



Health care professionals' attitudes about pregnancy termination for different fetal anomalies

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Abstract

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BACKGROUND:

Health care professionals (HCPs) may be involved in counselling women after an antenatal diagnosis of various fetal anomalies. Many pregnant women consider termination of pregnancy (TOP) after antenatal diagnosis of various fetal anomalies. Little is known, however, about the attitudes of HCPs regarding TOP for specific antenatal diagnoses.

OBJECTIVE:

To determine the attitudes and opinions of HCPs in maternal and child health regarding TOP for fetal anomalies of varying severity.

METHODS:

An anonymous questionnaire was distributed to four groups of HCPs: obstetric residents; paediatric residents; delivery room nurses; and neonatal intensive care nurses. Respondents were asked about TOP if they or their spouse were to receive an antenatal diagnosis for five prenatally diagnosed conditions: trisomy 21; trisomy 18; cleft lip and palate; Turner syndrome; and hypoplastic left heart syndrome.

RESULTS:

Two hundred eighty HCPs answered the questionnaire (90% response rate). Ten per cent of respondents would not consider TOP under any of the circumstances described. Among those who would consider TOP, they were most likely to do so for trisomy 18 and least likely for cleft lip and palate, and fairly evenly divided among the remaining three conditions (hypoplastic left heart syndrome [65%], trisomy 21 [56%] and Turner syndrome [37%]). Paediatric residents were less likely to choose TOP than other groups and obstetrics residents were most likely.

CONCLUSIONS:

Attitudes of HCPs toward TOP vary according to prenatally identified condition and professional group. More rigorous analysis should be performed regarding the process of counselling and the impact

of HCPs beliefs on parental decisions.

Keywords: Ethics, Health care providers' opinions, Pregnancy termination, Prenatal counselling, Prenatal diagnosis, Trisomy 18, Trisomy 21, Turner syndrome

Antenatal diagnosis is now possible for a wide range of conditions. Parents who receive an antenatal diagnosis must decide whether to consider termination of pregnancy (TOP) and generally turn to health care professionals (HCPs) for advice. HCPs generally strive to provide nondirective counselling. Parents, however, report that they are often given specific recommendations about the advisability of continuing or terminating pregnancies (1–3).

Little is known about how doctors and nurses themselves feel about various medical conditions for which antenatal diagnosis is available. These studies demonstrate a variability among HCPs in their acceptability of TOP for various diagnoses (4,5). These studies have not examined what physicians would do if their own fetus was found to have congenital anomalies. The aim of the present study was to determine the attitudes of residents and nurses who work in paediatrics and obstetrics about TOP after various antenatal diagnoses.

METHODS

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The present study is an anonymous questionnaire study, which received institutional review board approval. Residents and nurses in paediatrics and obstetrics were asked their personal opinions about TOP in various antenatal diagnosis scenarios. The target group of residents were training in one of the eight residency training programmes at the four Quebec university centres in 2007. The nurses were those who work in the delivery room, maternity ward and neonatal intensive care units (NICU) in one of the University Health Centers.

Respondents were asked about their attitudes regarding TOP for themselves or their spouse given five different prenatal diagnoses: Trisomy 21 (T21); Trisomy 18 (T18); hypoplastic left heart syndrome (HLHS); Turner syndrome; and cleft lip and palate (CLCP).

This was a pen and paper questionnaire which was given to respondents during a group meeting (eg, before a nursing meeting). The specific question asked was “If you/your partner were 16 weeks pregnant with any of the following confirmed diagnoses would you want the pregnancy terminated: Down Syndrome (T21); trisomy 18 (T18); unilateral cleft lip and palate; Turner syndrome (X0); and hypoplastic left heart syndrome (HLHS)?” The possible responses were: “yes”, “no”, “unsure”. Demographic information was also collected.

SPSS software (Version 16, IBM Corporation, USA) was used for statistical analysis. Descriptive statistics were used; χ^2 was used to compare proportions between groups. Multiple logistic regression was used to examine the relationship between answers related to termination and the following factors: age; having children or not; religion (entered as Christian, Muslim, atheist or other) and profession (five categories: paediatric resident, obstetric resident, and nurses who were entered as three separate groups based on the environment where they worked). Years in practice was not significant on initial analysis and was not considered in the multivariate regression. There was only one male nurse; therefore, we did not analyze sex as an independent variable. Results were considered to be statistically significant when $P < 0.05$.

RESULTS

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One hundred sixty-five of 173 residents (95%) and 115 of 136 nurses (85%) completed the survey. The demographic characteristics of the study population are shown in [Table 1](#). In the resident group, there were more males, the average age was younger and more respondents had no children. Children's hospital (CH) nurses were younger, had fewer years of experience and fewer had children.

TABLE 1

Demographic information of respondents

	DR	NICU-MAT	NICU-CH	Paeds	Obs
n	31	38	46	99	65
Age 25 to 30 years	7	8	26	66	65
Age 31 to 40 years	55	30	32	18	16
Junior resident	X	X	X	52	41
Nurse <5 years exp	19	24	41	X	X
Nurse >10 years exp	42	34	26	X	X
Female	100	100	96	70	83
Christian	90	86	85	61	62
Muslim	0	3	0	13	8
Jewish	0	0	0	5	6
Atheist	10	11	15	12	19
Other	0	0	0	9	5
Have a child	84	74	41	17	21

Data presented as %. DR Delivery room nurse; NICU-MAT Maternity neonatal intensive care nurse; NICU-CH Children's hospital NICU nurse; Paeds Paediatric residents; OB Obstetric residents; exp Experience; X Not applicable

The percentage that would choose termination of pregnancy in each of the five conditions is shown in [Table 2](#). There were four main findings: 10% of HCPs would not terminate for any scenario, this was only associated with religion and with no other factor; T18 was the condition where HCPs were most likely to say yes (82%) and religion was the only factor associated with this answer, (Muslim respondents were less likely to respond that they would terminate for T18); HCPs were least likely to say yes (6%) if the condition was CLCP, and this was not associated with any demographic factor of the respondents; and for the other three conditions – T21, Turner syndrome and HLHS – there was greater disagreement. HCPs had different answers, primarily depending on the HCPs work discipline, whether he/she has children and on religion. [Table 3](#) shows the OR from the logistic regression analysis, rounded to one decimal point; although age was entered into the regression it was not a significant factor for any of the diagnoses and is therefore not shown in the table. The details of these findings are given below.

TABLE 2

Percentage of respondents who chose termination of pregnancy (answered 'yes' to question) for different fetal anomalies

	DR	NICU-MAT	NICU-CH	Paeds	Obs
n	31	38	46	99	65
Trisomy 21	58	58	61	43	73
Trisomy 18	71	74	83	74	75
Turner syndrome	47	58	54	19	38
CLCP	7	6	8	5	5

	DR	NICU-MAT	NICU-CH	Paeds	Obs
HLHS	55	58	80	61	62

Data presented as % unless otherwise indicated. CLCP Cleft lip and palate; HLHS Hypoplastic left heart syndrome. DR Delivery room nurse; NICU-MAT Maternity neonatal intensive care unit nurse; NICU-CH Children's hospital NICU nurse; Peds paediatric residents; OB obstetric residents

TABLE 3

OR for willingness to terminate a pregnancy affected by certain disorders

Category	Group	Antenatal diagnosis				
		HLHS	Turner syndrome	CLCP	Trisomy 21	Trisomy 18
Profession						
	Paediatric residents	Reference	Reference	Reference	Reference	Reference
	Obstetric residents	0.8 (0.4 to 1.6)	2.6 (1.3 _* to 5.5)	0.8 (0.2 to 3.4)	4.5 (2.1 _{**} to 9.6)	2.1 (0.8 to 5.8)
	Delivery room nurses	0.6 (0.2 to 1.5)	5.6 (2.0 _{**} to 16.0)	4.5 (0.8 to 25.3)	2.9 (1.1 _* to 7.8)	0.6 (0.2 to 1.9)
	NICU-MAT nurses	0.6 (0.3 to 1.6)	5.8 (2.2 _{**} to 15.1)	0.7 (0.07 to 7.2)	2.9 (1.1 to 7.1) [*]	0.7 (0.2 to 2.1)
	NICU-CH nurses	2.55 (1.1 _* to 6.0)	5.5 (2.4 _{**} to 12.7)	1.9 (0.4 to 7.8)	2.3 (1.0 _{**} to 5.1)	0.9 (0.3 to 2.6)
Religion						
	Christian	2.1 (0.6 to 7.0)	1.2 (0.3 to 4.0)	0.4 (0.07 to 2.1)	0.88 (0.3 to 2.6)	0.5 (0.05 to 3.7)
	Muslim	0.2 (0.07 _* to 0.8)	0.4 (0.1 to 2.5)	N/E	0.08 (0.01 _{**} to 0.5)	0.07 (0.008 _* to 0.7)
	Atheist	2.1 (0.6 to 7.0)	0.8 (0.2 to 3.2)	0.7 (0.1 to 4.8)	0.2 (0.6 to 8.6)	0.4 (0.04 to 3.6)
	Other	Reference	Reference	Reference	Reference	Reference
Parenthood						
	Children	Reference	Reference	Reference	Reference	Reference
	No children	1.2 (0.6 to 2.3)	2.0 (1.0 to 3.9)	2.3 (0.6 to 8.9)	2.0 (1.0 _{**} to 4.0)	2 (0.9 to 4.3)

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Data expressed as OR (95% CI).

*P<0.05 compared to reference group;

**P<0.01 compared to reference group. CLCP Cleft lip and palate; HLHS Hypoplastic left heart syndrome; N/E Not estimable because zero respondents in this group would terminate; NICU-MAT Maternity neonatal intensive care unit; NICU-CH Children's hospital NICU

Trisomy 21:

There were fewer paediatric residents who would want termination for Down syndrome (43%) than in the other groups, particularly in comparison with obstetric residents (73% ($P < 0.001$)) ([Table 2](#)). In multivariate analysis, those who would choose termination for Down syndrome were less likely to be paediatric residents, have children themselves or identify their religion as Muslim. The ORs for willingness to terminate because of Down syndrome are shown in [Table 3](#).

Turner syndrome:

Residents were less likely to want termination than nurses ($P < 0.05$) ([Table 2](#)). The likelihood of choosing TOP because of Turner syndrome was not associated with age of respondents, sex, years of training/experience, or having children or not. Paediatric residents were less likely than others to choose termination for Turner syndrome ([Table 3](#): ORs between 2.6 and 5.8 [$P < 0.01$] for each comparison).

HLHS:

Paediatric and obstetric residents had similar answers (61% versus 62%, respectively). Eighty per cent of CH nurses would terminate pregnancy for HLHS, significantly more than other groups ($P < 0.05$) ([Table 1](#)). In the multiple logistic regression analysis, CH nurses were more likely to choose termination for HLHS ([Table 3](#)). Muslims were less likely to terminate than other religious groups.

DISCUSSION

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The majority of the previous studies examining people's attitudes and beliefs about pregnancy termination for fetal indications following antenatal diagnosis focus on the choices of parents, not professionals ([6](#)).

The underlying assumption of such studies appears to be that it is the parents' decision and that they come to it with well-formed values and preferences. We believe, however, that this overlooks an important part of the decision-making process. HCPs – both doctors and nurses – can have a big influence on parental understanding of antenatally diagnosed conditions and can, thus, influence parental decisions about TOP. HCPs are supposed to counsel parents nondirectively; however, when HCPs have strong personal beliefs it may be difficult to hide them. Furthermore, in some cases, parents ask professionals for an opinion or a recommendation.

We found that paediatricians in training would be less likely to terminate a pregnancy in a wide variety of conditions. This is important because among these groups, paediatricians are the ones who have the most direct contact with families living with children with these conditions. and the most in depth knowledge of what the quality of life is like. Paediatricians may also be less likely than the other groups to counsel pregnant women after an antenatal diagnosis. This could lead to decisions about termination that are not well informed. We did not find any difference between the opinions of junior and senior residents. It may be that residents quickly acquire these values during their training. Residents who routinely care for children with T21 are likely to acquire different values to those who are involved in prenatal counselling which may also involve terminations. It is also possible that the values of medical students influence which residency program they choose to enter. More studies are needed to determine if residents' opinions change over the course of their training or when they become attending physicians.

These findings raise interesting questions about nondirective counselling in delivery rooms or on paediatric wards. At the least, they suggest that paediatricians should be routinely involved in antenatal counselling; however, it is unclear how paediatricians should be involved. Paediatricians and obstetricians may not share common agendas when meeting these families. Should pregnant women who are facing difficult decisions have access to as much information and as many different points of view as possible, or should they meet several HCPs, for example a paediatric cardiologist, a cardiac

surgeon, a neonatologist and an obstetrician, simultaneously? The second option may increase patient and provider satisfaction.

We don't know what effect the beliefs of HCPs have on decisions by pregnant women about termination. To better understand that we would require data on actual decisions by people who received the antenatal diagnoses in question and more detailed qualitative data about the conversations that took place.

Questionnaire studies such as this have limitations. It is unclear whether opinions would translate into actions if the caregiver was truly in the specific situation. We do not know the degree to which professionals bias their presentation towards their own opinion when counselling pregnant women. Finally, the present study was performed in only one Canadian province; therefore, results might not be generalizable to other settings.

Given these limitations, our results should be taken as tentative, suggesting further lines of research rather than firm conclusions. The attitudes of HCPs about TOP following a variety of antenatal diagnoses suggest ways of thinking about and studying quality-of-life for children with various conditions. They also suggest the need for further study on the process and outcome of antenatal counselling in these clinical situations.

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