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Aufklärung

EXPERIENCE OF PREGNANCY AND PRENATAL DIAGNOSIS

**REPRESENTATIVE SURVEY OF PREGNANT WOMEN
ON THE SUBJECT OF PRENATAL DIAGNOSIS**

2006

REPRESENTATIVE SURVEYS

RESEARCH AND PRACTICE OF SEX EDUCATION AND FAMILY PLANNING

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Experience of Pregnancy and Prenatal Diagnosis

REPRESENTATIVE SURVEY OF PREGNANT WOMEN
ON THE SUBJECT OF PRENATAL DIAGNOSIS

ON BEHALF OF THE BUNDESZENTRALE FÜR GESUNDHEITLICHE AUFKLÄRUNG

INFORMATION COLLECTED: JANUARY TO OCTOBER 2004

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FOREWORD

In 1992 the Bundeszentrale für gesundheitliche Aufklärung was given the statutory mandate to develop target-group-specific concepts and media for sex education and family planning. In order to meet the requirements of specific target groups, social changes and, for example, new standards in prevention and health promotion must be taken into account.

In the field of prenatal diagnosis (PND) the rapid technical development of recent decades has led to considerable changes. Almost every woman is now offered at least one prenatal diagnostic investigation during her pregnancy.

However, with the rapid establishment of prenatal diagnosis in doctors' practices, it is not necessarily the case that women are better informed about the significance, purpose, methods and possible consequences of PND: the level of information of pregnant women does not appear to have kept pace with the spread of PND.

The Bundeszentrale für gesundheitliche Aufklärung has undertaken the task of developing appropriate educational services relating to prenatal diagnosis which are tailored to needs of the target group. The media, materials and pilot schemes are aimed at enabling pregnant women to make an informed, responsible decision on whether to make use of the prenatal diagnostic investigations available. These information and educational services are based on scientific knowledge gained from studies, expertise and evaluations.

The representative study 'Experience of pregnancy and prenatal diagnosis' is based on a survey of 559 women who were in the 20th to 40th week of pregnancy at the time of the survey, 16 women who lost their child after the 13th week of pregnancy and 170 women shortly after giving birth. The women filled in an extensive questionnaire with detailed questions regarding their experience of pregnancy, utilisation of various PND services, their level of information, their attitudes and their assessment of various aspects of medical advice and treatment.

The research report presented here briefly documents a few important results.

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COLOGNE 2006

1 RESEARCH QUESTIONS AND RESEARCH DESIGN

Since 1997 the subject of ‘pregnancy’ has been a focal point in sex education and family planning at BZgA. Various educational materials, such as a documentary film on fathers in the delivery room and a leaflet on the subject of prenatal diagnosis have been produced. A new form of cooperation between doctors and psychosocial counselling specialists who are involved in mentoring and advising pregnant women is currently being trialled in the pilot scheme ‘Quality circle in prenatal diagnosis’. Numerous other media, materials and measures will follow in the coming years aimed at providing pregnant women with appropriate explanations on the merits of importance for preventative health care.

THE QUESTIONS...

In order to learn more about the subjective feelings of pregnant women, their attitudes and their need for information, and to adapt the new media, materials and educational provisions better to these, the BZgA commissioned a survey of pregnant women. The subjects were selected at random by the opinion research institute TNS Healthcare and provided information about various aspects of their experience of pregnancy, prenatal diagnosis, their attitudes and expectations.

We were interested in the women’s view on what age is ‘best’ for pregnancy. What is the optimum number of children? How well do the pregnant women feel and what health problems do they have? What feelings are linked to pregnancy? How do the pregnant women get their information and what subjects are they particularly interested in?

In addition to the ‘experience of pregnancy’, ‘prenatal diagnosis’ is a second thematic focal point of the investigation. The further technical development of diagnostic procedures has enabled an ever greater number of pregnant women to take advantage of prenatal diagnosis. It now seems to be taken for granted that

PND is an integral part of medical prenatal care. Pregnant women hope the examinations will confirm that they can expect a healthy child. They often lose sight of the fact that prenatal diagnosis can mean having to take serious decisions.

We wanted to know to what extent the age risk for chromosome aberrations still influences the decision to make use of PND. We were also interested in how well pregnant women are informed about PND, how interested they are in obtaining information and how the information on PND influences the pregnant women. What reasons do women have for deciding for or against making use of prenatal diagnosis? How do they assess the investigations afterwards?

A third set of questions relates to the quality of medical advice and treatment and how this is assessed by the pregnant women. Are the women generally satisfied? From the women’s viewpoint, what are the strengths and weaknesses of the medical advice?

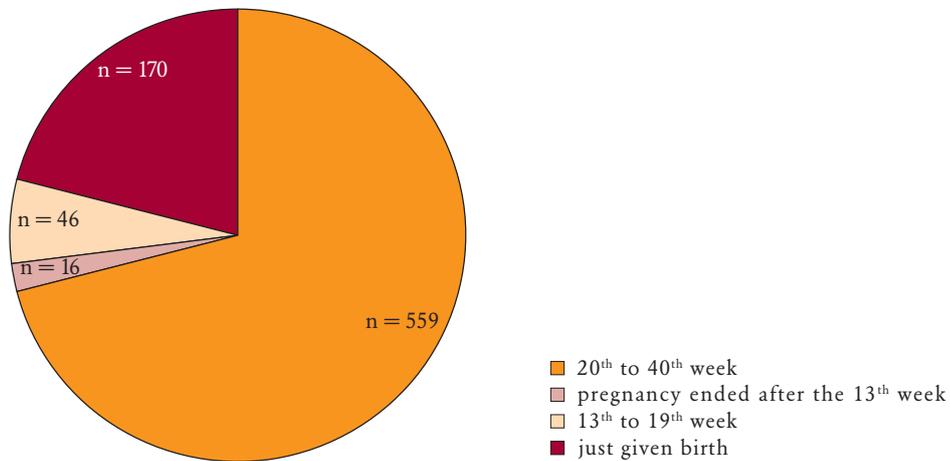
... AND THE ROUTE TO ANSWERS

During 2003 and 2004, three waves of rotational surveys of approximately 30,000 households, members of the TNS ACCESS panel, were used to put a screening question to pregnant members of the households.¹ In approximately 2% of the households there was a pregnant woman who could give the expected date of delivery. Between January and October 2004, deliberately after the 20th week of their pregnancy, a letter was sent to each of these women asking them to fill in an extensive questionnaire (25 pages).² The pregnant women’s willingness to participate was very good, with a response rate of 72%. A total of 791 returned questionnaires were assessed; 559 were from pregnant women in the 20th to 40th week of pregnancy.

1 The ACCESS panel consists of a pool of addresses of households which are willing to take part in surveys. The addresses are dispersed over all communities in Germany and are therefore regionally representative.

2 Most of the recipients also received another questionnaire which was intended to be passed on to another pregnant woman of the panel member’s acquaintance. However, the recruitment of other pregnant women through the ‘snowball effect’ was only partially successful: only 11% of the women were recruited for the investigation in this way. 89% came from the ACCESS panel.

FIGURE 1: COMPOSITION OF THE SAMPLE (ENTRIES IN ABSOLUTE FIGURES)



Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

This sample is representative of the population of pregnant women in Germany with regard to several criteria, for example the region in which they live, their age, the proportion of primiparas and multiparas and the proportion of working women. However, a middle class bias can be detected: fewer lower-educated women answered the questionnaire. Migrants were not included in this investigation.

2 OVERVIEW OF THE IMPORTANT RESULTS

The first part of the evaluation concentrates on the **experience of pregnancy**. It deals primarily with the planning of the pregnancy, the number of children the women wish to have and the women's views on the ideal age for starting a family. Attention is also paid to the women's general state of health during the pregnancy, health problems during pregnancy and the women's emotional life.

The second part deals with **prenatal diagnosis (PND)**. The results show how widespread the utilisation of PND is even amongst women for whom there is no age risk. They also show what motivates the pregnant women have for making use of or deciding against PND and how well or badly they are informed about the significance, purpose and methods of PND. The data also provide information about the causes of the low level of information.

The third part provides results relating to the quality of **medical advice on PND** from the women's point of view. It shows how satisfied the pregnant women are with various aspects of the advice and treatment provided by their gynaecologist.

EXPERIENCE OF PREGNANCY

Between the ages of 25 and 34 over 70% of the women questioned planned the pregnancy. In the other age groups the proportion of women who 'definitely intended to become pregnant' is considerably lower. Evidently between the mid-twenties and mid-thirties is regarded as the ideal age for starting a family.

The women who definitely intended to become pregnant are most often women who already have a child and with the second child are realising the ideal of a two child family. A first, third or fourth child is considerably less often planned.

Almost 70% of the women who state that they do not wish to have any more children after this child is born say that they now have the number of children they want. Unsuitable living conditions also play a role, particularly in families who already have more than one child.

The pregnant women are predominantly well. During their pregnancy 79% feel 'well' or 'very well'. However, this proportion falls considerably in the case of the more heavily stressed multiparas: 25% of them (compared with 17% of those pregnant for the first time) say that they feel 'less well' or 'not at all well'.

The pregnant women suffer most from 'tiredness' (95%), 'exhaustion' and 'back pain' (both 80%). These symptoms are classified as troublesome, but not really worrying. However, the pregnant women consider symptoms which involve a real health risk, such as 'non-typical bleeding' and 'premature labour', to be very worrying.

The vast majority of the pregnant women describe their overall feeling during pregnancy with terms such as 'happy', 'optimistic' or 'fulfilled'. It is mainly very young women and those pregnant over the age of 40 who are troubled. Almost half of these describe themselves as 'apprehensive'.

The type of support during pregnancy often misses what is required: often women who need it the most receive the least support. A quarter of the pregnant women state that they receive less financial or material support than they need. A fifth of the women lack confirmation and recognition, another fifth advice and information about practical matters. Those concerned here are particularly pregnant women on low incomes and/or with little education, of whom almost half say that they need more than they receive.

The doctor is the most important source of information in matters of pregnancy. Three quarters of the women have learnt something new in the gynaecological practice.

The women's interest in information applies particularly to subjects with a positive connotation. The expectant mothers are especially interested in the development of the child in the womb and what happens during pregnancy and the birth. Information on prenatal diagnosis, miscarriages, premature and still births, on the other hand, arouse much less interest.

PRENATAL DIAGNOSIS

Prenatal diagnostic procedures are now an integral part of prenatal care: only 15% of the women surveyed in their 20th to 40th week of pregnancy have refused PND. In addition to the three regular ultrasound examinations which are recommended in the maternity guidelines, over 70% have also undergone an additional one explicitly aimed at 'ruling out malformations in the child'. Over 40% had the nuchal translucency scan, 34% had the triple test and 29% the first trimester test (see the glossary for the processes and specialist terms). Amniotic fluid was taken from 11.5% of the pregnant women and chorionic villous tissue from 3.3% of them.

Invasive procedures are mostly taken up by older pregnant women: almost a third of women in the age group between 35 and 39 and 44% of those over 39 have an amniocentesis, compared with only about 6% of younger women. Non-invasive procedures, on the other hand, are taken up particularly by younger women. Thus, for example, 45% of the 18 to 24-year-olds have a triple test to detect any chromosome aberrations. It is now basically the case that women are faced with PND, whatever their age. However, age plays a role in deciding whether an invasive or non-invasive method is chosen.

When asked about their motives for having prenatal diagnostic investigations carried out, over 60% say that they have taken advantage of PND to 'ensure the health of the baby'. A quarter of them say that they have done so at the request of their doctor. Over a third assume that PND is part of general prenatal care.

The level of information about PND is extremely low. Even though 85% of the women surveyed have already had at least one definitively prenatal diagnostic procedure, about half of them either do not know the term 'prenatal diagnosis' at all or understand it to mean something different.

At the same time the interest in information is also very low. Only 18% of the women in their 20th to 40th week of pregnancy would have wished to have more information about PND at the beginning of their pregnancy. This result again indicates the tendency of pregnant women to close their eyes to unpleasant subjects or subjects which cause concern.

Overall, reactions to information about PND are ambivalent. On the one hand the women feel relieved by the prospect of confirmation of the health of their child, while at the same time feeling stressed by the chance of discovering some impairment.

Afterwards, most of the women are very satisfied with the PND: 77% of those surveyed are pleased that they took up the offer of PND. 69% would do the same again if they had another pregnancy and only 4% would refuse PND.

One in three women states that she could not accept any disability in her child. Only 18% of the pregnant women can well imagine living with a disabled child.

MEDICAL ADVICE AND TREATMENT

Doctors have almost as great an influence on whether PND is carried out as the partners of the pregnant women: 52% of the women say that their doctor had a great influence on their decision to have PND.

Almost half of the pregnant women are very satisfied with the information which they receive from their doctors about PND. 45% are very satisfied with the comprehensibility of the information and 40% with the amount of detail provided.

A more precise enquiry showed that the women had been advised very thoroughly regarding the medical aspects of the prenatal diagnosis, for example the reason for and aim of the investigation or the estimation of the statistical risk. Advice from doctors was much less detailed in terms of subjects which do not primarily come under the medical area of responsibility, such as the possible actions in the event of an abnormal result or the possibility of having psychosocial counselling.

In most cases the prenatal diagnostic finding was communicated in person by the doctor (78%).

For 5% of the pregnant women the finding was abnormal or pathological. Here too the women have conflicting views on the subsequent advice from their doctors: while medical information, such as about the causes of the

developmental disorder and on continuation or termination of the pregnancy is assessed positively, the women concerned are dissatisfied with the advice regarding the consequences for themselves and their families ('quite poor' 36%, 'poor' 16%). 71% assess the advice regarding preparation for life with a disabled child as poor and even the arrangement of further assistance was assessed by over 40% as 'very poor'.

3 RESULTS IN DETAIL: EXPERIENCE OF PREGNANCY

The questions on the experience of pregnancy and the desire for children were only answered by the women who were pregnant at the time of the survey. The fol-

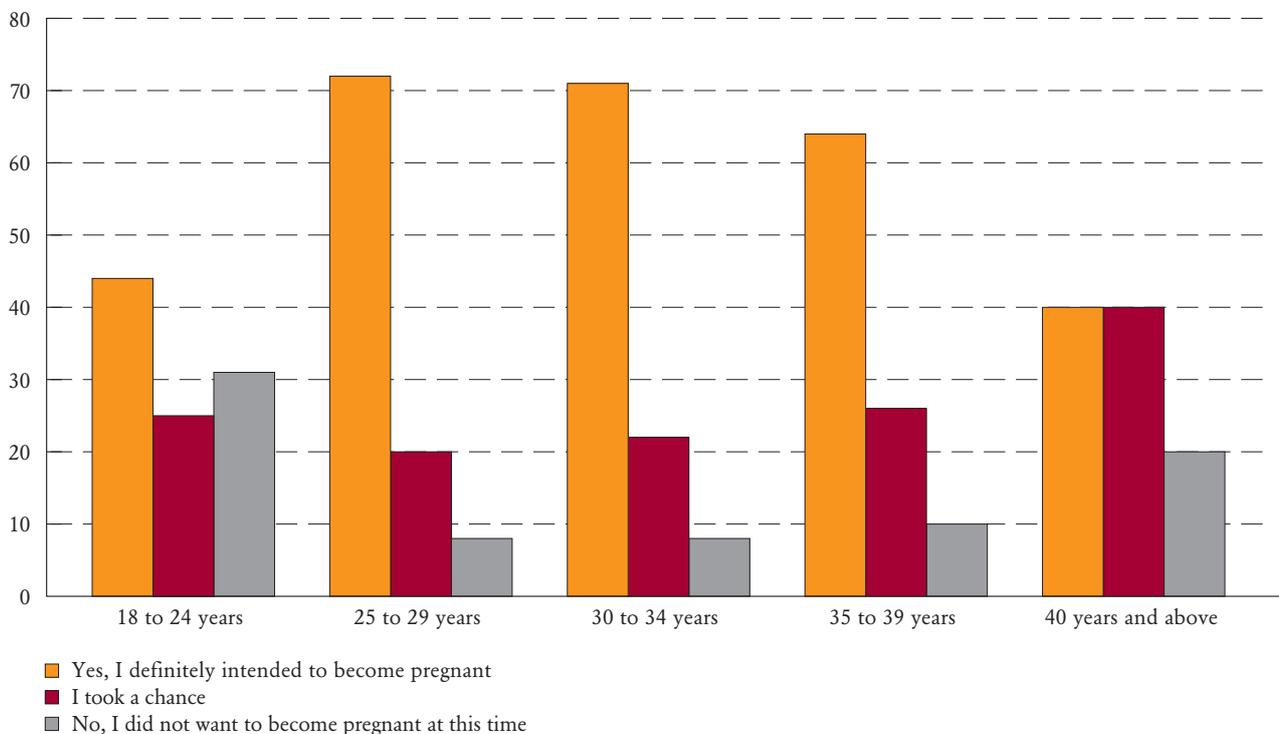
lowing evaluations relate exclusively to the 559 women who were in at least the 20th week of pregnancy.

3.1 BEST AGE AND OPTIMUM NUMBER OF CHILDREN

Since children tend to be planned when the age of the parents is (also) judged to be appropriate, the proportion of planned pregnancies in an age group can pro-

vide information about the age which is generally considered to be 'the best' for a pregnancy.

FIGURE 2: PLANNING OF PREGNANCY BY AGE CATEGORY (ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

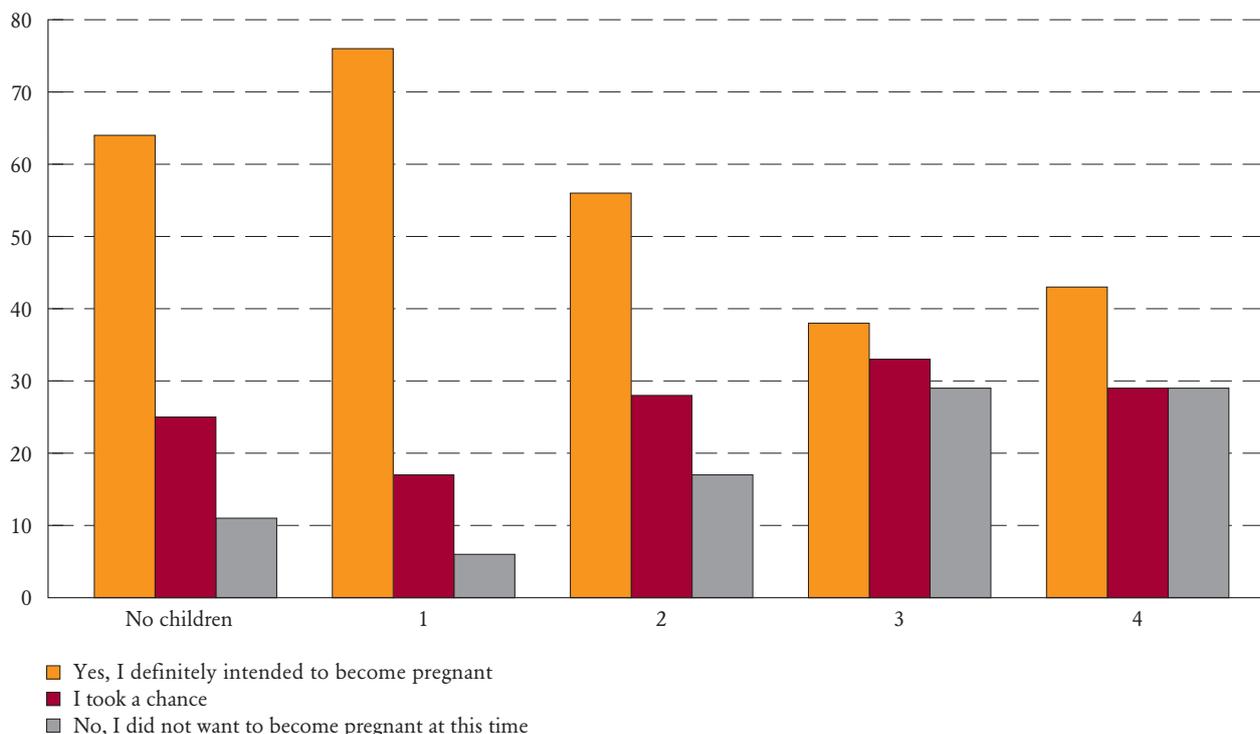
Over 70% of the women surveyed between the ages of 25 and 34 say that they definitely intended to become pregnant. Less than one in ten of the women in this age group said that the pregnancy was not wanted at the present time. A very different view is expressed by the very young and the older pregnant women: the majority of under 25s and over 40s state that the pregnancy

was not planned or was not wanted at the present time. There appears to be a broad consensus that women 'should not have children until their mid-twenties'. According to the women's estimation the optimum time window closes again at 35, or certainly at 40 plus.

It is particularly women who already have a child who say that they definitely intended to become pregnant: 76% of the one-child mothers have planned their second child. Only 6% say that they did not want to become pregnant at this time. If there are already two children in the family, a third child is planned by only about

half of the mothers and a fourth child by 38%. The results confirm the widespread preference for a two child family.

FIGURE 3: **PLANNING OF PREGNANCY BY THE NUMBER OF CHILDREN ALREADY IN THE FAMILY**
(ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy

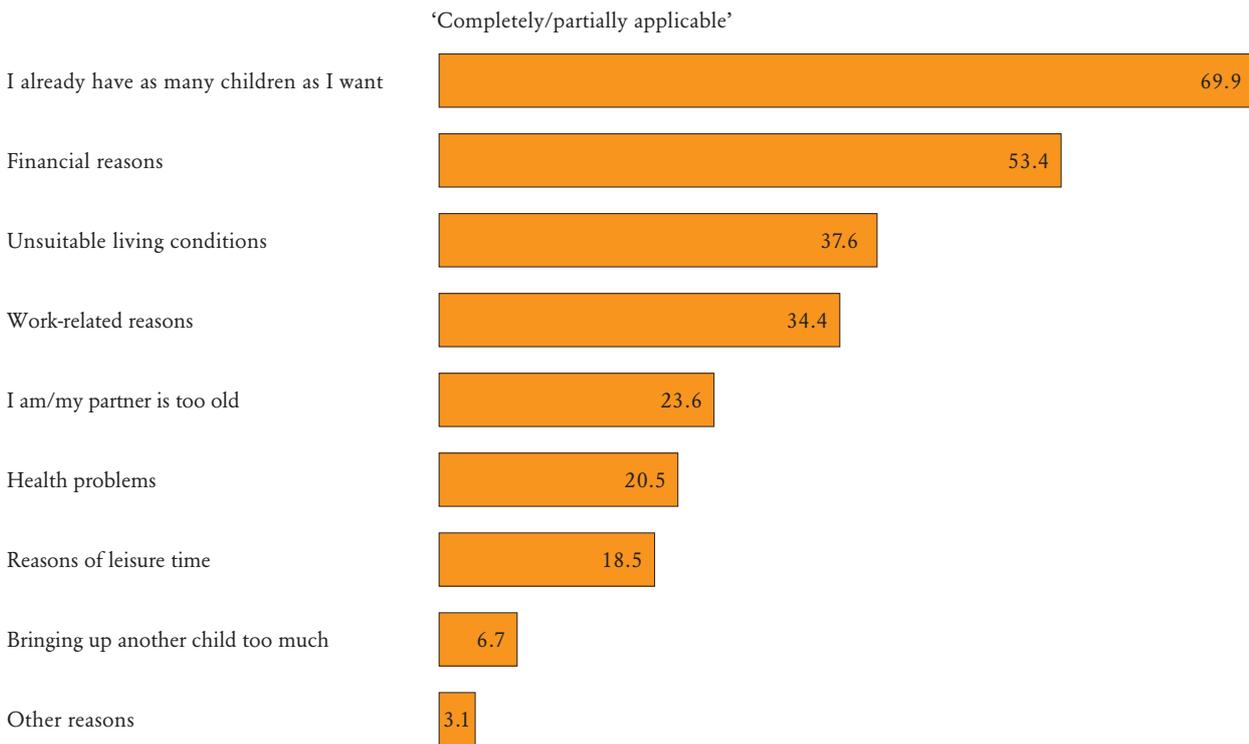
Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

3.2 REASONS NOT TO HAVE ANOTHER CHILD

We asked why many parents decide not to have a second, third or fourth child. 322 of the expectant mothers say that they do not want to have another child. The reason given by most of the pregnant women (70%) is that with the birth of the baby they now have the num-

ber of children they want. Over half of the women state that financial considerations (also) play a part in their desire for children. The third and fourth most common factors quoted are unsuitable living conditions and work-related reasons.

FIGURE 4: REASONS NOT TO HAVE ANOTHER CHILD (ENTRIES IN %)



n = 322; women in at least the 20th week of pregnancy who do not want to have any more children; multiple responses possible

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

At the time of the current pregnancy the women who say that they now have the number of children they want are predominantly mothers of one child who, with the birth of the baby, are realising the ideal of a two child family (85%); unsuitable living conditions are a factor in not wanting another child especially in families with

two or more children (49%) and work-related reasons are quoted particularly by childless pregnant women (42%).

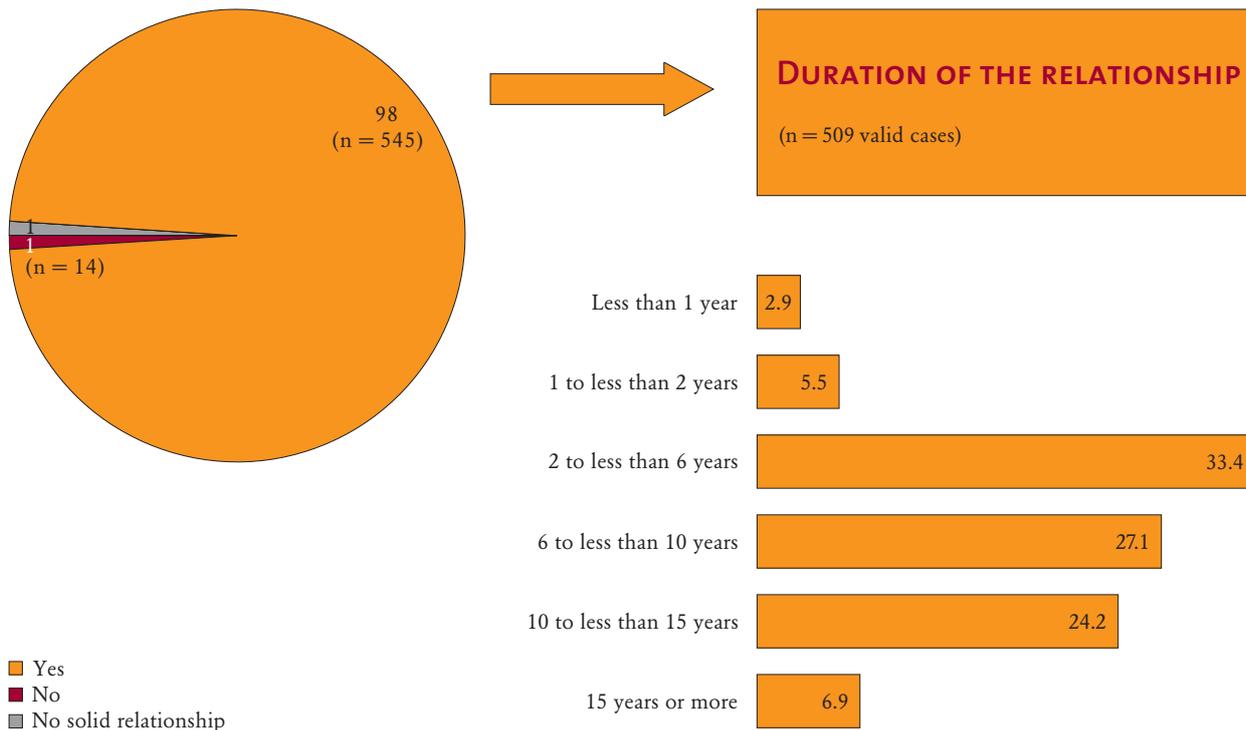
3.3 DURATION AND STANDING OF THE RELATIONSHIP WITH THE CHILD'S FATHER

Almost all of the pregnant women are living in a solid relationship with the father of their unborn child (98%). Most of these relationships have existed for several years:

92% of the women have had the child's father as a partner for more than two years; 31% for ten years or longer.

FIGURE 5: RELATIONSHIP WITH THE CHILD'S FATHER (ENTRIES IN %)

Is your current partner the father of your unborn child?



n = 559; women in at least the 20th week of pregnancy

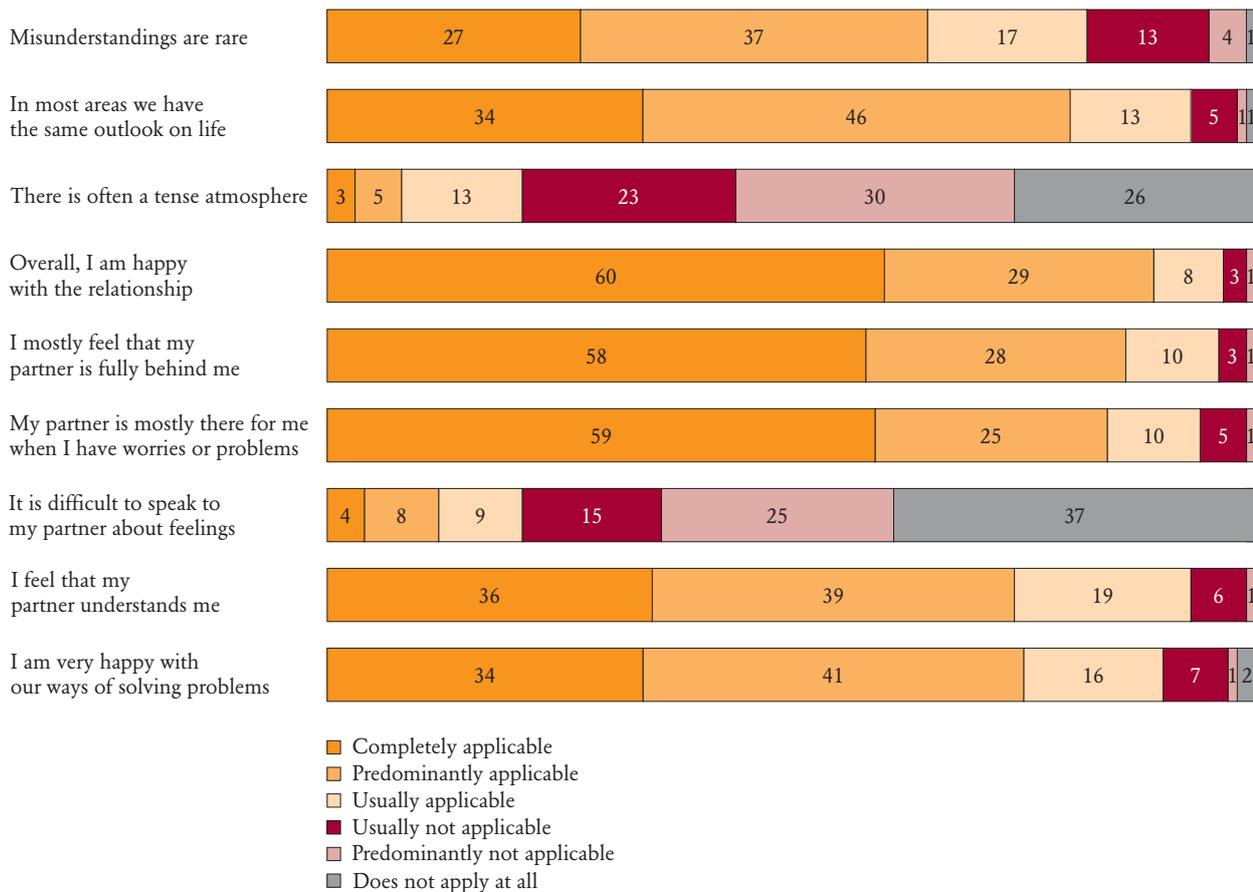
Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

To the question 'What is your partner's attitude to the child?' over 90% of the pregnant women replied that he has a positive attitude to the child. In relationships which are less than two years old this proportion is a good 10% lower.

ner understands them and 86% of the women generally have the feeling that their partner is fully behind them. Only one in five of them finds it difficult to talk to their partner about their feelings.

Overall, the relationship to the child's father is seen as predominantly very positive: 96% are generally happy with their relationship. Over 90% feel that their part-

FIGURE 6: QUALITY OF THE RELATIONSHIP (ENTRIES IN %)



n = 551; women in at least the 20th week of pregnancy, with partner

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

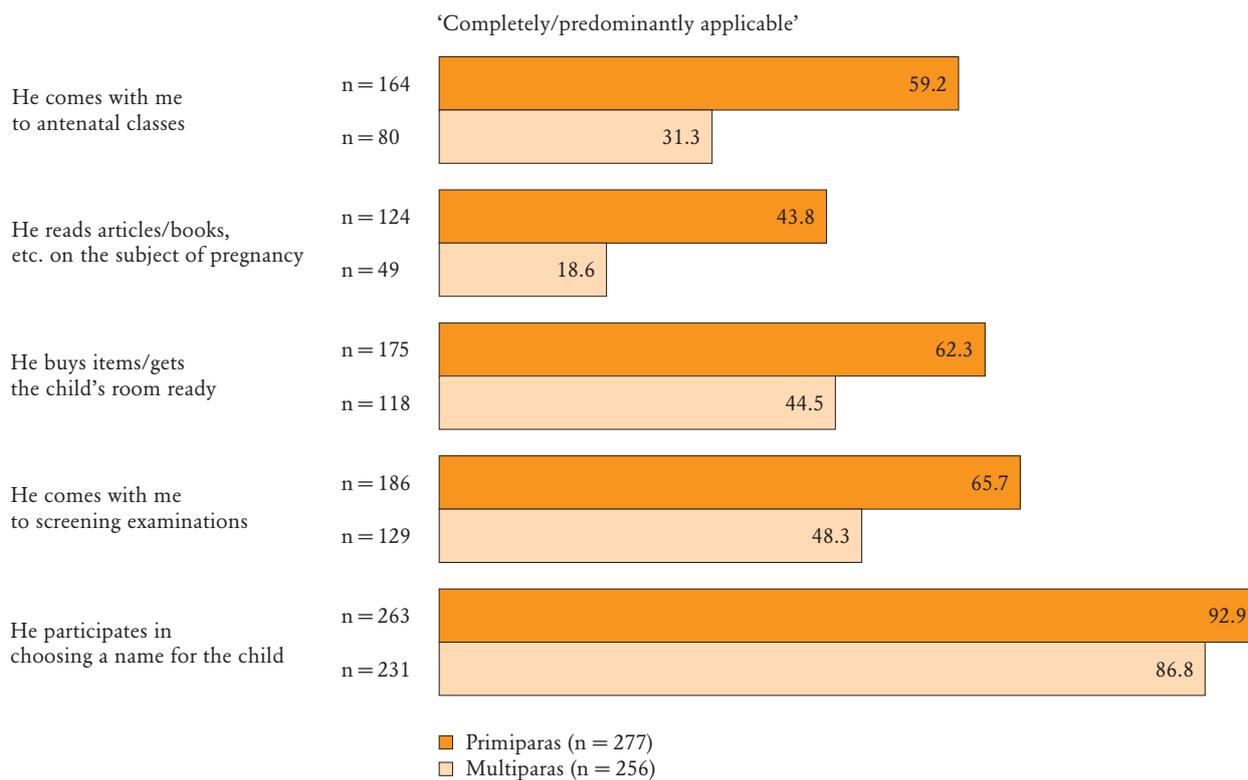
Many fathers-to-be also support their partner during pregnancy by means of activities which are directly relevant to the pregnancy and their future life with the child. For example, almost half of the women who take part in antenatal classes are accompanied by their partner.

However, the child's father's commitment decreases considerably with the second or third child: while approximately 66% of men whose partner is expecting her first child go with her to screening examinations, only 48% of the partners of multiparas do so. Even when it comes to reading on the subject of pregnancy the percentages of those who are becoming a father for the first time are considerably higher than those for men who are expecting their second or third child.

This does not necessarily mean that fathers are less interested when it comes to a second or third pregnancy. It may be because of their experience already gained with the first child that fathers limit their activities. Also, Helfferich, for example, points out that fathers increase their work commitments when the first child is born.³ In addition, when there are already infants/children in the family, it can often be more difficult to organise for both the mother and father to attend a screening appointment or an antenatal class. Possibly the father's commitment is shifted to other areas of family work so as to relieve the newly pregnant mother.

³ Helfferich, C; Kleidworth, H; Wunderlich, H. (2005) männer leben [men live]. A study of lives and family planning. Basic report, BZgA (publisher), Cologne

FIGURE 7: COMMITMENT OF THE PARTNERS OF PRIMIPARAS AND MULTIPARAS (ENTRIES IN %)



n = 551; women in at least the 20th week of pregnancy, with partner

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

3.4 SENSE OF WELL-BEING AND HEALTH

In order to be able to rate the general state of health of the pregnant women, the women were asked the number of days in the last four weeks on which they had had to stay in bed for health reasons. 23% of the women had been confined to bed for an average of 6.1 days. It is surprising that the older pregnant women on average spent fewer days in bed than the younger women: the average for 18 to 24-year-olds is 7.8 days while the average for 35 to 39-year-olds is only 4.4 days.

When asked about their general state of health, most women say that they feel 'well' or 'very well' during their pregnancy (79%). In the case of multiparas the proportion of women who describe their condition as 'less well' or 'not at all well' is considerably higher than is the case for childless pregnant women (25% compared with 17%). Possibly this is an expression of the generally greater strain faced by pregnant mothers.

FIGURE 8: GENERAL CONDITION DURING PREGNANCY (ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

3.5 HEALTH PROBLEMS DURING PREGNANCY

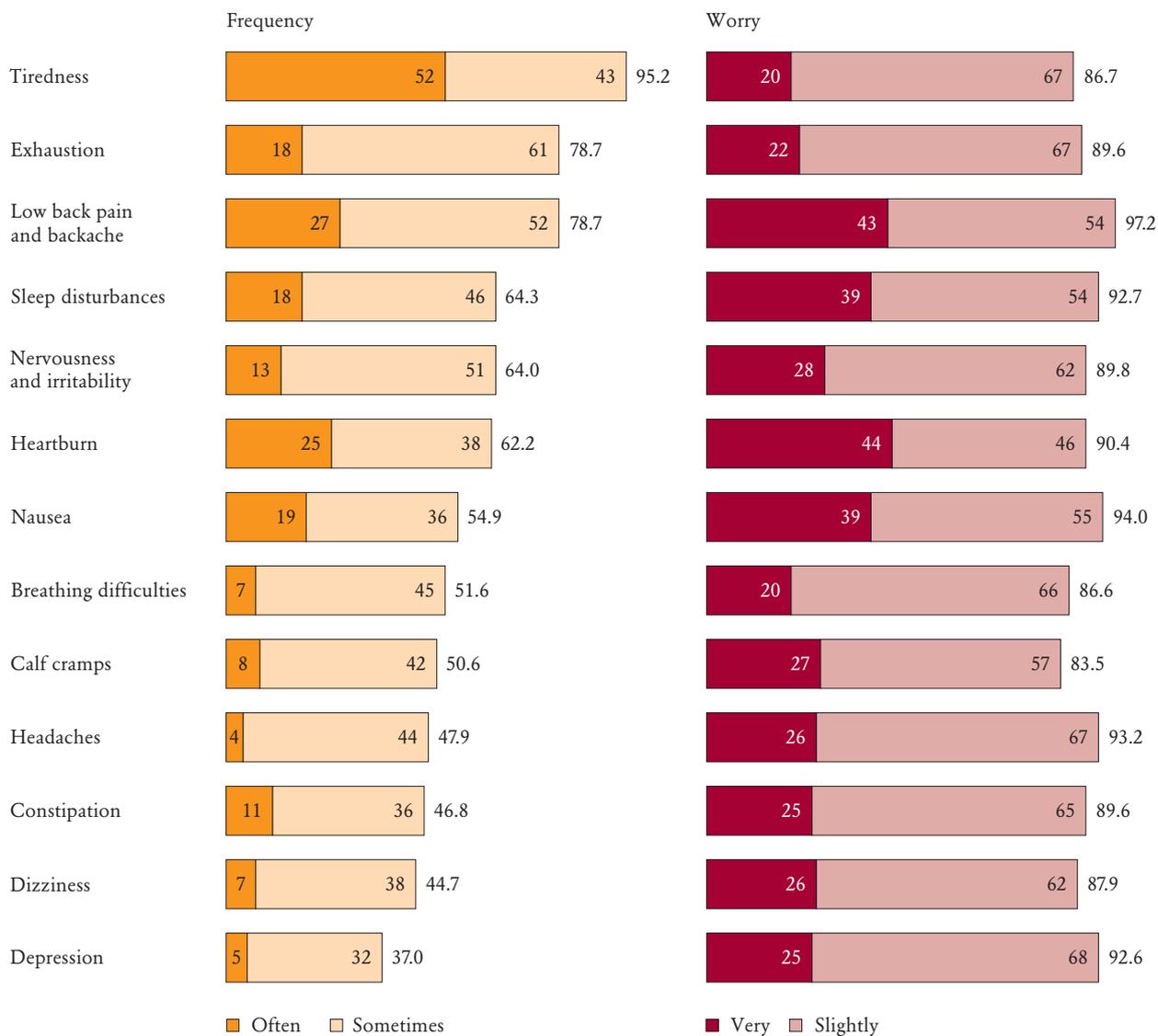
Almost all of the pregnant women report slight health problems such as tiredness or heartburn. On the other hand impairments involving a high health risk for mother and child occur rarely, but are considered to be particularly worrying.

The most commonly quoted complaint is 'tiredness': 95% of the pregnant women state that they 'often' or 'sometimes' feel tired. One in five of these women consider the tiredness to be 'very worrying'. Almost 80% suffer exhaustion and back pain, 64% sleep disturbances.

These 'typical' health problems which often occur during pregnancy are described as troublesome, but – with the exception of low back pain and backache – are generally not rated as worrying.

FIGURE 9: HEALTH PROBLEMS DURING PREGNANCY (ENTRIES IN %)

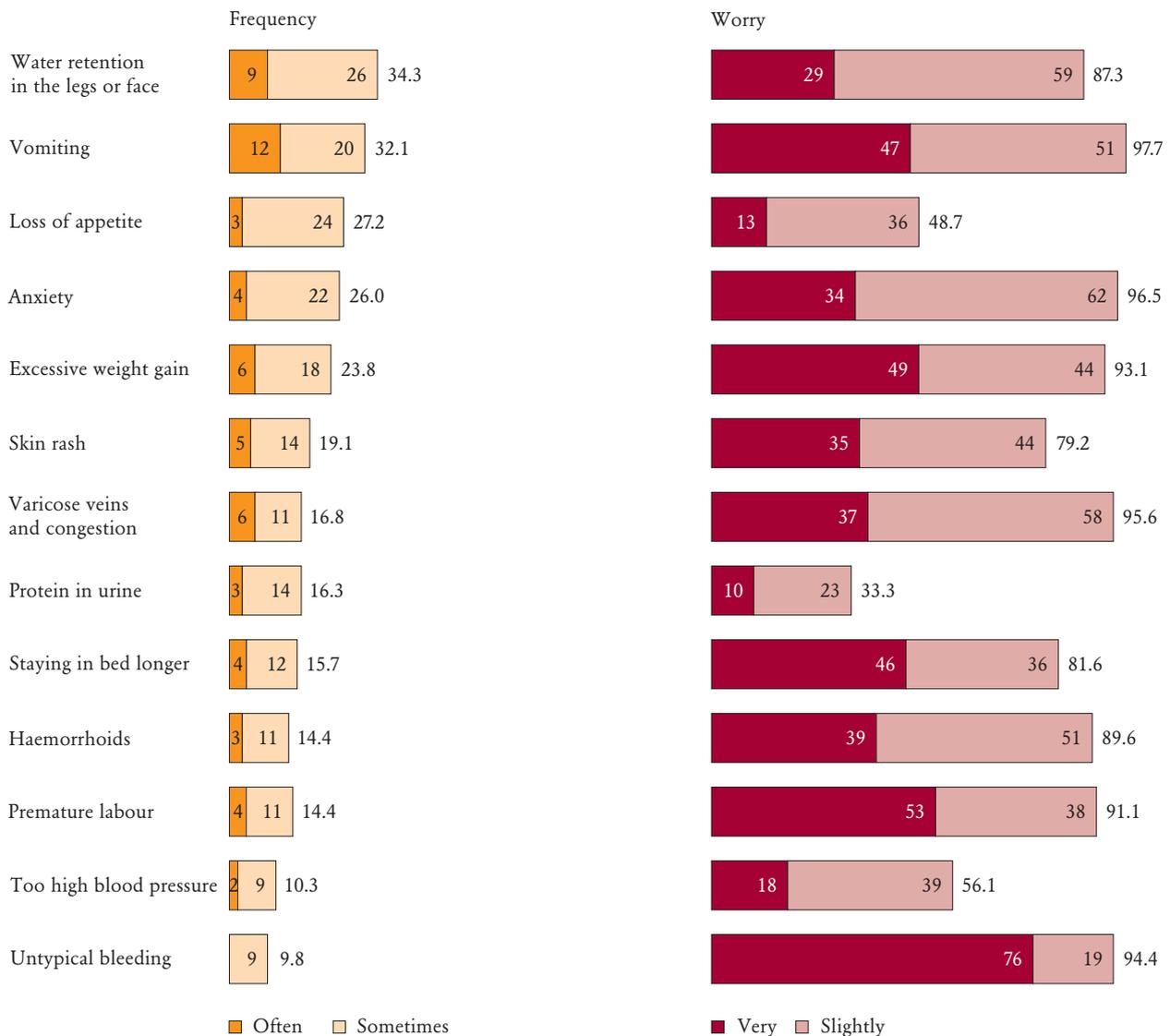
Numbers 1–13



Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

FIGURE 10: HEALTH PROBLEMS DURING PREGNANCY (ENTRIES IN %)

Numbers 14–26



Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

‘Untypical bleeding’ is the most rarely quoted symptom, but it is particularly keenly felt in the experience of pregnancy: 76% of the women with ‘untypical bleeding’ feel ‘very stressed’ as a result. Other health problems which

involve high risks for mother and child, for example ‘premature labour’, also have a great effect on their well-being.

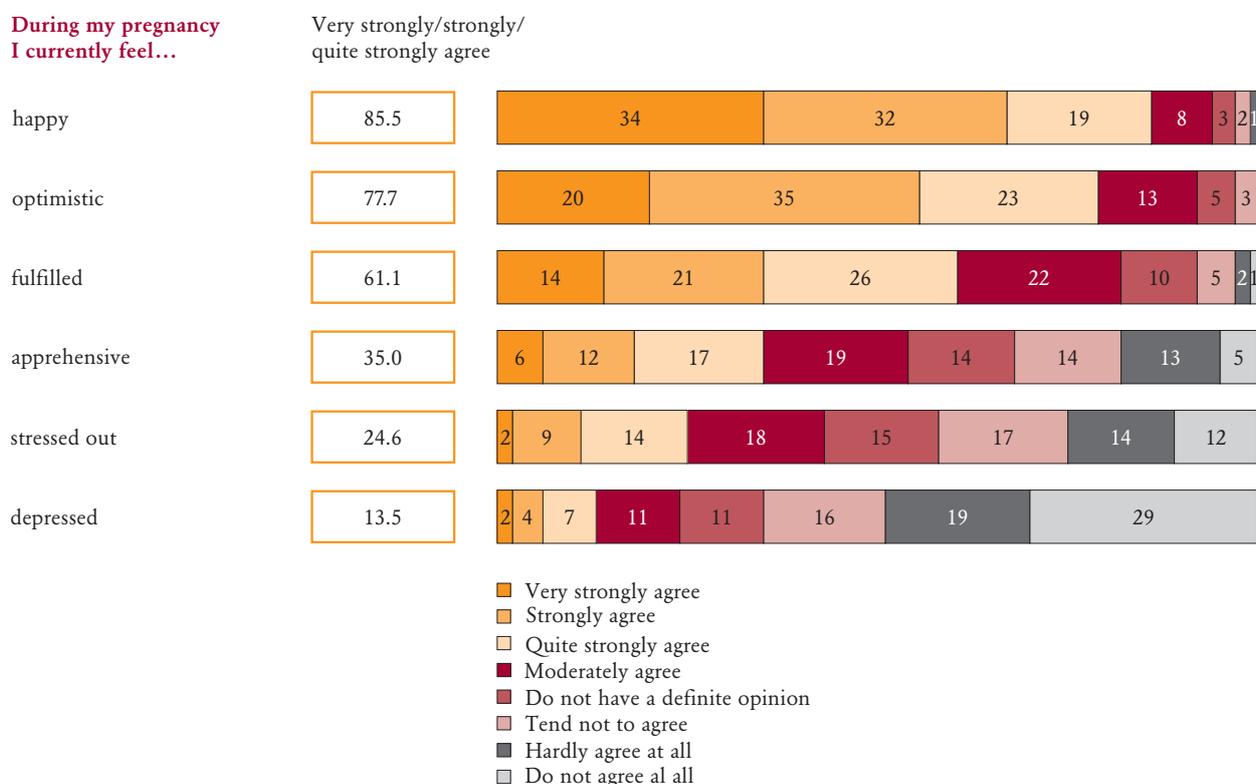
3.6 AMBIVALENCES DURING PREGNANCY

A large majority of the pregnant women say that they feel ‘well’ or ‘very well’ during their pregnancy. As well as this general assessment, we wanted to get an insight into the precise feelings which may be linked to pregnancy, so the women were also asked explicitly about various aspects of their current emotional situation. Over 85% of the pregnant women respond that, at the time of the survey, they are ‘happy’ about their pregnancy; 78% describe themselves as ‘optimistic’, 61% as ‘fulfilled’. This indicates an extremely positive experience of pregnancy. However, at the same time the women also report negative feelings: 35% are (also) ‘appre-

hensive’; a quarter describe themselves as ‘stressed’ and 13% of the women feel ‘depressed’.

In spite of the almost universally positive attitude to pregnancy, many women also harbour negative feelings. The pregnant women who feel stressed are especially those in the middle age groups; concerns are expressed particularly by very young women and pregnant women over the age of 40, almost half of whom say they are ‘apprehensive’. The proportion of depressed women is approximately the same in all the age groups.

FIGURE 11: EXPERIENCE OF PREGNANCY (ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy; multiple responses possible

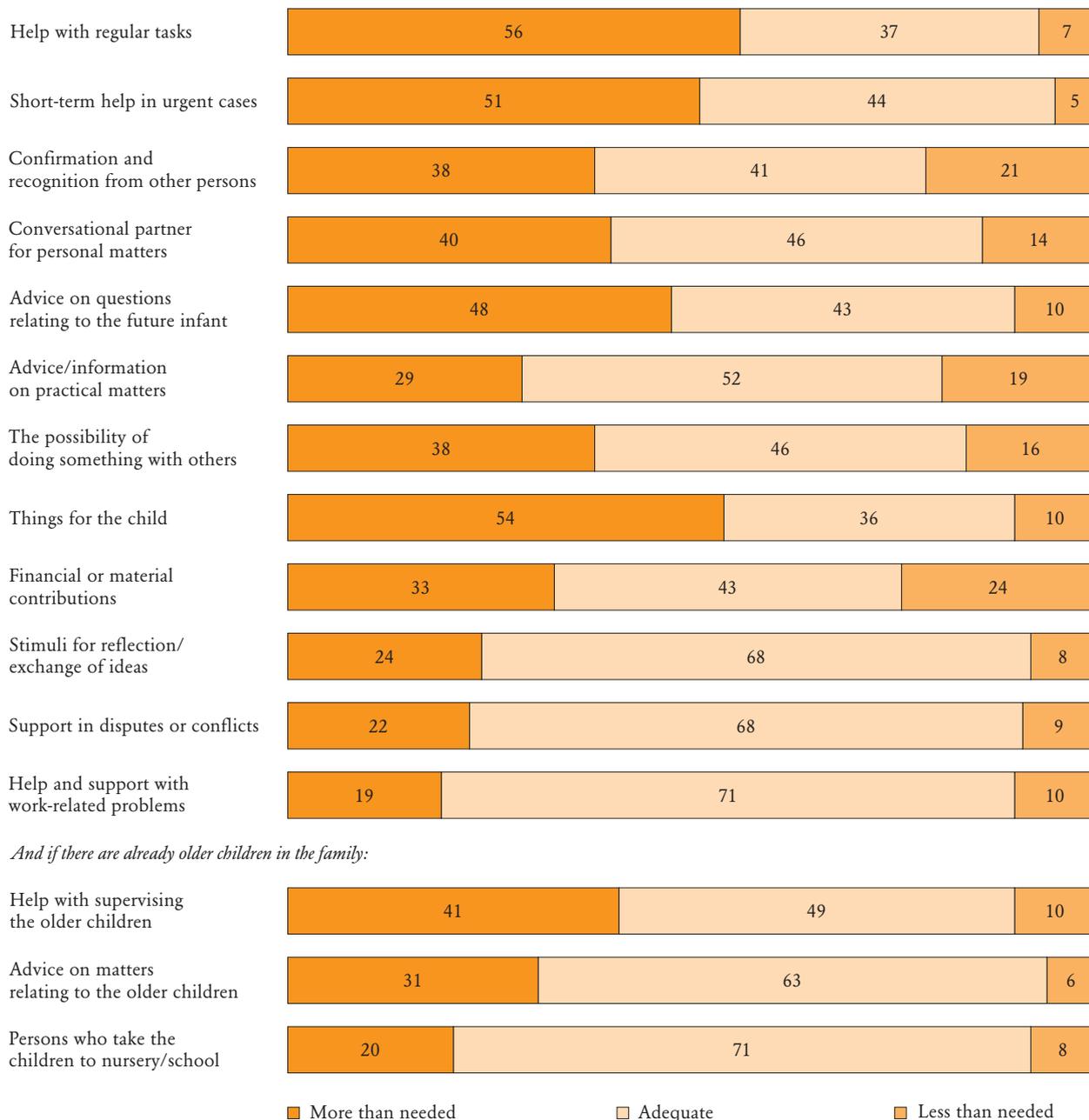
Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

3.7 NEED FOR SUPPORT

The pregnant women were asked what kind of support they need and what they receive. For some types of support more than half of the women surveyed state that they receive more support than they actually need, for example with regular tasks and short-term help in

urgent cases. The women are also often given more 'things for the child' (e.g. clothing or toys) than they actually need.

FIGURE 12: SUPPORT NEEDED AND RECEIVED (ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

In contrast, other forms of support are often lacking: a quarter of the pregnant women say that they receive less financial or material contributions than they need. A fifth lack confirmation and recognition from other persons; a further fifth require advice and information on practical matters.

It is interesting to compare the answers of pregnant women from different social backgrounds. Using various indicators (e.g. education and income) the women were allocated to a position on a social scale. According to their own assessments, expectant mothers with a low level of education and/or low income require considerably more support than other women: the grea-

ter need does not only apply to financial or material contributions – almost half of this group need more than they receive –, but also, for example, to confirmation and recognition from other persons (30%), a conversational partner for personal matters (28%) or advice/information on practical matters (33%).

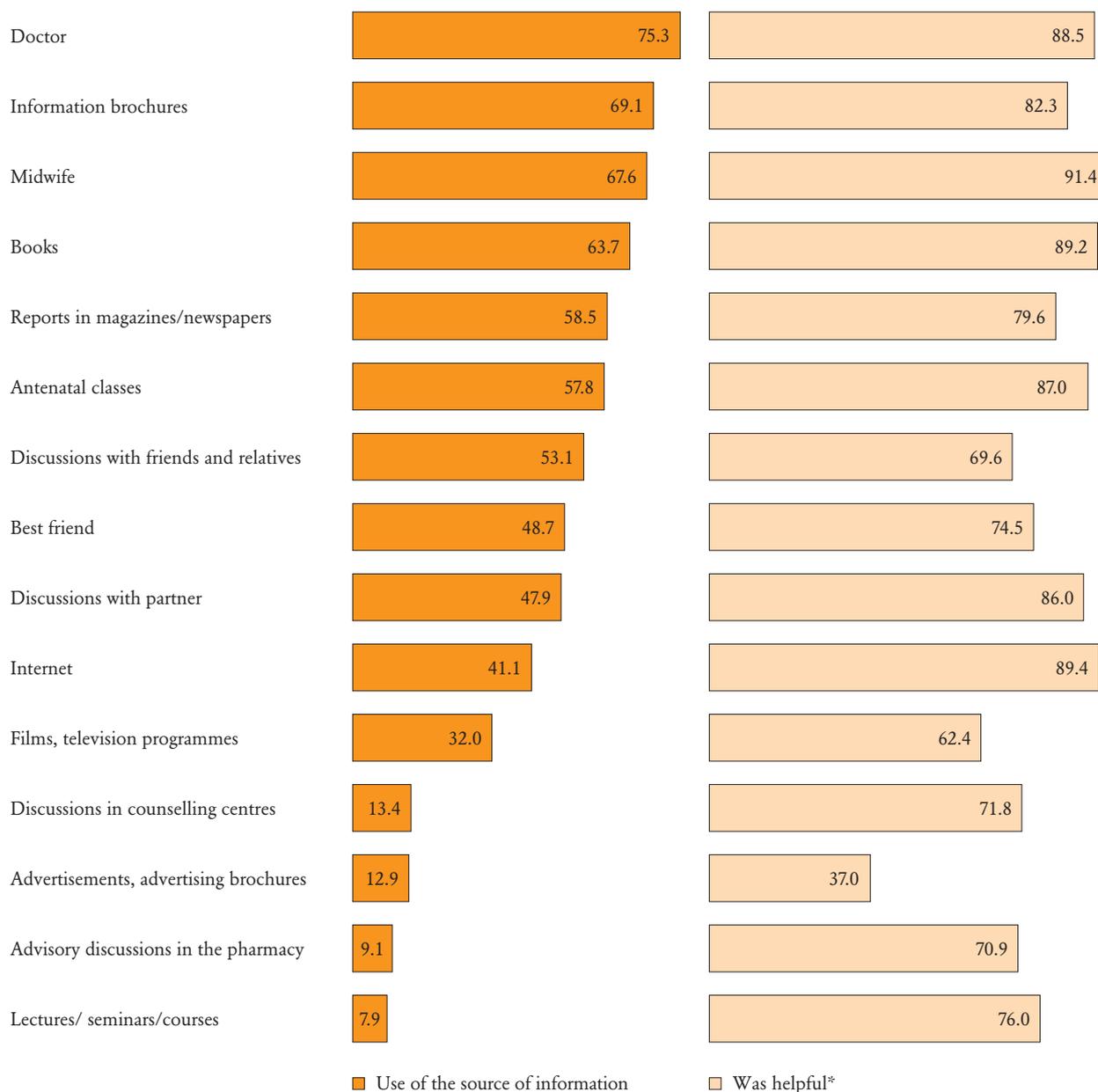
3.8 SOURCES OF INFORMATION

The most commonly used source of information during pregnancy is the doctor: Three quarters of the women have learnt something new in the gynaecological practice. Slightly fewer (69%) obtained information from brochures, midwives (68%) or books (64%). Pregnant women rarely get information from counselling centres (13%), advertisements (13%), pharmacies (9%) or via lectures, seminars or courses (8%).

The doctor and midwife are by far the most important contacts for pregnant women. They are not only the most commonly used source of information, but are also rated as particularly helpful: 91% of the pregnant women who learnt something from a midwife found this information useful; 89% (also) rated the medical advice as particularly worthwhile.

Those women who obtained information via the Internet were also particularly satisfied. Although only 41% of the women searched for anything new about pregnancy on the Internet, 89% of these rated the information found there as helpful. Clearly the Internet has not completely established itself as the information medium of choice for expectant mothers, but it appears very well suited to providing information.

FIGURE 13: SOURCES OF INFORMATION DURING PREGNANCY AND THEIR USEFULNESS (ENTRIES IN %)



n = 559; women in at least the 20th week of pregnancy; multiple responses possible

*Percentage figures relate to those women who used the relevant information services

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

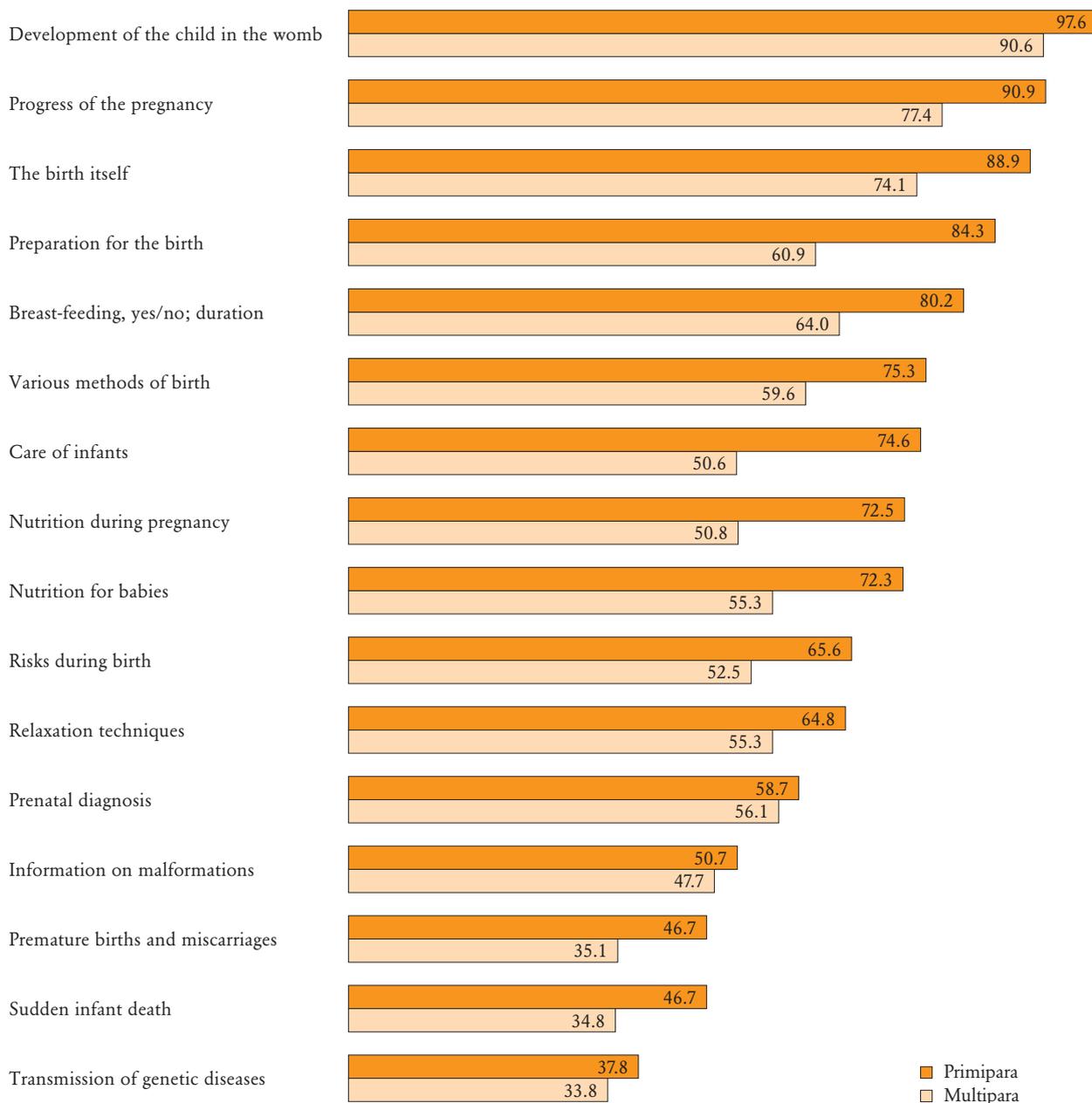
3.9 WHAT INTERESTS THE PREGNANT WOMEN?

Almost all of the pregnant women – 98% of the primiparas – have obtained information about the child’s development in the womb. The second most important subject is the progress of the pregnancy, followed

by the birth, preparation for the birth and breast-feeding. It is hardly surprising that primiparas are more likely to have sought information on all subjects than women who have already had at least one child.

FIGURE 14: SUBJECTS OF INTEREST TO PREGNANT WOMEN, DEPENDENT ON WHETHER THEY ARE PRIMIPARA OR MULTIPARA (ENTRIES IN %)

I have been very/quite interested in the following subjects...



n = 559; women in at least the 20th week of pregnancy; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

In response to an open question the women explained the reason for their particular interest in a certain subject. It is noticeable that the pregnant women are more interested in obtaining information with a positive connotation: for example, the development of the child in the womb, which almost all the women were interested in and also experienced in a positive way. For a majority of the pregnant women 'every week, every month is really fascinating, whatever happens,' some consider this to be the 'most interesting and most beautiful aspect of pregnancy' and describe it as the 'wonder of nature'.

Far fewer of the women sought information about subjects associated with negative feelings. The least interesting subjects for them were prenatal diagnosis, malformations, premature births and miscarriages, sudden

infant death and the transmission of genetic diseases. Their primary interest in pleasant subjects during pregnancy and the blocking out of information which may cause anxiety can be seen as a self-protective mechanism. It contributes to women in the exceptional situation of a pregnancy being able to retain an optimistic, calm attitude. However, it is also important that the subjects with negative associations, which nevertheless are particularly significant in terms of antenatal care and prevention, can be communicated to the pregnant women in such a way that they do not have a negative effect on the experience of pregnancy.

4 RESULTS IN DETAIL: PRENATAL DIAGNOSIS

The questions on the experience of pregnancy were only answered by the women who were pregnant at the time of the survey. The questions on prenatal diagnosis were

also aimed at women who were no longer pregnant at the time of the survey (see figure 1).

4.1 CHARACTERISTICS OF THE SAMPLE

Most of the ‘previously pregnant’ women received the questionnaire in the 20th to 40th week of pregnancy, but did not fill it in and return it immediately, only some time after their delivery. We have not included these women in this analysis.

that these women will look back on the prenatal diagnostic investigations from a different perspective, so the picture would be incomplete without their experiences.

However, some of the ‘previously pregnant’ women would have been in the 20th to 40th week of pregnancy at the time when they filled in the questionnaire, but had lost their child through a miscarriage or stillbirth, or a termination after the 12th week of pregnancy, some of them after prenatal diagnosis. Although only a few women whose pregnancy came to an unfortunate end filled in the questionnaire, we have taken their data into account in the evaluations. It is to be expected

The evaluations are therefore based on 559 women who were in the 20th to 40th week of pregnancy and a further 16 women whose pregnancy ended unfortunately after the 13th week of pregnancy (overall total n = 575).

4.2 FOCAL POINTS OF THE SURVEY ON PND

In recent years both the range of prenatal diagnosis and the demand from expectant parents has increased steadily. Prenatal diagnosis now seems to have become an integral part of medical prenatal care. It is often overlooked that prenatal diagnosis can also lead to serious decisions having to be taken, such as parents having to consider terminating a wanted pregnancy because of the findings.

We wanted to know to what extent PND has now actually become part of the ‘normal’ medical prenatal care, or whether PND is still mainly taken up by pregnant women at increased risk, for example because of their advanced age.

If it is true that prenatal diagnosis is used for pregnant women – irrespective of any classification as ‘risk pregnancy’, then it is particularly important that parents are very well informed about the significance, purpose, methods and possible consequences of the investigations. For this reason we wanted to find out how much the pregnant women know about prenatal diagnosis and how intensively they look into the subject.

We were also interested in the degree to which the pregnant women were satisfied with various aspects of the medical treatment and advice provided.

DIGRESSION: DEVELOPMENT OF PRENATAL DIAGNOSIS

Prenatal diagnosis is a generic term for investigations carried out on the pregnant woman and the unborn child to determine any chromosome aberrations, hereditary metabolic or muscular disorders and malformations in the child. Prenatal diagnostic procedures include certain ultrasound examinations, the nuchal translucency scan, the first trimester test, the triple test, chorionic villus sampling, amniocentesis and umbilical cord puncture.⁴

At the same time as the rapid technological development in the area of prenatal diagnosis, the various procedures became established in prenatal care. Whereas 30 years ago only a very small proportion of pregnant women had prenatal diagnostic investigations, today nearly all women look into the various offerings of prenatal diagnosis. For example, since the costs were taken over by the health insurance funds in 1976, there has been a continuous increase in the proportion of pregnant women who take advantage of invasive (see glossary) investigation methods. From 1991 to 2003 alone amniotic fluid sampling doubled.⁵ However, the spread of invasive diagnostic methods to an ever greater number of pregnant women is limited by the risk of miscarriages, since in younger pregnant women the risk of a miscarriage caused by the procedure is greater than the probability of ‘discovering’ a child with chromosome aberrations.

Non-invasive investigation methods, as alternatives without the risk of miscarriage, have therefore become more and more established in recent years. Ultrasound technology in particular has become more powerful and – often in combination with blood analyses – enables ever more precise estimates of the risk of impairments to the health of the unborn child. This has also meant that non-invasive investigation methods have been offered, and requested, more frequently in doctors’ practices.

⁴ In the appendix to this brochure the individual prenatal diagnostic procedures are described in detail, including the times at which they are carried out, what results they can produce and what risk they may entail.

⁵ Western Germany – Source: Zentralinstitut für kassenärztliche Versorgung [Central institute for care under statutory health insurance]; in accordance with Nippert, I. 2005: 75.255 Amniotic fluid investigations in the whole Federal Republic of Germany

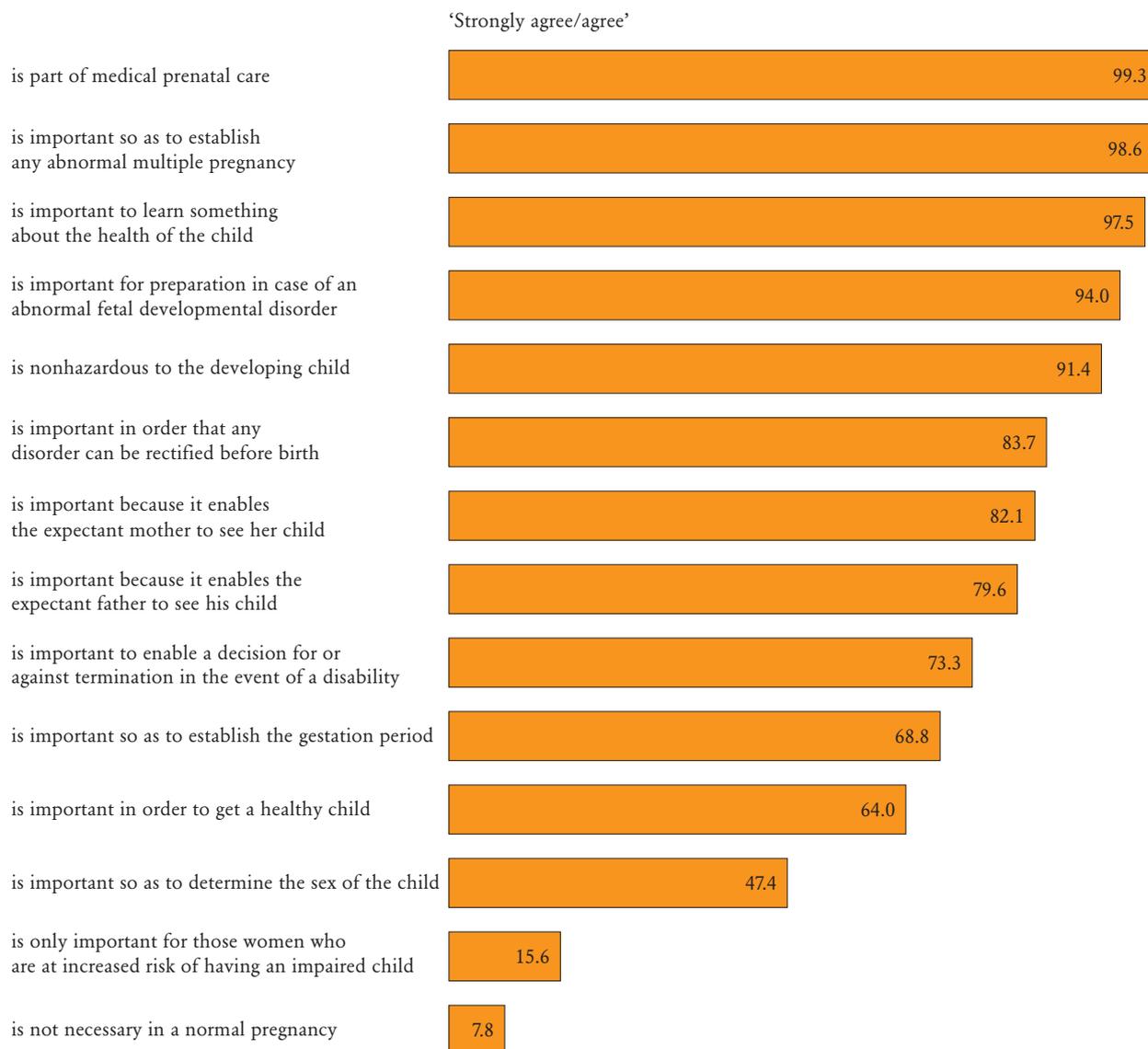
4.3 ULTRASOUND EXAMINATIONS – THE THREE REGULARS

The three regular ultrasound examinations recommended in the maternity guidelines have not been included in the definition of prenatal diagnostic procedures in the narrow sense. However, differentiation between ‘simple ultrasound’ during the screening examination and the targeted search for abnormalities

using ultrasound is difficult: abnormalities in the unborn child can (or should) be detected even with ‘normal’ ultrasound. Therefore the results on the utilisation of the three regular ultrasound examinations should be provided separately in advance.

FIGURE 15: ATTITUDES TO ULTRASOUND EXAMINATIONS (ENTRIES IN %)

Are you of the opinion that ultrasound examination during pregnancy...



n = 575; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

Almost all the women have the three ultrasound examinations. 98% of the women who were between the 20th and 40th week of pregnancy at the time of the survey had had the first investigation, 95% had had the second and 58% the third investigation. For a further 40% of the pregnant women the third investigation was still to come.

Ultrasound is a diagnostic method which is widely accepted by the pregnant women. Over 99% of the women surveyed say that 'ultrasound examination is part of medical prenatal care'. 64% believe that ultrasound is important 'in order to get a healthy child'. Only a few believe that this investigation 'is not necessary in a normal pregnancy'.

No doubt the ultrasound examination has become so significant to the pregnant women because they get a first view of their unborn child on the screen. Thus four out of five women consider the ultrasound examination to be important because 'it enables the expectant mother to see her

child'. Almost as many consider the ultrasound important because it enables the father to see the unborn child.

According to the recommendations of the maternity guidelines⁶ three ultrasound examinations are part of normal prenatal care; an assessment which is shared by almost all the pregnant women. These three regular examinations are not included in the following considerations. Ultrasound is only assessed as a definitive prenatal diagnostic procedure if a woman has at least one additional ultrasound examination 'to rule out malformations in the child'.

4.4 PROCEDURES UTILISED

85% of the women who were in the 20th to 40th week of pregnancy and the women who lost their child after the 13th week of pregnancy had already had at least one definitive prenatal diagnostic procedure. The diagnostic method most commonly used is the malformation ultrasound. Over 70% of the women had at least one extra ultrasound examination to rule out malformations in addition to the three ultrasound examinations recommended in the maternity guidelines.

Ultrasound is also used specifically – in the case of the nuchal translucency scan and the first trimester test – to estimate the risks of chromosome aberrations in the unborn child. Thus, on the basis of ultrasound results in combination with the analysis of blood values, and taking the mother's age into account, the first trimester test calculates a statistical risk value (see the description of the individual processes in the appendix).

These diagnostic methods are widespread: over 40% of the pregnant women have the translucency of the unborn child's nuchal fold measured and 29% have the first trimester test.

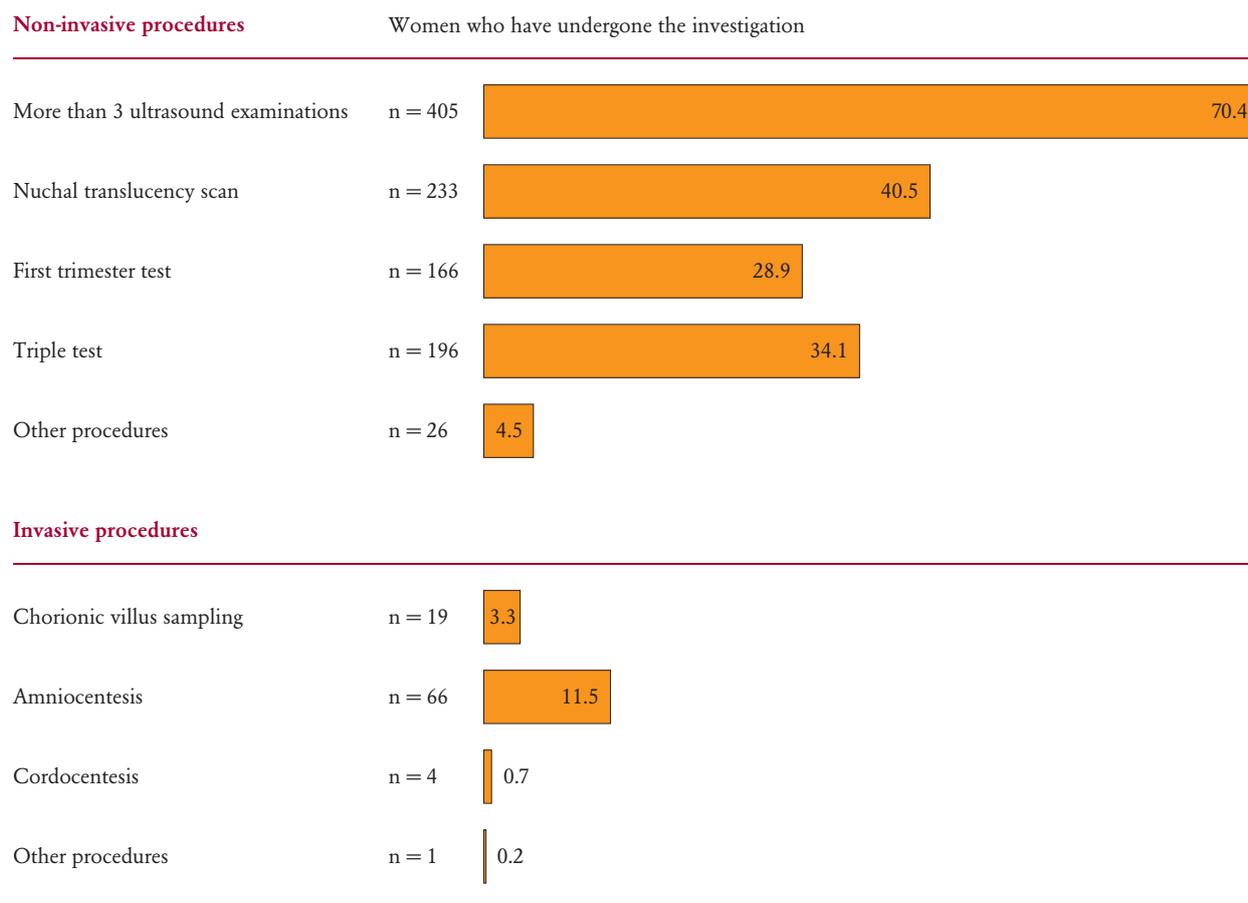
More than a third of the pregnant women state that, to get an estimate of the risk, the doctor has examined various blood values (triple test).

Invasive diagnostic procedures are more rarely utilised: amniotic fluid was taken from 11.5% of the pregnant women, chorionic villous tissue from 3.3%. Four pregnant women had a cordocentesis (umbilical cord puncture).

Only 15% of the women refused prenatal diagnosis altogether.

⁶ Federal committee of doctors and health insurance funds (Germany): version dated 10 December 1985, last amended 24 March 2003

FIGURE 16: UTILISATION OF PRENATAL DIAGNOSIS (ENTRIES IN %)



None n = 88 (15%)

n = 575; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy

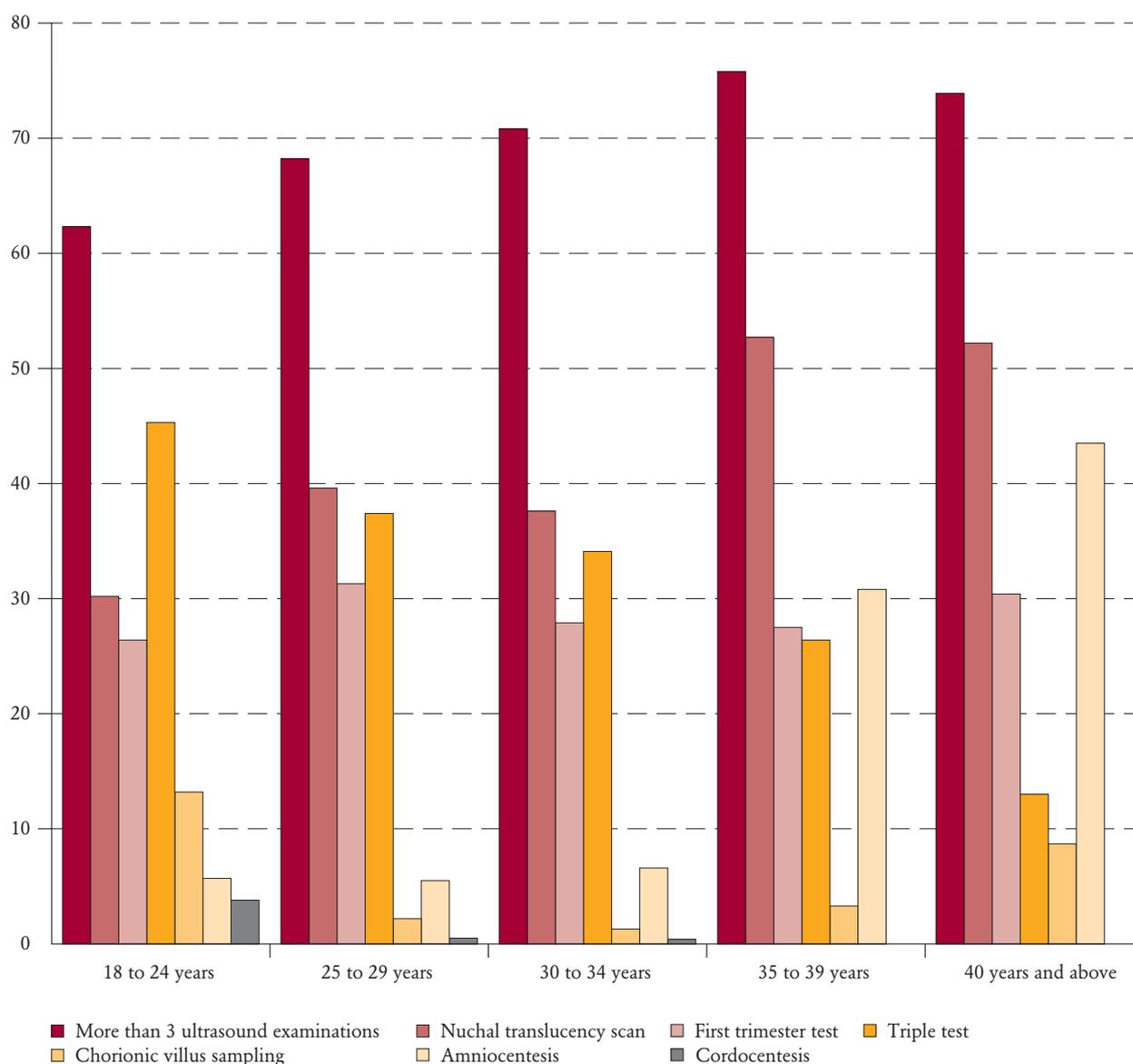
Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

4.5 UTILISATION AND AGE RISK

With the mother's increasing age the statistical risk of a chromosome aberration in the unborn child (e.g. trisomy 21) also increases.⁷ This is why prenatal diagnostic investigation of the unborn child is recommended particularly to women with an increased age risk, that

is women aged 35 and above (maternity guidelines, see footnote 6, page 31). We were interested in finding out to what extent the actual utilisation of PND today is still based on the increased risk due to the woman's age.

FIGURE 17: PRENATAL DIAGNOSIS AND AGE (ENTRIES IN %)



Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

⁷ According to statistics, at the age of 30 one in every thousand women has a child with Down's syndrome, at the age of 35 this increases to three and at the age of 40 to nine in every thousand.

The proportion of pregnant women who had more than three ultrasound examinations, one of which was used specifically to detect diseases and malformations, varies in the different age groups at a very high level between 62 and 76%. However, the malformation ultrasound does not specifically search for chromosome aberrations which occur with increased age.

What is the connection between age and utilisation of procedures which are used specifically for detecting chromosome aberrations?

Detection of chromosome aberrations is by means of invasive procedures (particularly amniocentesis and chorionic villus sampling) and non-invasive procedures (particularly the nuchal translucency scan, the first trimester test and the triple test).

The results of the survey demonstrate clearly that amniocentesis is utilised particularly by women of 35 years and above. Amniotic fluid was only taken from 6% of the under 35s. For women aged 35 to 39 this increased to almost a third of the pregnant women and for those over 39 to 44%. This shows that the mother's age still plays an important role in deciding for or against utilising an invasive investigation method.

It is different with the non-invasive procedures which are used to detect chromosome aberrations. The triple test, for example, is utilised more by younger pregnant women: 45% of the 18 to 24-year-olds stated that they had made use of this examination, but only 26% of the 35 to 39-year-olds and only 13% of the oldest pregnant group did so.

So the age risk no longer determines whether PND is used to detect chromosome aberrations. Pregnant women of all ages are now faced with PND. However, age plays a role in deciding on the prenatal diagnostic procedure: while younger pregnant women prefer a non-invasive investigation, women over 34 often opt for an amniocentesis or chorionic villus sampling.

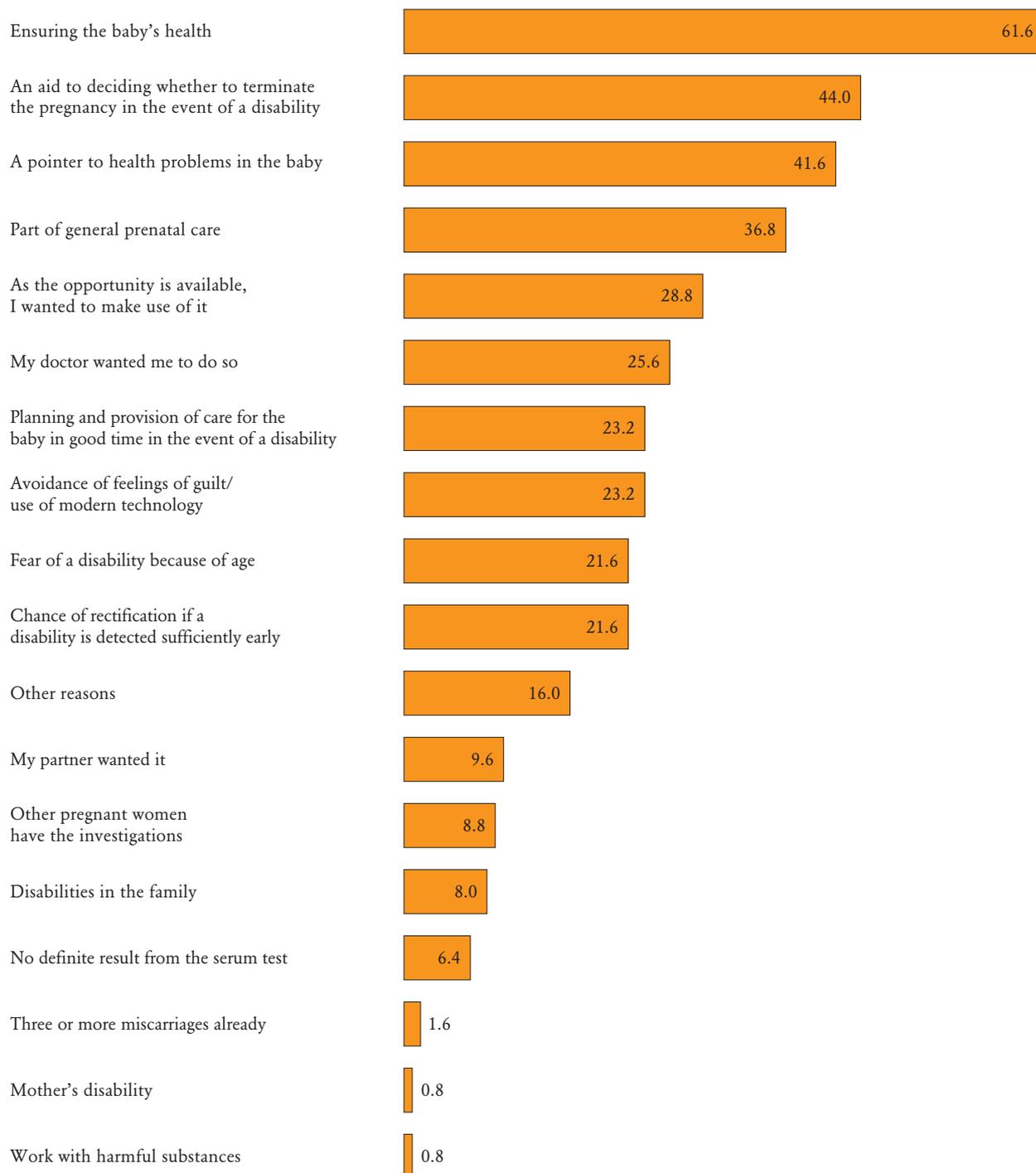
4.6 WOMEN'S REASONS FOR AND AGAINST PND

The hoped for confirmation that the child is healthy is the main reason for the decision to have prenatal diagnostic procedures carried out. Over 60% of the women gave their reason as to 'ensure the health of the baby'.

A quarter of the pregnant women give their reason for taking advantage of prenatal diagnosis as that their doctor wanted them to do so. More than a third assume that PND is part of general prenatal care. These results

are further evidence of the very high acceptance of PND as part of general prenatal care in gynaecological practices.

FIGURE 18: REASONS FOR UTILISING PRENATAL DIAGNOSIS (ENTRIES IN %)



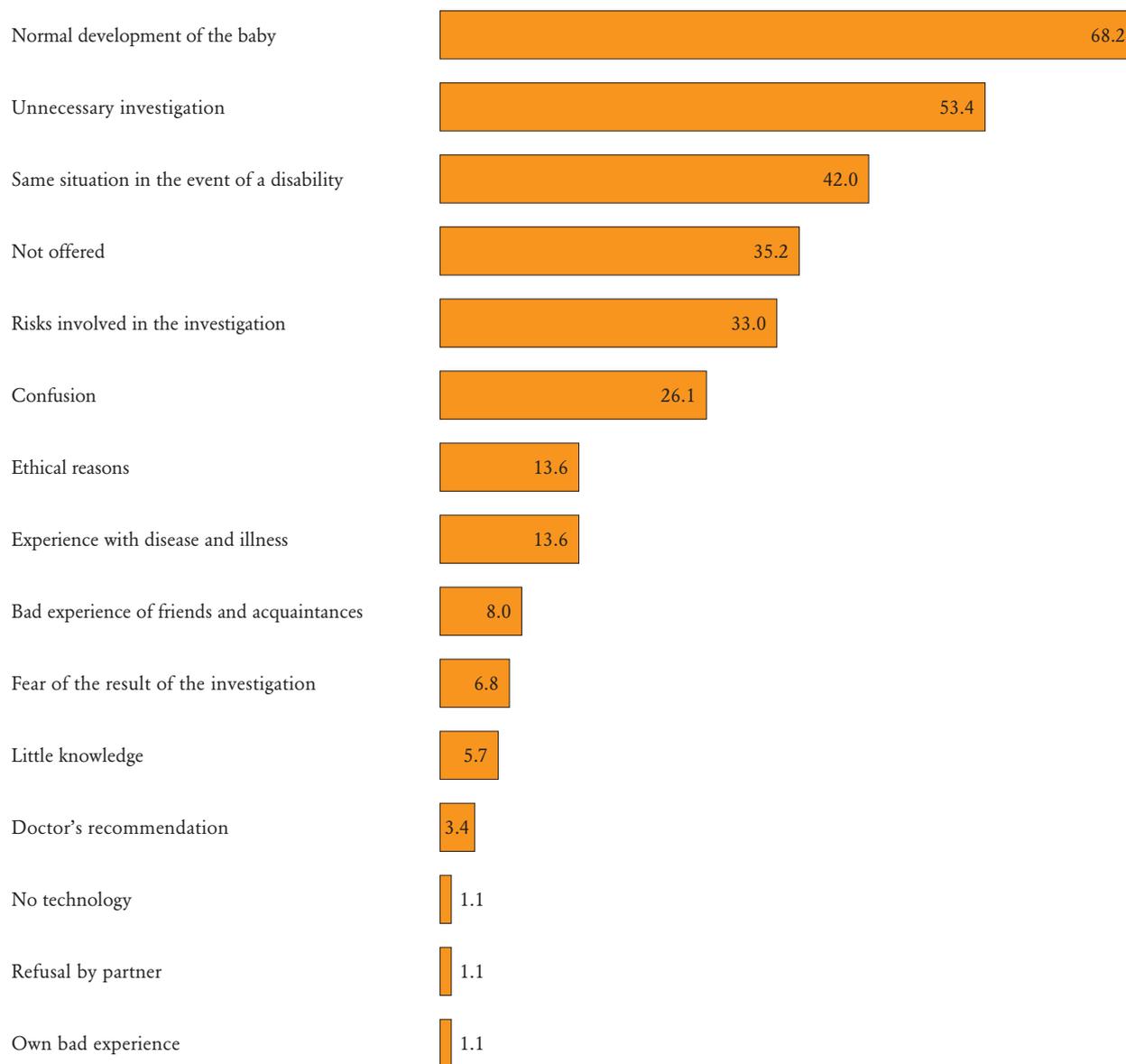
n = 380; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who utilised prenatal diagnosis and replied; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

15% of the pregnant women did not have any PND. The main reasons for this decision were the conviction that the child was developing 'normally', the belief that PND was an 'unnecessary investigation' and that it would not change the situation even if the baby did have a disability. Bad experiences by friends or acquaintances, or fear of the result of the investigation were rarely mentioned. While a quarter of the women who had the PND did so upon the advice of their

gynaecologist, only 3% of the women who refused PND based their decision on a doctor's recommendation. Clearly doctors tend to suggest that their patients make use of PND, irrespective of the age risk.

FIGURE 19: REASONS FOR REFUSING PRENATAL DIAGNOSIS (ENTRIES IN %)



n = 88; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who refused prenatal diagnosis; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

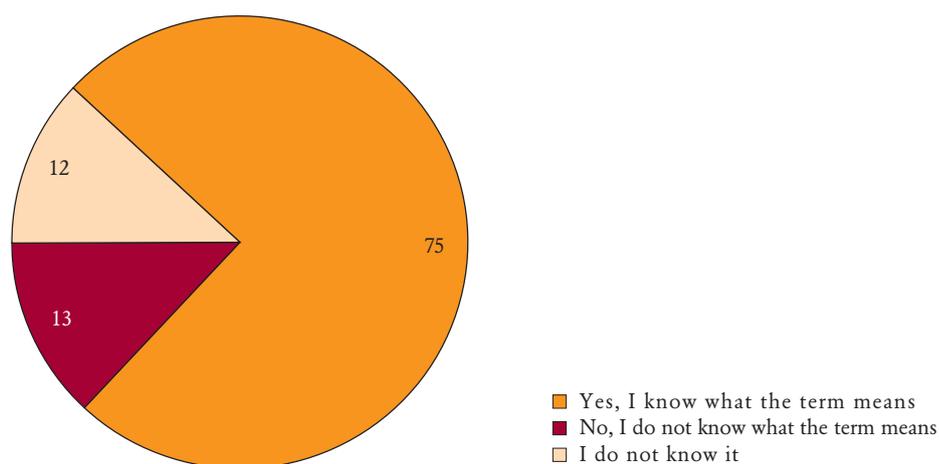
4.7 LEVEL OF INFORMATION OF PREGNANT WOMEN

Since prenatal diagnosis is offered to almost all pregnant women, irrespective of the age risk, the question arises: to what extent do the women understand the significance, purpose, methods and possible consequences of PND? How well are they informed?

One indicator for the level of information is knowledge of the term 'prenatal diagnosis'. The pregnant women

in at least the 20th week of pregnancy and women who have lost their child after the 13th week of pregnancy were asked at the beginning of the interview whether they know what the term 'prenatal diagnosis' means. Three quarters of the women answered this question in the affirmative. 25% said that either they do not know the term or its meaning.

FIGURE 20: KNOWLEDGE OF THE TERM 'PRENATAL DIAGNOSIS' (ENTRIES IN %)



Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

The higher the educational attainment, the greater the proportion of women who answer the question about knowledge in the affirmative: while only 44% of those who had attended a secondary general school claimed to know the term 'prenatal diagnosis', this proportion rose to 70% of the pregnant women who had graduated from intermediate school and 92% of the women with a high school diploma.

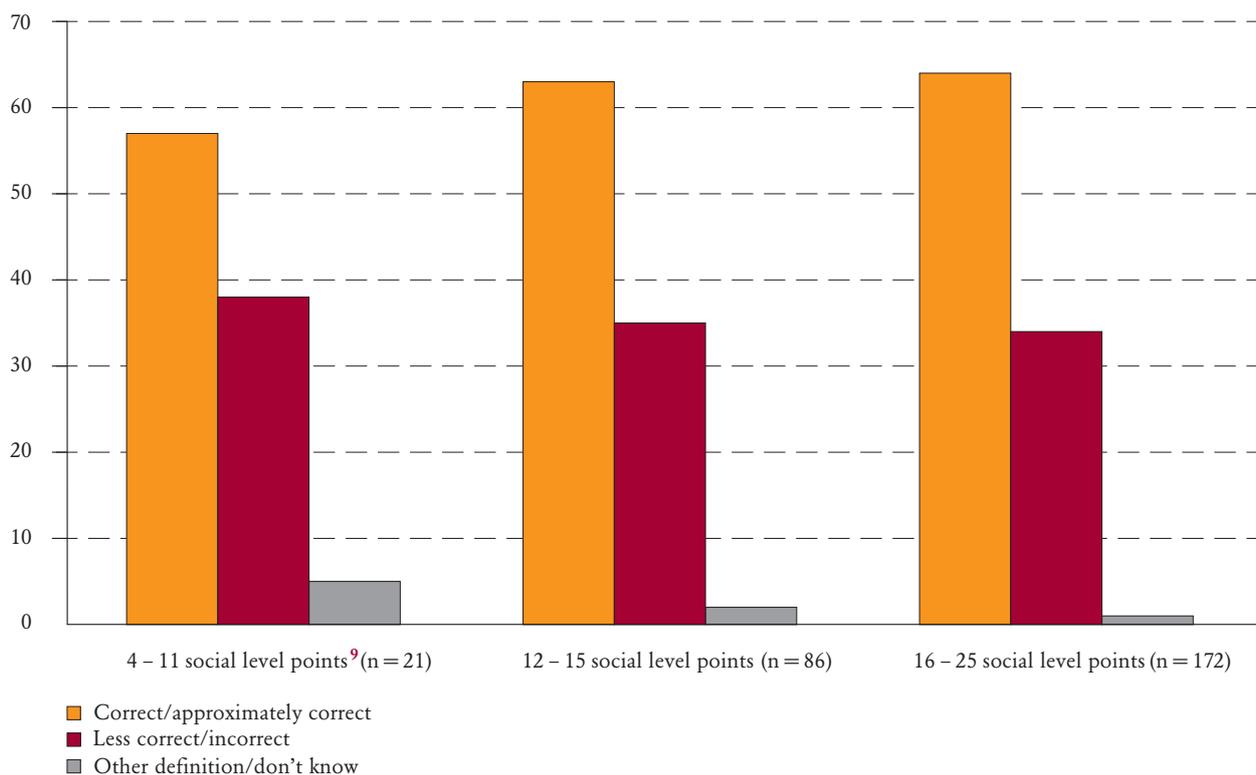
In order to check whether the statements of the pregnant women who say that they know the term are reliable, they were asked to define 'prenatal diagnosis' briefly in their own words. It then became clear that many of the women understand the term to mean something different: of those women who attempted to give a definition, almost 40% either gave an incorrect

definition or replied 'don't know'. 'Prenatal diagnosis' was most commonly confused with general prenatal care in gynaecological practices.

Unlike the claim to know the term, this result was hardly dependent on social position: women with a higher educational attainment and income who think that they understand the term defined it wrongly almost exactly as often as women with a lower educational attainment and lower income.

On the basis of these results we can state that approximately half of the women surveyed between the 20th and 40th week of pregnancy either do not know the term 'prenatal diagnosis' at all or understand it to mean something different.⁸ This is all the more surprising as

⁸ 25% of the pregnant women said that they do not know the term. Of the other 75% about a third understood 'prenatal diagnosis' to mean something different. In all that is about half of the women surveyed. It must be taken into consideration here that the subjects in this study are women who are better educated than the average of pregnant women in Germany. In addition, all the women questioned have a very good knowledge of German. It is therefore assumed that the level of information in the population as a whole is considerably lower.

FIGURE 21: CORRECT OR APPROXIMATELY CORRECT DEFINITION OF THE TERM 'PRENATAL DIAGNOSIS'
(ENTRIES IN %)

n = 279; women in at least the 20th week of pregnancy who have defined the term

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

all the women are between the 20th and 40th week of pregnancy, so are already in an advanced stage of pregnancy and have already had prenatal diagnostic investigations carried out. Although 85% indicated on the questionnaire that they had made use of at least one definitely prenatal diagnostic procedure, about half of the women could not answer the question asked at the beginning about their knowledge of the term or could not answer it correctly.

This means that the utilisation of PND is indeed very widespread among the pregnant women, irrespective of the age risk, but that the overall level of information, measured by the significance placed on PND during pregnancy, is extremely low.

⁹ For decades TNS Healthcare has used the point group procedure for determining the social standing of those surveyed. This is based on the consideration that the social level is influenced by the financial power of a household, the level of education and the work situation. The characteristics of these three attributes are converted into points, which increase with the pronouncement of the attribute. The points total resulting from these three attributes produces the social position of the person surveyed. The frequency distribution of the points totals is subdivided into five categories, so that the class frequencies form a spread with one peak centred on the middle class: the points groups or social strata. The allocation of points values is checked and if necessary corrected every two years on the basis of changing income levels and changes in income distribution.

4.8 REASONS FOR THE LOW LEVEL OF INFORMATION

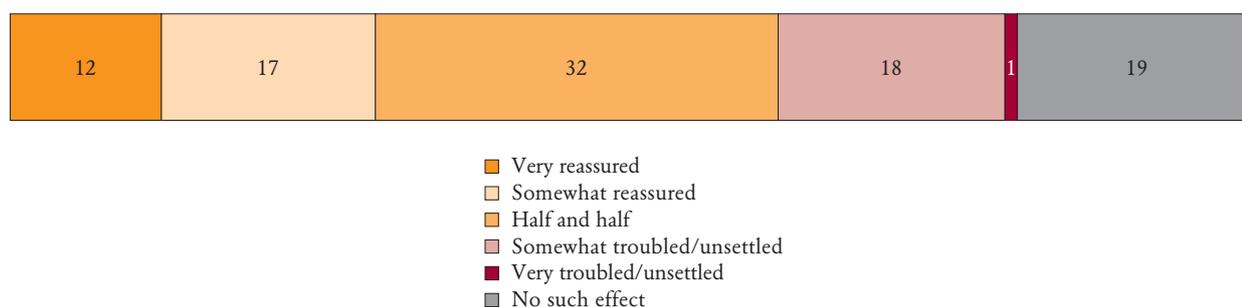
Although the lack of knowledge of the term ‘prenatal diagnosis’ indicates a low level of information overall, only a few of those surveyed say that they need additional information: only 18% of the women replied in the affirmative when asked whether they would have liked to have more information about PND at the start of their pregnancy.

The results suggest that the low level of information is the result of a low level of interest in information. This is also demonstrated by the answers to the general question about the subjects which have particularly interested the women so far in their pregnancy. Most of the pregnant women have been interested in the ‘development of the child in the womb’ (see figure 14). The subjects around PND (‘prenatal diagnosis’, ‘information on malformations’ and ‘transmission of genetic diseases’) are amongst the five subjects which have interested the pregnant women the least, together with ‘sudden infant death’ and ‘premature births and miscarriages’. All these subjects are associated with nega-

tive feelings which means that, possibly ‘for reasons of self-protection’, women do not become especially involved with them during pregnancy. In this case the pregnant woman may also possibly accept her doctor’s advice uncritically so as to avoid having to deal with an unpleasant subject.

The pregnant women are quite ambivalent about information on prenatal diagnosis: a third of the women who stated that they were informed about PND before or during their pregnancy felt ‘reassured’ as a result of obtaining the information. They were reassured because in their view PND can confirm the health of their unborn child or diagnose any illnesses or malformations. However, after receiving the information almost 20% of the women felt rather troubled or unsettled. They were worried about making a decision in the event of a disability, about the accuracy of the result or about the risk of a miscarriage following amniotic fluid investigations.

FIGURE 22: EFFECT OF INFORMATION ON PRENATAL DIAGNOSIS (ENTRIES IN %)



PARTICULARLY REASSURED (N = 61)

Confirmation of the child’s health
 Diagnosis of disease/malformation
 Possibility of treatment in the event of illness/malformation

PARTICULARLY TROUBLED (N = 54)

Decision in the event of a disability
 Not a 100% result/no certainty
 Risk of miscarriage following amniotic fluid investigation

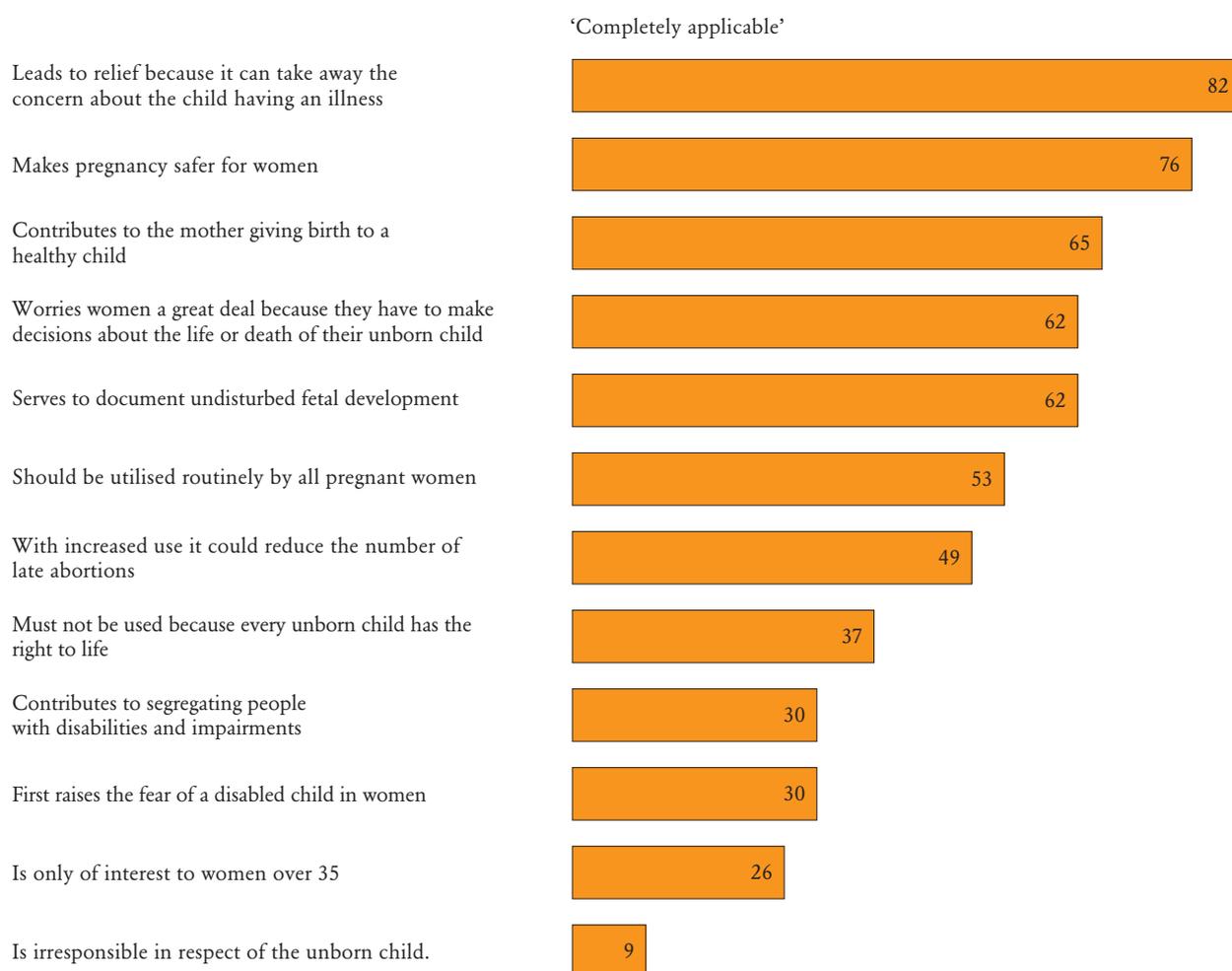
n = 359; women who have been informed during their pregnancy

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

The notion that information on PND can trigger ambivalent feelings is also confirmed by the agreement about various, partly contradictory statements on prenatal investigations: 82% of the pregnant women and women who have lost their child after the 13th week of pregnancy state that prenatal diagnosis brings relief ‘because it can take away the concern about the child having an illness’. The agreement on this statement illustrates a fundamentally positive effect of PND on the experience of pregnancy. On the other hand 62% of the women (also) agree with the statement that PND worries women a great deal ‘because they have to make

decisions on the life or death of their unborn child’. Therefore many pregnant women feel both relieved and worried in connection with prenatal investigations; relieved by the prospect of confirmation of the health of their unborn child, but worried about the risk of discovering an impairment.

FIGURE 23: VIEWS ON PRENATAL DIAGNOSIS (ENTRIES IN %)



n = 575; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy; multiple responses possible

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

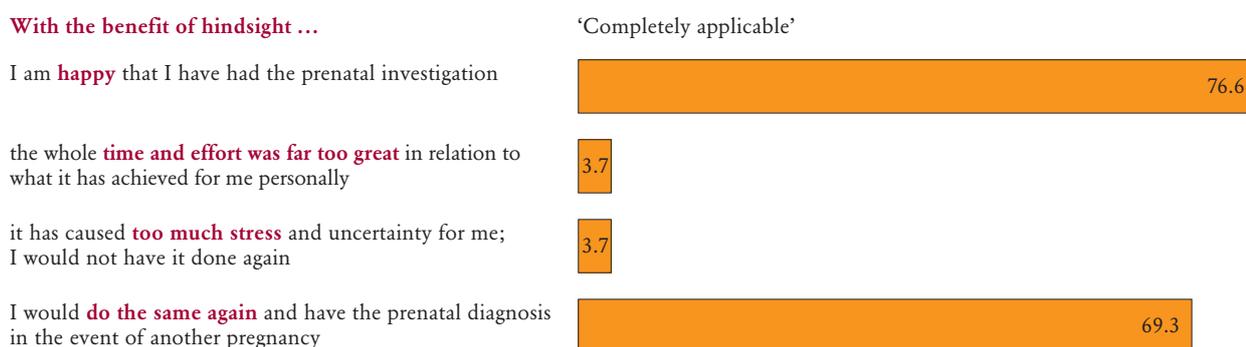
4.9 SATISFACTION WITH PND

Information on PND (also) provokes unpleasant feelings; accordingly, pregnant women rarely wish to inform themselves about the subject and are likely to have a low level of information.

Nevertheless, women are extremely positive in their assessment of PND afterwards: 77% of those surveyed who have already had an investigation say ‘with the benefit of hindsight, I am happy that I have had the

prenatal investigation’. 69% (also) fully agree that they would do the same again in the event of another pregnancy. Only a small minority, about 4% of the pregnant women in each case, find that the ‘whole time and effort was far too great in relation to what it has achieved’ or that it caused ‘too much stress and uncertainty’.

FIGURE 24: STATEMENTS IN RELATION TO PRENATAL DIAGNOSIS (ENTRIES IN %)



n = 487; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who had prenatal diagnosis

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

The fact that, with the benefit of hindsight, most of the pregnant women are happy to have had the investigation is no doubt (also) because the vast majority of

them did not receive any results suggesting a possible disability or illness and were able to assume that the child was healthy.

4.10 ATTITUDES TO LIVING WITH A DISABLED CHILD

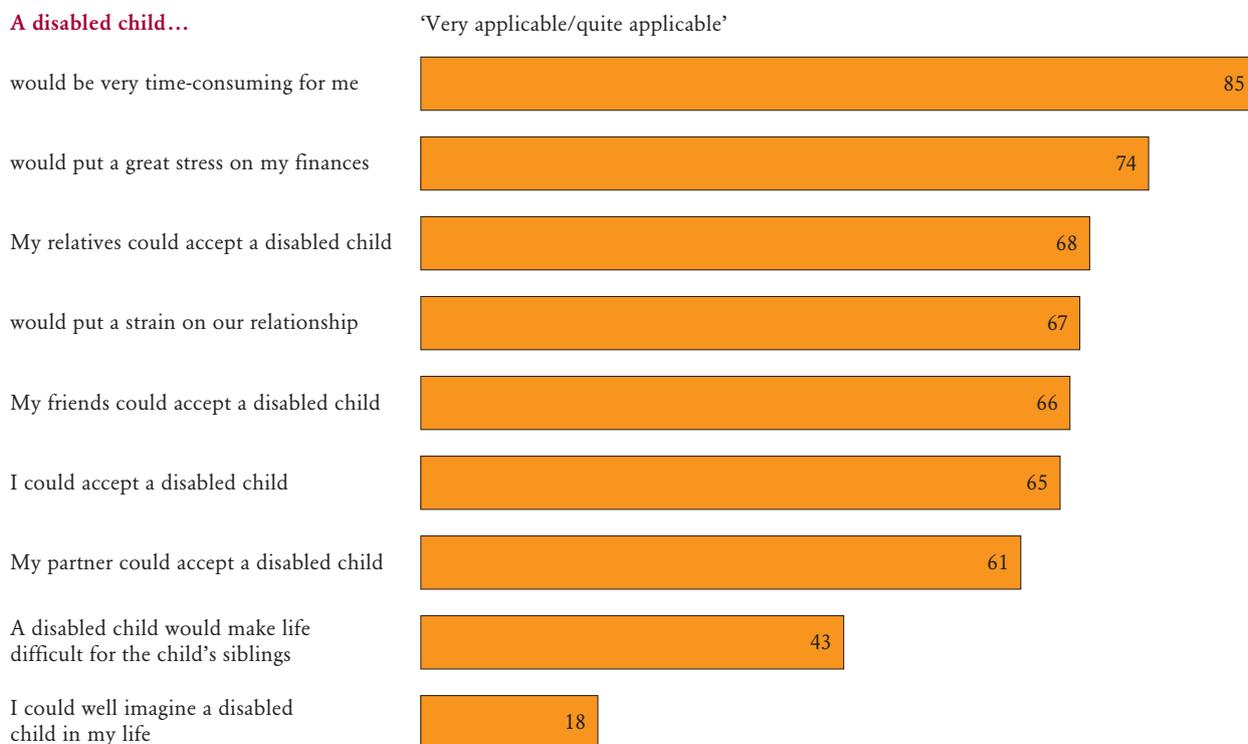
PND has such a high level of acceptance in particular because the fear of the child possibly having a disability is very pronounced amongst pregnant women. Over half of the women agree with the statement ‘I am afraid that my child could be disabled. Only 12% say that they do not have any fears or anxieties about the health of their child. The women see PND as an opportunity to contain these fears so as to go through their pregnancy with less stress and worries.

The fact that a possible disability in the unborn child causes anxiety and that a child with a disability in one’s own family is difficult to imagine is also demonstra-

ted by the responses to various questions about attitudes. About two thirds of the pregnant women state that they would accept a disabled child, or to put it another way, one in three women could not accept a disability in their child.

This is a very high proportion when it is considered that acceptance of the child, even if it has a disability, is the socially expected response. Only 18% of the women could well imagine having a disabled child in their life.

FIGURE 25: ATTITUDE TO LIVING WITH A DISABLED CHILD (ENTRIES IN %)



n = 575; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy; multiple responses possible

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

5 RESULTS IN DETAIL: ASSESSMENT OF GYNAECOLOGICAL ADVICE AND TREATMENT

Most pregnant women have their prenatal care carried out by a registered gynaecologist (93%). Only a very few look go to a midwifery practice or get a midwife

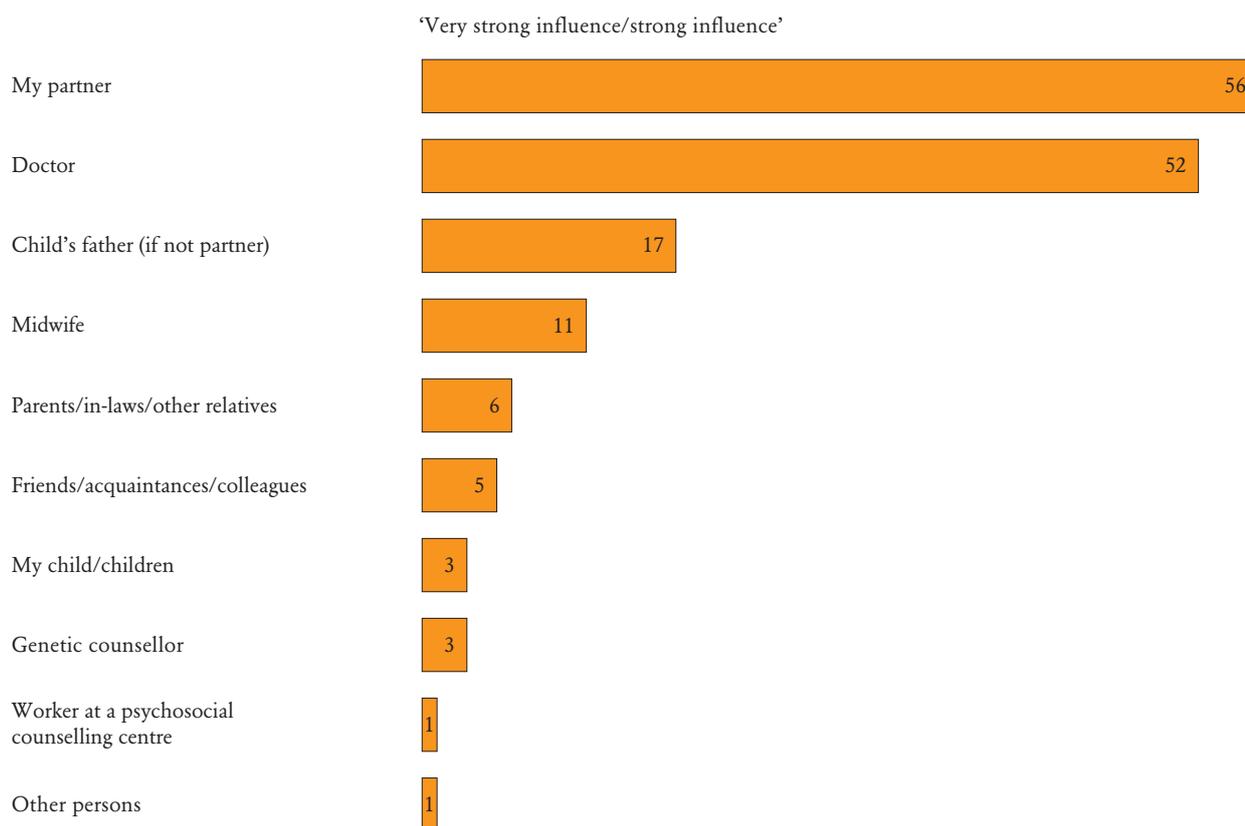
to provide care at home. The doctor thus has a particularly great influence on the decision as to whether women utilise a prenatal diagnostic procedure or not.

5.1 INFLUENCE ON THE DECISION FOR PND

Over half of the pregnant women say that their doctor had a 'very strong' or 'strong' influence on their decision to have PND. Thus the gynaecologists exert a similar influence to that of the partners of the pregnant women when it comes to deciding for or against PND.

In fact a quarter of the pregnant women only decide on PND 'because my doctor wanted it' (see above). Friends and relatives and employees at psychosocial counselling centres have hardly any influence here.

FIGURE 26: PERSONS WITH INFLUENCE ON THE DECISION FOR OR AGAINST PRENATAL DIAGNOSIS (ENTRIES IN %)



n = 575; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

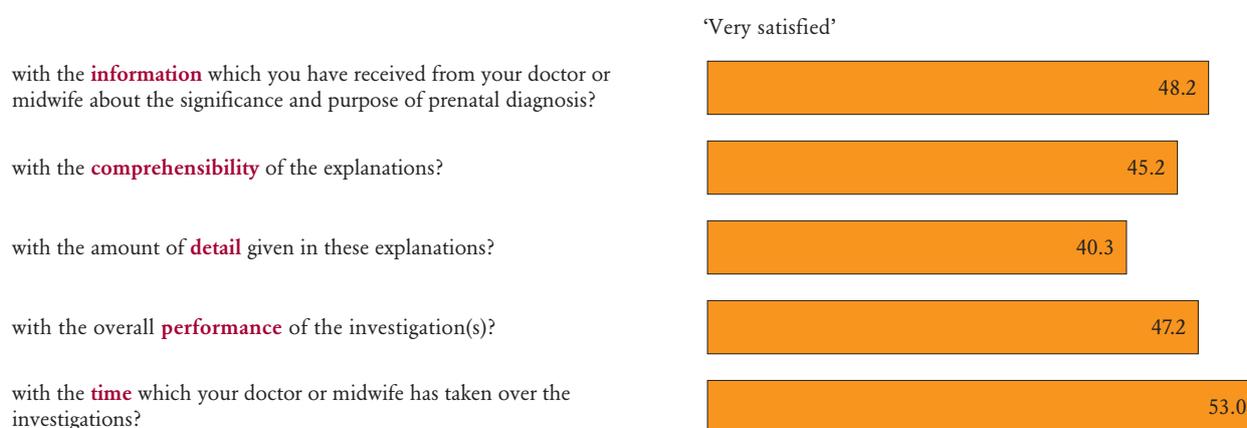
5.2 OVERALL SATISFACTION

Almost 98% of the pregnant women said ‘I feel that I am in good hands with the doctors and midwives’. 14% supported this statement completely, a further 27% predominantly.

Overall the women were satisfied with various aspects of the prenatal diagnostic treatment which they received in the gynaecological practice. About half the pregnant women chose the highest values on a five value scale for each of the factors. 48.2% of the pregnant women were ‘very satisfied’ with the information which

they received from their doctor or (in a few cases) from their midwife about the significance and purpose of PND. 45% were (also) ‘very satisfied’ with the comprehensibility of the explanations and 40% with the amount of detail provided. An even higher proportion of women expressed great satisfaction with the way the investigations were carried out as well as the time which the doctor or midwife had taken. Very few women were ‘dissatisfied’ with the various aspects of the treatment.

FIGURE 27: HOW SATISFIED ARE YOU ... (ENTRIES IN %)



n = 395; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who have received information from their doctor or midwife on further investigations

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

5.3 SATISFACTION IN DETAIL

We were also particularly interested in the assessment of various aspects of the provision of information in gynaecological practices. What are the strengths and weaknesses of medical advice about PND?

The women who had had PND were asked about the amount of detail and comprehensibility of the medical advice which they were given by the gynaecologist

before the diagnostic investigations. The questions were based on the content of the advice as recommended in the maternity guidelines, for example clarification of the ‘reason for the investigation’ or the ‘aim of the investigation’. The pregnant women’s replies related to non-invasive and invasive investigation methods, with the two types of investigation methods being evaluated separately.

ADVICE BEFORE CARRYING OUT A NON-INVASIVE INVESTIGATION:

By their own estimation pregnant women were given detailed advice about the reason for and aim of the investigations before a non-invasive procedure was carried out, 46% and 51% respectively saying that they had been given detailed or very detailed information on these aspects.

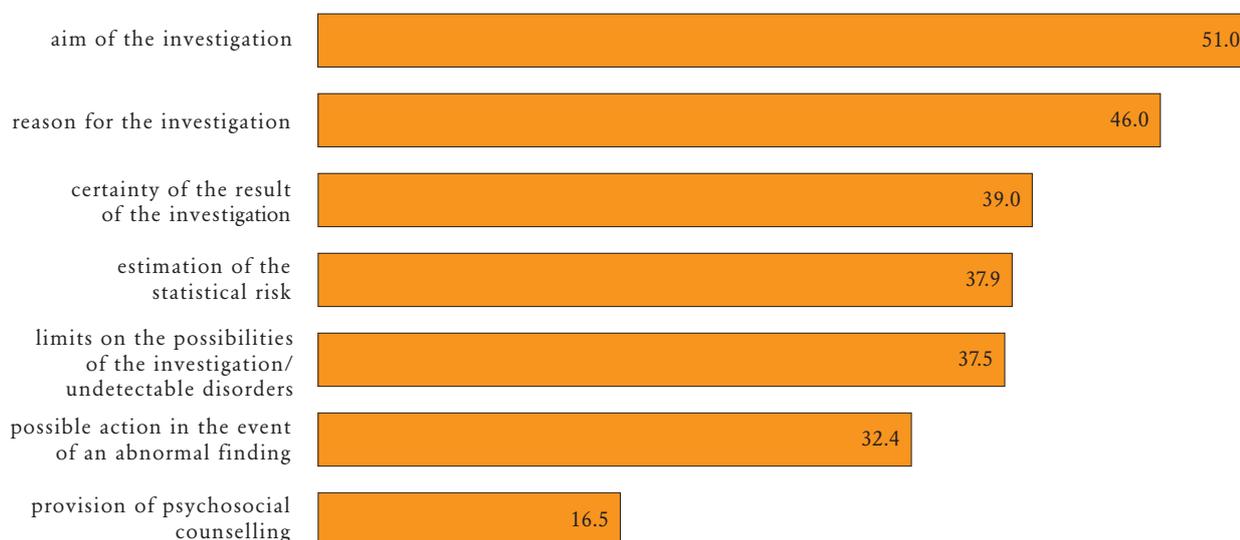
Less detail was given in the medical information about the estimation of the statistical risk, the limits on the possibilities of prenatal investigations and the certainty of the result of the investigation. In each case almost

a third said that they had been informed only 'a little' or 'not at all'.

Even less detail was provided by the advice on subjects which do not primarily come under the medical area of responsibility, but which can be very significant when women are pregnant: 43% received no information at all or not very detailed information about possible action in the event of an abnormal result. And more than half were 'not at all' informed about the possibility of further psychosocial counselling.

FIGURE 28: **ADVICE BEFORE CARRYING OUT PND – NON-INVASIVE INVESTIGATION** (ENTRIES IN %)

I have been given detailed information on the subjects ...



n = 487; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who had prenatal diagnosis; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

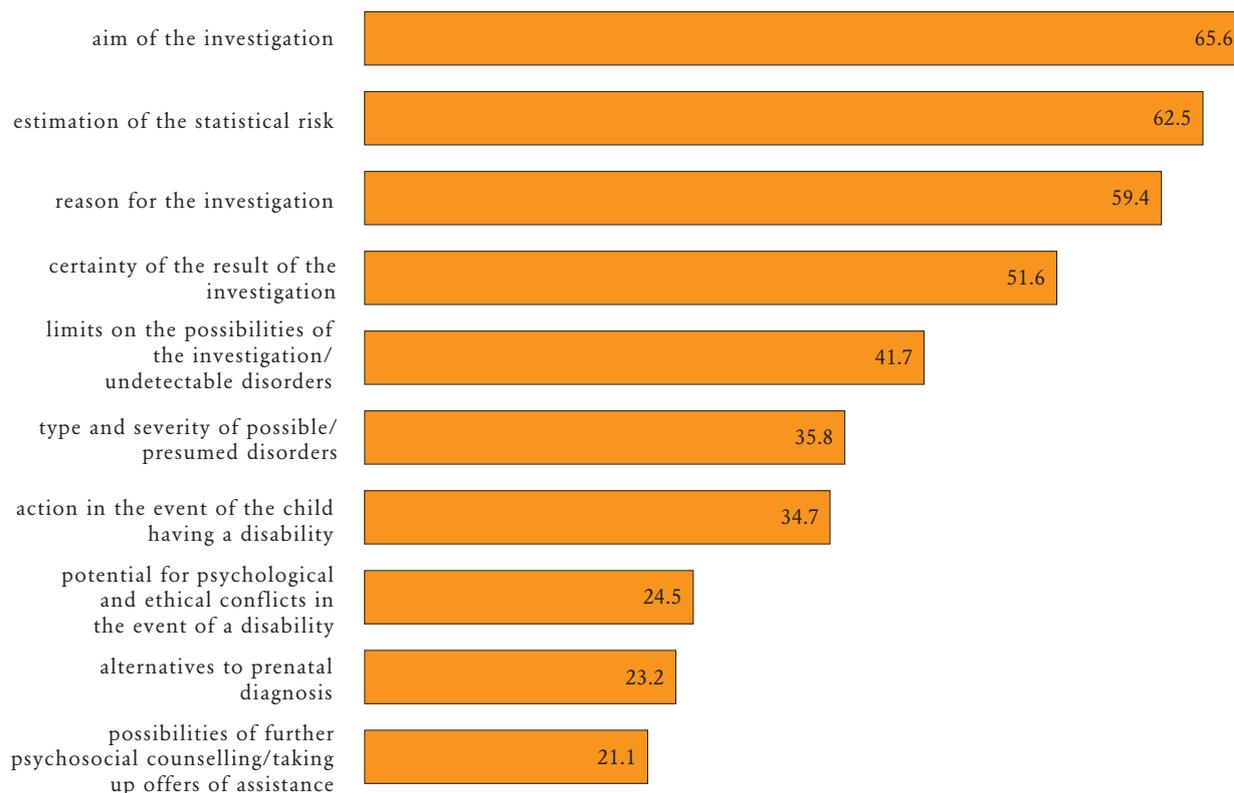
ADVICE BEFORE CARRYING OUT AN INVASIVE INVESTIGATION:

A similar picture is seen for the advice provided before making use of invasive diagnostic procedures. Doctors provided detailed information on the reason for the investigation, the aim, the risk and the certainty of the result. On the other hand, a high proportion of the pregnant women received no information or very little information about the potential for psychological and

ethical conflicts in the event of the child having a disability (37% none at all) or about alternatives to prenatal diagnosis. And of the pregnant women who had an invasive investigation about half were ‘not given any’ information about the possibility of making use of further psychosocial counselling.

FIGURE 29: **ADVICE BEFORE CARRYING OUT PND – INVASIVE INVESTIGATION** (ENTRIES IN %)

I have been given detailed information on the subjects ...



n = 487; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who had prenatal diagnosis; multiple responses possible

Source: BZgA, data record ‘Experience of pregnancy and prenatal diagnosis’, 2006

NOTIFICATION OF THE FINDING

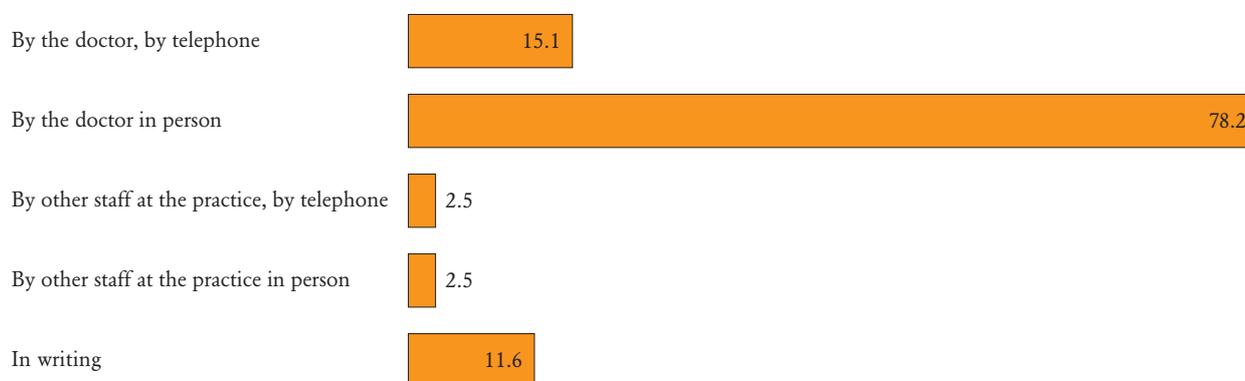
Four out of five women who took up the offer of PND gave their consent to it. 7% stated that they had not given their consent and 9% of the pregnant women could not remember at the time of the interview.

The pregnant women who had already had at least one definitively prenatal diagnostic procedure were asked how they were informed of the result. The majority of the women said that their doctor had informed them in person of the finding (78%). 15% of the pregnant women were informed by telephone and 12% in

writing. Only 5% of the women did not receive the result from the gynaecologist, but from other staff at the practice. Multiple responses were possible here; in some cases a result was given in writing as well as verbally.

All in all, the women have great trust in their doctor's prenatal diagnostic expertise: over 60% stated that their trust in the correctness of the medical diagnosis was 'very great'. A further 40% reported 'fairly great trust'. Only 1% were sceptical.

FIGURE 30: HOW WERE YOU INFORMED OF THE RESULT? (ENTRIES IN %)



n = 487; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy who had prenatal diagnosis; 83% of the pregnant women replied; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

Almost 95% of the women who had PND and filled in the questionnaire received a finding of 'normal' or 'no abnormalities'. For slightly more than 5% of the pregnant women the finding was 'abnormal' or 'pathological'. The working diagnosis was predominantly

given in the 17th and 22nd week of pregnancy, times at which the results of the amniotic fluid investigation are available or the precision ultrasound is carried out.

FIGURE 31: WHAT WAS THE RESULT OF THE PRENATAL DIAGNOSIS? (ENTRIES IN %)



n = 474; women in at least the 20th week of pregnancy who had prenatal diagnosis; excluding n = 138 women who have already given birth

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

EXPLANATION AND ADVICE IN THE EVENT OF AN ABNORMAL FINDING

After notification of the result of the PND the doctor is the first contact for the pregnant women. The 27 women (5%) with an abnormal 'pathological' finding were asked for an assessment of the medical advice on various subjects regarding their situation. The women had very mixed opinions about the advice from their doctor.¹⁰

The advice on the type and possible causes of the developmental disorder or predisposition to an illness was assessed as very good: 70% of the women gave a positive response. The women were also satisfied with the medical information on continuing the pregnancy or the possibility of a termination and with information on the options for medical treatment.

On the other hand they found the advice regarding the consequences for themselves and their families predominantly 'poor' (16%) or 'quite poor' (36%). The assessment of the advice on the possibility of preparing for life with a disabled or impaired child was even more negative: 71% assessed it as poor.

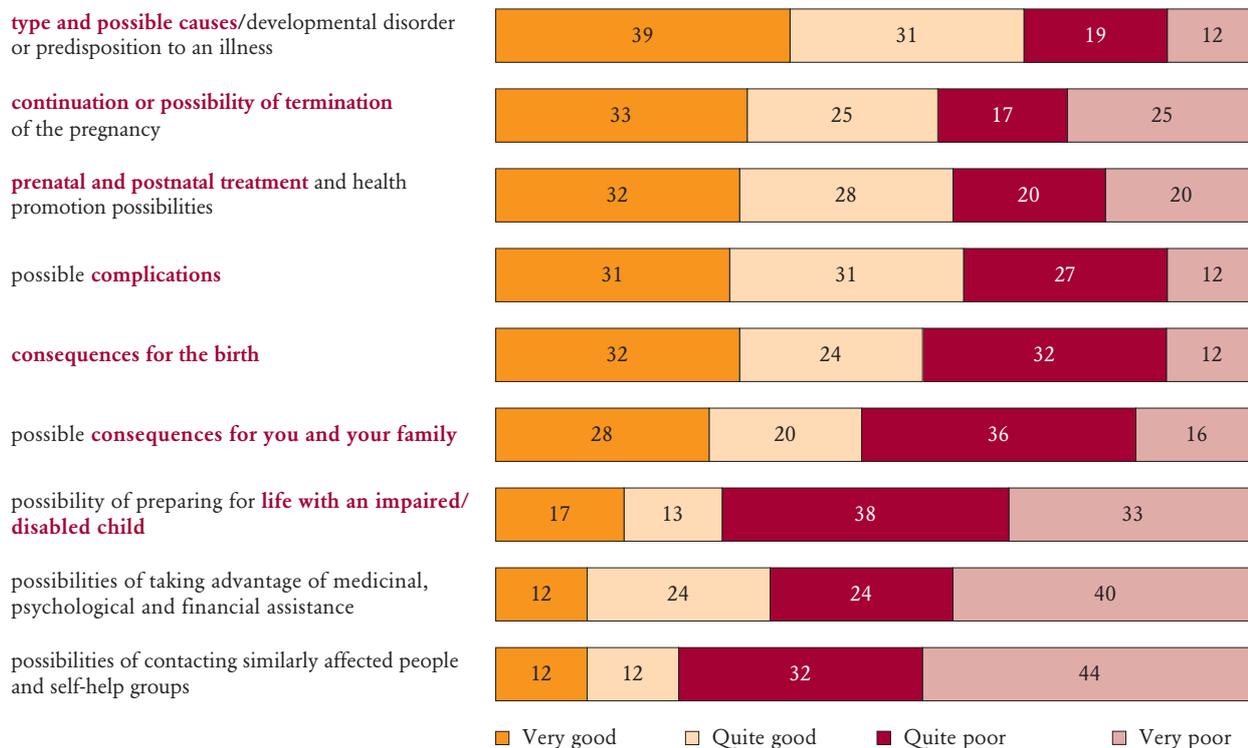
The women surveyed were almost unreservedly dissatisfied with the advice on obtaining further assistance and arranging contacts with similarly affected people and self-help groups: 40% and 44% respectively chose the attribute 'very poor'.

Here too the majority of the women were satisfied with the advice on subjects of a definitively medical nature. There are deficits from the viewpoint of women who had an abnormal prenatal diagnostic finding, here again in terms of advice on subjects going beyond purely medical matters and in the arrangement of further assistance.

¹⁰ As only 27 women received an abnormal prenatal diagnostic finding, the results can only be taken as indications.

FIGURE 32: **ASSESSMENT OF THE ADVICE FOLLOWING AN ABNORMAL OR PATHOLOGICAL RESULT**
(ENTRIES IN %)

Advice on ...



n = 27; women in at least the 20th week of pregnancy and women whose pregnancy ended after the 13th week of pregnancy with an abnormal or pathological result; multiple responses possible

Source: BZgA, data record 'Experience of pregnancy and prenatal diagnosis', 2006

Only about a third of the women sought out a further counselling centre after receiving the prenatal diagnostic finding. Seven out of the eight women went to a human

genetics counselling centre and one woman underwent counselling in the social welfare division of the evangelical church.

6 OUTLOOK

The results of this investigation show a high requirement for qualified and comprehensive advice. Since prenatal diagnostic investigations now appear to be an integral part of prenatal care, information on this subject is all the more important. Pregnant women often do not know exactly what is meant by the term ‘prenatal diagnosis’, and yet they largely make use of the procedures as a matter of course. This represents an information deficit which goes against the image of the responsible patient: women should be able to make informed decisions.

Other investigations associated with prenatal diagnosis confirm the insufficient level of information of pregnant women. For example, evaluation of the BZgA leaflet ‘Prenatal diagnosis’ showed that for the most part pregnant women do not know that there are counselling centres covering ‘prenatal diagnosis’, and they are quite unaware that they have a legal right to advice.¹¹

Doctors – generally the first contact in the event of a pregnancy – clearly do not regularly point out the possibility of psychosocial counselling. Particularly if an abnormal or positive finding is obtained, the women feel psychologically overstretched: yes, the medical possibilities have been explained to them, but they are left alone to come to a decision. ‘With the extension of prenatal diagnosis to a screening procedure during pregnancy, the terms of reference for advice have clearly increased. But the possibilities of early recognition of malformations and delays in development, and the early suspicion of a disability in the unborn child mean that the conflict situation for the pregnant woman and her partner has also intensified.’¹²

Both professional groups – medical personnel and psychosocial counselling – feel responsible for advice, but at the same time there are competitive fears which prevent a culture of referral.¹³ These and other results show amongst other things that the communication structures between the two advisory occupational groups are not yet very robust.

With the aim of producing an effective improvement in the quality of advice for pregnant women, the promotion of collaboration between medicine and psychosocial counselling has now been made a key area for the BZgA. Thus the pilot scheme ‘Quality circle in prenatal diagnosis’ has been installed. In this the specialists from medicine and counselling attempt to work together more constructively, to inform themselves about the work of the other occupational group, to go beyond professional barriers, to recognise their own limitations and to make use of the expertise of the other occupational group. The ‘interprofessional quality circles’ continue to be run independently.

With the same aim, optimisation of the advisory network and the quality of advice for pregnant women, comprehensive materials are currently being produced by the BZgA for doctors and psychosocial counselling specialists.

Prenatal diagnosis will also be an important header in the advisory channel of the BZgA portal www.schwanger-info.de, thereby publicising the legal entitlement to psychosocial counselling for pregnant women and promoting uptake of the service.

The medical and psychosocial areas of prenatal care should be encouraged by these measures to move closer together and to cover pregnant women’s needs for advice with varying emphases. This can be achieved most effectively by close collaboration, meaning that, in addition to the quality circle work, further case-related forms of collaboration must be developed.

¹¹ BZgA (2006): ‘Prenatal diagnosis – advice, methods and assistance’, evaluation of a leaflet

¹² Cierpka et al. (2001): Psychosocial advice in prenatal diagnosis – a practice handbook, Hogrefe

¹³ Ibid.

7 APPENDIX

7.1 PRENATAL DIAGNOSTIC PROCEDURES

ULTRASOUND INVESTIGATIONS

How?	Why?	When?
<ul style="list-style-type: none"> • The sound waves emitted by a transducer are reflected back and converted into a picture on the monitor. • Ultrasound via the abdominal wall: the transducer is placed on the abdominal wall. • Vaginal ultrasound: the rod-shaped transducer is introduced into the vagina. 	<p>Part of general prenatal care:</p> <ul style="list-style-type: none"> • to establish a pregnancy and determine the stage of pregnancy • to rule out an abdominal or tubal pregnancy • to recognise multiple pregnancies • to check fetal growth • to check fetal cardiac activity • to check development of the placenta and the unborn child • to determine the position and measure the blood supply to the placenta and the unborn child, e.g. to investigate premature induction of labour if the supply is defective <p>but also when looking for malformations:</p> <ul style="list-style-type: none"> • for preparing/monitoring amniotic fluid tests and chorionic villus sampling • for the so-called nuchal translucency scan 	<ul style="list-style-type: none"> • Ultrasound investigations via the abdominal wall are possible throughout the pregnancy • Vaginal ultrasound in the first trimester • According to the maternity card three ultrasound investigation are designated: <ul style="list-style-type: none"> 9–12th week 19–22nd week 29–32nd week
<ul style="list-style-type: none"> • Doppler ultrasound Special ultrasound via the abdominal wall 	<ul style="list-style-type: none"> • for measuring the perfusion in the umbilical cord and important blood vessels of the unborn child 	<ul style="list-style-type: none"> • normally after the 20th week of pregnancy

WHAT DO I LEARN?

- how far the pregnancy is advanced
- how the growth of the unborn child is progressing
- the position of the child and the placenta for planning the birth
- information on the development and function of the organs, e.g. a normally filled bladder confirms renal activity
- information on the body shape of the unborn child: limbs, vertebral column, head, trunk. Neural tube defects (so-called open back) can thus be seen.
- the so-called nuchal fold thickness in the unborn child as an indicator, for example of Down's syndrome

WHAT MUST BE OBSERVED?

- If there are abnormalities in an ultrasound investigation, women are unsettled even if the suspicions are not confirmed.
- Ultrasound results alone are often not sufficient; abnormalities lead to further investigations: first trimester test, amniotic fluid test or chorionic villus sampling.
- Incorrect interpretations are possible, depending on the equipment used and the experience of the user.
- The image on the monitor can displace one's own feelings and experience.
- The expected date of delivery can only be determined relatively reliably in the first 12 weeks.
- More precise investigations of the organs are generally not possible until after the 19th week.
- If the ultrasound investigation indicates a possible disability, in most cases there is no treatment; the question of a possible termination may arise.

- whether the child has an optimum supply of nutrients and oxygen, which can provide information about the development of the heart

- Doppler ultrasound utilised ten times the amount of energy as normal ultrasound and should not be used in the early stages of pregnancy.

PROCEDURES FOR ASSESSING THE RISK	How?	Why?	When?
	<p>Nuchal translucency scan</p> <ul style="list-style-type: none"> The unborn child's so-called nuchal fold is measured with ultrasound. If a certain value is reached, the patient is referred to specialists who calculate a statistical risk value with the help of a computer program. The woman's age, the exact gestation period and the size of the unborn child are also taken into account. <p>First trimester test</p> <ul style="list-style-type: none"> Blood is taken from the woman and the hormone and protein levels are determined (hCG; PAPP-A). To produce the statistical risk value by means of a computer program, the so-called nuchal fold measurement and the woman's age are added. <p>Triple test</p> <ul style="list-style-type: none"> Blood is taken from the woman; hormone levels (hCG; oestriol) and the alpha-fetoprotein (AFP) are determined. Using these values, the exact gestation period and the woman's age and weight, the risk is estimated. 	<ul style="list-style-type: none"> All the tests are carried out as a basis for deciding on further investigations, such as amniotic fluid testing or chorionic villus sampling in addition to the statistical risk estimation for possible Down's syndrome or another chromosome aberration, it is also used to look for neural tube defects (e.g. open back) in the unborn child 	<ul style="list-style-type: none"> 12–14th week 11–13th week 16–18th week. The results are available within a week

WHAT DO I LEARN?

- A statistical risk estimation for possible Down's syndrome, another chromosome aberration or a heart defect
- The first trimester test produces more precise results than the triple test
- A high AFP value can indicate a neural tube defect (so-called open back) in the unborn child.

WHAT MUST BE OBSERVED?

- A statistical risk estimation does not provide any information about the actual situation; it is a calculation of probabilities.
- Abnormal values unsettle women.
- Abnormal values lead to further investigations, e.g. the amniotic fluid test, which are associated with greater risks; it is only in this way that more precise information can be obtained.
- A suspected finding often proves to be incorrect.
- Inaccurate, incorrect application and evaluation (e.g. when the time of conception is not clear; in the case of twins) lead to false 'abnormal' values.
- The findings are dependent on the computer program used, the type/duration of implementation and the experience of the user.

These risk estimation procedures are offered as individual health provisions (IGeL) and must be paid for separately.

The health insurance fund only pays for services which are medically necessary and appropriate, e.g. the follow-up investigation if a regular screening investigation produces an abnormal finding.

	How?	Why?	When?
CHORIONIC VILLUS SAMPLING	<ul style="list-style-type: none"> • Puncture of the developing placenta with a hollow needle, usually through the woman's abdominal wall. • Chorionic villous tissue (from which the placenta is formed later) is removed. • The cells obtained are examined in the laboratory for their chromosome set (immediately and after cultivation of cells), possibly DNA analysis. 	<ul style="list-style-type: none"> • to look for a chromosomal anomaly in the unborn child • if a metabolic illness is suspected • after an abnormal ultrasound result • to look for a hereditary illness/disability as part of genetic counselling 	<ul style="list-style-type: none"> • 10–12th week; the results are available after 1–8 days or after about 2 weeks in the case of a long-term culture
AMNIOTIC FLUID TEST	<ul style="list-style-type: none"> • Puncture of the amniotic sac with a hollow needle through the woman's abdominal wall. Approx. 15–20 ml of amniotic fluid with the detached cells of the unborn child is removed. • The living cells are cultivated until the cells divide, and the number and structure of the cells is investigated. • Further investigations are possible: DNA analysis, determining the AFP. 	<ul style="list-style-type: none"> • to look for chromosomal aberrations in the unborn child • in the event of abnormalities in the ultrasound, including the nuchal translucency, first trimester or triple test • in the event of previous miscarriages with a suspected chromosomal anomaly • in the event of neural tube defects or a chromosomal anomaly in the premature child • to look for diagnosable hereditary diseases as part of genetic counselling • in the event of high antibody values in Rh negative women 	<ul style="list-style-type: none"> • 14–20th week; the results are available after 2 weeks. • Using the so-called quick test, information on the number of chromosomes 13, 18, 21 and the sex chromosomes can be given after one day. These results should always be checked.
UMBILICAL CORD PUNCTURE	<ul style="list-style-type: none"> • Puncture through the woman's abdominal wall. • Fetal blood is taken from the umbilical cord. • The unborn child's blood is examined. 	<ul style="list-style-type: none"> • if an infection of the unborn child is suspected, e.g. with German measles • to look for a diagnosable hereditary disease in genetic counselling • in the case of rhesus incompatibility • to check unclear findings following an amniotic fluid test 	<ul style="list-style-type: none"> • from the 16th week; the results are available after 2–4 days.

WHAT DO I LEARN?	WHAT MUST BE OBSERVED?
<ul style="list-style-type: none"> • Chromosomal anomalies in the unborn child • After a targeted DNA analysis hereditary illnesses/ disabilities, e.g. muscular and metabolic disorders, can be determined. 	<ul style="list-style-type: none"> • In most cases where there are abnormal findings there is no treatment; the question of a possible termination may arise. • The risk of a miscarriage is 0.5–2%. • Pain and bleeding are possible after the procedure. • Only limited information is provided about the severity and extent of the findings. • If maternal cells are taken instead of fetal cells, the investigation must be repeated. • If not all of the cells examined have the same finding (1.5% mosaic finding) the investigation must be repeated or a long-term culture must be included. • Misdiagnoses can occur.
<ul style="list-style-type: none"> • Chromosomal anomalies in the unborn child • Neural tube defects, so-called open back • After a targeted DNA analysis hereditary illnesses/ disabilities, e.g. muscular and metabolic disorders, can be determined. Chorionic villus sampling is generally recommended instead in such cases. 	<ul style="list-style-type: none"> • In most cases where there are abnormal findings there is no treatment. • There is a 0.5–1% risk of a miscarriage: one in 200 women has a miscarriage. • Contractions and slight bleeding can occur. • The long waiting time for the findings is stressful. • In the case of a late termination of the pregnancy a delivery process is induced. • The investigation sometimes has to be repeated. • Only limited information is provided about the severity and extent of the findings. • Findings of rare chromosomal changes, the effects of which are not known, are possible. • Misdiagnoses can occur.
<ul style="list-style-type: none"> • Findings like those after an amniotic fluid test are possible. • If the child is anaemic (rhesus incompatibility) a blood transfusion may be necessary • In the case of infections, medicines for treating the unborn child are normally given via the woman 	<ul style="list-style-type: none"> • There is a 1–3% risk of a miscarriage. • The question ‘What do I do in the event of an abnormal finding?’ can arise here, as is the case with the other investigations.

7.2 GLOSSARY

SPECIALIST MEDICAL TERMS

Alpha-fetoprotein (AFP): Protein which is excreted by the unborn child into the amniotic fluid and, by absorption of the amniotic fluid, into the woman's bloodstream. It can indicate obstructive disorders of the vertebral column and Down's syndrome.

Chromosome: Carrier of genetic information. Each human cell normally contains 23 pairs of chromosomes. The chromosome sets of egg cells and sperm are brought together on fertilisation.

Chromosome analysis: Microscopic examination of chromosomes.

Chromosome aberrations refers to excessive or missing chromosomes or partial chromosomes, as in the case of trisomy 21, 13, 18, Turner's syndrome (XO) or Klinefelter's syndrome (XXY).

DNA analysis: Costly targeted search for hereditary diseases, the cause of which is attributable to a single gene. For a DNA analysis the building block sequence of the gene to be investigated must be known. An investigation of several family members is necessary for this. It is only carried out in a few cases.

Invasive: Investigation methods in which instruments penetrate into the body.

Non-invasive: Investigation methods in which instruments do not penetrate into the body.

Termination of pregnancy: A termination of pregnancy after the 12th week is only permissible if, taking into account the current and future living conditions, the doctor considers the woman's physical and mental health to be at risk and the danger cannot be averted in any other way which is reasonable for the woman (medical indication). A termination of pregnancy after the 16th week cannot be carried out as in the earlier stage of pregnancy by suction or curettage under anaesthesia. At this late stage the delivery process is induced by giving oxytocic drugs. As the pregnancy advances, correspondingly higher requirements must be placed on the indication for a termination of pregnancy, particularly when there is potential viability of the child outside the womb (from approximately 24 weeks onwards). Further information on termination of pregnancy can be provided by doctors, midwives and counselling centres.

Screening: Serial examination, preventive examination.

MARKET RESEARCH TERMS

Access panel: Pool of addresses of households which are willing to take part in surveys. The addresses are dispersed over all communities in Germany and are therefore regionally representative.

Bias: Specialist term from epidemiology; means distortion.

Subject: Participant in scientific investigations.



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