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Original Paper

# Selective Withholding of Treatment of Severely Handicapped Newborns : The Ethical Views of Nursing and Medical Students

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Key words : medical ethics, withholding of treatment, nursing and medical education, questionnaire survey

Abstract

A questionnaire survey on the ethical attitudes of nursing and medical students towards a heavily handicapped fetus or newborn posed two kinds of questions: *how would they react if their (or their wives') fetus or newborn was diagnosed as severely handicapped,* and *how would they respond to decisions about treatment by other parents whose fetus or newborn was said to be severely handicapped.* The results reported in this paper show significant differences between two student groups in their ethical attitudes. The nursing students show concerns about the improvement of the handicapped baby's living environment; the medical students focused on the physical and mental conditions of the handicapped per se.

## Introduction

Highly developed specialties as well as close teamwork are expected of medical professionals in contemporary medical fields as they work together for patients. It is reported, however, that various medical professionals have developed different professional values and ethical principles, and those kinds of differences have been observed between nurses and physicians more than between any other medical professionals. The survey revealed that the roles each profession is expected to perform lead to the consolidation of different ethical attitudes towards patients (Watanabe 1997). One of the reasons for this differentiation may lie in the fact that it is only the professionals in individual medical fields who are responsible for the education of newcomers to their fields. Nursing students acquire their professional knowledge and values from senior nurses actually working with patients, while medical students learn from practicing medical doctors. The same is the case in professional fields such as physical therapists, occupational therapists, speech therapists, and social workers.

Nurses, who are required to cooperate with physicians, are experiencing ethical dilemmas in their one-sided relations with physicians, partly because they are often rejected as to their care proposals by physicians, and have to follow physicians' directions (Fry, 1994:p179). Even if the ethical differentiation between different medical professions is inevitable, it does not seem to be desirable to leave the wide ethical gap between nurses and physicians such as it is, since they have to work together in close interaction with patients. This ethical gap may foster mistrust among patients towards medical services as a whole.

In other words, proper medical service can't be provided if all medical professionals, who work for the same purpose of helping patients towards recovery, do not share the same basic values and ethical principles.

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It has been of great interest to medical researchers as to whether it can be permissible or even desirable for a particular medical profession to develop specific values and ethical principles and whether this kind of differentiation is already observed in the very early stages of professional education.

A questionnaire survey was conducted on the ethical attitudes of nursing and medical students towards heavily handicapped fetuses or newborns. Two kinds of questions were asked: how would they react if their (or their wives') fetus or newborn was diagnosed as severely handicapped, and how would they respond to the decisions about treatment by other parents whose fetus or newborn is said to be severely handicapped. The results reported in this paper show significant differences between two student groups in their ethical attitudes.

## Purpose and Method

The purpose of this research is to analyze the respective views of nursing and medical students concerning the medical treatment for severely handicapped fetuses and newborns. The questionnaire survey was conducted between April 1999 and March 2000. The Chi-square test was applied to define the difference between the two student groups.

## Results and Discussion

1. Gender and Age of Respondents

Table 1 refers to the gender and age groups of the respondents. It shows that 95.9% of the nursing students and 46.7% of the medical students are female, and that 44.6% of the nursing students are less than 20 years old, while 52.7% of the nursing students and 72.4% of the medical students are between 20 and 24.

2. Reactions when their own Fetus is Diagnosed as Defective

When asked how they would react if their (or their wives') fetus was found to be 'mentally defective' while an abortion was still possible (See Table 2), the first choice of the nursing students (42.5%) was that they would 'ask for as much treatment as possible' for their 'mentally defective' fetus, while only 16.4%

Table 1 Description of the Respondents

| | Nursing students (n=74) | | Medical students (n=30) | |
|---|---|---|---|---|
| | n | % | n | % |
| Gender | | | | |
| Male | 3 | 4.1 | 16 | 53.3 |
| Female | 70 | 95.9 | 14 | 46.7 |
| total | 73 | 100.0 | 30 | 100.0 |
| Age | | | | |
| -19 | 33 | 44.6 | 3 | 10.3 |
| 20-24 | 39 | 52.7 | 21 | 72.4 |
| 25-29 | 2 | 2.7 | 4 | 13.8 |
| 30-34 | 0 | 0.0 | 1 | 3.4 |
| total | 74 | 100.0 | 29 | 100.0 |

No answers were excluded

Table 2 Reactions When Your Fetus Is Diagnosed as Handicapped

| | Nursing students (n=74) | | Medical students (n=30) | | $\chi_2$ |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Reactions when your fetus is found to be mentally handicapped while an abortion is still possible | | | | | |
| 'ask for abortion.' | 12 | 16.4 | 13 | 43.3 | |
| 'ask for as much treatment as possible' | 31 | 42.5 | 8 | 26.7 | |
| 'take no action' | 2 | 2.7 | 0 | 0.0 | ns |
| 'D.K.' | 28 | 38.4 | 9 | 30.0 | |
| total | 73 | 100.0 | 30 | 100.0 | |
| Reactions when your fetus is found to be physically handicapped while an abortion is still possible | | | | | |
| 'ask for abortion.' | 4 | 5.5 | 2 | 6.7 | |
| 'ask for as much treatment as possible' | 40 | 54.8 | 14 | 46.7 | |
| 'take no action' | 3 | 4.1 | 0 | 0.0 | ns |
| 'D.K.' | 26 | 35.6 | 14 | 46.7 | |
| total | 73 | 100.0 | 30 | 100.0 | |

No answers were excluded

of them chose abortion. A substantial percentage of them (38.4%) answered 'don't know' and suspended judgment. On the other hand, 43.3% of the medical students answered that they would chose abortion, while only 26.7% of them said they would 'ask for as much treatment as possible'. This shows a sharp contrast between the two student groups. The percentage of medical students who answered 'don't know' (30.0%) was almost as high as the nursing student group.

When asked what to do if their fetus was physically handicapped, more than half of the nursing students (54.8%) answered that they would 'ask for as much treatment as possible'. The percentage is higher by more than 10 points compared with the hypothetical case of mentally defective infants. The percentage of nursing students who chose abortion was as low as 5.5%, and the percentage of those who suspended judgment was 35.6%. In both cases of mentally and physically defective fetuses, about 40% of the nursing students answered 'don't know' and suspended judgment. But compared with the medical students, the nursing students opted for more treatment showing their pro-life attitude in both cases where the fetus' brain was so damaged that his/her mental development would not be expected, and where he/she was so physically defective that the chance of his/her physical development was very low.

On the other hand, 46.7% of the medical students answered that they would 'ask for as much treatment as possible' for a physically handicapped fetus. The percentage is higher by 20 points compared to the case where he/she was mentally handicapped. The percentage choosing abortion when he/she was 'physically' handicapped was only 6.7%, which is lower by 36.6 points than in the case where he/she was mentally handicapped. This indicates that the students have a more positive and pro-life attitude for a physically handicapped than a mentally handicapped fetus. But the percentage that chose 'don't know' was 46.7%, and it was as high as the percentage choosing the option 'ask for as much treatment as possible'. This means that when a fetus was physically handicapped, the opinions of medical students were divided between 'don't know' and 'ask for as much treatment as possible'.

3. Opinions about Providing Treatment to Newborns According to the Severity of Handicaps

The study presented four cases of newborns with different handicap prognoses to determine how the severity of handicaps affected the opinions of the nursing and medical students (Fig. 1-4).

The questions asked surveyed their opinions covering the withholding of treatment. Case 1: would be for a critically handicapped newborn who, according to the physician's prognoses, die within a few days; Case 2: for a handicapped newborn who could live several more years if treatment is provided; Case 3: for a handicapped newborn who is expected to live in a vegetative state throughout his/her life even when treatment is provided; and Case 4: for a severely handicapped newborn.

In Case 1, 27.0% of the nursing students answered 'treatment can be withheld', while 8.1% answered 'treatment should be provided'. Of those, 59.9% answered 'depends', which means approximately 60%

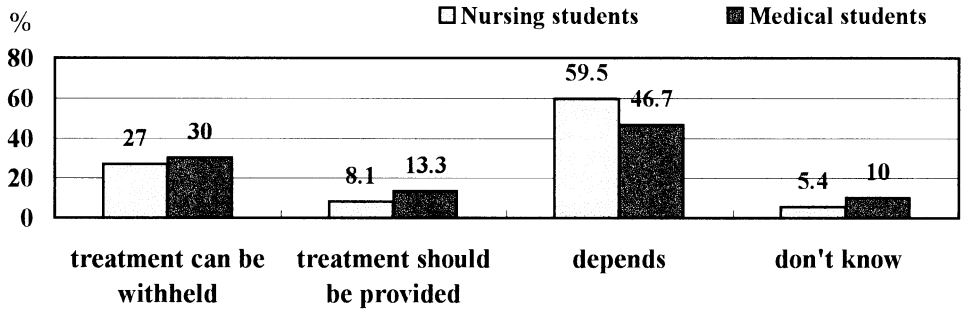


Fig. 1 Opinions on the Withholding of Treatment for 'a Critically Handicapped Newborn Who is Expected to Die within a Few Days' (Case 1)

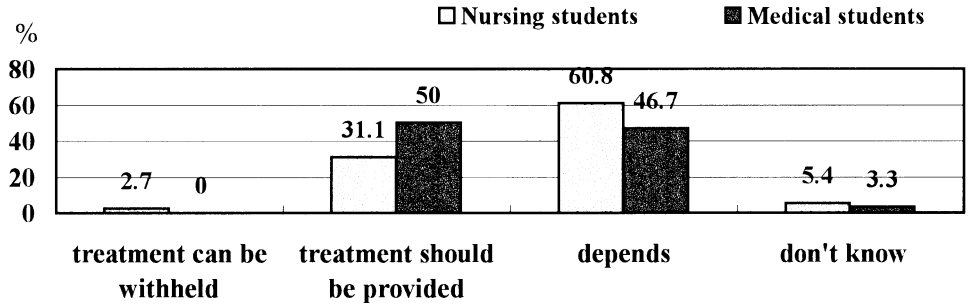


Fig. 2 Opinions on the Withholding of Treatment for 'a Handicapped Newborn Who Might Live Several More Years When Treatment is Continued' (Case 2)

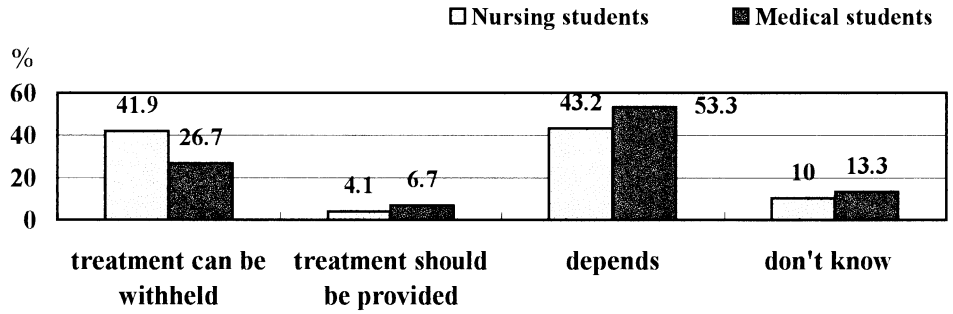


Fig. 3 Opinions on the Withholding of Treatment for 'a Handicapped Life Who is Supposed to Live in the Vegetative State Through his Life When Treatment is Continued' (Case 3)

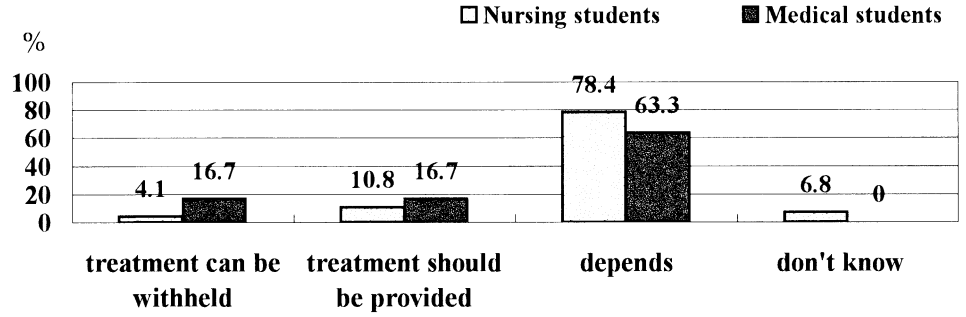


Fig. 4 Opinions on the Withholding of Treatment for 'a Severely Handicapped Newborn' (Case 4)

of the nursing students suspended judgment. The medical students showed a similar tendency: 30.0% of them answered 'treatment can be withheld', and 13.3% of them answered 'treatment should be provided'. The percentage of suspension among medical students was 46.7%, which is lower by more than 10 points compared with the equivalent in the nursing students. In this case, both the nursing and medical students approved of non-treatment when a baby is critically handicapped and he/she would die, according to the medical prognosis, within a few days.

In Case 2, where a baby can live several more years, the majority of the nursing students (60.8%) answered 'depends', and suspended judgment just as with Case 1. But 31.1% answered that 'treatment should be provided'. The percentage is higher by 23 points than the equivalent in Case 1, where a baby can live only a few days. The percentage who chose the answer 'treatment can be withheld' was only 2.7%. On the other hand, 50.0% of the medical students answered 'should be provided'. The percentage was higher by 18.9 points when compared with the nursing students. And while 46.7% of medical students answered 'depends', no one chose the option that 'treatment can be withheld'. The fact that their opinion is divided between the provision of treatment and the abstention of judgment with no answers for non-treatment suggests that the medical students show a stronger tendency for providing treatment than the nursing students when the prospect for life still remains.

In Case 3, there is a great possibility for a life-long vegetative state, which means that the child will not be able to communicate with his/her parents for life and can expect only a very limited mental development. The nursing and medical students who chose 'should be provided' were few. The percentages were 4.1% and 6.7% respectively. On the other hand, more students, that is 41.9% of the nursing students and 26.7% of the medical students, approved the withholding of treatment. The fact that the percentage of the nursing students who approved non-treatment was higher by 15.2 points than that surveyed from the medical students should be noted. Further, 53.3% of the medical students and 43.2% of the nursing students responded 'depends'. This was the only case in which a higher percentage of medical students suspended judgment than did the nursing students.

In Case 4, wherein a baby is severely handicapped, 4.1% of the nursing students chose 'treatment can be withheld,' while 10.8% of them answered 'should be provided,' and 78.4% said 'depends'. The fact that the percentage of those suspending judgment was highest in this case shows that they seemed to hesitate strongly about deciding whether to provide treatment or not. The percentage of the medical students who answered 'treatment can be withheld' and 'should be provided' are both 16.7%, which shows a clear contrast, though the percentage itself is low. This kind of contrast of opinions between pro-treatment and non-treatment was observed only in this case. But the medical students also showed as high a ratio of suspending judgment as did the nursing students. The vague specification of case details might be the

reason for the low ratio of clear pro-and-con and the high ratio of suspended opinion.

In all four cases a higher percentage of the medical students chose 'should be provided' than did the nursing students which indicates that the medical students are already building a specific frame of mind influenced by their future role as providers of medical treatment. But in the two cases in which 'a newborn is predicted to live in a vegetative state' and 'a newborn is predicted to die within a few days', both groups showed a readiness to accept non-treatment. There was a tendency among the nursing students to avoid clear judgment. The option of 'depends' was the first choice of the nursing students in all four cases.

4. Selective Non-treatment and the Best Interest of the Child

Since it is difficult to foresee the effect of treatment on a critically handicapped newborn, any decision, whether it is for treatment or for non-treatment, tends to put medical practitioners into a serious bioethical dilemma (Nishida 1987). Nevertheless, a decision on treatment must be made either by parents or physicians since the baby lacks decision-making ability. And the decision to be formed should be based on the best interest of the child (Suzuki 1998).

In my survey, twelve factors which are thought to be the constituents of 'the best interest of the child' were presented and asked to be prioritized for the purpose of knowing which factors the students weighed more heavily (Tables 3 and 4).

Table 3 Opinions of Nursing Students on Factors in the Best Interests of the Child

| | very important | | fairly important | | not so important | | not important at all | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| To help the child be accepted by his family | 60 | 83.3 | 11 | 15.3 | 1 | 1.4 | 0 | 0.0 |
| To help the child be accepted by neighbors | 58 | 78.4 | 14 | 18.9 | 2 | 2.7 | 0 | 0.0 |
| To relieve the child of mental pain | 55 | 74.3 | 15 | 20.3 | 4 | 5.4 | 0 | 0.0 |
| To give substantial social support to the child | 53 | 71.6 | 19 | 25.7 | 2 | 2.7 | 0 | 0.0 |
| To relieve the child of physical pain | 45 | 61.6 | 25 | 34.2 | 3 | 4.1 | 0 | 0.0 |
| To give substantial social support to the child's family | 45 | 60.8 | 26 | 35.1 | 3 | 4.1 | 0 | 0.0 |
| To broaden the possibility of a cure for the disease | 43 | 58.9 | 25 | 34.2 | 5 | 6.8 | 0 | 0.0 |
| To help the child grow up mentally | 34 | 45.9 | 31 | 41.9 | 9 | 12.2 | 0 | 0.0 |
| To help the child grow up physically | 25 | 33.8 | 34 | 45.9 | 15 | 20.3 | 0 | 0.0 |
| To lessen mental burdens of the child's family | 19 | 26.0 | 41 | 56.2 | 13 | 17.8 | 0 | 0.0 |
| To prolong the child's life | 17 | 23.0 | 36 | 48.6 | 21 | 28.4 | 0 | 0.0 |
| To lessen financial burdens of the child's family | 16 | 21.9 | 35 | 47.9 | 22 | 30.1 | 0 | 0.0 |

The top five factors chosen by the nursing students as most important were: 'to help the child be accepted by his family' (83.3%); 'to help the child be accepted by neighbors' (78.4%); 'to relieve the child of mental pain' (74.3%); 'to give substantial social support to the child' (71.6%); and 'to relieve the child of physical pain' (61.6%).

Judging from the results above, the nursing students seem to put more weight on the living conditions of the child such as the acceptance by his/her family and neighbors and the provision of substantial social support.

The medical students also placed their first priority on helping the child be accepted by the family (73.3%), which shows that they too considered the child's living conditions to be the most important. The second to the fifth factors on the list indicate, however, that the medical students put more emphasis on analgesic effects and the child's development than did the nursing students: 'to relieve the child of physical pain' was chosen by 70.0%; 'to help the child grow up mentally' 60.0%; 'to relieve the child of mental pain' 60.0%; and 'to help the child be accepted by neighbors' 56.7%.

Table 4 Opinions of Medical Students on Factors in the Best Interests of the Child

| | very important | | fairly important | | not so important | | not important at all | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| To help the child be accepted by his family | 22 | 73.3 | 8 | 26.7 | 0 | 0.0 | 0 | 0.0 |
| To relieve the child of physical pain | 21 | 70.0 | 8 | 26.7 | 1 | 3.3 | 0 | 0.0 |
| To help the child grow up mentally | 18 | 60.0 | 12 | 40.0 | 0 | 0.0 | 0 | 0.0 |
| To relieve the child of mentally pain | 18 | 60.0 | 12 | 40.0 | 0 | 0.0 | 0 | 0.0 |
| To help the child be accepted by neighbors | 17 | 56.7 | 10 | 33.3 | 1 | 3.3 | 2 | 6.7 |
| To give substantial social support to the child | 16 | 53.3 | 12 | 40.0 | 2 | 6.7 | 0 | 0.0 |
| To help the child grow up physically | 15 | 50.0 | 14 | 46.7 | 1 | 3.3 | 0 | 0.0 |
| To give substantial social support to the child's family | 13 | 43.3 | 16 | 53.3 | 1 | 3.3 | 0 | 0.0 |
| To broaden the possibility of a cure for the disease | 12 | 40.0 | 15 | 50.0 | 2 | 6.7 | 1 | 3.3 |
| To prolong the child's life | 6 | 20.0 | 17 | 56.7 | 7 | 23.3 | 0 | 0.0 |
| To lessen mental burdens of the child's family | 6 | 20.0 | 19 | 63.3 | 4 | 13.3 | 1 | 3.3 |
| To lessen financial burdens of the child's family | 3 | 10.0 | 16 | 53.3 | 11 | 36.7 | 0 | 0.0 |

The medical students put more emphasis on removing a child's physical pain, as well as the potential of a child's mental development and removing a child's mental pain.

The factors that received the least response in terms of percentage among the two groups were the same: 'to prolong the child's life'; 'to lessen mental burdens of the child's family'; and 'to lessen financial burdens of the child's family'. The last factor was at the bottom of the priority list. It might be interpreted as the students viewins medical expenses as a problem to be taken over by society as a whole, as opposed to any one single family.

As to the importance of 'broadening the possibility for a cure of the disease', 58.9% of the nursing students said it was very important (the $7^{th}$ on the list), while only 40.0% of the medical students considered it very important (the $9^{th}$ on the list). The medical students seem to put less weight on the possibility of curing diseases in deciding treatment.

No nursing students regarded any factors listed as 'not important at all.' But some medical students chose three factors as 'not important at all'. Those were: 'to help the child be accepted by neighbors'; 'to broaden the possibility of a cure for the disease'; and 'to lessen the mental burdens of the child's family'. We observed that the nursing students tended to look at the daily conditions surrounding the child while the medical students tended to focus on the relief of suffering and the development of the child.

5. In the Case of Parents and Medical Practitioners Having Opposing Opinions

Medical expenses are sometimes quite heavy when a critically handicapped infant is to be treated. Social assistance might be available as part of public policies for neonatal medicines or for medical treatment of refractory diseases. In most cases, however, when parents are told at the birth of their child that their baby is severely handicapped and asked to decide whether treatment is to be provided, it would be their urgent concern as to how much of the expense they should be ready to pay. It has been reported recently that medical practitioners experience an ethical dilemma when they can't start treatment for a handicapped newborn because of the refusal by his/her parents (Sakata 1995). Financial and other considerations might be affecting the parents' decision for non-treatment.

Nursing and medical students were asked questions that referred to parents' refusal of treatment. The results are showed in Table 5.

When asked for their opinion about the parent's refusal of treatment because of a heavy financial burden, the nursing students were divided exactly into two groups. They answered 'understandable' (50.0%) and 'depends' (50.0%). Some medical students disapproved of the refusal, choosing 'not understandable' (6.9%), but many of them responded that it can be 'understandable' (51.7%), or 'it depends' (41.4%).

Responding to the question as to whether parents have a right to refuse treatment when the baby's handicap is not critical, the first choice of the nursing students was 'it depends' (39.2%), followed by 'yes' (36.5%), and the negative answer 'no' was chosen by 17.6%, and 'don't know' by 6.8% of them. On the other hand, the first choice of the medical students was 'no' (46.7%), followed by 'depends' (43.3%), and 'yes' (6.7%).

When a child's right to receive treatment conflicts with the parents' right to decide on treatment including non-treatment, many of the nursing students supported the parents' decision to refuse treatment, while the medical students were negative in approving the parents' refusal ($p<0.01$).

Physicians cannot provide treatment to children when their parents refuse it (Otani 1997). Then, a question about how medical professions should react to the parents' refusal was posed. Asked whether the physician in charge of a baby should provide treatment on their own judgment against parent's refusal when the baby's handicap is not critical, 5.4% of the nursing students answered 'yes,' 47.3% of them answered 'no', and 39.2% said 'depends.' By contrast, 20.0% of the medical students answered 'yes', 33.3% of them

Table 5 Opinions on Treatment When Parents and Medical Practitioners Have Opposing Opinions

| | Nursing students (n=74) | | Medical students (n=30) | | $\chi_2$ |
|---|---|---|---|---|---|
| | n | % | n | % | |
| On the parents' refusal when family is under heavy financial burden | | | | | |
| 'understandable' | 36 | 50.0 | 15 | 51.7 | |
| 'not understandable' | 0 | 0.0 | 2 | 6.9 | |
| 'depends' | 36 | 50.0 | 12 | 41.4 | ns |
| 'don't know' | 0 | 0.0 | 0 | 0.0 | |
| total | 72 | 100.0 | 29 | 100.0 | |
| On the parents' right to refuse treatments when the baby's handicap is not critical | | | | | |
| 'yes' | 27 | 36.5 | 2 | 6.7 | |
| 'no' | 13 | 17.6 | 14 | 46.7 | |
| 'depends' | 29 | 39.2 | 13 | 43.3 | $p<0.01$ |
| 'don't know' | 5 | 6.8 | 1 | 3.3 | |
| total | 74 | 100.0 | 30 | 100.0 | |
| On the continuation of treatments on the physician's own judgment against the parents' refusal when the baby's handicap is not critical | | | | | |
| 'yes' | 4 | 5.4 | 6 | 20.0 | |
| 'no' | 35 | 47.3 | 10 | 33.3 | |
| 'depends' | 29 | 39.2 | 12 | 40.0 | ns |
| 'don't know' | 6 | 8.1 | 2 | 6.7 | |
| total | 74 | 100.0 | 30 | 100.0 | |

No answers were excluded

answered 'no', and 40.0% said 'depends'.

In this question, too, the nursing students expressed their position for respecting a parent's decision to refuse treatment rather than the continuation of treatment based on a medical judgment. Medical students, on the other hand, showed strong preference for providing treatment and less inclination towards accepting a parent's decision.

Medical information about a child given to parents strongly influences the decisions about treatment parents make for the child. The way the information is transferred from physicians to parents also affects the decision-making. Then, how much information should be disclosed to a patient's family in order to guarantee responsible decision-making by them needs to be discussed.

Responding to our question as to whether physicians have a duty to give all the information they have on a patient to his/her family, the majority of the nursing students (67.6%) answered 'yes', 29.7% of them answered 'depends', and 2.7% said 'no'. As for the medical students, on the contrary, the majority (56.7%) answered 'depends', 30.0% of them answered 'yes', and 13.3% said 'no'. Judging from this result, while

the nursing students seemed to have a strong inclination to think that all information on a child should be given to the parents, the medical students showed a tendency to think that all information should not necessarily be disclosed to parents. The latter could be interpreted as the medical students holding a positive attitude towards information control by medical professionals.

One questionnaire survey to inpatients (Tanaka 2001) shows that 30% of respondents were of the opinion that it should be left to doctors as to how much medical information should be revealed for each patient to make a responsible decision. It is a big problem in the patient-physician relationship that patients still remain dependent on and controlled by medical professionals in deciding medical treatment.

## Conclusion

The following has appeared evident from the questionnaire survey of nursing and medical students concerning medical treatment for severely handicapped fetuses and newborns:

**1.** The nursing students tend to choose as much treatment as possible for a fetus, whether it is mentally or physically defective. They did not give different weight to the possibilities of physical and mental development of the fetus. The medical students, on the other hand, showed a tendency to opt for non-treatment for a mentally defective fetus, which is a negative attitude showing a contrast with a pro-treatment attitude by the nursing students for a physically defective fetus.

**2.** Many respondents in both student groups suspended judgment concerning treatment in Cases 1 through 4. But they showed an inclination to approve selective non-treatment in Cases 1 and 3. The medical students were more strongly in favor of treatment in all four cases. In other words, the medical students seemed to believe in the effects of treatment more than the nursing students.

**3.** Concerning factors in the best interest of the child which should be considered first when a decision is to be made on the treatment of a child, the nursing students put more weight on the living conditions of the child than on their physical and mental conditions, while the medical students chose the latter as more important.

**4.** The nursing students tended to respect a parent's decision even if the parent, as an agent of a child, refused treatment for the child, while the medical students showed a tendency to opt for commencement and continuation of treatment.

The nursing and medical students, who will eventually work together as medical professionals, are at an early stage of their career as students already forming different ideals and values regarding a patient's life. Questions raised are: whether these kinds of differences in attitude can be acceptable on the grounds that the students will be expected to perform different professional roles; how much ethical attitudes should be shared by both groups since they have to work in close collaboration; and how much differentiation can be allowed or might be desirable. They are still to be answered.

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