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Pregnant women's informational needs prior to decisions about prenatal diagnosis for chromosomal anomalies—A Q methodological study

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Abstract

Objective: To study pregnant women's subjective viewpoints on what is important when receiving information prior to decision-making regarding prenatal testing for chromosomal anomalies.

Method: Data were collected using Q methodology. During January 2020—October 2021, 45 pregnant women in Sweden completed a 50-item Q sort. Statements regarding what is important when receiving information about prenatal screening and diagnosis were prioritized through ranking in a fixed sorting grid on an 11-point scale, from "most important" to "least important." Socio-demographics and coping styles were surveyed through questionnaires.

Results: Three groups represented different viewpoints on what pregnant women consider important when receiving information about prenatal screening and diagnosis. Factor 1: *Stepwise information and decision-making*: viewing information and decision-making as a step-by-step process. Factor 2: *Decision-making as a continuous process based on couple autonomy*: Striving for an informed decision as a couple about tests, test results and conditions screened. Factor 3: *As much information as early as possible—the importance of personal autonomy in decision-making:* Prioritizing autonomous decision-making based on non-directive information early in the pregnancy.

Conclusion: This study highlights the complexities involved when providing information. As shown by the differing viewpoints in this study, pregnant women's informational needs differ, making individual and personalized information preferable.

Key points

What's already known about this topic?

- Pre-test counseling is important to enable informed decision-making concerning prenatal tests. Pregnant women have different information needs. More knowledge is needed concerning what information women prefer to receive.

What does this study add?

- This study provides an insight into pregnant women's varying informational needs concerning prenatal testing for chromosomal anomalies. It highlights the need for individual and personalized pre-test counseling and information.

1 | INTRODUCTION

Prenatal diagnosis (PND), including both diagnostic and screening procedures, for chromosomal anomalies (CA) is offered as part of the public antenatal care in Sweden. Around 70% of all pregnant women undergo a combined ultrasound and biochemistry test (CUB test),[1] which is the primary screening method used in Sweden for CA. Non-Invasive Prenatal testing and invasive testing are usually offered when the CUB test has indicated a high probability of a CA.

According to the laws and guidelines in Sweden, all pregnant women should be offered general information on PND[2] during the first visit at the antenatal care unit.[3] The Swedish National Council on Medical Ethics has recommended that the information should include both the medical and the psychosocial aspects of Down syndrome (DS) as well as perspectives of having a child with a CA.[4] Despite this recommendation, the information given usually focuses on the probability assessment of expecting a fetus with a CA, the test methods and risks associated with invasive tests. Often, no or sparse, information about different aspects of DS is given.[5] Previous studies have indicated that information given to pregnant women, as well as their own knowledge prior to decision-making concerning PND is often insufficient, making it difficult to make informed decisions.[5–10]

Research indicates that pregnant women prefer verbal, in-person information from a knowledgeable healthcare professional.[11,12] Women focus on the risks of the different tests.[13,14] Information about DS and the probability of expecting a fetus with DS, is also desired early in pregnancy, prior to PND.[11,15] The perceived quality of life for the child, as well as the impact on parents and family life, are important for the decision-making regarding PND.[13,14] The probability of expecting a fetus with a CA in a current or previous pregnancy can affect women's informational needs.[11,16] Informational needs may also be dependent on whether the decision to undergo or abstain from PND has already been made when attending the pre-test counseling. Having already made a decision can result in less need of information, whereas being undecided can result in a need for more extensive information.[17] Crombag et al.[18] argue that women might use information to justify their intuitive choice rather than basing an informed decision on information received in non-directive pre-test counseling.

Undergoing PND can be seen as a threatening medical condition where the pregnant women may need to cope with a stressful situation and difficult decisions. When dealing with a potentially threatening medical situation, two different psychological coping styles have previously been identified: "monitoring," that is, focusing on and seeking threat-relevant information and "blunting," that is, avoiding threat-relevant information and seeking distraction.[19] Coping styles have been found to be related to informational needs and information satisfaction in other medical areas.[19,20]

Women with higher levels of knowledge about PND seem to experience not only less decisional conflict and regret concerning decisions regarding screening for CAs, but also a higher level of wellbeing and less anxiety.[21,22] This highlights the need for both more and higher quality information. To be able to improve the quality of information given to women (thereby better enabling informed choices regarding PND and decreasing decisional conflict), it is important to know what information they need. The present study aimed to explore pregnant women's subjective viewpoints on what is important to them when receiving information prior to decision-making regarding PND, with a focus on DS. The secondary aim was to investigate if informational needs differ with different sociodemographic backgrounds and coping styles.

2 | METHODS

2.1 | Q methodology

Q methodology is a method developed for studying subjective viewpoints related to a specific area of interest. It is often used to explore highly complex and socially contested concepts.[23] The central part of any Q methodological study is the collection of data in the form of *Q sorts*. By sorting a set of items or statements covering different aspects of the studied issue (i.e. *Q set*) along a standardized ranking distribution participants create a personal Q sort that reflects their subjective viewpoint. The *Q set* is sampled from the *concourse*, which is a collection of knowledge and experience that represents the various opinions and views about the subject of interest.[24]

After the collection of *Q sorts* (i.e. participants' individually sorted *Q set*), the second key feature of a Q methodological study is the Q factor analysis, which is a by-person factor analysis looking at intercorrelations between the participants' *Q sorts*.[25,26] This is in contrast to the standard use of factor analysis, where data are usually analyzed by variable, statement or trait.[24] *Factors* can be identified through the by-person factor analysis.[25] In a Q methodological study, *factors* are the groups of similarly sorted Q set, that is, a factor is a group of individuals who share a similar viewpoint on the subject (and hence have sorted the statements in the Q set similarly). Guidelines for reporting Q methodological studies have been followed.[26]

2.2 | Materials—sampling the concourse, Q set design and content

With the question "what is important for you when you receive information about PND?" participants were asked to sort a set of 50 cards with statements (see Table 1 in the Results section) related to information on PND and CAs. Participants assigned each of the statements a ranking in a fixed quasi-normal distribution (Figure 1) on an 11-point scale, ranging from +5 for statements that are considered "most important" through 0 to −5 for statements considered "least important."

A draft for the *Q set* was sampled from the *concourse*, based on the current peer-reviewed literature, interviews with 24 pregnant women (as part of another study with focus on women's perspectives of information and decision-making) and written communication with four mothers of children with DS. The statements were reduced and refined through discussions within the research group with clinical experience such as obstetricians, a midwife and a genetic counselor, resulting in the final *Q set* of 50 statements. The aim was to include a wide range of statements covering different aspects of information about PND,[23] regarding the ways of receiving information and what the information contained. The Q set was not piloted, but was reviewed by one mother with a child with DS.

In addition to the *Q set*, two questionnaires were used: the Threatening Medical Situations Inventory (TMSI)-questionnaire identifying different psychological coping styles, that is, monitors and blunters[27] and a questionnaire with sociodemographic questions developed specifically for the study.

2.3 | Participants, procedure and administering the Q sort

From January 2020—October 2021, pregnant women who called to book their first appointment with their midwife at antenatal care clinics in three Swedish, middle-sized cities (Eskilstuna, Örebro and Uppsala) were asked by the midwife if they were interested in participating in the study. Inclusion criteria were women in early pregnancy, aged 18 years or above and with a good command of the Swedish language. If they consented, they were sent written information together with the Q set and the questionnaires by post. Eligible participants were only given brief verbal information before receiving the more comprehensive written information with the study material. Many midwives, at many antenatal care facilities helped with the recruitment, making it difficult to fully determine the response rate.

A total of 45 pregnant women were included, completed the Q sort and filled in the questionnaires at home and sent them back by post. Women's timing for filling in the questionnaires and doing the Q sort varied, and some waited until they had received information about PND and some underwent PND before returning the material. Due to the Covid-19 pandemic, it was impossible to conduct interviews with the participants, so qualitative data was derived from written comments that all participants were asked to provide when ranking the Q set. Further, it was difficult to offer an interpreter, which hindered the inclusion of non-Swedish speaking women.

2.4 | Analysis

An inductive approach to Q-methodological analysis with exploratory factor analysis was used. Q factor analyses were conducted using the Q dedicated software package PQMethod (version 2.35) with Centroid factor extraction and Varimax factor rotation (Figure 2). Initially, seven factors were extracted according to the "magic number seven"[25,28] and Watts and Stenner's advice to start with extracting a factor for every six to eight participants.[25] After examining the eigenvalues and factor loadings of the seven extracted factors, a three-factor solution was chosen based on the Kaiser–Guttman criterion, factors with two or more significant loadings, and Humphrey's rule.[25]

The centroid factor extraction was repeated with three factors, followed by a factor rotation with Varimax. Initially, manual flagging of participants' Q sorts loading exclusively and significantly on one of the factors was applied. Since the results were similar to the auto flag option in PQMethod, this was instead used to identify unique loaders, that is, *defining Q sorts* for each factor in the final analysis. The software used these *defining Q sorts* to produce *factor arrays* with an *idealized Q sort* for each factor that was calculated through weighted averages of the *defining Q sorts* produced by participants who shared the viewpoint of one factor. Factor arrays were used to produce crib sheets[25] to help in the process of factor interpretation. In-depth factor interpretation was performed using factor arrays, crib sheets,[25] qualitative data from participants' comments on their sorting process and sociodemographic data from the questionnaire. The women's comments gave a more in-depth understanding of their reasoning during the sorting process. Special attention was also placed on *distinguishing statements* (i.e. statements that were significantly differently ranked between factors) and *consensus statements* (i.e. statements that did not distinguish between any pair of factors) at a $p < 0.01$ level.

Intermediate factor analyses were performed at 30, 40, 45 and 50 participants looking at background information to make sure the participant group was heterogeneous and comparing factor loadings and factor arrays. When comparing intermediate analyses at 45 and 50 participants, both background characteristics, factor loadings and factor arrays indicated that saturation was reached at 45 participants. Recruitment was therefore discontinued and in-depth factor interpretation was performed with 45 participants.

The TMSI questionnaire was analyzed by summing up the relevant items for monitoring and blunting for each scenario. The total blunter scores were subtracted from the total monitor scores, giving a total score. Higher scores indicate a monitoring coping style and lower (negative) scores indicate a blunting coping style.

TABLE 1 *Factor array* with the 50 statements and the ranking of each statement for the three factors: Factor 1 (F1), Factor 2 (F2), Factor 3 (F3).

No	Statement	F1	F2	F3	Distinguishing or consensus
5	To receive neutral information that does not reflect the personal values of the midwife/doctor.	4	2	3	F1
9	To receive information on prenatal diagnosis at a separate occasion when no other pregnancy related information is given.	−1	−4	−4	F1
11	To not receive too much information at one occasion.	0	−2	−3	F1
15	To receive information that down syndrome leads to intellectual disability to a varying degree.	−1	−1	0	F1
21	That the midwife/doctor have sufficient time for me.	2	4	5	F1
24	To receive information on special demands on me when caring for a child with down syndrome.	−2	2	1	F1
25	To receive information on care programs and available support from the society for children with down syndrome and their families.	−3	0	0	F1
28	To get advice from my midwife/doctor on whether to have a test or not.	0	−3	−2	F1
34	To receive information about the cognitive consequences of down syndrome for example, the ability to learn to talk, read, write or walk.	−4	−1	−1	F1
35	To receive information about the medical consequences of down syndrome (e.g. congenital heart defects, hearing problems, gastrointestinal anomalies).	−2	0	0	F1
36	To receive written information.	0	−1	−1	F1
6	To receive oral information individually.	0	−3	0	F2
10	To receive equal and corresponding information about all the chromosomal anomalies (trisomy 13, 18, 21) that prenatal diagnosis is offered for, even if down syndrome (trisomy 21) is the most common chromosomal condition.	1	−1	1	F2
20	To receive information about when in the pregnancy different tests can be done.	2	0	2	F2
23	To receive information about the limitations of the tests, that is, what the test cannot detect.	2	0	2	F2
27	That I can make a decision about prenatal diagnosis without pressure from the midwife/doctor.	3	1	3	F2
38	To receive information only about the tests that can be offered to me in my region.	−2	−4	−3	F2
2	That both my partner and I receive information about prenatal diagnosis.	3	4	−1	F3
12	That it is emphasized that information about prenatal diagnosis is optional.	0	−1	−3	F3
37	To receive updated and fact-based information.	5	5	1	F3
39	To receive information about interpretation of test results, for example, probability assessment with combined ultrasound and biochemistry test.	2	3	1	F3
43	To receive information about the life expectancy for individuals with down syndrome.	−5	−3	−2	F3
46	To receive information from patient organizations or parents in similar situations.	−3	−3	−2	F3
8	That both my partner and I have the possibility to be part of the decision to undergo or abstain prenatal diagnosis.	1	4	−2	F1, F2, F3
13	That the information is given early in the pregnancy.	2	0	4	F1, F2, F3
17	To have the possibility to discuss ethical values related to prenatal diagnosis.	−1	0	−4	F1, F2, F3
18	To receive as much information as possible.	1	2	4	F1, F2, F3
22	To receive information on how family life, the parent's relationship or siblings can be affected by having a child with down syndrome in the family.	−2	1	−1	F1, F2, F3
32	To receive information about what life can look like for a child with down syndrome during childhood, school years and adolescence.	−3	1	−1	F1, F2, F3
41	To receive information about how long it takes to receive the test results.	0	−2	2	F1, F2, F3

TABLE 1 (Continued)

No	Statement	F1	F2	F3	Distinguishing or consensus
42	To receive information about anomalies or conditions for example, Down syndrome only after a diagnosis has been confirmed.	−1	−2	1	F1, F2, F3
48	To receive information about how adult life can be like for an individual with down syndrome (medical care, living arrangements, occupation and support from society).	−4	−1	−2	F1, F2, F3
1	That the person providing me the information has sufficient knowledge on the subject.	5	5	5	Consensus
3	To receive information about possible choices regarding pregnancy management if the test indicates an anomaly (further tests, continued management during pregnancy or a possible termination of pregnancy).	3	3	2	Consensus
4	To emphasize that prenatal diagnosis is not a guarantee to have a healthy baby.	1	0	0	Consensus
7	To receive information on the reliability of a test and its strengths and limitations.	3	2	3	Consensus
16	To receive some information on the conditions that can be detected, for example, Down syndrome before I make a decision whether to undergo or abstain prenatal diagnosis.	0	1	0	Consensus
19	That the incidence of the medical consequences among children with down syndrome is put in relation to the incidence among other children.	−1	−2	−3	Consensus
26	To receive information on risks of the different tests.	4	2	3	Consensus
29	To receive information that it is not possible to foresee how severe the symptoms will be for a specific individual with down syndrome just by looking at the chromosomes.	−1	−1	−1	Consensus
30	To receive information also about tests that are not offered in my region, but are offered in other regions or by private clinics.	−1	0	0	Consensus
31	That my questions/thoughts are taken seriously.	4	3	4	Consensus
33	To have time to reflect between receiving information and making a decision.	1	3	2	Consensus
40	To receive the information in a way that makes me understand the implication (wording and knowledge level).	1	1	1	Consensus
44	To receive information that there might be a need for more follow-up tests to verify a diagnosis.	1	1	1	Consensus
45	To not receive information about prenatal diagnosis too early in the pregnancy.	−3	−4	−4	Consensus
47	To receive oral information in group.	−4	−5	−5	Consensus
49	To receive information on what management and support is available during the course of the pregnancy if the fetus has an anomaly.	0	1	0	Consensus
50	To receive information on what causes down syndrome.	−2	−2	−1	Consensus
14	To have the possibility to discuss religious values related to prenatal diagnosis.	−5	−5	−5	Neither

Note: Distinguishing statements (i.e. statements that were significantly differently ranked between factors) are indicated with F1, F2 and F3 respectively depending on which factor they are a distinguishing statement for (e.g. a statement can distinguish one factor from the others, or all factors from each other). Consensus statements (that do not distinguish between any pair of factors) are also shown. One statement is not distinguishing nor consensus and is referred to as "Neither" in the table.

The factors (i.e. viewpoints) were compared regarding socio-demographic data and coping styles using SPSS Statistics version 28.0.1. Comparisons of nominal data were analyzed using Fisher–Freeman–Halton exact test, and continuous ratio data (i.e. age) were compared using the Independent-Samples Kruskal–Wallis test. A significance level of $p < 0.05$ was used for all comparisons. When comparing women's responses on having had personal experience of someone with a congenital anomaly or not, response alternatives were sorted into "yes" and "no" due to small numbers, where "yes" includes the participants with experience in the close family, extended family and/or among friends.

3 | RESULTS

In total, 45 pregnant women with diverse sociodemographic backgrounds from three middle-sized cities in Sweden participated. Age ranged from 23 to 38 (mean 29.9) years, almost half of the women were parous and a majority had higher education. Three factors were found to represent different viewpoints on what is important to pregnant women when receiving information about PND. Together, they explain 56% of the study variance. Each viewpoint consists of *defining Q sorts* (i.e. Q sorts of participants who share that viewpoint), with 15 Q sorts in Factor 1 (F1), 8 in Factor 2 (F2) and 11 in Factor 3

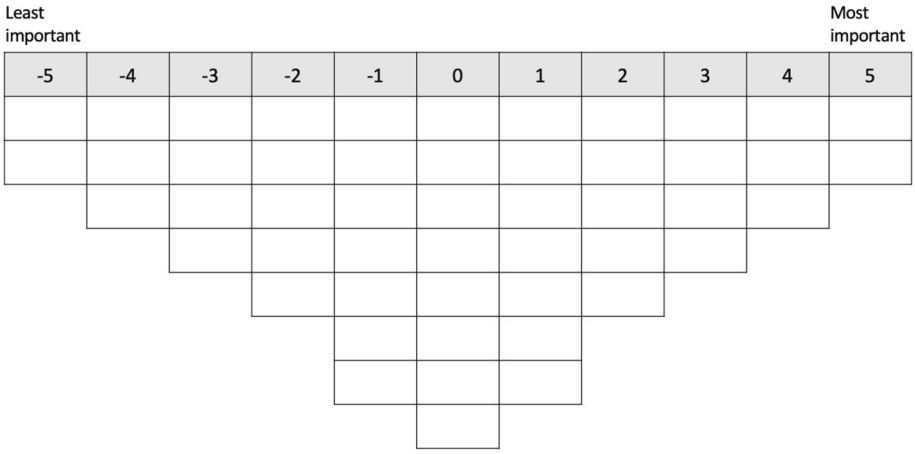

FIGURE 1 The fixed quasi-normal distribution sorting grid that was employed for this study. Participants sorted the 50 statements of the Q set, one statement per square in the grid, to indicate their prioritization of the statements relative to each other. For example, only two statements can be ranked as most important at +5.

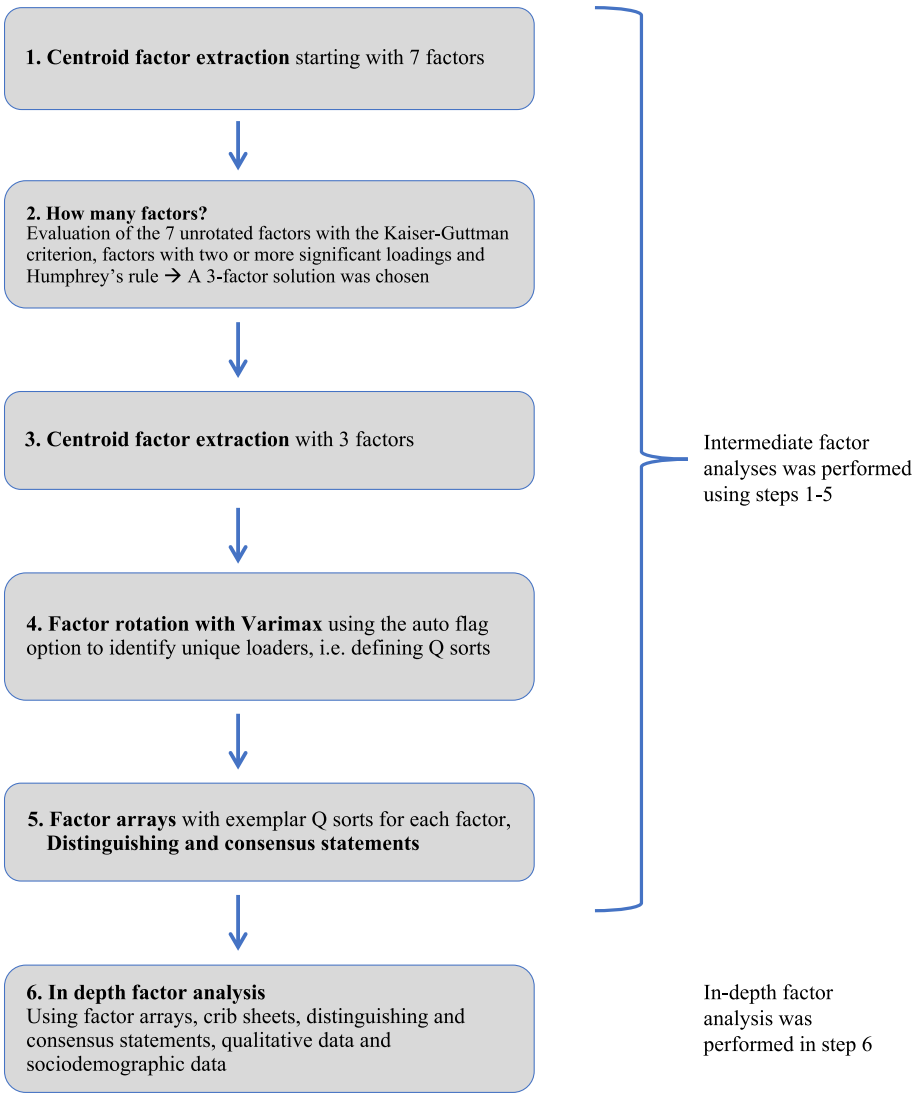

FIGURE 2 Overview of the steps of the Q factor analysis process.

(F3). Since not all participants' Q sorts were *defining sorts* for any of the factors, Q sorts of 11 participants are not included in the three defined factors. No significant differences between the participants who produced defining Q sorts for the three factors were found when comparing background demographics and coping styles (Table 2).

Table 1 displays a factor array with the ranking of each statement for the three factors, as well as *distinguishing* and *consensus statements*. When describing the viewpoint of each factor below, the ranking of statements that inform the interpretation are included in brackets in the text where, for example, (20:+2) indicates that statement 20 was ranked at +2.

Seventeen of the statements are *consensus statements* that do not distinguish between any pair of factors (Table 1). To receive information from someone with sufficient knowledge was ranked as most important from all three viewpoints. To have their thoughts and questions taken seriously was also a priority for the women (31:+4, +3, +4) as was having time to reflect between receiving information and decision-making (33:+1, +3, +2). The opportunity to discuss religious values related to PND was not a priority (14:−5, −5, −5) and neither was verbal information in groups (47:−4, −5, −5).

3.1 | Factor 1—Stepwise information and decision-making

Factor 1 has an eigenvalue of 21.48 and explains 22% of the study variance. Q-sorts of 15 pregnant women exemplify this factor.

The women representing viewpoint 1 see information and decision-making as a step-by-step process, where step 1 is focused on information and decision-making regarding PND. Information about conditions screened for is desired in step 2, if screening indicates an increased probability for an anomaly. In a written comment, one woman felt that (prior to a diagnosis) information about conditions could cause unnecessary concern. Compared to the other viewpoints, the women with viewpoint 1 place greater value on being informed that receiving information about PND is optional (12:0). However, they value receiving updated, fact-based (37:+5) and neutral information (5:+4), together with their partner (2:+3) in an individual, separate consultation (6:0, 47:−4, 9:−1). They do not want too much information on a single occasion or too early in the pregnancy (45:−3, 18:+1, 11:0). They are open to receiving advice from healthcare professionals on making a choice about testing (28:0), but want to make decisions without pressure from healthcare professionals (27:+3). It seems important to these women that their partner also receives information (2:+3), though not necessarily involved in the decision-making (8:+1).

Statements concerning information about test methods are highly ranked (7:+3, 20:+2, 23:+2, 26:+4), while diagnosis-specific information is ranked low, indicating a preference for a step-by-step process (15:−1, 16:0, 22:−2, 24:−2, 32:−3, 34:−4, 35:−2, 43:−5, 48:−4, 50:−2). They do not wish to receive information from patient organizations (46:−3) or about care programs and support from society for an affected child and its family (25:−3). They are interested in information about reproductive choices if a test indicates an anomaly (3:+3), but not about management and support available during an affected pregnancy (49:0).

3.2 | Factor 2—Decision-making as a continuous process based on couple autonomy

Factor 2 has an eigenvalue of 2.06 and explains 17% of the study variance. Q-sorts of eight pregnant women exemplify this factor.

The women representing viewpoint 2 strive for an informed decision together with their partner (2:+4, 8:+4) regarding the complete concept of accepting or declining screening and how to handle the test result (39:+3, 3:+3, 49:+1). These women wish to receive information about test characteristics, although this is not as highly prioritized as for the women with the other viewpoints (7:+2, 20:0, 23:0, 26:+2, 41:−2). Women with viewpoint 2 place greater value on information about the possible effects (for both the child and the family) of the conditions screened for (42:−2, 34:−1, 35:0, 32:+1, 22:+1, 24:+2, 25:0, 48:−1). Information regarding all these aspects is desired prior to decision-making.

As with women in viewpoint 1, receiving updated and fact-based information (37:+5) is highly prioritized. They value having the possibility to discuss ethical values related to PND (17:0) and having time for reflection between receiving information and decision-making (33:+3), as do women with the other viewpoints. Women with viewpoint 2 do not prioritize receiving information regarding PND on a separate occasion (9:−4) and prefer written information over verbal (6:−3, 36:−1, 47:−5).

3.3 | Factor 3—As much information as early as possible—The importance of personal autonomy in decision-making

Factor 3 has an eigenvalue of 1.85 and explains 17% of the study variance. Q-sorts of 11 pregnant women exemplify this factor.

The women representing viewpoint 3 want to get as much information as possible, as early as possible (18:+4, 13:+4, 45:−4, 11:−3, 9:−4). An autonomous decision is prioritized and the women have less need to involve a partner in the process (2:−1, 8:−2). They value individual, verbal, non-directive information, without pressure from healthcare professionals (5:+3, 27:+3, 6:0, 36:−1, 47:−5). They value the meeting with healthcare professionals and that sufficient time is reserved for them (21:+5). They do not wish to discuss ethical values related to PND (17:−4). Compared to the other viewpoints, these women place less emphasis on receiving updated and fact-based information (37:+1) and have less need to be informed that information regarding PND is optional (12:−3).

These women seem to prioritize information regarding test methods (7:+3, 23:+2, 20:+2, 26:+3, 41:+2) over information on conditions screened for, which they however also seem to value

TABLE 2 Background socio-demographics and coping styles for all 45 participants and for the participants who produced defining Q sorts for each factor (Factor 1: F1, Factor 2: F2, Factor 3: F3), respectively.

	All participants *N* (%)	F1 *N* (%)	F2 *N* (%)	F3 *N* (%)	*P*-value
City					**0.586**
Uppsala	17 (37.8)	7 (46.7)	3 (37.5)	2 (18.2)	
Örebro	7 (15.6)	3 (20.0)	1 (12.5)	2 (18.2)	
Eskilstuna	21 (46.7)	5 (33.3)	4 (50.0)	7 (63.6)	
Age					**0.103**
21–25	4 (8.9)	0 (0.0)	0 (0.0)	2 (18.2)	
26–30	20 (44.4)	5 (33.3)	6 (75.0)	4 (36.4)	
31–35	17 (37.8)	8 (53.3)	2 (25.0)	4 (36.4)	
36–40	4 (8.9)	2 (13.3)	0 (0.0)	1 (9.1)	
Parity					**0.084**
Nulliparous	23 (51.1)	6 (40.0)	7 (87.5)	4 (36.4)	
Parous	21 (46.7)	9 (60.0)	1 (12.5)	6 (54.5)	
Missing value	1 (2.2)	0 (0.0)	0 (0.0)	1 (9.1)	
Education					**0.165**
Elementary school	1 (2.2)	0 (0.0)	0 (0.0)	1 (9.1)	
Upper secondary school	10 (22.2)	1 (6.7)	2 (25.0)	3 (27.3)	
University/college	33 (73.3)	14 (93.3)	6 (75.0)	7 (63.6)	
Missing value	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	
Marital status					**0.105**
Married	13 (28.9)	8 (53.3)	1 (12.5)	2 (18.2)	
Co-habiting	30 (66.7)	7 (46.7)	7 (87.5)	8 (72.7)	
In a relationship, living separately	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	
Single	1 (2.2)	0 (0.0)	0 (0.0)	1 (9.1)	
Professing a religion					**0.105**
Yes	8 (17.8)	5 (33.3)	0 (0.0)	1 (9.1)	
No	36 (80.0)	10 (66.7)	8 (100.0)	10 (90.9)	
Prefer not to answer	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	
Experience of down syndrome					
Yes, in the close family	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Yes, in the extended family	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Yes, among friends	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	
No	44 (97.8)	15 (100)	8 (100.0)	11 (100.0)	
Experience of another congenital anomaly					**0.224**
Yes, in the close family	4 (8.9)	0 (0.0)	0 (0.0)	3 (27.3)	
Yes, in the extended family	4 (8.9)	2 (13.3)	0 (0.0)	1 (9.1)	
Yes, among friends	3 (6.7)	0 (0.0)	1 (12.5)	0 (0.0)	
Yes, in both extended family and friends	1 (2.2)	0 (0.0)	0 (0.0)	1 (9.1)	
No	33 (73.3)	13 (86.7)	7 (87.5)	6 (54.5)	

TABLE 2 (Continued)

	All participants *N* (%)	F1 *N* (%)	F2 *N* (%)	F3 *N* (%)	*P*-value
Termination of pregnancy					**0.621**
Would consider it	17 (37.8)	5 (33.3)	3 (37.5)	5 (45.5)	
Undecided/ambivalent	24 (53.3)	8 (53.3)	3 (37.5)	6 (54.5)	
Would not consider under any circumstances	4 (8.9)	2 (13.3)	2 (25.0)	0 (0.0)	
Received information about prenatal diagnosis					**0.660**
Yes	21 (46.7)	9 (60.0)	3 (37.5)	4 (36.4)	
No	22 (48.9)	6 (40.0)	5 (62.5)	5 (45.5)	
Missing value	2 (4.4)	0 (0.0)	0 (0.0)	2 (18.2)	
Attitude towards prenatal diagnosis					**0.884**
Gave reasons to undergo	27 (60.0)	8 (53.3)	4 (50.0)	7 (63.6)	
Gave reasons to abstain	3 (6.7)	2 (13.3)	1 (12.5)	0 (0.0)	
Gave reasons to both undergo and abstain	15 (33.3)	5 (33.3)	3 (37.5)	4 (36.4)	
Undergone prenatal diagnosis					**0.295**
Yes	8 (17.8)	4 (26.7)	3 (37.5)	1 (9.1)	
No	37 (82.2)	11 (73.3)	5 (62.5)	10 (90.9)	
Monitor or blunter					**0.792**
Monitor	32 (71.7)	11 (73.3)	5 (62.5)	9 (81.8)	
Blunter	12 (26.7)	4 (26.7)	3 (37.5)	2 (18.2)	
Neither (total score 0)	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)	

Note: *P*-values for comparisons of background characteristics between factors, with no significant differences at $p < 0.05$ level. Comparisons between factors were not analyzed for experience of Down syndrome since there were no Yes-answers in either factor. The numbers on received information and having had PND or not concern the ongoing pregnancy and not previous pregnancies for parous women.

(16:0, 15:0, 22:−1, 24:+1, 25:0, 32:−1, 34:−1, 35:0, 43:−2, 48:−2, 50:−1). Information about how long it takes to receive test results is more important compared to women holding the other viewpoints (41:+2). Information about the interpretation of test results, for example probability assessment, is not as highly prioritized as it is for the other viewpoints (39:+1).

4 | DISCUSSION

This study aimed to explore pregnant women's subjective viewpoints on what is important when receiving information prior to decision-making regarding PND. Three different viewpoints were found that illustrate the wide range of informational needs. Some prefer a step-by-step process starting with information and decision-making concerning the tests. Others want more extensive information from the start, including taking into account the effects of the conditions screened for and what decisions regarding the pregnancy they may have to make, depending on the test result. This highlights the complexities when providing information to pregnant women.

Receiving updated, fact-based information from a knowledgeable healthcare professional was highly prioritized from all three viewpoints. Previous studies have shown that healthcare professionals providing information to pregnant women had varying or low levels of knowledge regarding PND and DS,[29–33] that their self-perceived knowledge was insufficient[34–36] and that more education was valued.[29–31,36] This highlights the need to better educate healthcare professionals if the needs of pregnant women are to be met. Educational efforts have shown good results both in counsellors' confidence in giving information as well as their perceived and actual knowledge.[30–32,34]

A woman's probability of a fetal anomaly in a previous or current pregnancy may affect what kind of information she values to receive.[11,16] Also, parity and age have been shown to affect information needs.[37] However, we found no significant differences in sociodemographic background data between the three viewpoints (Table 2). Moreover, a "monitor" or "blunter" coping style did not seem to affect informational needs. This is interesting as one might expect that "monitors" would like to receive more extensive information (like viewpoint 3), while "blunters" would avoid threat-relevant information (like viewpoint 1).[19,20] As this was not the case, women's informational needs seem to be affected by something other than their coping style or sociodemographic background, thus making it difficult to predict a woman's informational needs based on demographics.

Different individuals have different informational needs,[38] making it difficult to design standardized information that suits every pregnant woman. Information in groups got a low ranking in all viewpoints and is thus not optimal at pre-test counseling. Individual in-person meetings give the healthcare professional a chance to discern both how and what information needs to be provided to this particular woman, so that she can make an informed decision regarding PND. It has been suggested that alternative methods for pre-test counseling should be explored since proper pre-test counseling is resource demanding.[39] The use of decisional aids has shown improved decision-relevant knowledge and informed decision-making.[40,41] Decisional aids could work as a complement to individual counseling, but should not replace individual counseling as a woman's informational needs cannot be identified in advance and need to be explored during the counseling session.

It has previously been reported that women may use a multi-step decision process and that some consider each decision separately, anticipating that they will feel differently at the time of follow-up decisions.[17] This is consistent with viewpoint 1's desire for a step-by-step information process, probably because women with this viewpoint also apply a multi-step decision process. Information about conditions screened for is not routinely given prior to testing,[5] which suits these women. However, this stepwise approach, does not meet the informational needs of the women with viewpoints 2 and 3 who also desire information about the effects of conditions screened for. It is not surprising that information about conditions screened for is important to some pregnant women since the perceived quality of life for an individual with a CA and the effect on the child and family seem to affect decision-making regarding PND.[13,14] Healthcare professionals need to be aware that this information is important and should be provided if desired.

Previous research indicates that women's decision-making process regarding PND is often influenced by their partners' opinions and many strive for a consensus decision with their partner.[11,12,14,17,42,43] The women's need to involve their partner in the process also varied depending on their viewpoints. Time between receiving information and decision-making is needed to have the chance to discuss the decision with their partner. This illustrates the varying needs regarding how to receive information and how to make decisions concerning PND.

5 | CONCLUSIONS

Pregnant women's informational needs vary, seemingly independent of background characteristics, thus making a standardized information process unsuitable. To enable informed decision-making and to ensure that women's varying informational needs are met personalized information and individual counseling with healthcare professionals trained in pre-test counseling is needed.

6 | GENERALIZABILITY/STRENGTHS AND WEAKNESSES

We included women with diverse backgrounds, giving a good representation of pregnant women in today's Swedish healthcare system. Therefore, it is likely that similar viewpoints are found among other pregnant women under similar circumstances.

Non-Swedish speaking women were not included in the study because of language barriers, which is a weakness. The Covid-19 pandemic prevented in-person meetings, which might otherwise have facilitated the inclusion of non-Swedish speakers. The pandemic also hindered in-person interviews with the participants, which could have given a deeper understanding of the viewpoints.

A potential limitation is self-selection bias, which is a general problem with this kind of research as those interested in PND may have stronger reasons to participate. However, by including some women who indicated that they would not have PND and some that appeared to be undecided, we think the viewpoints of women not interested in PND have been included.

Comparative analyses between the factors must be interpreted with caution. Due to the small numbers, minor differences may not have been detected. However, comparisons between the viewpoints were not the main aim of the study. Since the Q methodology rarely includes a large number of participants, but rather aims at stopping inclusion once saturation has been reached, large groups will not be attained in this kind of study setup.

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CONFLICT OF INTEREST STATEMENT

None of the authors have any conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon request.

ETHICS STATEMENT

The study was approved by the ethics committee at the Medical Faculty of Uppsala University (2019-00267) and conforms to the recognized standards of the declaration of Helsinki. Participation was optional and did not affect the care given at the unit. Participants gave written consent.

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