The impact of the prenatal ultrasonography on birth of babies with Korean pediatric surgical index diseases

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Purpose: The purpose of this study is to examine the impact of prenatal ultrasonography (US) on the birth of babies with diseases listed on the Korean pediatric surgery index diseases (IDs).

Methods: Depending the ease of diagnosis using prenatal US, [diagnostic facility if prenatal US] IDs were divided into easily diagnosed (ED), not easily diagnosed (NED) and detected with difficulty (DD) groups. Five-year data were obtained for the total live birth number (TBN) from the Korean Statistical Information Service, and the actual birth number of IDs (ABNID) from the Korean Health Insurance Review and Assessment Service. The certified incidences of IDs (I) were obtained from a prestigious textbook of pediatric surgery. The estimated abortion rate (AR) of fetus in each group was obtained using the following formula: AR (%) = \[1 - \frac{(ABNID)}{(TBN \times I)}\] × 100.

Results: The AR with all IDs was 38 to 77%. The AR was 78 to 93% for ED group, 38 to 66% for NED group and 0% for DD group.

Conclusion: In spite of high survival rates after treatment, the AR of each group depends on the ease of diagnosis using prenatal US in Korea. A recommendatory policy for the fetus with IDs should be urgently established after general consensus within the related medical societies.

Key Words: Prenatal ultrasonography, Birth rate, Induced abortion, Congenital, Fetus

INTRODUCTION

With economic growth and easy accessibility to medical services, prenatal ultrasonography (US) has been popular in Korea. With improved resolution of US and development of related diagnostic modality, the diagnostic accuracy of prenatal US has also been increased. Owe to these, fetuses with anatomical abnormality have been more frequently detected and accurately diagnosed by prenatal US in Korea.

Some of anatomical abnormalities that are prenatally detected or diagnosed are surgically correctable disease entities by pediatric surgeons, in which the survival rate and quality of life are remarkably improved after appropriate surgical treatment. The survival rate in these babies has been generally reported up to 90% [1-5].

The Korean Association of Pediatric Surgeons (KAPS) had selected major surgical diseases of infants as Korean...
pediatric surgical index diseases (IDs), and has reviewed annually the trend in their incidence, diagnostic tools, treatment modalities, and prognosis of ID [1-5]. In recent years, however, the incidence of some IDs has severely decreased, and such IDs exactly matched with those that can easily be diagnosed on prenatal US. These phenomena suggest that it is highly related with inappropriate abortions occurred in this group of IDs despite the high survival rate after appropriate postnatal treatment. This is presumed to cause many serious ethical, social and academic issues [6].

The aim of this study is to examine the impact of prenatal US diagnosis on abortion of these IDs in Korea, to recognize the seriousness of this issue, to establish the opportunity for building consensus between related medical and social authorities, and to obtain appropriate solutions.

METHODS

Study period

In Korea, the most accurate nationwide patient statistics can be obtained from the Health Insurance Review and Assessment System (HIRA) as almost all Korean citizens are currently covered by a national health insurance system. Accordingly, we could use the data collected over the past five years, from January of 2005 to December of 2009 from HIRA, since this study began in April 2010.

The selection and group assignment of IDs

We selected seven pediatric surgical IDs which have relatively high incidence and require unique surgical treatment within postnatal two months. Selected IDs were classified into three groups based on the ease of diagnosis using prenatal US as shown below:

1) A group of diseases which can easily be diagnosed on prenatal US (easily diagnosed group; ED group)
   - Congenital diaphragmatic hernia (CDH)
   - Gastroschisis or omphalocele (GO)
   - Intestinal atresia including duodenal atresia (IA)
2) A group of diseases which can be detected on prenatal US but cannot accurately be diagnosed (not easily diagnosed group; NED group)
   - Esophageal atresia (EA)
3) A group of diseases which cannot be detected on prenatal US (detected with difficulty group; DD group)
   - Biliary atresia (BA)
   - Anorectal malformation (ARM)
   - Congenital megacolon (CMC)

Total live birth number (TBN)

We obtained the annual TBN during study period from the Korean Statistical Information Service. Since the TBN of 2009 was not available while this study was conducted, we estimated it using a formula shown below:

\[
\text{The estimated TBN of 2009} = \frac{\text{the 2008’s TBN + the 2010’s estimated TBN}}{2}
\]

Actual birth number of IDs (ABNID)

If the ABNID should be evaluated based on the diagnosis recorded in the HIRA data, it could include false patients with presumptive diagnosis. Fortunately, all seven selected IDs are fetal diseases required immediate postnatal surgical management. Besides, the methods of surgical treatment for these seven IDs were not performed for other diseases but done uniquely for each ID. Accordingly, for the accurate assessment of ABNID, it would be more relevant to estimate the number of patients who were surgically treated for ID rather than to estimate the number of patients based on the diagnosis. In this study, we determined the ABNID as the number of patients who were surgically treated for ID based on the diagnosis.

On April 7, 2010, KAPS made a request to HIRA for annual number of pediatric patients under age of five years and treated surgically for the seven IDs during study periods. Corresponding codes of health insurance cost for unique surgical procedures for seven IDs were claimed on an official note as shown below [7]:

1) Surgery for esophageal atresia (Ja-241; Q2411, Q2412, Q2413)
2) Surgery for diaphragmatic hernia (Ja-161; O1610)
3) Surgery for gastroschisis or omphalocele (Ja-278; Q2781)
Table 1. Annual actual birth number of diseases listed on the Korean pediatric surgical index from 2005 to 2009

| Year | TBN   | ABNID | ED | NED | DD |
|------|-------|-------|----|-----|----|
|      |       |       | CDH| GO  | IA | EA | BA | ARM | CMC |
| 2005 | 435,031| 56    | 7  | 45  | 56 | 27 | 160| 158 |
| 2006 | 448,153| 67    | 3  | 60  | 67 | 41 | 150| 158 |
| 2007 | 493,189| 66    | 20 | 62  | 66 | 43 | 167| 172 |
| 2008 | 466,000| 63    | 26 | 75  | 63 | 52 | 160| 167 |
| 2009a) | 450,000| 66    | 27 | 83  | 66 | 48 | 188| 162 |
| Total | 2,292,373| 318 | 83 | 325 | 318| 211| 825| 817 |

ABNID, actual birth number of Korean pediatric surgical index diseases; TBN, total live birth number; ED, easily diagnosed group; NED, not easily diagnosed group; DD, detected with difficulty group; CDH, congenital diaphragmatic hernia; GO, gastroschisis or omphalocele; IA, intestinal atresia including duodenal atresia; EA, esophageal atresia; BA, biliary atresia; ARM, anorectal malformation; CMC, congenital megacolon.

a) Estimated total birth number.

4) Surgery for intestinal atresia including duodenal atresia (Ja-283; Q2831, Q2832)

5) Surgery for congenital megacolon (Ja-267; Q2687, Q2688, Q2676)

6) Surgery for anorectal malformation (Ja-298; Q2981, Q2982, Q2983, Q2984, Q2985)

7) Surgery for biliary atresia (Ja-737; Q7371, Q7372)

On April 23, 2010, KAPS received the requested information produced based on criteria for determining the hospitalization with a five-year cumulated electronic data interchange from HIRA. We analyzed these data for ABNIDs.

Estimated fetal number of index disease (EFNID)

According to an internationally accredited and specialized textbook, the relative incidence (I) of IDs to total birth number were obtained [8]. Thus, EFNID is presumed to be the number of fetuses delivered without effects of prenatal US in Korea based on the formula as shown below:

\[ \text{EFNID} = \text{TBN} \times I \]

Estimated abortion rate (AR) of fetus with ID

AR with each ID and each group of IDs were also obtained using a formula as shown below:

\[ \text{AR(\%)} = \left[ 1 - \frac{\text{ABNID}}{\text{EFNID}} \right] \times 100 \]

In the cases with negative AR, the AR was set as 0.

RESULTS

TBN and ABNID

Table 1 shows the TBN and ABNID of each ID and each group of IDs during the study period.

EFNID

Table 2 shows the EFNID of each ID and each group of IDs during the study period.

AR

Table 3 shows the AR for each ID and each group of IDs during the study period. The overall AR of fetuses with ID was found to be 38 to 77%. The AR for ED, NED and DD group were 78 to 93%, 38 to 66%, and 0% respectively.

Compare with estimated fetal number of biliary atresia (EFNBA) and actual birth number of biliary atresia (ABNBA)

Table 4 shows EFNBA and ABNBA during the study period. The ABNBA from 2005 to 2007 was matched to EFNBA and ABNBA form 2008 to 2009 was larger than EFNBA.
Table 2. Estimated number of fetuses with Korean pediatric surgical index diseases from 2005 to 2009, and their incidence and survival rate from the textbook

| Congenital disorders | EFNID     | Incidence (%) [8] | Survival rate (%) [8] |
|----------------------|-----------|-------------------|-----------------------|
| Easily diagnosed group |           |                   |                       |
| Congenital diaphragmatic hernia | 458-1,146 | 0.02-0.05         | 80-93                 |
| Gastrochisis or omphalocele | 903-2,236 |                   |                       |
| Gastrochisis          | 445-1,090 | 0.02-0.049        | 97                    |
| Omphalocele           | 458-1,146 | 0.02-0.05         | 94                    |
| Intestinal atresia including duodenal atresia | 1,911-7,176 |                   |                       |
| Duodenal atresia      | 229-383   | 0.01-0.0167       | 95                    |
| Small bowel atresia   | 1,528-6,947 | 0.0667-0.303    | 90                    |
| Not easily diagnosed group |         |                   |                       |
| Esophageal atresia    | 509-939   | 0.0222-0.41       | 85-95                 |
| Detected with difficulty group | 922-1,208 |                   |                       |
| Biliary atresia       | 137-229   | 0.006-0.01        | 99                    |
| Anorectal malformation| 458       | 0.02              | 99                    |
| Congenital megacolon  | 327-521   | 0.0143-0.0227     | 99                    |
| Total                 | 4,703-12,705 |                 |                       |

EFNID, estimated fetal number of index diseases.

Table 3. Estimated abortion rates of fetuses with Korean pediatric surgical index diseases from 2005 to 2009

| Group (diseases)               | Abortion rates (%) |
|--------------------------------|--------------------|
| Easily diagnosed group         | 78-93              |
| Congenital diaphragmatic hernia | 31-72              |
| Gastrochisis or omphalocele    | 91-96              |
| Intestinal atresia including duodenal atresia | 83-95     |
| Not easily diagnosed group     | 38-66              |
| Esophageal atresia             | 38-66              |
| Detected with difficulty group  | 0                  |
| Biliary atresia                | 0-8                |
| Anorectal malformation         | 0                  |
| Congenital megacolon           | 0                  |
| Total                          | 38-77              |

Table 4. Annual actual birth number and estimated number of fetuses with biliary atresia from 2005 to 2009

| Year | ABNBA | EFNBA |
|------|-------|-------|
| 2005 | 27    | 26-44 |
| 2006 | 41    | 27-45 |
| 2007 | 43    | 30-49 |
| 2008 | 52    | 28-47 |
| 2009 | 48    | 27-45 |
| Total| 211   | 138-230 |

ABNBA, actual birth number of biliary atresia; EFNBA, estimated fetal number of biliary atresia.

DISCUSSION

Prenatal US has promptly progressed since the 1980s, and recently widely used in Korea. It has greatly contributed to medical examination and treatments in obstetrics as it allowed accurate diagnosis of various types of structural diseases occurring in fetus during pregnancy.

A positive aspect of prenatal diagnosis of structural diseases is that various types of complications can be monitored by screening a high-risk group during pregnancy. Serious complications can be prevented by preemptively planning postnatal treatment. Furthermore, as fetal development of congenital diseases can be monitored during intruterine period, various interventional procedures such as fetal surgery can also be performed.

However, a negative aspect of prenatal US also could not ignore, and it can increase inappropriate abortion in Korea. According to Article 14 of the Maternal Child Health Law of Korea, “The restricted permission of abortion of pregnancy,” abortion is not allowed when it is performed for fetal diseases.

Nevertheless, abortion abuse is an unavoidable and harsh truth in Korea and still frequently performed for illegal reasons, including:

1) In Korea, anatomical abnormalities present at birth are commonly called “gi-hyung” in Korean (deformity in English). Traditionally, this term has a negative conno-
tation. For this reason, pregnant women with fetal congenital malformation tend to consider abortion at least once.

2) Under the Confucian thoughts in Korea, open discussion on sex is avoided. So, adequate sexual and contraceptive educations have been insufficiently provided until nowadays. As a result, many women end up with unwanted babies.

3) Since the 1960s, the Korean government has actively implemented a family planning policy to control population increase by lowering the birth rate. Meanwhile, abortion has been easily accepted and considered as one of the contraceptive methods.

4) Besides, the cost of Korean health insurance coverage for delivery, one of major income of obstetricians, has been seriously underestimated. To compensate this, many obstetricians have performed illegal abortions which are not subsidized by the national health insurance and that is why expensive.

From a worldwide perspective, it has been analyzed that 24 to 32% of pregnancy cases are aborted [8]. In Korea, no definite statistic data have been collected because most abortions are illegal under the current Korean law “the Maternal Child Health Law of Korea” and have been performed in secret. The only available nationwide statistics on number of abortions in Korea are found in a study commissioned by the Korean Ministry of Health and Welfare and conducted by Korea University Research and Business Foundation in 2005 [10]. According to this study, based on a questionnaire survey of 201 among a total of 1,900 obstetric clinics, more than 342,000 abortions occurred annually. This figure corresponds to 78% of TBN in the corresponding year in Korea. However, these results are considered to be still underestimated, and so the actual number of abortion is expected to be higher [10]. In 1994, the Gallup Korea performed a questionnaire survey on 1,000 women. According to the survey, an annually performed abortions were approximately 1,500,000 which is a two-fold increase from 720,000 in 1995. In U.S., whose population is six times greater than Korea and abortion is legally permitted, more than 346,000 abortions have been occurred annually. In the neighboring country, Japan, annually 300,000 abortions have been reported. Therefore, the Korean status of abortion is considered as very serious abuse than other countries [10].

The motives of this study is that occurrence of some newborn diseases has significantly dropped as compared with decrease of birth rate in Korea. Common feature of these diseases is can be easily diagnosed or detected on prenatal US [11]. Therefore, we established a hypothesis for this study that ease for prenatal diagnosis of fetal disease on US contributed to fetal abortions in Korea. It was very difficult to design a study to prove our hypothesis because there is no accurate data about illegally and secretly performed abortions. To overcome this practical limitation, we estimated abortion rate using actual birth number and estimated birth number in each fetal disease. This study may not show actual abortion rate for each fetal disease. However, we still believe that our study is significant because the data were estimated with reasoning due to a lack of the accurate data in Korea. The reliability of estimated data in this study can be found for BA as follows:

1) BA is proper example for confirming the reliability because it cannot be diagnosed with prenatal US and actual incidence does not decrease by abortion.

2) The reliability of this study can be confirmed by comparing the estimated fetal number of BA and the actual birth number of BA (Table 4).

3) As shown in Table 4, the actual number of patients with BA during the study period was exactly matched to that of fetuses that were presumed to have BA.

The results of this study indicate that the fetal diseases which are easily diagnosed on prenatal US lead to more prevalent abortions in Korea, and the abortion rate of each group depend on the ease of diagnosis using prenatal US (Table 3). This could be accepted as a matter of course considering a harsh truth that abortions are easily attempted even for normal fetuses in Korea. With our results, however, it is unavoidable to discuss the seriousness of misuse of abortions for fetal diseases in Korea (Table 2). Of diseases in ED group, GO are good examples. As shown in our data, 91 to 96% of fetuses with GO were aborted, despite postoperative survival rate was 95% (Table 2). There are no any other specific problems in GO except surgical scars in their abdomen, so these abortion cannot be
acceptable. The prenatal US finding might strongly influence parents’ decision on abortion because intra-abdominal organs protruded from abdominal wall and it may be regarded as a monster. We also assume that obstetrician would not provide sufficient medical information to parents. Recently, the severe decrease of GO would lead to lack of clinical experiences for more young Korean pediatric surgeons. This also poses serious issues with academic continuity in Korean society of pediatric surgeons.

In western countries, such as U.S., the issue of “pro-life” (advocating protection of fetus and opposing abortion) versus “pro-choice” (advocating mothers’ choice and accepting abortion as means) has already been debated in the realm of politics. It is also considered as key indicator for the competition of policy between conservatism and liberalism. In Korea, however, the abortion debate has just begun. Even today, abortions are overtly performed under an implied agreement from medical field and the government. Recently and fortunately, the misuse of abortion has become a hot issue in Korea since some members of the Korean Society of Obstetrics and Gynecology raised ethical problem. The Korean government recently also changed its policy from previous policy lowering birth rate to promote since the nation’s birth rate has dropped to a serious low level.

At the core of these issues associated with abortion, there are universal values such as humanitarianism, as shown in issues such as euthanasia or death with dignity. Accordingly, the existence of issues about abortion implies that imprudent abortion is against the value of humanitarianism, and, thus, it cannot be justified. We think that the generalized misuses of abortion in Korea is presumed to be the most responsible cause of abortion for fetal disease, and it could be improved gradually as Korean society changes its perception of abortion.

Aside from the general abortion debates, we would like to discuss about collaboration between related medical societies and appropriate measures against imprudent abortions for fetal malformation. According to many pediatric surgeons, few mothers who are pregnant with fetal defects voluntarily choose abortion when obstetricians refer them to pediatric surgeons who are responsible for the postnatal treatment. This might be because pediatric surgeons provide more sufficient and accurate medical information about the illness, treatment courses and prognosis than obstetricians. In other words, mothers become more serious in deciding on the abortion based on the above information.

These opinions have already been presented by members of the Korean Pediatric Society [12]. According to study of Choi et al. [12], an analysis of the effects of prenatal diagnosis of congenital heart diseases on the mothers’ decision on the continuation of pregnancy, there were such unethical situations where abortions were attempted for fetuses with heart diseases which can be completely cured. As appropriate measures, they recommended that a collaborative approach should be made between obstetricians and pediatric cardiologists who are mainly in charge of the fetal cardiac anomalies. They also proposed that each related academic society should establish official medical guidelines for prenatal detected fetal cardiac anomalies [12].

We, including the members of KAPS, completely agree with above proposal of the Korean Pediatric Society. It is true that obstetricians cannot give sufficient information to mothers because they are not expert and also have lack of clinical experience about clinical course of fetal diseases after birth. It seems that mothers are rarely referred to doctors who are responsible for postnatal management when the prenatal US detects a fetal disease. In that case, mothers have to make a decision on abortion in such an unstable psychological condition without sufficient medical information or appropriate medical recommendation from experts.

It is, therefore, presumed that obstetricians are obliged to provide mothers with a chance to get more accurate medical information by referring them to specialists with more knowledge and experience about the corresponding fetal diseases. In this way, they can share their legal and ethical responsibilities with experts specializing in fetal diseases. Besides, the medical data after delivery could be shared by both parties. This also gives obstetricians an additional academic opportunity to improve their diagnostic accuracy of prenatal US.

In conclusion, at the present time, the Korean Society of Obstetrics should take the initiative in establishing official
medical guidelines for fetal diseases which are diagnosed on prenatal US by collaborating with other related academic medical societies. By doing so, medical societies might play an initiative role in drawing social agreement on issues associated with abortions performed for fetal diseases.

CONFLICTS OF INTEREST

No potential conflict of interest relevant to this article was reported.

REFERENCES

1. Kim WK, Kim SY, Kim SK, Kim IK, Kim JC, Park KW, et al. Current status (1994) of neonatal surgery in Korea: survey among the members of Korean Association of Pediatric Surgeons. J Korean Assoc Pediatr Surg 1996;2:26-32.
2. Kim IK, Kim SY, Kim SK, Kim WK, Kim JE, Kim JC, et al. Intestinal atresia: a survey by the Korean Association of Pediatric Surgeons. J Korean Assoc Pediatr Surg 1999; 5:75-81.
3. Lee MD, Kim SY, Kim WK, Kim IK, Kim JU, Kim JC, et al. Anorectal malformations in Korea: a clinical survey by the Korean Association of Pediatric Surgeons, 1999. J Korean Assoc Pediatr Surg 2000;6:106-23.
4. Lee MD, Kim SY, Kim WK, Kim IK, Kim SC, Kim SK, et al. Index cases in pediatric surgery, 2000: national survey by the Korean Association of Pediatric Surgeons. J Korean Assoc Pediatr Surg 2001;7:147-56.
5. Kim JC, Kim DY, Kim SY, Kim SC, Kim IK, Kim JE, et al. Congenital posterolateral diaphragmatic hernia in Korea: a survey by the Korean Association of Pediatric Surgeons. J Korean Assoc Pediatr Surg 2006;12:53-69.
6. Han SJ. Impact of the prenatal ultrasonography on birth of babies with Korean pediatric surgical index diseases. In: Proceeding of the 26th annual meeting of The Korean Association of Pediatric Surgeons; 2010 Jun 10-11; Daegu, Korea. Seoul: Korea Association of Pediatric Surgeons; 2010.
7. Ministry of Health & Welfare. The list of medical or non-medical care benefits of the national health insurance and relative value point of medical care benefits [internet]. Seoul: Ministry of Health & Welfare; 2009 [cited 2010 April, 7]. Available from: http://www.mw.go.kr/front/jb/sjb0401ls.jsp?PAR_MENU_ID=03&MENU_ID=030401.
8. Grosfeld JL, O'Neil JA, Fonkalsrud EW, Coran AG. Pediatric Surgery. 6th ed. Grosfeld JL, editor. Philadelphia: Mosby; 2006.
9. Tietze C, Henshaw SK. Induced abortion: a world review, 1986, 6th ed. New York: Alan Guttmacher Institute; 1986.
10. Kim HJ, Ahn HY, Kim SD, Park M, Park CS, Lim JE, et al. Report of the survey of induced abortion and it's comprehensive measures. Seoul: Ministry of Health and Welfare; 2005 Sep. Report No.: R0408081. p.211.
11. Pathak S, Lees C. Ultrasound structural fetal anomaly screening: an update. Arch Dis Child Fetal Neonatal Ed 2009;94:F384-90.
12. Choi EY, Lee CH, Yoon MJ, Han ES, Hong JS, Jung YS, et al. Impact of fetal diagnosis of congenital heart disease on parents. Korean J Pediatr 2006;49:1073-8.