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Conditions for autonomous reproductive decision-making in prenatal screening: A mixed methods study



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ABSTRACT

Background: Pregnant women should be able to make autonomous and meaningful decisions about prenatal screening for fetal abnormalities. It remains largely unclear which circumstances facilitate or hinder such a decision-making process.

Objective: To investigate what conditions Dutch pregnant women and professional experts consider important for autonomous reproductive decision-making in prenatal screening for fetal abnormalities, and the extent to which, according to women, those conditions are met in practice.

Methods: A mixed methods study was conducted in the Netherlands in 2016–2017. A conceptual model was used to interview professional experts (n = 16) and pregnant women (n = 19). Thematic analysis was performed to identify important conditions. Subsequently, a questionnaire assessed the perceived importance of those conditions and the extent to which these were met, in the experience of pregnant women (n = 200).

Results: Professional experts stressed the importance of information provision, and emphasized a rational decision-making model. Pregnant women differed in what information they felt was needed, and this depended on the screening decision made. Questionnaire findings showed that women prioritized discussion and consensus with partners. Information about test accuracy and miscarriage risk of invasive follow-up testing was also considered important. Two key conditions were not adequately met, in the experience of women: (1) having information about miscarriage risk; (2) not being directed by health professionals in decision-making.

Conclusion: According to women, discussion and consensus with partners was considered a highly important condition for an autonomous and meaningful decision-making process. Access to information about safety of testing and ensuring that women are not being directed in their decision-making by health professionals seem to be areas for improvement in prenatal care practice.

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Introduction

The aim of prenatal screening for fetal disorders such as Down syndrome is generally considered to enable pregnant women to make autonomous, meaningful reproductive decisions (Dondorp et al., 2015). Policy and healthcare guidelines recommend that programs enable women to make informed choices (Dondorp et al., 2015; Nuffield Council on Bioethics, 2017), i.e. choices based on relevant knowledge, consistent with the decisionmaker's values and behaviorally implemented (Marteau et al., 2001). Making informed choices is known to be positively associated with psychological outcomes such as low decisional conflict (van den Berg et al., 2005). It has been argued that to make a fully informed decision, women should be encouraged to deliberate on the various alternatives, their pros and cons, and their consequences (van den Berg et al., 2006).

In the Netherlands, all pregnant women are informed about the possibility of prenatal screening for fetal disorders by their obstetric healthcare provider, generally a primary care midwife.

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https://doi.org/10.1016/j.midw.2023.103607 0266-6138/© 2023 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/) Health professionals thus serve as an important resource and support women's decision processes by providing information about screening and pre-test counseling (Martin et al., 2015). Other aspects known to influence women's decision processes are their own social environment and life experiences (Carroll et al., 2012; Etchegary et al., 2008; Reid et al., 2009; van den Berg et al., 2006). This corresponds to what is known from the decision-making literature, namely that people do not only base their decisions on a systematic consideration of information provided (Gigerenzer and Selten, 2001). Factors influencing the decision-making process overall include characteristics of: 1) the decision problem (e.g. information complexity; Payne et al., 1993; Timmermans, 1993); 2) the decision-maker (e.g. educational level, experiential knowledge; Bruine de Bruin et al., 2007), 3) the situation/environment (e.g. social norms, costs; Timmermans, 2013). This does not necessarily mean that decision-making is non-deliberated or uninformed if people do not make full use of information provided (Gigerenzer and Selten, 2001), but it does pose the question regarding which circumstances foster autonomous and meaningful decision-making.

Research into prenatal screening decision-making has mostly focused on information provision, showing that women differ in information needs Shiloh et al., 2006), and that prenatal counselors are mostly not their only information source (Carroll et al., 2012; Garcia et al., 2008; Lagan et al., 2011). This line of research has not yielded a clear path of how and when pregnant women should be informed for an optimal decision-making process. Combining different strategies, e.g. written leaflets or extra counseling sessions, seems to improve the knowledge of (mainly highereducated) women (Skjoth et al., 2015). It is not clear whether this is also beneficial for those with a lower educational level. Counselors seem to be worried about overloading women with information (Skjoth et al., 2015), but information provision is also known to often be insufficient in fully describing the screened disorders (John et al., 2019; Ternby et al., 2015), suggesting that women may need to be provided with additional information (John et al., 2019; Martin et al., 2021).

Several studies identified women's pre-existing knowledge and perceptions that can influence decision-making (Crombag et al., 2013; Reid et al., 2009). Furthermore, expectations and perceptions of having a child with Down syndrome and the associated parenting burden/reward, as well as perceptions of motherhood and pregnancy termination are all known to play a role (Choi et al., 2012; Crombag et al., 2013; Garcia et al., 2008, 2022; Reid et al., 2009). Research has shown that not all women make deliberate decisions; women who accept screening overall appear to deliberate less than women who decline (van den Berg et al., 2006). Women often seem to use a multi-step decision process, first considering screening and only secondly considering follow-up options (e.g. invasive diagnostic testing by chorionic villus sampling or amniocentesis) in the case of a positive screening result (Holtkanp et al., 2018).

Women's personal characteristics, e.g. educational level or experiences (e.g. knowing someone with Down syndrome) are also known to affect the decision-making process (Etchegary et al., 2008; Potter et al., 2008). Situational factors such as how the screening is offered, whether it feels routine, and trust in the person offering it all play a role (Gottfreðsdóttir and Árnason, 2011; Reid et al., 2009). Other situational factors of importance are costs of the test (Verweij et al., 2014), reimbursement policy (Crombag et al., 2016a), and women's social environment, e.g. available social services (Choi et al., 2012). Insight into which contextual factors foster or impede autonomous decision-making is important in the light of new screening possibilities such as non-invasive prenatal testing (NIPT) (Allyse et al., 2015; Cernat et al., 2019). It has been argued that screening decisions may be-

come less informed with NIPT, because offering such an accurate, safe, and early test may feel as pressure to accept screening (Cernat et al., 2019; Dondorp et al., 2015; Van der Meij et al., 2022)

Prenatal screening decisions are thus complex, with many factors of influence, but it is not clear how those different circumstances facilitate or hinder autonomous and meaningful decisionmaking process as emphasized in health policy. This study therefore aimed to investigate what conditions Dutch pregnant women and professional experts consider important for such a process. Furthermore, we aimed to assess the extent to which those conditions are met in practice, in the perspective of women themselves. Because previous research indicated that women's attitude towards prenatal screening is key to decision-making (Di Mattei et al., 2021), we also compared women who accepted screening versus those who declined. The study specifically focused on prenatal screening for fetal aneuploidy (Down, Edwards and Patau Syndrome). At the time of our study, Dutch pregnant women who were interested in prenatal screening received oral counseling and written information about prenatal screening using the first-trimester combined test (FCT; costs €168 in 2017) from their midwife or gynecologist. At the start of this study, NIPT was only commercially available abroad, or after a high-risk FCT result for trisomy (Oepkes et al., 2016). During data collection for the questionnaire, NIPT also became available as a first-line screening test at comparable costs (€175), including a 30-minute pre-test counseling session by a certified counselor (Van Schendel et al., 2017; Van der Meij et al., 2022).

Methods

Study design

A conceptual model was constructed based on the decisionmaking literature (Timmermans, 2013), describing three types of conditions for autonomous reproductive decision-making, i.e. characteristics of: a) *the decision problem*; b) *the decision-maker*; c) *the situation or environment in which the choice is presented*. The model was used to develop a qualitative study among pregnant women and professional experts, followed by a questionnaire study among pregnant women. The Medical Ethical Committee of Amsterdam UMC approved the study protocol (VUMC2015.398).

Qualitative study

Interviews with Dutch professional experts in prenatal screening (n = 16) and pregnant women (n = 19) were conducted. Indepth analysis on women's decision-making was previously reported in a study comparing women's perspectives between 2003 and 2016 (van Bruggen et al., 2018). The current paper focuses on the conditions needed to make autonomous decisions, capturing women's views as well as the views of professional experts. The interview guides included open phases, to allow participants to tell their own stories, and semi-structured questions concerning conditions from the conceptual model. Interviews lasted between 30 and 90 min. All participants signed informed consent.

Interviews with professional experts

Professional experts were interviewed between October 2015 and February 2016. The criterion for including them was that they needed to be an expert in prenatal screening and the decisions made by women and professionals in this context, meaning that they were or had been involved in national steering or advisory groups for policy and/or education on prenatal screening. We included: (clinical) midwives (n = 5), gynecologists (n = 2), ultrasound experts (n = 2), patient organization representatives (n = 1), policy makers (n = 2), educators of midwives (n = 1), ethicists (n = 1), pediatricians (n = 1) and clinical geneticists (n = 1). Interviews were audio-recorded and summarized, and member checks were performed. Data saturation was reached after 16 interviews. Interviews were conducted by one researcher (D.I.). Emerging themes were analyzed by three researchers (D.I., O.D., L.H.) and re-formulated into conditions.

Interviews with pregnant women

Interviewees were between 7 and 17 weeks pregnant, and were interviewed by two researchers (D.I., H.B.) between February and April 2016. They were recruited via two Dutch midwifery practices, snowball sampling, and social media. The interview guide used a timeline to structure the open phase with open questions such as "Can you tell me how you made your decision?" and "What were the most important considerations for you?"(also see Supplementary material). Subsequently, we posed semi-structured questions such as "What did you think of the risk information provided?" and "Were there any practical circumstances that played a role in your decision?" (Probes: costs, travel time, location; (also see Supplementary material). Participants were also asked to fill out a brief questionnaire about age, educational level, marital status, number of children, experiences with prenatal screening, and religiosity. Interviews were performed at the university medical center, by phone or at participants' homes. Data saturation was reached after 19 interviews. All interviews were transcribed verbatim and coded using Atlas.ti by D.I., five were coded by a second researcher (L.H.). Codes were based on the conceptual model and consensus meetings were held with three researchers (D.I., O.D., L.H.).

Questionnaire study

The conceptual model and interview findings were used to construct a list of conditions for making autonomous and meaningful decisions. This list was presented in a questionnaire that assessed pregnant women's perceived importance of the conditions and the extent to which these were, in their experience, met in practice.

Participants and procedure

Participants were recruited through a Dutch online panel via email in May 2017 (FlyCatcher Internet Research; ISO 26,362; 16,000 members and additional recruitment among 260,000 panel members through partner agencies). All women were at least 20 weeks pregnant, thereby avoiding interference with their actual decision-making process for first-trimester prenatal screening. Participants received a brief explanation about first-trimester prenatal screening for fetal aneuploidy, and answered questions concerning their prenatal screening decisions. Participants were shown three domains of conditions containing items about the decision problem (16 items), decision-maker (10 items), and situation/environment (12 items). Participants were asked to rate how important each item was for their decision (importance items) and to what extent each item had been met, in their experience (experience items).

Questionnaire variables

Importance items. Items with a 5-point scale ranging from not important at all (1) to very important (5). Examples from each of the three domains are: "It is important for my decision... to have information about the accuracy of the test" (decision problem); "... that I think about the values that are important to me concerning my pregnancy" (decision-maker); "...that I can discuss the decision with my partner" (situation/environment).

Experience items. Items with a 5-point scale ranging from definitely not (1) to definitely (5). Examples from each of the three domains are:"Did you receive information about the

accuracy of the test?" (decision problem); "... think about the values that are important to you concerning your pregnancy?" (decision-maker); "... discuss the decision with your partner?" (situation/environment). Five items were reverse-coded, so for each item, a higher rating indicated a more positive experience (i.e. greater extent to which the condition was met).

Potential for improvement. To identify areas with potential for improvement (i.e. important conditions that were not adequately met), we combined importance scores with experience scores using the formula: proportion negative experience * importance score (Damman et al., 2009; Sixma et al., 2007).

Screening choice. Participants' decisions concerning prenatal screening for Down, Edwards and Patau Syndrome using FCT ("Did you have the combined test in this pregnancy?" (yes/no/no, but I had the NIPT)).

Socio-demographic variables. Age, having children, educational level, ethnicity, religious activity.

Analysis

Descriptive analyses were used to assess the extent to which the conditions were considered important and the extent to which these were met, in the women's opinion. Scores of 1 and 2 on experience items – from definitely not (1) to definitely (5) – were considered a negative experience. Potential for improvement was analyzed by combining importance scores with experience scores using the formula: proportion negative experience * importance score. ANOVAs were used to assess differences between subgroups of women for screening choice made. For these analyses, the significance level was set to .p<.01, to reduce the chance of type 1 errors. All analyses were performed using SPSS for Windows version 22.

Results

Table 1 summarizes participants' characteristics in both the qualitative study and the questionnaire study. A response rate to the survey could not be calculated, since it was not known how many women in the online panel were pregnant.

Qualitative study

Table 2 shows the identified themes, structured by our conceptual model, exemplary quotes, subthemes, and corresponding questionnaire items.

Characteristics of the decision problem

Several professional experts stressed that women should be made aware that decisions have to be made, and the potential consequences of decisions. According to professional experts, women might not realize that they may need to make difficult decisions about pregnancy termination at the end of the screening trajectory. Women said that they considered each decision separately, because they expected to feel differently at the time of those follow-up decisions. Professional experts emphasized that women should be informed about test characteristics, e.g., test accuracy and procedure. This was not often mentioned by women themselves. Women indicated that the risk of a miscarriage as a result of prenatal diagnostic follow-up testing was important to them, and also that this information had not always been adequately communicated to them. Most women knew what Down syndrome was, but some indicated that the different levels of severity of Down syndrome were not fully clear from the information provided.

Table 1

Participant characteristics.

| | Qualitative study $N = 19$ | Quantitative study $N = 200$ |
|--|----------------------------|------------------------------|
| Mean age (SD); years range | 31.7 (5.2); 22–41 | 30.6 (5.5); 19–41 |
| Having children, n (%) | | |
| Yes | 6 (32) | 94 (47) |
| No | 13 (68) | 106 (53) |
| Educational level ^a , n (%) | | |
| Low/Medium | 5 (26) | 69 (35) |
| High | 14 (74) | 131 (65) |
| Religion, n (%) | | |
| None | 8 (42) | 121 (61) |
| Protestant | 4 (21) | 33 (17) |
| Catholic | 5 (26) | 26 (13) |
| Muslim | 1 (0.5) | 8 (4) |
| Other | 1 (0.5) | 12 (6) |
| Level of religiosity, n (%) | | |
| (Somewhat) active | 7 (37) | 53 (27) |
| Not active/not religious | 12 (63) | 147 (74) |
| Ethnicity, n (%) | | |
| Western | 16 (84.2) | 183 (91.5) |
| Non-Western | 2 (10.5) | 15 (7.5) |
| Missing | 1 (5.3) | 2(1) |
| Chose screening for fetal | | |
| aneuploidy in current | | |
| pregnancy, n (%) | | |
| Yes | 9 ^b (47) | 96 ^c (48) |
| No | 9 (47) | 104 (52) |
| Undecided | 1 (5) | 0 (0) |

^a Educational level defined as highest level of completed education. The standard categorization of Statistics Netherlands was followed, which defines primary school, lower level of secondary school and lower vocational training as 'low education', higher level of secondary school or intermediate vocational training as 'medium education', and higher vocational training or university as 'high education'.

^b Combined test.

^c Combined test (n = 83) or non-invasive prenatal test (n = 13).

Professional experts emphasized that pregnant women receive a lot of oral and written information during counseling which is essential for the decision-making process. Women differed in their views on information provision. With regard to the type of information, some said they preferred to use leaflets as a reference at home, while others did not remember receiving leaflets. Most women said they received enough information, but some said they received more than needed or, by contrast, that they had wanted more information, e.g., about pregnancy termination. When asked, many explicitly stated that they did not base their decision on information, but rather on personal experiences, such as a previous choice to undergo screening in previous pregnancies or knowing someone with Down syndrome.

Differences between women regarding informational needs seemed to depend on whether or not women had already made a decision to screen or not before counseling, regardless of whether this was for or against screening. Several women who chose screening argued that they needed little information in the counseling, because they already knew what they wanted. Similarly, some women stated that information about, for example, test characteristics was of little importance, as they had already decided against screening prior to counseling. In contrast, women who were still undecided when counseled, more often indicated that they needed information, e.g., about the risk of having an affected child.

Characteristics of the decision-maker

The importance of individual values in the decision-making process was mentioned by professional experts in a general sense, but typically not further specified. Women were asked about their values concerning life, pregnancy termination, screening and medicalization, motherhood, and religion. Some women did not express explicit individual values, others expressed their religious views, e.g. on pregnancy termination. Several women stated that they did not want to think about these values until a choice based on the screening outcome had to be made. They indicated that they would discuss it with their partner at the proper time. Professional experts emphasized that for autonomous decision-making, deliberation (i.e., weighing pros and cons, and reflection) is needed. Women generally said that they thought about the implications of the decision, but also stressed a more heuristic decision-making style based on one argument, e.g., the belief that they were not at risk because they were young. Several women also stressed a more intuitive decision-making style, e.g., relying on feeling at peace with their decision, or on the feeling that prenatal testing is unnatural.

Characteristics related to the situation

Professional experts talked about the limited amount of time available for counseling about prenatal screening in current practice. Some women indicated that the time for decision-making after counseling was short and reported experiencing time pressure. As previously reported (van Bruggen et al., 2018), some women mentioned pressure from society, i.e. that they had to justify their decision regarding prenatal screening, given the societal debate. According to both professional experts and women, costs for a prenatal screening test might be a barrier for forming autonomous decisions, as not all women can afford it. On the other hand, it was argued by professional experts that costs might be a signal indicating that tests are not standard prenatal care, compelling women to consider the choices carefully. Women indeed mentioned that costs made them more aware of the screening decision. Women mostly viewed their decision as something very personal and typically only discussed it with their partner. They stressed that being in agreement with their partner was essential.

Questionnaire study

Table 3 shows the perceived importance of all items and corresponding experience ratings. The top five highest rated importance items were: *I can discuss the decision with my partner* [M: 4.45; SD.90]; *I have information about the probability of a miscarriage after a follow-up test* [M: 4.35; SD.84]; *My partner and I have the same views on prenatal screening* [M:4.34; SD:83]; *I have information about the accuracy of the test* [M:4.34; SD.84]; and *I listen carefully to my feelings and intuition* [M:4.34; SD.78].

Combining importance and experience scores showed that two items in particular had potential for improvement: *Information about the probability of a miscarriage after a follow-up test* [mean importance: 4.35; proportion negative experiences: 19%], and *Not being directed by the health professional in what one should choose* [mean importance: 4.01; proportion negative experiences: 28%] (Fig. 1). This indicated that although information about the probability of a miscarriage was considered important, 19% reported not to have received this (i.e. 1 or 2 on the 5-point scale). Similarly, while women considered it important not to be directed in their decision by health professionals, 28% reported that they had experienced being directed by their health professional regarding what they should choose.

Subgroup differences for screening choice made. Women who chose screening (N = 96) rated the provision of various types of information as more important than women who declined screening (N = 104); significant differences between the two groups were found on four information-related items: "...that I know the different tests I can choose from" (M = 4.26;SD=0.84 for women who chose screening and M = 3.89; SD=1.06 for women who declined screening; F = 7.27; p=.008), "...that I know what is possible after a positive test result" (M = 4.42; SD=0.69 for

Table 2

| Results from c | jualitative | study. |
|----------------|-------------|--------|
|----------------|-------------|--------|

| Main concepts from conceptual model | Subthemes | Professional experts' quotes | Pregnant women's quotes | Items |
|--|---|---|---|---|
| Decision problem | Information about decision problem | | "And she [midwife] also gave us a leaflet that we could study at home." (V9, test decliner, aged 26) | I know which decisions are to be made at what time I receive written information about screening from my healthcare professional I receive oral information about screening from my healthcare professional |
| | Information about test characteristics | "With the combined test it is all about chances The result is a probability, you get a number. Instead of it being a suspicious result or not suspicious, like with the NIPT, which makes it way easier." (P2, Ultrasound expert) | "If you indeed have an increased risk and you can go into the amniocentesis process, then there is a chance that the child is healthy, but because of the amniocentesis, you miscarriage. I thought well do I take that risk?" (V16, test acceptor, aged 33). | I do not receive too much information I know the different tests I can choose from I have information about the probability of a miscarriage after a follow-up test I have information about the accuracy of the test I know what test outcomes are possible I know what is possible after a positive test result I have information about how the test works |
| | Information about the disorders screened for | "They (women and partner) know why they are here, to be informed about Down. So they want to know from me: what is Down, what can I expect? Basically, the whole story about the life of a child with Down."(P9, Pediatrician) | "What made me doubt about the combined test, were those two other syndromes. She [midwife] said that those are syndromes with no life expectancy for the child. And that it's different for Down syndrome." (V8, test decliner, aged 28) | I know what disorders are screened for I know the probability of having a child with one of the disorders screened for I have information about what it is like to live with a child with these disorders I have information about the health of people with the disorders screened for I can talk to other women that have already made the prenatal screening decision I can talk to the parents of children with the disorders screened for |
| Decision-maker | Values | "If you get the final diagnosis, Down or something else, you encounter the difficult decision about abortion which is very burdensome for women. You should really realize that can be the end result of the screening trajectory." (P15 Ethicist) | "[concerning terminating a pregnancy] You know it's a very difficult decision. So I don't think: if it's a bit inconvenient now, maybe next year, so I'll do it [have an abortion]. No, that's nonsense. But the fact that it's possible, that's good." (V16, test acceptor, aged 23) | I think about the values that are important to me concerning possibly terminating a pregnancy I think about the values that are important to me concerning possibly screening my unborn child I think about the values that are important to me concerning motherhood I think about the values that are important to me concerning my pregnancy |
| | Deliberate | "The decision is informed whenshe [a pregnant women] is allowed to make her decisions concerning screening and to get an overview of the consequences." (P13, Policy maker) | "If it happens [a child with Down syndrome], we can handle it. It may even be nice. I have worked with a lot of people with Down syndrome, which makes a difference as well." (V1, test decliner, aged 41) | I listen carefully to my feelings and intuition I think about the consequences of my decision I make all prenatal screening decisions consciously I make sure that I have enough information about prenatal screening I really deliberate on all the facts on prenatal screening I think about my experiences with people with the disorders screened for |
| Situation/ environment | Practical environment | "When people have to pay, the uptake is lower. That's because of the money itself, people say: "I could also spend it on something else", but also the very negative signal it gives. If the government pays for it, it's something important."(P5, Gynecologist) | "We thought: if it is reimbursed, let's just do it, then we know. And when it turned out not to be reimbursed, that was a wake-up call, which made us think: 'why did we want this?'" (V6, test acceptor, aged 27) | I do not feel time pressure to make a decision I do not have to pay too much for the screening I can take care of a child with these disorders I know that there are good facilities for children with the disorders screened for |
| | Social environment | "Some pregnant women ask: "what do most people do?' or 'what would you recommend?'. Then they want to receive support with their decision but you don't want to help them by directing them." (P7, Midwife/researcher) | "We made the decision together. We talked about it like: okay, are we going to do the screening and if yes, what are we going to do with the results?" (V4, test acceptor, aged 40) | I can discuss the decision with my partner my partner and I have the same views on prenatal screening I can ask my health professional questions my health professional does not direct (steer) me in my decision there is no societal pressure to participate in screening I receive help from my health professional to make this decision I receive help from my health professional to make this decision I can discuss the decision with other pregnant women |

Table 3

Importance and experience ratings, sorted by importance.

| Characteristics of the | Item: It is important for my decision that | Mean rating importance (SD) Scale 1–5 | Mean rating experience (SD) Scale 1–5 | Proportion negative experience [#] in% |
|------------------------|---|---|---|--|
| Decision | I have information about the probability of a miscarrigge after a follow up test | 4.35 (0.84) | 3.61 (1.16) | 18.5% |
| problem | I have information about the accuracy of the test | 434 (084) | 4.01 (0.92) | 7.0% |
| | L know what test outcomes are possible | 4.34 (0.84) | 4.01 (0.52) | 2.0% |
| | L know what is possible after a positive test result | 4.31 (0.82) | 4.10 (0.75) | 5.0% 9 E% |
| | L have information about how the test works | 4.24 (0.85) | 3.80 (0.93) | 0.J% 4.5% |
| | L know what disorders are screened for | 4.10 (0.95) | 4.04 (0.87) | 4.3% |
| | L know which decisions are to be made at what | 4.12 (0.99) | 4.10(0.02) | 16.0% |
| | time | 4.10 (0.79) | 5.45 (0.97) | 10.0% |
| | I know the different tests I can choose from | 4.07 (0.97) | 4.05 (0.91) | 6.5% |
| | I know the probability of having a child with one of the disorders screened for at my age | 3.86 (0.93) | 3.57 (1.04) | 17.0% |
| | I receive written information about screening from my health professional | 3.82 (0.96) | 3.91 (1.06) | 12.5% |
| | I receive oral information about screening from my | 3.81 (0.97) | 3.73 (1.12) | 14.0% |
| | I have information about what it is like to live with | 3.79 (1.03) | 2.80 (1.24) | 42.0% |
| | a child with these disorders | 3 72 (0 99) | 3 17 (1 19) | 30.0% |
| | the disorders screened for | 5.72 (0.55) | 5.17 (1.15) | 50.0% |
| | I do not receive too much information [†] | 3.01 (1.15) | 3.30 (1.25) | 31.5% |
| | I can talk to the parents of children with the disorders screened for | 2.93 (1.14) | 2.43 (1.31) | 60.5% |
| | I can talk to other women who have already made the prenatal screening decision | 2.87 (1.22) | 2.64 (1.34) | 50.0% |
| Decision- | I listen carefully to my feelings and intuition | 4.34 (0.78) | 4.45 (0.74) | 1.5% |
| maner | I think about the consequences of my decision | 4 32 (0 73) | 4 30 (0.85) | 3 5% |
| | I make all prenatal screening decisions consciously | 4 20 (0.85) | 4 34 (0.82) | 14 5% |
| | I think about the values that are important to me | 4.18 (0.87) | 4.20 (0.95) | 5.0% |
| | concerning possibly terminating a pregnancy | | | |
| Situation | I make sure that I have enough information about | 4.15 (0.90) | 4.17 (0.82) | 2.5% |
| | I think about the values that are important to me | 4.13 (0.88) | 4.13 (0.92) | 6.0% |
| | I think about the values that are important to me | 4.13 (0.85) | 4.24 (0.85) | 4.0% |
| | concerning motherhood I really deliberate on all the facts on prenatal | 4.12 (0.94) | 4.14 (0.93) | 5.0% |
| | screening I think about the values that are important to me | 4.12 (0.84) | 4.21 (0.85) | 3.5% |
| | concerning my pregnancy I think about my experiences with people with the | 3.34 (1.13) | 3.43 (1.13) | 23.0% |
| | disorders screened for | 4.45 (0.00) | 4.42 (0.95) | 2.0% |
| /environment | can discuss the decision with my partner | 4.45 (0.90) | 4.43 (0.85) | 3.0% |
| | my partner and I have the same views on prenatal screening | 4.34 (0.83) | 4.37 (0.82) | 3.0% |
| | I can ask my health professional questions | 4.05 (0.93) | 4.00 (0.99) | 8.0% |
| | my health professional does not direct me in what I should or should not choose [†] | 4.01 (1.00) | 3.50 (1.38) | 28.0% |
| | I know that there are good facilities for children with the disorders screened for | 3.83 (1.00) | 3.44 (1.01) | 15.5% |
| | I can take care of a child with these disorders | 3 81 (1 03) | 3 21 (1 10) | 23.0% |
| | I do not have to have too much for the screening | 3.69 (1.03) | 3.13 (1.10) | 25.0% |
| | I do not feel time pressure to make a decision [†] | 3 25 (1 28) | 3.13(1.29) 3.25(1.29) | 30.5% |
| | there is no societal pressure to participate in | 3 55 (1 22) | 3 53 (1 30) | 23.0% |
| | screening [†] | 5.55 (1.22) | 5.55 (1.50) | 25.0% |
| | I receive help from my health professional to make this decision | 3.55 (1.05) | 3.37 (1.19) | 25.0% |
| | my family/friends support my decision | 3.16 (1.23) | 3.52 (1.30) | 17.0% |
| | I can discuss the decision with other pregnant women | 2.81 (1.21) | 2.72 (1.30) | 45.5% |

[†] Reverse coded experience items.

[#] Scores of 1 and 2 on experience items – from definitely not (1) to definitely (5) – were considered a negative experience.

women who chose screening and M = 4.06;SD= 0.91 for women who declined screening; F = 10.28; p=.002), "....that I have information about what it is like to live with a child with these disorders" (M = 4.01; SD=0.92 for women who chose screening and M = 3.59; SD=1.08 for women who declined screening; F = 8.87; p=.003), "... that I know which decisions are to be made at what time" (M = 4.27; SD=0.72 for women who chose screening and M = 3.94; SD=0.82 for women who declines screening; F = 8.99; p=.003). Concerning the experience scores, women who chose screening, compared to those who declined, more often said to have received oral information from their professional (F = 8.01; p=.005; with M = 3.96 and SD=0.96 ver-



Fig. 1. Questionnaire items (n = 2) that were rated relatively important [mean importance score ≥ 4], and showed a high proportion of negative experiences [$\geq .15$].

sus M = 3.52 and SD=1.21 for the two groups respectively) as well as information from other parents who have a child with the disorders screened for (F = 8.01; p=.005; with M = 2.70 and SD=1.35 versus M = 2.18 and SD=1.22, respectively) and information from other parents who already made a prenatal screening decision (F = 16.55; p < .001; with M = 3.02 and SD=1.36 versus M = 2.28 and SD=1.22, respectively). Women who chose screening also more often reported to have received help from their professional (F = 10.02; p=.002; with M = 3.64 and SD=1.11 versus M = 3.12 and SD=1.21, respectively) but at the same time also to have experienced being directed by their health professional (F = 8.87; p=.003; with M = 3.20 and SD=1.39 versus M = 3.77and SD= 1.32 respectively, note that this item has been reversecoded). Differences were also found for items related to support by others, i.e. women who chose screening more often reported to have had support from family/friends (F = 7.14; p=.008; with M = 3.74 and SD=1.04 versus M = 3.32 and SD=1.18, respectively) and to have discussed the decision with other pregnant women, compared to women who declined screening (F = 6.96; p=.009; with M = 2.97 and SD=1.31 versus M = 2.49 and SD=1.25 respectively). Women who chose screening (M = 2.70; SD=1.18) more often reported that the costs of screening were too high for them, compared to women who declined screening (M = 3.53; SD=1.26; note that this item has been reverse-coded (F = 23.04; p < .001).

Discussion

This study investigated what conditions Dutch pregnant women and professional experts consider important for autonomous reproductive decision-making in prenatal screening for fetal abnormalities, and the extent to which, according to women, those conditions are met in practice. Professional experts stressed the importance of information provision and a rational decision-making model. Women also emphasized an intuitive decision style and consensus with their partner. The questionnaire findings indicated that in the experience of women, two conditions were not adequately met, and could thus be improved in practice: access to information about procedure-related miscarriage risk and not being directed by health professionals in decision-making. Some differences were found between women who chose screening and those who declined.

An important finding was the importance attached by women to discussion with, and sharing the same view as, their partner. Previous studies found that partners want to be actively involved (Dheensa et al., 2013; Farrell et al., 2019), and that they actually influence decision-making (Jaques et al., 2004; Ukuhor et al., 2017). Different patterns of decision-making of couples have been identified in previous studies, varying in the degree to which couples actually discuss the decision with each other (Carroll et al., 2012; Wätterbjörk et al., 2015; Williams et al., 2011). This emphasizes the challenging task for counselors to support and involve both partners in decision-making (Martin et al., 2021). Since the study was done, in 2017, with the introduction of NIPT, additional quality requirements were implemented to optimize counseling in both health education and decision-making support (Martin et al., 2021).

A relatively large proportion of women (28%) reported that they experienced being directed by health professionals in decisionmaking. Women who chose screening stressed this even more. This is important in the light of professional policy bodies that stress the importance of neutral and non-directive counseling, and decisions being made free of coercion (Dondorp et al., 2015). A study in the United Kingdom (Ukuhor et al., 2017) also reported on women experiencing being directed by providers to participate. Interestingly, a questionnaire study on parental preferences showed that 44% of Dutch women and partners considered decision support from counselors as (very) important, including advice on whether or not to test (Martin et al., 2021). In the Netherlands, previous studies have nevertheless shown that in general, few women report having had, or having declined prenatal screening because their health professionals advised them to do so (Bakker et al., 2012; Crombag et al., 2016b; van der Meij et al., 2022).

It may be more the perceptions of women rather than actual practice that drove these experiences as reported in our study. An older Dutch study reported that counselors' own attitudes did not predict pregnant women's decisions about prenatal screening, but that pregnant women's perception of counselors' attitudes/advice did predict women's screening attitudes (van den Berg et al., 2007). However, the decision situation of prenatal screening has changed since this study, with new screening possibilities and perhaps also an evolved societal norm. In the Netherlands, half of the women today accept prenatal screening, perhaps leading women to feel pressure to accept screening, as was previously shown (van Bruggen et al., 2018). The perception of women may also be caused by professionals emphasizing the increased risk related to age (Crombag et al., 2016a) or by the simple fact that screening is offered, which can be perceived as a sign of endorsement (Potter et al., 2008). A study on prenatal diagnosis suggested that clinicians unintentionally influence women's choices through their counseling approach and content (van der Steen et al., 2019). A study using hypothetical vignettes about prenatal diagnostic testing showed that perceived disagreement with the partner and motivation to comply with professionals' perceived preference were strong predictors of decisional conflict (Muller and Cameron, 2016), underlining the important task of counselors to provide their counseling in a neutral way. Further research is needed to unravel the question of whether and in what direction women are implicitly or explicitly directed in their decisions, and how to address this.

Women in our study, including those who declined screening, considered information about the risk of miscarriage associated with confirmative invasive testing to be important, as shown previously (Dane et al., 2018). However, a relatively high proportion of women (19%) reported not having received this information. Again, we cannot say whether women did not receive this information, or whether they 'only' perceived this. Perhaps for the women we surveyed, midwives gave less information about this because of the reduced need of invasive testing with the introduction of NIPT as a second-tier (follow-up) test in 2014 (Oepkes et al., 2016). Abnormal NIPT results, however, still need to be confirmed using invasive testing, which is considered key information for counseling (Sachs et al., 2015).

Interviewed professional experts recognized a variety in information needs among pregnant women. The questionnaire study underlined this, showing that women varied in their needs depending on their screening decision. This corresponds to what is known from previous studies, such as that women prefer multiple information sources (Jaques et al., 2004;) including websites (Martin et al., 2021), that nulliparous women need more information (Nykänen et al., 2017), and that couples who think relatively long about their decision might need specific benefit/harm information (Wätterbjörk et al., 2015). Muller and Cameron (2016) demonstrated that being childless was an important independent predictor of decisional conflict, highlighting the need to deal with potential uncertainty among nulliparous couples and to carefully adjust information accordingly.

In contrast to what other studies found about women's need for more experiential information (Carroll et al., 2012; Wätterbjörk et al., 2015), this was considered of less importance by women in our study. Our study also included a survey, which may have forced women to prioritize some aspects above others. Moreover, it should be kept in mind that we instructed respondents to think about different aspects in relation to their *decision-making*, where several previous studies more broadly focused on information needs.

Strengths and limitations

One strength is that both professional experts' and women's views were included. Moreover, in the survey, both women who accepted screening and those who declined screening participated. A limitation is that the survey data were gathered through convenience sampling, with the research agency having difficulty recruit-

ing sufficient pregnant respondents; additional members were thus recruited through partner agencies, which may have led to selection bias. About half of the survey respondents (48%) had prenatal screening, which was somewhat more than the average portion in the Dutch target population at the time of our study, namely 43% in 2017 (Liefers et al., 2016). Additionally, we do not know whether the questions were fully understood. Moreover, our sample was not large enough to study subgroups of age, ethnicity or religious activities. The gradual implementation of NIPT in the Dutch prenatal screening program during our study may have influenced participants' views, especially since this has been associated with media attention (van Bruggen et al., 2018; van Schendel et al., 2017).

Conclusion

Our study suggested that several conditions for autonomous decision-making were not always met in practice, according to pregnant women themselves. Further research is needed, in particular regarding the perceived directiveness of health professionals, as the ongoing widening scope of screening will further complicate pregnant women's autonomous decision-making.

Credit author statement

D.T. conceptualized the initial study idea. O.D. and L.H. were involved in the conceptualization. O.D., L.H. and D.T. together designed the methodology. L.H. and D.T. had a supervising role in research activity planning and execution. D.v.d.IJ. conducted the data collection. The formal analysis was done by D.v.d.IJ an O.D. The initial full version of the paper was drafted by O.D. All authors discussed the results and commented on the manuscript.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.midw.2023.103607.

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