 versus 29.3 years; Statistics Denmark, 2018). Thus, this group may be more 'delayed' or ambivalent and it cannot be said that this is the experience of all women of reproductive age. However, this study provides the first long-term follow-up of women receiving personalized fertility assessment and guidance and points to its value as a fertility awareness intervention.

# Conclusion

This research suggests that the FAC clinic is a useful concept in increasing women's fertility awareness.

The participants viewed the personalized fertility knowledge and advice they received as important aids to their fertility decision-making and they believed the benefits outweighed the risks of receiving personalized fertility information. As such, the findings provide support for an individualized approach to fertility education, assessment and counselling, provided at a time when it is relevant to the individual's current fertility decision-making (i.e. eager for specific information, sought it out themselves) and supports previous calls for customized, tailored fertility education interventions (e.g. Daniluk and Koert, 2015; Garcia et al., 2016; Boivin et al., 2018a,b; Pedro et al., 2018). The

women's accounts underscore the value in the principle 'don't guess, assess' and provide support for the FAC clinic's usefulness as a screening tool and promoting informed fertility decision-making. This research supports a two-pronged approach to fertility education and awareness, with the inclusion and development of fertility interventions providing personalized fertility information on an individual or couple level, along with broad fertility education strategies (e.g. video, brochure, website) providing general fertility information to a wider population.

# **Authors' roles**

All co-authors contributed to the concept and design of the study and analysis/interpretation of the data, and critically revised and provided final approval of the manuscript. E.K. conducted the interviews and drafted first draft of the manuscript and integrated the co-authors' feedback into the final version.

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### **Conflict of interest**

J.B. reports that the risk evaluation form used at the Fertility Assessment Clinic was inspired by the Fertility Status Awareness Tool FertiSTAT that was developed at Cardiff University for self-assessment of reproductive risk (Bunting and Boivin, 2010). J.B. also reports personal fees from Merck KGaA, Merck AB, Theramex, Ferring Pharmaceuticals A/S and a research grant from Merck Serono Ltd outside the submitted work. A.N.A. has received personal fees from both Merck Pharmaceuticals and Ferring and grants from Roche Diagnostics outside the submitted work. The other authors report no conflicts of interest.

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