Prenatal counselling

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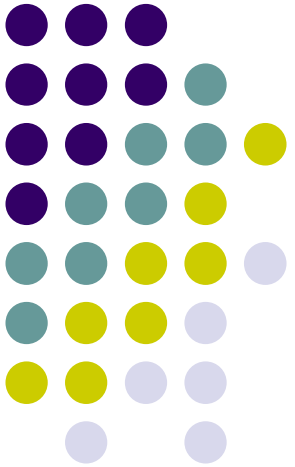


Prental Medicine – a medicohistorical and psychological view

- For a million years the evolving child was hidden in the darkness of the womb
- The pregnant woman was the only one interacting with her child to be
- This interaction was by thoughts, fantasies, feelings and verbal dialogue with the imaginated child
- The „knowledge“ about the child was almost exclusively with the mother

Intimate, exclusive mother-child relationship

Prental Medicine – a medicohistorical and psychological view

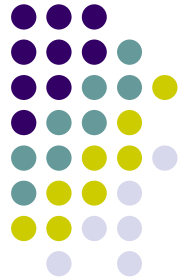
- Prenatal medicine has brought light and vision into uterus and has made the fetus „public“
- The medical professional has become an important protagonist of the interaction, putting the mother in the position of the „uninformed“ layperson
- The interaction has become more „materialistic and realistic“. The pregnant woman‘s inner dialogue is modified or even directed by the medical language
- The knowledge about the child to be comes mainly from the medical professional and the woman has to learn, understand and process (interprete) this information

A triangulated „objectivised“ medical professional – mother – child relationship

Types of „new* information about the child to be

- Type A) Information about the healthy status and development the foetus (in the majority of cases) leading to a reduction in anxiety and an increase in confidence and attachment.
- Type B) Information about **the risk of foetal** pathology or abnormality.
- Type C) Information about **foetal pathology or abnormality.**

Types of „new* information about the child to be



- Type C) Information about foetal pathology or abnormality.
  - 1) Foetal pathology **amenable to therapeutic interventions** with **predictable postnatal prognosis**
  - 2) Foetal pathology **amenable to therapeutic interventions** with **unpredictable or very variable prognosis**
  - 3) Foetal pathology **not amenable to therapeutic** interventions with **high predictability of prognosis**
  - 4) Foetal pathology **not amenable to therapeutic** interventions with **low predictability or variable prognosis**.

Prenatal medicine – an ethical perspective

Respect the values and wishes of the pregnant woman

Autonomy

Do not harm the emotional and physical condition of the pregnant woman and her relationship with the foetus

Non maleficience

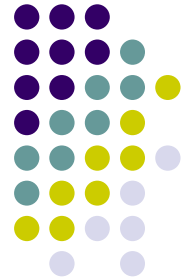
Justice

Give all women the same chance; do not withheld help for any reason

Beneficience

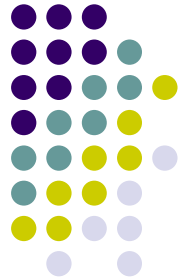
Take harm away and support the physical and emotional health of the pregnant woman; enhance the mother-foetus relationship

Communication and prenatal counselling – the ethical challenges



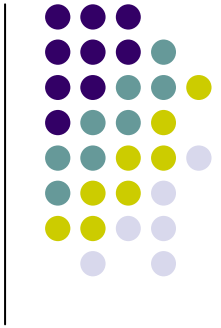
Respect of autonomy	• Clarification of the patient's objectives and the obstetricians mandate
Beneficience and justice	• Individualized information giving and education about prenatal investigations
Autonomy , Benificience, Non maleficience	• Shared decision making regarding tests and investigations
Non-maleficience	• Breaking (bad, ambivalent) news
Beneficience	• Caring for patients with an affected child

Clarification of the patient's objectives and the obstetricians mandate.



- Directly asking the patient:
- Ex.; *Have you got already some information about pregnancy care and prenatal medicine ? What are your wishes and concerns regarding pregnancy care….*
- Giving basic information about routine care and then asking about individual concerns:
- Ex.: *In our routine care we see pregnant women every four weeks. The controls serve two purposes. One to assure that you remain in good health and do not suffer complication and the other to follow and assure the normal development of the child. Do you have special concerns or wishes…..*

Clarification of the mandate
Respect for autonomy



The patient has already decided before the consultation that she wants a prenatal diagnosis, because she is either sure, that she will not be able to care for a handicapped child and that she would perform an abortion, or because she wants to prepare herself

The patient:

Is not or only partially informed

Has not taken a decision

Wants the doctor to decide

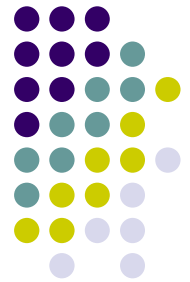
The patient has decided that she wants to accept the child as it is and does not want any investigations into inborn deficits because she would not draw any consequences

Information about the risks of diagnostic procedures

Comprehensive individualized information exchange

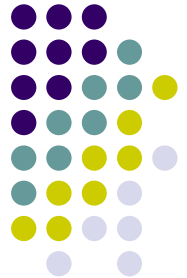
Regular pregnancy care

Individualized Information giving and education about prenatal investigations (Beneficience and justice):



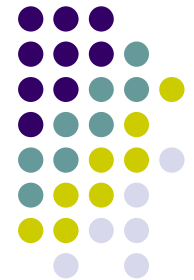
- Structure the information
- Give information in small units
- Announce important pieces of information
- Encourage questions
- Assure feedback

Information exchange – Basic principles



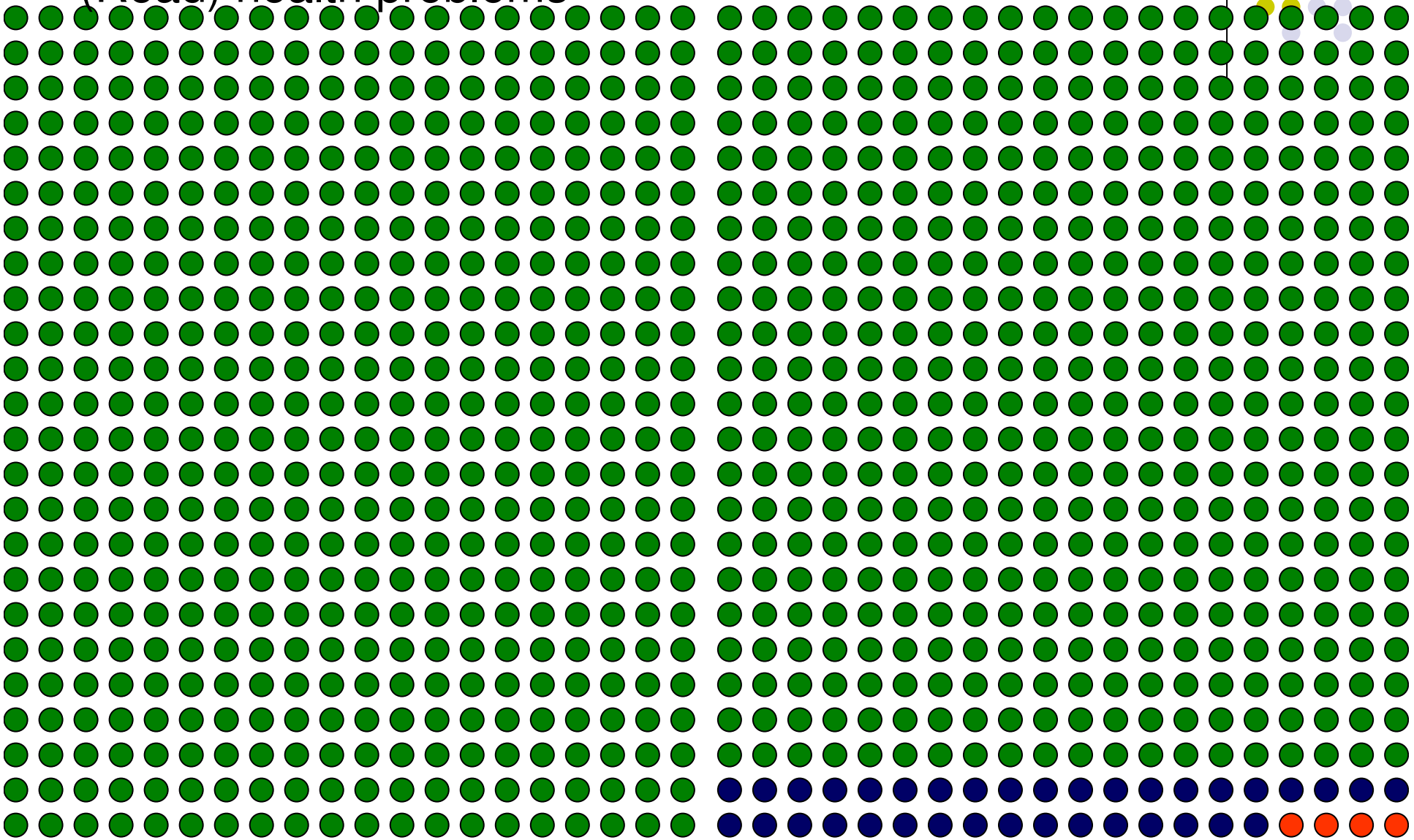
- Elicit: Patients pre-existing knowledge and questions
- Provide: Give information in small units and short sentences.
- Elicit: Patient's understanding and evaluation of the information. "What does this information mean to you?"

Individualized Information giving and education about prenatal investigations:

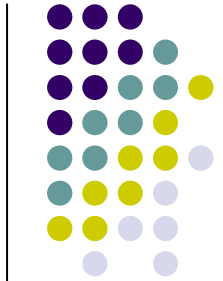


- **Physician: A pregnancy is always something very special, accompanied by many good feelings. At the same time pregnanct women do have concerns and worries. What about you...are there any concerns ?**
- **Patient: Poeple talk a lot about malformations etc.……**
- **Physician: If you agree I would like to give a short overview about what we know with respect to pregnancy outcomes in your age group. Imagine a big hall in which 1000 pregnant women are together:**
  - **In 960 of 1000 the baby is completely healthy.**
  - **In 30-40 of 1000 babies we find minor health problems, which can be treated**
  - **4 out of 1000 babies are affected with a serious inborn health problem for which we do not have an adequate treatment.....**
  - **This means that the prospective is very positive**

The chances that the child is perfectly healthy (Green) and the risk of minor (Blue) and severe (Read) health problems



Individualized Information giving and education about prenatal investigations:

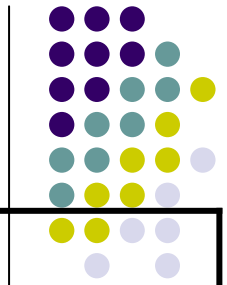


- **Today we have different methods to get information about the child in the uterus. I want to present to you briefly these methods so that you can decide which ones you would like to have to be performed and used.**
- **First of all there is Ultrasound…….**

Individualized Information giving and education about prenatal investigations:

Method	Objective/Aim	Advantage	Problem/ Disadvantage
Ultrasound	**Growth of the child; Development of organs and placenta; Vitality** (frequent findings)	**No risk for the child; therapies are possible**	**Not everything is detectable; what to do with minor malformations ? No guarantee**

Individualized Information giving and education about prenatal investigations:



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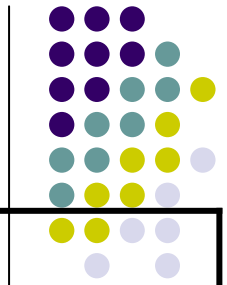
Placenta and Amniotic Fluid Punction	**Detection of chromosomal abnormalities (rare condition 1: 2000**	Diagnostic certainty; Basis for decisiion	**Risk of miscarriage 1:200; emotional distress; ethically difficult decision**

Individualized Information giving and education about prenatal investigations:



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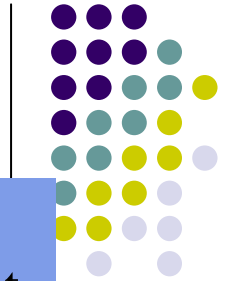
Ultrasound	**Growth of the child; Development of organs and placenta; Vitality** (frequent findings)	**No risk for the child; therapies are possible**	**Not everything is detectable; what to do with minor malformations ? No guarantee**
Screening with Ultrasound and Blood Test	Risk estimation for chromosomal abnormalities	No risk for the child; Avoidance of unnecessary intervention	Only risk estimates (number) unnecessary anxiety, false security
Placenta and Amniotic Fluid Punction	**Detection of chromosomal abnormalities (rare condition 1: 2000**	Diagnostic certainty; Basis for decisiion	**Risk of miscarriage 1:200; emotional distress; ethically difficult decision**

Decision making – preference sensitive decision



Attitude and knowledge about Handicap

Clarify needs and value system of the patient

Attitude and knowledge about abortion

What is Benefit ?

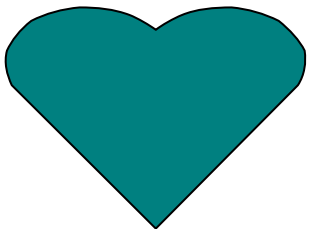
Inform according to EBM :
1) Make statistics understandable

What is risk ?

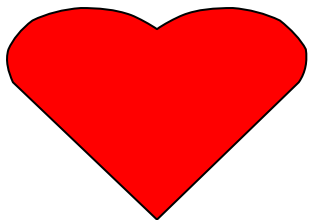
Benefit of an intervention in absolute numbers

Inform according to EBM :
2) Explain risk benefit ration in patient‘s language

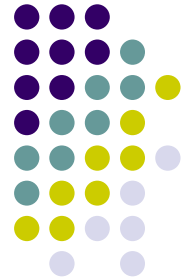
Risk of an intervention in absolute numbers



Encourage the patient to give her values to the numbers



Shared decision making 1. Step



Clarify values

„Talking about prenatal investigation will bring us necessarily to the point, where we have to discuss the rare situations in which we may find a chromosomal abnormality which may eventually lead to considering an abortion……Poeple have very different attitudes with respect to this….. What are your feelings and thoughts regarding chromosomal abnormalities and abortion….. „

Decision making – preference sensitive decision

Attitude and knowledge about Handicap

Clarify needs and value system of the patient

Attitude and knowledge about abortion

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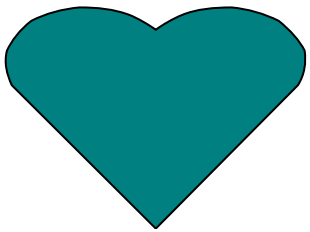

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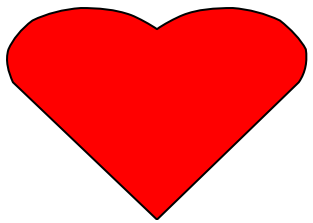
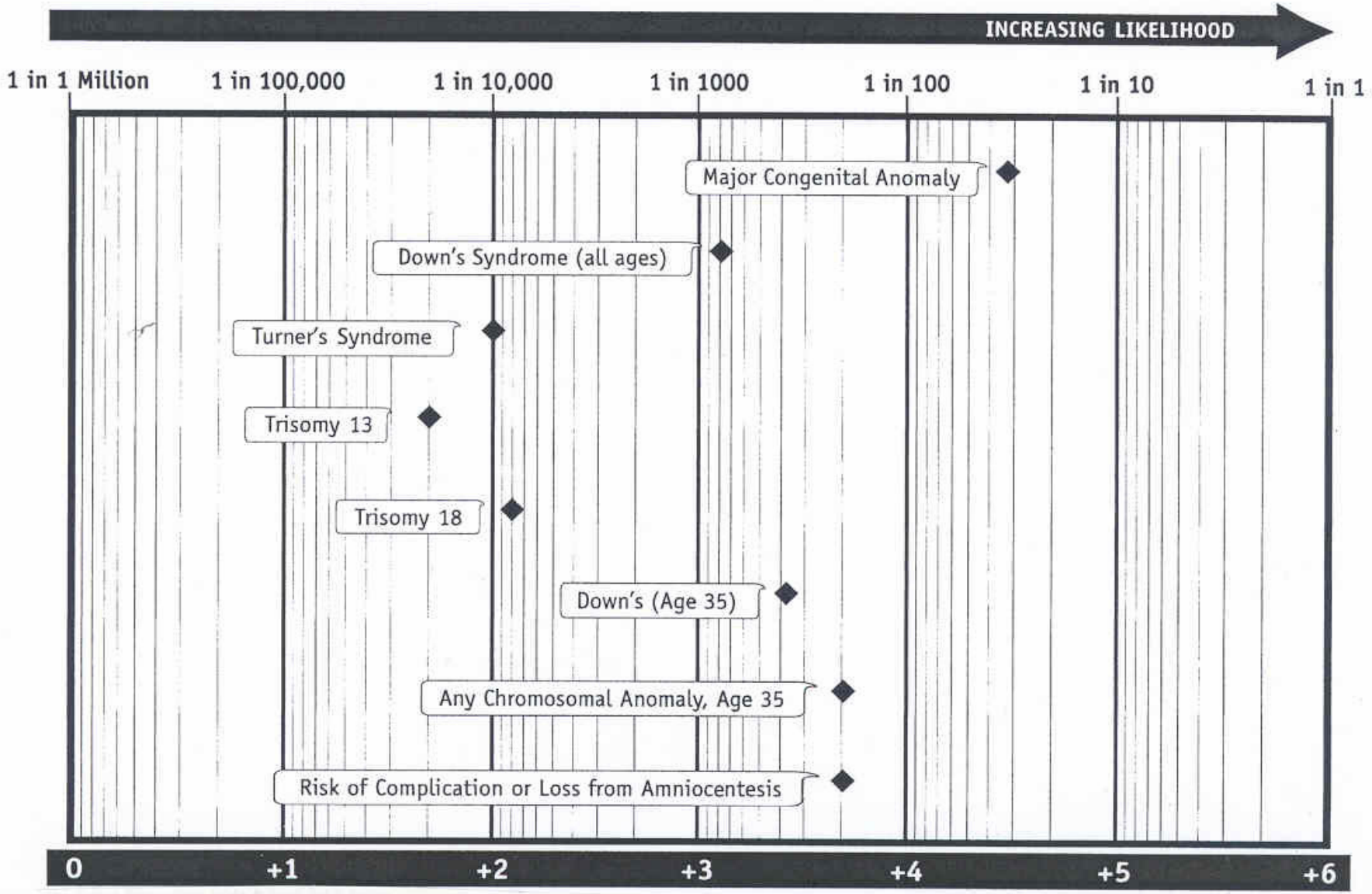


Shared decision making 2. Step

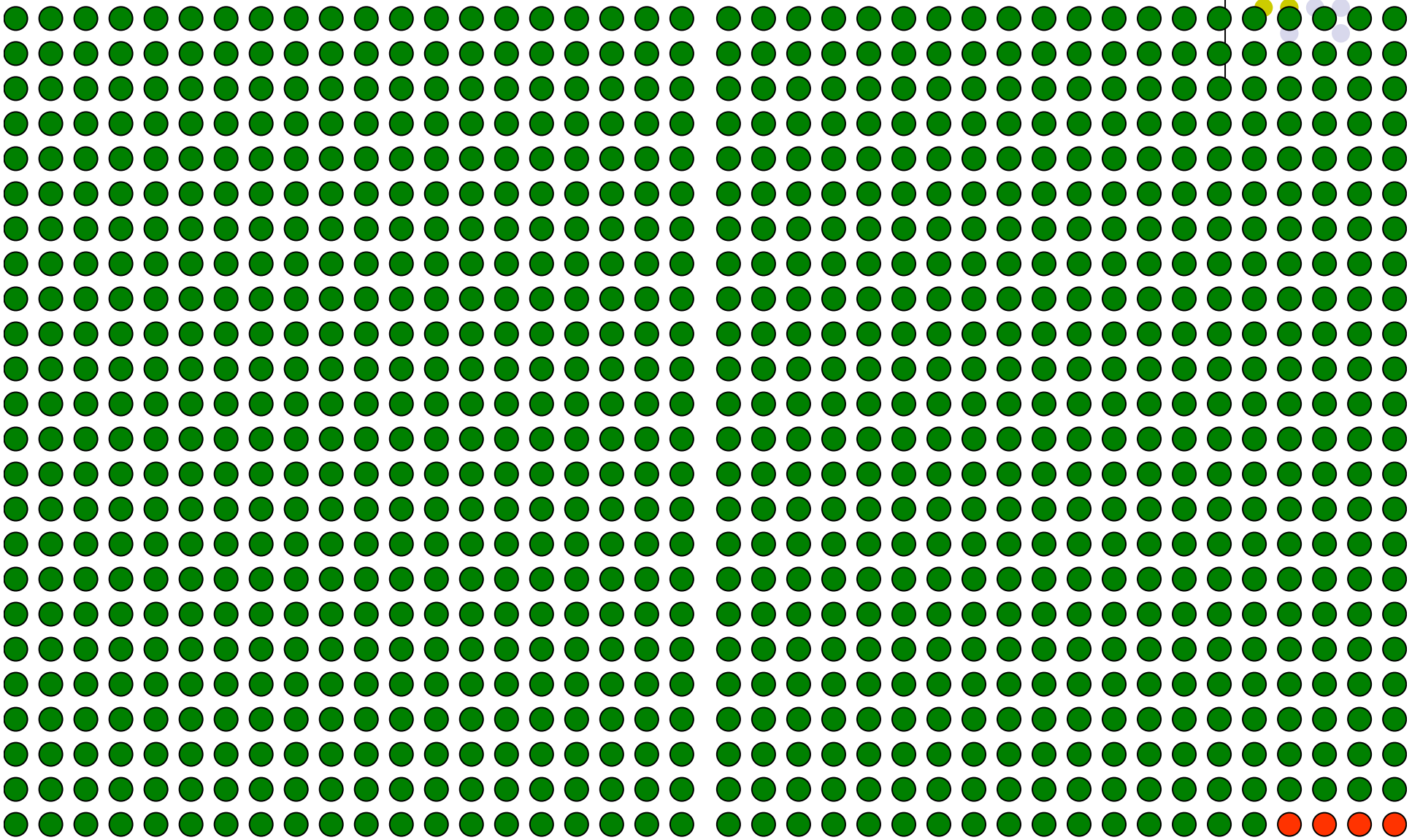
Inform according to EBM; make statistics understandable for patients

- Try to illustrate verbal expression like high, medium low risk with numbers related to a defined reference population
- Put these numbers into an everyday perspective
- Use natural frequencies, absolute risk and a common denominator
- Avoid changing the denominator
- Show positive and negative outcomes
- Visualize probabilities


INCREASING LIKELIHOOD
1 in 1 Million
1 in 100,000
1 in 10,000
1 in 1000
1 in 100
1 in 10
1 in 1
Major Congenital Anomaly
Down's Syndrome (all ages)
Turner's Syndrome
Trisomy 13
Trisomy 18
Down's (Age 35)
Any Chromosomal Anomaly, Age 35
Risk of Complication or Loss from Amniocentesis
0
+1
+2
+3
+4
+5
+6

The probability that the child has a chromosomal abnormality

The probability that the child is healthy



Decision making – preference sensitive decision

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Clarify needs and value system of the patient

Attitude and knowledge about abortion

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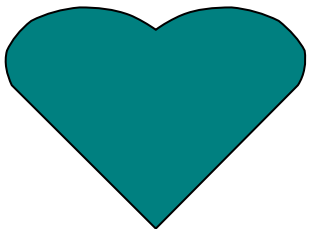

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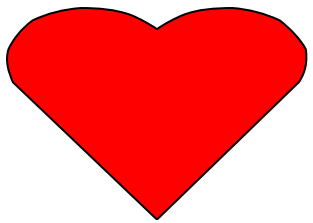
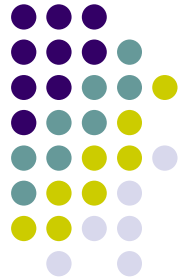


Shared decision making– preference sensitive decision Step 3

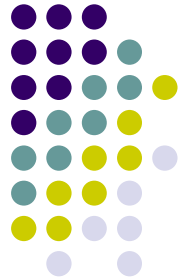


Inform according to EBM; Help to understand benefit and risk

Nuchal translucency Test

Advantage	Disadvantage
No risk for mother or child	No clearcut message; Only probabilites
Risk calculation in number which may permit comparison	High risk (1:100) estimate with in reality normal baby may lead to unnecessary anxiety, Low risk (1:2000) with in reality affected child may lead to false security
Additional argument for decision	Decision to make invasive procedure under false assumption; Anxiety during the waiting time

Shared decision making– preference sensitive decision Step 4



Encourage patient to give her individual evaluation

•What are your feelings and thoughts about such a risk evaluation; do you think such a number could help you to feel more safe or could serve you as a basis for further decisions ?……..

•Let us assume that we find an estimated risk of 1:200. What would that mean to you ? Do you think you could handle such a number ?.....

Decision making – preference sensitive decision

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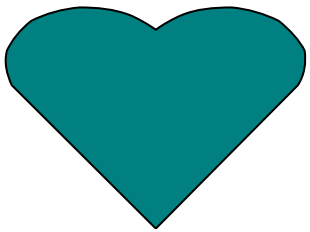

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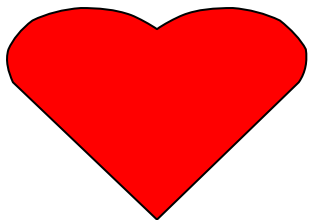

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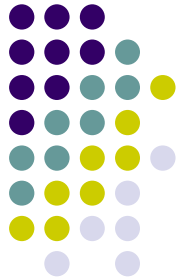
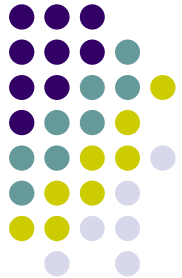


CVS, Amnio

Inform according to EBM; Help the patient to understand risk and benefit

Advantage	**Disadvantage**
Accurate Diagnosis in 995 of 1000 cases	Risk of Miscarriage in 0.5 1%
Decision for or against continuing the pregnancy possible	Possibly ethically difficult decision
In case of negative result increased feeling of security	Even with this test not all diseases can be exluded

Shared decision making– preference sensitive decision Step 4



Encourage patient to give her individual evaluation

- How do you personally value this information ? What are your personal priorities and concerns ? Would you need more information ? Would it be important to discuss this with your partner, that you have some more time ?
- What is your priority:

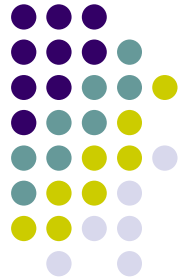
To be sure that there is no abnormality or the fear of a interventions provoked miscarriage.....

- *Try to imagine a moment, that after the intervention a miscarriage would occur. What do you think would be your reactions how would you handle this ?*

Breaking (bad, ambivalent news)

- Preparation for the encounter. (Quiet setting, enough time, is all the information needed available ? Does the patient come alone are accompanied by a family member or friend ? What is the emotional situation of the physician ?)
- Introduction (Joining with the patient by using a more personal issue, a brief summary of the previous events and the objective of the consultation)
- Announcement (Unfortunately I have to give you bad news)

Breaking (bad, ambivalent news)



- Statement (Give the diagnosis in simple words)
- Waiting for the individual reaction of the patient (Stunned, paralized, confused, shocked, desperate, crying, stoic, denying etc.)
- Response to the reaction (Emotion handling, reflecting, summarizing)
- Encouraging questions and giving further information in small pieces
- Give hope (There is always something that can be done)
- Structure the near future (What is the patient going to do next, define next steps to be taken and give appointments)