Ethical decision-making in prenatal diagnosis

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Objectives

1. To elucidate ethical values/norms physicians have with regard to prenatal diagnosis
2. To identify physician perceptions of professional roles in prenatal diagnosis
3. Obtain information that may be useful for development of institutional guidelines for pregnancy termination

Background

1. Physicians will confront morally challenging situations with improvement in prenatal diagnostic capabilities
2. Abortion in 1st trimester is tolerated from the legal and moral perspectives
3. Request for 3rd trimester abortions appear to be increasing
4. Moral discomfort with third trimester abortions amongst health care professionals

Methods

- Cross sectional survey of academic pediatricians
- Semi quantitative seven page questionnaire distributed anonymously
- Responses analyzed was according to sex, the importance of religion and participation in the prenatal diagnosis clinic
- Statistical significance was determined using student -† test, Fisher exact test or Pearson chi squared

Summary of questions

1. What factors are important in decision making when counselling a couple where a foetal congenital malformation is detected
   - Capacity to predict a long term prognosis associated with the foetal anomalies

Summary of questions

2. According to your values (the physician's) do you agree or disagree with the following proposition (Please provide explanations for your opinions if desired)
   - In certain situations, it is acceptable to withdraw a vital treatment which would lead to death
   - In certain situations, it is acceptable to give a medication with the intention to cause death
   - There is an ethical difference between interruption of a pregnancy before or after viability

☐ Yes ☐ No

Summary of questions

3a) According to your values, one could not agree with a couple's decision to interrupt a pregnancy since:

- The couple could change their mind
- This responsibility belongs to physicians

☐ Yes ☐ No

Summary of questions

3b) What should be the role of an ethics committee specialised in prenatal diagnosis in the decision making process

Commentaries:

- No role
- Consultative in individual cases
- Obligatory consultation before all interruption
- Responsible for the final decision for individual cases

Summary of questions

3c1) To what extent does the physician influence the decision process of a couple when deciding about pregnancy termination

- In reality
- According to your ideal

Summary of questions

3c2) What are the three most important roles of a physician in prenatal diagnosis?

- ☐ diagnosis
- ☐ counselling
- ☐ orientation
- ☐ prevention

Summary of questions

4. In your opinion, is it acceptable to terminate a pregnancy for the following antenatal diagnosis:
   - Severe cardiopathy and palliative surgery possible
   - Severe cardiopathy and curative surgery possible
   - Trisomy 21 and severe cardiopathy
   - Trisomy 21 without cardiopathy
   - Cystic fibrosis before viability
   - Cystic fibrosis after viability

☐ Yes ☐ No

1. Results

- N = 100/400
- Females = 54% Males = 46%
- Catholic = 56%, Protestant = 5%, Jewish = 4%, Other = 35%
- Importance of religion or spirituality – yes = 33%
- Exercises in Prenatal diagnosis = 37%
- Assistance - Foetal anomalies reunion = 24%
- < 10 years practice = 26%
- > 20 years practice = 39%
- 56% indicated speciality: Pediatricians = 23%, Radiologist: 12.5%, Obstetricians = 2%, Other = 24.5%

2. Results
Significant factors important in decision making (> 90% ± 8-10)

- Capacity to arrive at a long term prognosis
- Discussion with the parents
- Adequate way to relay information
- Scientific rigor of the information given
- Quality of the comprehension by the parents
- Quality of life expected of the patient*
- Intellectual handicap expected**

*90% ± 14 **84% ± 19

3. Results
Less significant factors (< 70%)

- Legal constraints
- Discussion with colleagues
- Discussion with other professionals outside medicine
- Public debate or political will on the subject
- Existence of an institutional policy
- Solidarity in society towards the handicaped

4. Result

It is acceptable to consider euthanasia even if the law does not authorize it vs Sex

Acceptable to consider euthanasia

	SEX		
	M	**F**	**Total**
No	8 18.2%	22 43.1%	30 31.6%
Yes	36 **81.8%**	29 **56.9%**	65 68.4%
P < .009	44 100%	51 100%	95 100%

5. Results

Even with a severe intellectual handicap, life is always better than no life at all vs Sex

Life with severe intellectual handicap

	SEX		
	M	**F**	**Total**
No	34 **77.3%**	45 **93.8%**	79 85.9%
Yes	10 22.7%	3 6.3%	13 14.1%
P = .035	44 100%	48 100%	92 100%

6. Results

In certain situations it acceptable to give a medication with the intent to cause death vs Sex

Acceptable to give a medication to cause death

	SEX		
	M	**F**	**Total**
No	11 25%	30 **61.2%**	41 44.1%
Yes	33 **75.0%**	19 38.8%	52 55.9%
P < .001	44 100%	49 100%	93 100%

7. Results

There is an ethical difference between pregnancy termination before or after viability vs Sex

Ethical difference to termination before or after viability

	SEX		
	M	**F**	**Total**
No	20 45.5%	10 19.6%	32 31.6%
Yes	24 **54.5%**	41 **80.4%**	65 68.4%
P < .007	44 100%	51 100%	95 100%

8. Results

In certain situations, it is acceptable to give a medication with intention to cause to death vs Religion is an important aspect

Give medication with intention of causing death

	Religion is an important aspect		
	No	**Yes**	**Total**
No	22 34.9%	20 **64.5%**	42 44.7%
Yes	41 **65.1%**	11 35.5%	52 55.3
P = .007	63 100%	31 100%	94 100%

9. Results

Interruption of cardiopathy and palliative surgery vs Religion is an important aspect

Interruptionn of cardiopathy and palliative surgery

	Religion is an important aspect		
	No	**Yes**	**Total**
No	11 17.5	15 48.4%	26 27.7%
Yes	52 **82.5%**	16 **51.6%**	68 72.3%
P < .002	63 100%	31 100%	94 100%

10. Results

Interruption of cardiopathy and curative surgery vs Religion is an important aspect

Interruption of cardiopathy and curative surgery

	Religion is an important aspect		
	No	**Yes**	**Total**
No	33 **52.4%**	27 **84.4%**	60 63.2%
Yes	30 47.6%	5 15.6%	35 36.8%
P < .002	63 100%	32 100%	95 100%

11. Results

Interruption of trisomy 21 and severe cardiopathy vs Religion is an important aspect

Interruption of trisomy 21 and severe cardiopathy

	Religion is an important aspect		
	No	**Yes**	**Total**
No	7 10.9%	11 34.4%	18 18.8%
Yes	57 **89.1%**	21 **65.6%**	78 81.3%
P < .006	64 100%	32 100%	96 100%

12. Results
Trisomy 21 without cardiopathy before viability vs Religion is an important aspect

Trisomy 21 without cardiopathy before viability

	Religion is an important aspect		
	No	**Yes**	**Total**
No	9 14.1%	12 37.5%	21 21.9%
Yes	55 **85.9%**	20 **62.5%**	75 78.1%
P < .009	64 100%	32 100%	96 100%

13. Results
Cystic fibrosis before viability vs Religion is an important aspect

Cystic fibrosis after limits of viability

	Religion is an important aspect		
	No	**Yes**	**Total**
No	20 31.7%	20 **62.5%**	40 42.1%
Yes	43 **68.3%**	12 37.5%	55 57.9%
P = .004	63 100%	32 100%	95 100%

14. Results

In certain situations it is acceptable do give a medication with the intent to cause death vs Prenatal diagnosis practice

Acceptable to give a medication with intent to cause death	Prenatal diagnosis practice: No	Prenatal diagnosis practice: Yes	Total
No	34 55.7%	9 26.5%	43 45.3%
Yes	27 **44.3%**	25 **73.5%**	52 54.7%
P = .006	61 100%	34 100%	95 100%

15. Results

Interruption of trisomy 21 and severe cardiopathy vs Prenatal diagnosis practice

Interruption of trisomy 21 and severe cardiopathy	Prenatal diagnosis practice		
	No	**Yes**	**Total**
No	17 27.9%	2 5.6%	19 19.6%
Yes	44 **72.1%**	34 **94.4%**	78 80.4%
P < .007	61 100%	36 100%	97 100%

16. Results

Interruption of trisomy 21 without severe cardiopathy after viability vs Prenatal diagnosis practice

Interruption of trisomy 21 without severe cardiopathy of the viability

	Prenatal diagnosis practice		
	No	**Yes**	**Total**
No	40 **66.7%**	11 31.4%	51 53.7%
Yes	20 33.3%	24 **68.6%**	44 46.3%
P < .001	60 100%	35 100%	95 100%

17. Results

Even with a severe mental handicap, life is always better than no life at all vs Attendance foetal anomaly reunion

Even with a severe mental handicap life is always better than no life

	Attendance foetal anomaly reunion		
	No	**Yes**	**Total**
No	56 **80 %**	23 **100 %**	79 84.9%
Yes	14 20%		14 15.1%
P < .018	70 100%	23 100%	93 100%

18. Results

In certain situations it is acceptable to give a medication with the intent of causing death vs Attendance foetal anomaly reunion

Acceptable to give medication with the intent of causing death

	Attendance foetal anomaly reunion		
	No	**Yes**	**Total**
No	41 56.9%	2 9.1%	43 45.7%
Yes	31 **43.1%**	20 **90.9%**	51 54.3%
P < .000	72 100%	22 100%	94 100%

19. Results

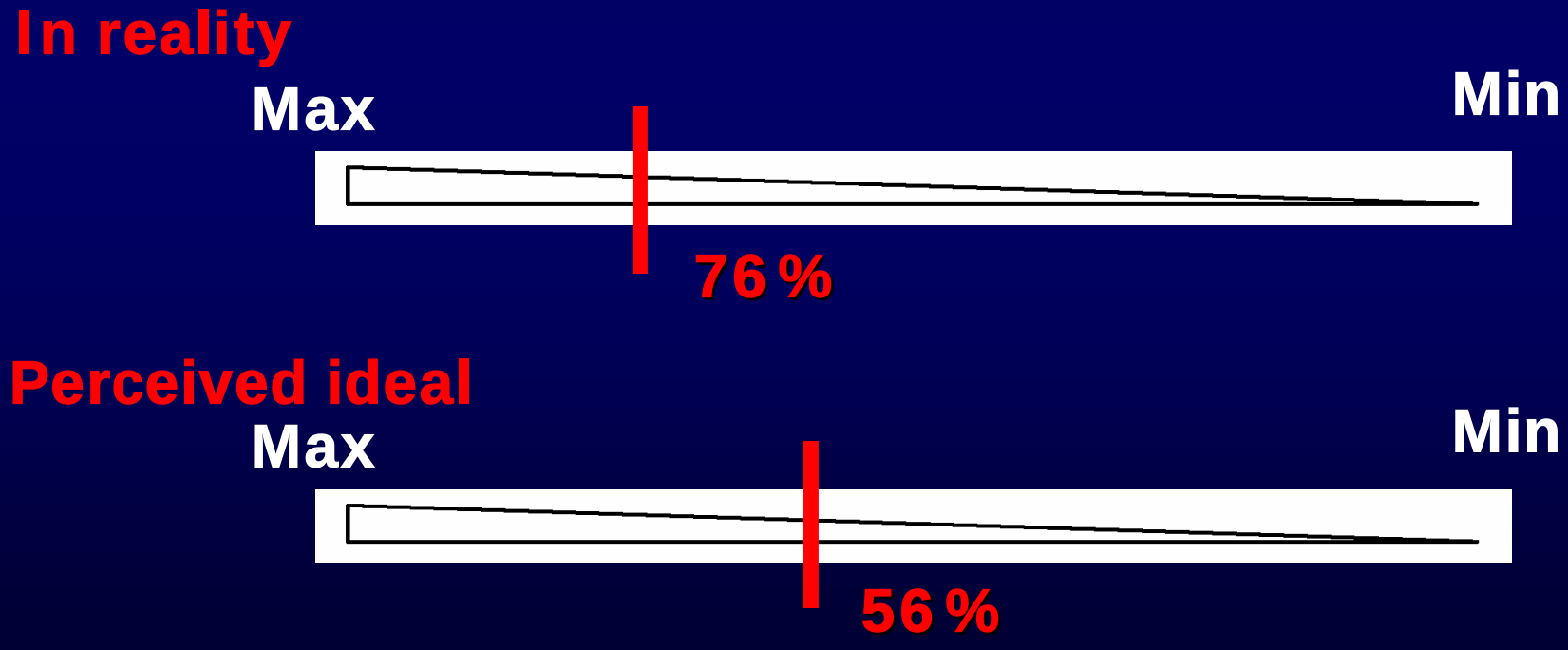
Interruption of trisomy 21 without cardiopathy after viability vs Attendance foetal anomaly reunion

Interruption of trisomy 21 without cardiopathy after viability

	Attendance foetal anomaly reunion		
	No	**Yes**	**Total**
No	45 **62.5%**	5 22.7%	50 53.2%
Yes	27 37.5%	17 **77.3%**	44 46.8%
P = .001 RR 5.6	72 100%	22 100%	94 100%

20. Results

- Physician's influence on the decision making process by a couple with regards to pregnancy termination



21. Results

- Physician's roles in prenatal diagnosis practice

1st	Making a diagnosis	74%
2nd	Counselling	36%
3rd	Supporting	22%

What should the role an ethic committee specialised in prenatal diagnosis in the decision making process be?

1.	None	5%
2.	Establish general rules without intervening in individual cases	65%
3.	Consultative role in individual cases	85%
4.	Consultative role obligatory before all pregnancy terminations	25%
5.	Consultative role optional before all pregnancy terminations	65%
6.	Responsibility for the final decision for individuals cases	25%
7.	Evaluation for completeness of foetal investigation	50%

Summary (1)

- Life is not the supreme good
- Severe handicap is not tolerated
- Euthanasia is possible even if not legal
- Euthanasia and termination of pregnancy is ethically different
- Viability is an important concept for termination of pregnancy
- Potential bias

Summary (2)

- Those that practice prenatal diagnosis will more likely tolerate
  - Euthanasia
  - Termination of pregnancy with various conditions including cystic fibrosis or trisomy 21 without severe cardiopathy

Summary (3)

- Physician's role in decision making is greater than his own ideal
- Interruption of pregnancy is more likely if importance of spirituality in the physician's life is low

Summary (4)

- Severe handicap is less tolerated by women
- Men are more likely to tolerate euthanasia for severe handicap
- The roles of ethics committees:
  - Consultative
  - Optional
  - Partially regulatory

1. Discussion

- Comparables studies
  - France 1989 : Acceptability of termination of pregnancy in southern France.
    - N = 853 practioners/specialists
    - Interruption: Down's 78%
      Cystic fibrosis 40%
      - Directive 33%
      - More interruption if diagnosis possible in 1st trimester

Julian C, Huard P, Couvernet JF. Physician's acceptability of termination of pregnancy after prenatal diagnosis in Southern France. Prenatal Diagnosis 1989;9:77-89.

1. Discussion

- Comparables studies
  - UK 1993
  - N = 263/500 pediatricians
    - Active steps to terminate the life of a newborn infant with severe defects
    - Yes 29% No 72%

Outherson C. Newborn infants with severe deficits: A survey of paediatric attitudes and practices in the United Kingdom. Bioethics 1993;7(5):420-435.

1. Discussion

- Factors determing acceptability of abortion
- Quebec/France 1993 (N=3000)
  - Negatively correlated
    - religious practice
    - parenthood
  - Positively correlated
    - perceived severity of condition
    - anglophone in Quebec
    - Obstetricians-gynecologists, radiologists

Renaud M, Bouchard L, Kremp O et al. Is selective abortion for a genetic disease an issue for the medical profession? A comparative study of Quebec and France. Prenatal Diagnosis 1993;13:691-706

1. Discussion

- France
  - Positively correlated
    - perceived severity
  - Negatively correlated
    - religious practice
- Directiveness: Quebec
  - Positively correlated
    - french
    - religious practice
    - age (older)
  - Negatively correlated
    - acceptability of abortion

Renaud M, Bouchard L, Kremp O et al. Is selective abortion for a genetic disease an issue for the medical profession? A comparative study of Quebec and France. Prenatal Diagnosis 1993;13:691-706

Selective abortion for a genetic disease in Quebec and France

% Agreement

	FQ	AQ	French
> 75%		Trisomy 21 MD HD	MD
66-74%	Trisomy 21	CF	Trisomy 21
60-65%			HD
Debate (30-59%)	MD SB HD Heart defect CF	SB Heart PKU	Heart defect SB

Renaud M, Bouchard L, Kremp O et al. Is selective abortion for a genetic disease an issue for the medical preofession? A comparative study of Quebec and France. Prenatal Diagnosis 1993;13:691-706

1. Discussion

- Quebec
  - Gyneco-obsteticians, pediatricians, radiologists
    - Female: more liberal access to amniocentesis
    - Selective abortion
    - Less directive

Bouchard L and Renaud M. Female and male physicians'attitudes toward prenatal diagnosis: A pancanadian surgery. Soc Sci Med 1997;44(3):381-392

2. Discussion

- Decision making will become more difficult with advanced technology
  - Diagnostic uncertainty
  - Prognostic uncertainty
  - Uncertainty of the good for respect of parental autonomy
  - Increasing responsibilities ≠ legal responsibilities
  - Conscious of the absent fœtal rights
- When does transgressison of moral law occur?
- For whom and for what is trangression acceptable?
- What roles should parents, physicians, society share in the decision making
- Who speaks for the foetus?

2. Discussion

- Attitudes of obstetricians in prenatal diagnosis of cystic fibrosis
  - Prenatal care providers are less concerned about imperfect test results and impact
  - Worried about time required to answer questions
  - Worried about legal liability

Rowley PT, Hoader S, Leventson JE, Philips CT. Cystic fibrosis screening: knowledge and attitudes of prenatal care providers. Am J Prev Med; 1993;9(5):261-266.

2. Discussion

- Attitudes of obstetricians in prenatal diagnosis of Down's syndrome
  - Serum screening according to criteria
  - Inadequate resources for counseling
  - Women don't understand the test
  - Women not informed about false results

Green JM. Serum screening for Down's syndrome: Experiences of obstetricians in England and Wales. BMJ 1994;309:769-772.

3. Discussion

- Informed consent is the most prevalent issue:
  - Screening is presented to encourage women to undergo testing
  - Presentation does not maximise informed decisions about whether to participate in the screening program

- William C, Alderon P and Farsides B. What constitutes balanced information in the practioners'portrayals of Down's syndrome? Midwifery 2002;18:230-257.
- Veach P McCarthy, Bartels DM, LeRoy BS. Ethical and professional challenges posed by patients with genetic concerns. A report of focus group discussions with genetic counselors, physicians, and nurses. Journal of Genetic Counselling 2001;10(2):97-119.
- Marteau TM, Slach J, Kidd J, Shaw Rw. Presenting a routine screening test in antenatal care: Practice observed. Public Health 1992;106:131-141.
- Georges E. Fetal ultrasound imaging and the production of authoritative knowledge in Greece. Medical Anthropology Quaterly 1996;10(2):157-175.

3. Discussion

Role of Genetic Counselling

- Medical Model
- Non directiveness – an oxymoron?
- Not in non English speaking contries
- The quiet revolution – from risk to population based
- Culturally laden values
- Social construction of disability

- Wentz DC. Genetic counselling in Mexico. American Journal of Medical Genetics 1998;75:424-425.
- Carnevale A, Lister R, Villa AN, Armendares S. Attitudes of mexican geneticist towards prenatal diagnosis and selective abortion. American Journal of Medical Genetics 1998;75:426-431.
- Alderson P. Down's syndrome: cost, quality and value of life. Social Science and Medicine 2001;53:627-638.
- Wong SI. At home with Down syndrome and gender. Hypatia 200217(3):89-117.

3. Discussion

- Non directiveness
  - Medical model – Self fulfillment linked with multiplicity of opportunities
  - Majoritarian cultural prejudice
    - No cultural benefit can be greater than social or medical risks
  - “normal” = “optimal”
  - “risk” = possibility of suffering
  - Medecine/genetics → reduce likelihood of propagating the condition
- Doubt about neutrality – core bias is against abnormality
- Disability Rights Movements
  - Disability is linked to physiological chracteristic and not to characteristics of the society in which people with the condition live their lives

4. Discussion

- Genetic Counseling Series
  - Switch from negative consequences focus
  - Prospective realistic views
    - One trait ≠ whole person
  - Social construction theory of disability
    - Tolerance
    - Golden rule variation
    - Acceptance of vulnerability and inevitable disability of most of our lives
    - Value disabilities as a difference
    - Respect perspective and knowledge that is unfamiliar to us
    - Need for communication of multiple voices

- Patterson A and Satz M. Genetic counseling and the disabled: Feminism examines the stance of those who stand at the gate. Hypatia 2002;17(3):118-142
- Turbull D. Genetic counselling: Ethical mediation of eugenic futures? Futures 2000;32:853-865

Conclusion

- PDC should perform audits of its decisions
- Multidisciplinary evaluations in all third trimester interruptions is strongly recommended
- Intrahospital clinical ethics consultation service could be responsible for pedagogy
- Model of genetic counseling needs to be contextualized
- Physicians and communities need to debate the role of prenatal diagnostic services

Conclusion

- Future studies
- Acceptability of handicap: physician, family, community
- Morality: Responsibility for prevention of suffering, costs to society vs slippery slope towards eugenism

Conclusion

- Future studies
- Decision making process in perinatal medicine
- Perceived and actual roles of physicians by speciality, by sex
- The practice :role of genetic counseling by type (directive or less directive) and diseases