



Babies with MMC in Poland

parents' attitudes on fetal surgery versus
termination of pregnancy

MMC – prenatal diagnosis and ..



- Knowledge of MMC and potential therapy should help parents to decide

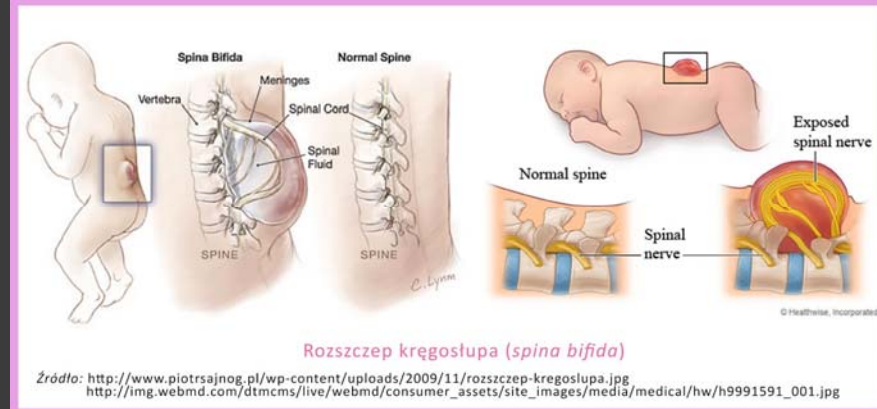
(prenatal surgery, antenatal surgical treatment or termination of pregnancy)

Methods



- 58 parents of children with MMC were invited to a lecture on MMC
- a 12-item questionnaire was administered
- Differences in the answers were tested statistically by applying the chi-square test and compared according to maternal age, education level, working status and subjective assesment of children's disability

Questionnaire



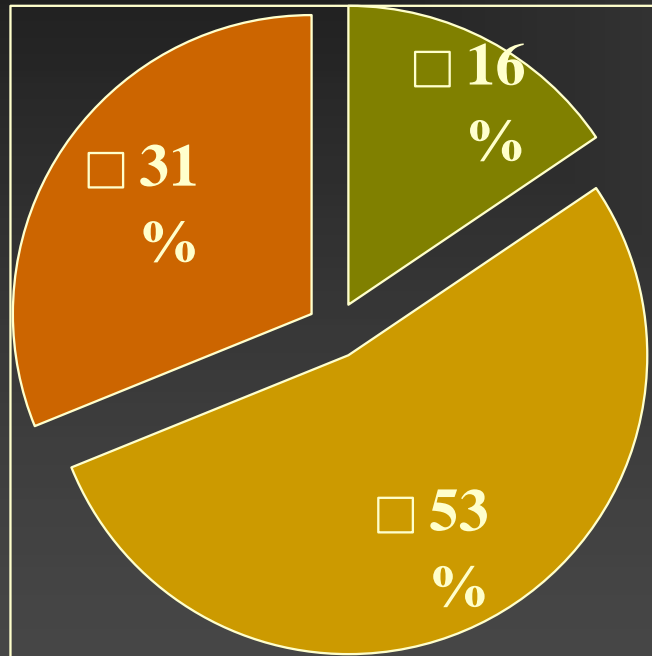
1. Did you know anything about MM before pregnancy?
2. When was MMC diagnosed in your baby?
3. When have you learnt about the necessity for surgery in your baby?
4. When did you receive complete information about MMC?
5. What kind of information did you obtain from your attending physician after a definite diagnosis?
6. Did your child have hydrocephalus?
7. When was hydrocephalus diagnosed?
8. If you had known about your baby's anomaly in early pregnancy – and in the light of present – day knowledge of the disease – would you have considered abortion?
9. After being informed on the potential risks and benefits associated with fetal surgery, would you give consent to this procedure?
10. How would you assess your baby's mental development?
11. Is your baby independent or wheelchaired?
12. How would you judge the Polish medical care for babies with myelomeningocele?

Characteristics of the group



- Maternal age at birth ranged between 20 and 44 years (average: 32 years)
 - At the time the questionnaire was filled out, children with MMC were between 3 and 20 years of age (average: 10 years)
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68,96% returned to work



- university certificate
- college degree
- primary diploma



- 40 (out of 58) women had attended their work before delivery, and 24 returned to work

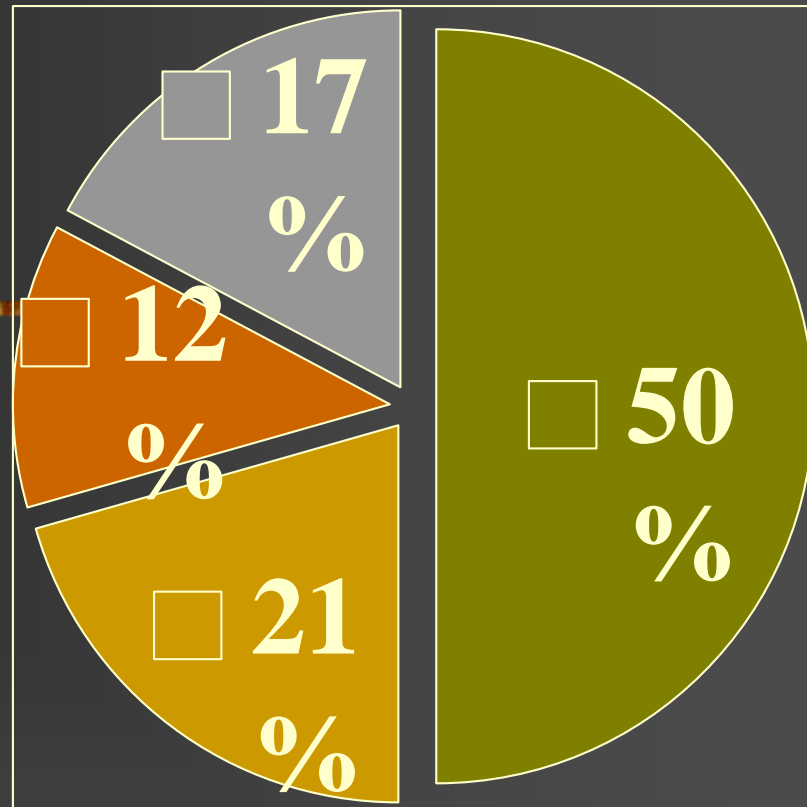
Only ...out of 58 2004



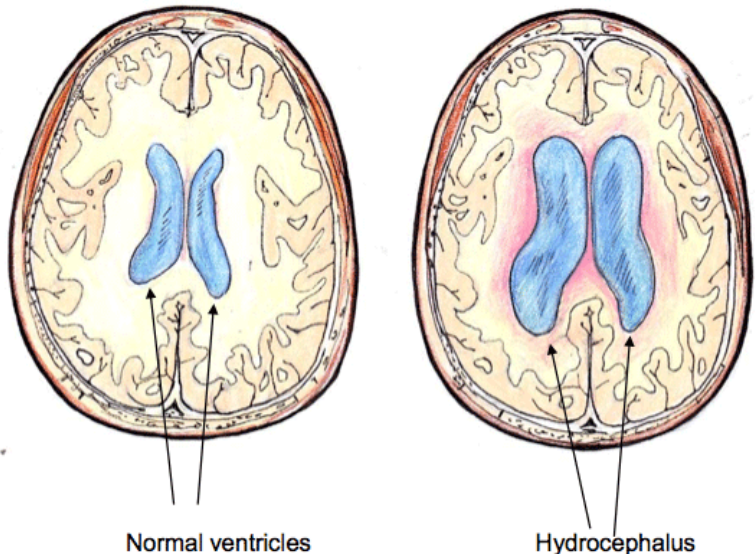
- Only 6 parents (10,34%) had any knowledge about MMC before diagnosis
 - Only in 11 (18,96%) MMC was prenatally diagnosed
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Hydrocephalus

- Hydrocephalus was diagnosed in 48 patients (82,75%)



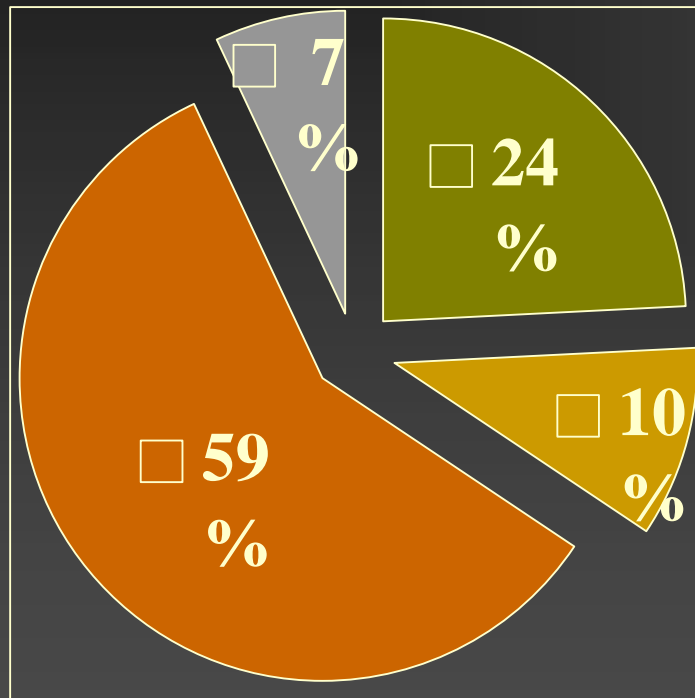
- H. after surgery
- H. after birth
- H. during pregnancy
- without



- 20 were wheelchair dependent
14 were able to move with help
14 (24,13%) were able to move autonomously
- mental development
3 children severely retarded
6 as moderately retarded,
5 as middle retarded
44 (75,86%) as normal or nearly normal



Results I



- TOP 24%
- TOP or Fetal Surgery 10%
- Fetal Surgery 59%
- None therapy 7%

24 % of mothers would have considered a TOP

not associated with maternal education level [chi-square test ($p=0,38$)]

59% of mothers expressed approval to the fetal surgery procedure

not associated with maternal education level [chi-square test ($p=0,26$)]

10% of mothers would have consented to a TOP or fetal surgery

Results II



- Fetal surgery for MMC is not currently performed routinely in many centers, some physicians still consider the procedure as experimental treatment

Results III



- Parents of MMC babies are potentially interested in the use of fetal surgery
 - Appropriate counseling can help parents to understand the risks, benefits, and limitations of this procedure, as well as decide between abortion and fetal surgery
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