

End-of-life care in Korea

: Current status in children

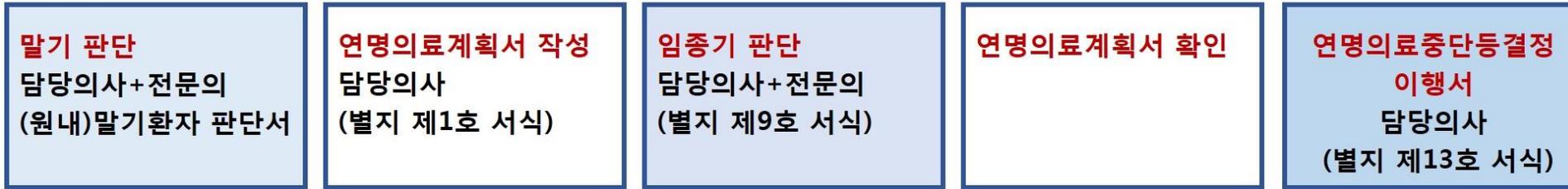
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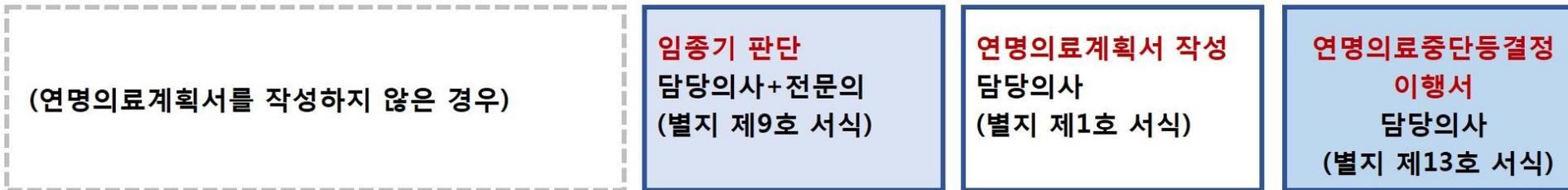
Decision on life-sustaining treatment in minor patients

의사 표현을 할 수 있는 말기 또는 임종기 환자

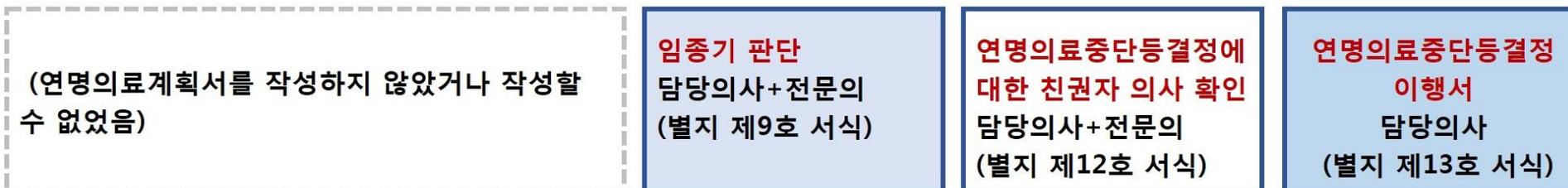
1) 말기에 연명의료계획서를 작성



2) 임종기에 연명의료계획서를 작성



의사표현을 할 수 없는 임종기 환자



Fill out official form after discussing with a child and the legal representative

No way to discuss care plan in advance for patients limited in decision-making capacity

Terminal patients who cannot express their opinion

- Three-year-old Sua (pseudonym) was diagnosed with metachromatic leukodystrophy in Jan 2017. She was gradually deteriorated in cognition and motor function for several months after diagnosis.
- Currently, she cannot recognize her mom and she is on tube feeding with intermittent unstable respiration.
- Sua's parents have searched several sources to find ways to cure the disease, but they have come to accept that the disease' s prognosis is so bad that she would die within the next several years.
- Sua's parents said they would like the child to be comfortable without receiving life-sustaining treatment if the child becomes in critical condition.
- However the doctor said they could not fill the form according the Decision Act **because she is not at the end-of-life period.**

Terminal patients who cannot express their opinion

- In Feb 2018, Sua was referred to the emergency room with desaturation with intermittent apnea and increased spasticity.
- The medical staff judged Sua's condition to be at the end-of-life period and wrote the physician's form, but at that time, Sua's father was on business trip, so there was only her mom in the emergency room.
- The doctor explained about the law to her mom and got the signature on the form
- The doctors called Sua's father and recorded his opinions that he did not want Sua to receive medical care including resuscitation and respirators.

(Progressive) incurable diseases

Prolonged dwindling

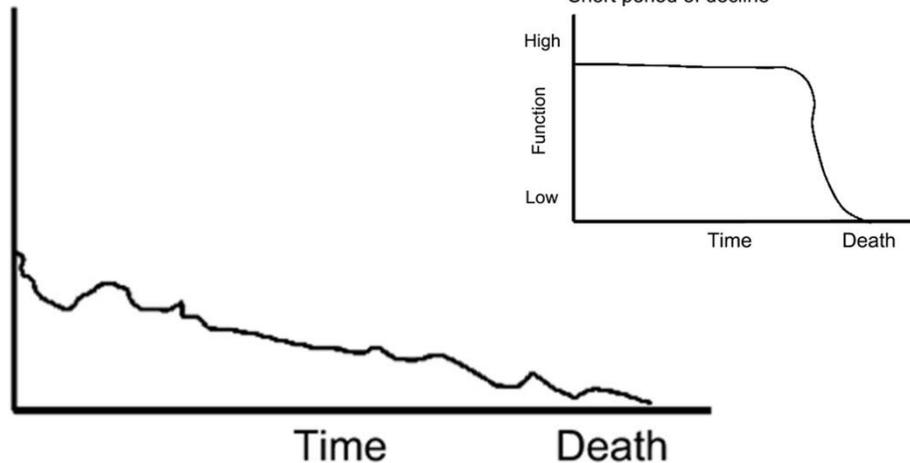


Table 2. Proportion of CCC-attributed pediatric deaths by disease category and age group, 2005–2014

Category	Infant (< 1 yr)	Children (1–9 yr)	Adolescent (10–19 yr)	All ages (0–19 yr)
Total No. of subjects	5,662	3,068	3,785	12,515
Neurologic and neuromuscular	380 (6.7)	890 (28.9)	982 (25.9)	2,252 (17.9)
Cardiovascular	1,690 (29.8)	361 (11.7)	324 (8.6)	2,375 (18.9)
Respiratory	181 (3.2)	31 (0.9)	10 (0.3)	222 (1.8)
Renal and urologic	76 (1.3)	15 (0.4)	25 (0.7)	116 (0.9)
Gastrointestinal	230 (4.0)	71 (2.2)	29 (0.8)	330 (2.5)
Hematologic or immunologic	51 (0.9)	134 (4.3)	174 (4.5)	359 (2.8)
Metabolic	85 (1.5)	82 (2.6)	67 (1.7)	234 (1.9)
Other congenital or genetic defect	771 (13.6)	141 (4.5)	60 (1.5)	972 (7.8)
Malignancy	186 (3.3)	1,325 (43.0)	2,126 (56.2)	3,637 (29.0)
Neonatal	2,070 (35.6)	47 (1.5)	1 (0)	2,070 (16.5)

Values are presented as number of patients (%).
CCC – complex chronic condition.

- Neurodegenerative disease
- Severe hypoxic ischemic encephalopathy
- Brain malformation
- Severe renal dysplasia or renal agenesis
- Syndromes with short life-span (Trisomy 13, 15, 18)
- Metabolic disorders

Issues

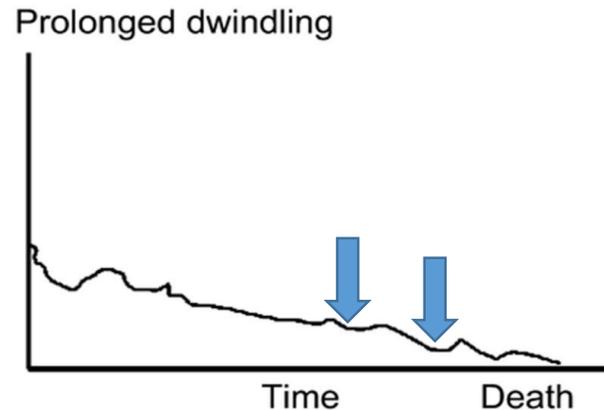
1. Low Quality of End-of-life care

- By limiting the time when the care plan can be formally established to an end-of-life period, the parents perform administrative tasks such as filling out the form at the moment of child death.
- The purpose of the Decision Act is to enhance the dignity of human beings through the reflection of the last period of life. In the case of children, however, the decision is made at a later date than before the enactment of the law.
- Patients such as HIE, neurodegenerative ds, or infant are unable to disclose their opinion on life-sustaining treatment, so decision can only be made by an agreement with the family or legal representatives.
- There should be ways to officially formulate a care plan in advance for patients who cannot express opinions such as patients with brain damage.

Issues

2. Terminal vs End-of-life process (by the law)

- **Terminal patients:** a patient who has been diagnosed as expected to die within a few months because there is no possibility of a fundamental recovery, and the symptoms gradually worsen despite proactive treatment
- **End-of-life process:** a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly



How can we recognize the end-of-life process in the patients with incurable disease?

Ethical decision making– The “Four boxes” approach

End-of-life process?

Prognostic disclosure to minor patients

- Jinho(pseudonym), 11-year-old, was diagnosed with acute lymphoblastic leukemia in December 2017 and received chemotherapy. He did not respond to induction treatment, and in response to the treatment by changing the anticancer drug, he continued chemotherapy and was preparing for hematopoietic stem cell transplantation.
- In March 2018, he was referred to emergency room with fever and headache, and recurrence was confirmed by blood tests and bone marrow examinations. Re-induction treatment was tried but it did not improve his condition.
- In the meantime, fungal infection occurred in the lungs. Although antifungal agents were used, there was no improvement in his condition and pleural effusion was rapidly increased.
- The doctor explained to the parents that it was no longer possible to try chemotherapy, and that a decision about life-sustaining treatment was needed.
- Because Jinho had the ability to understand the situation, he had to discuss his own life-sustaining treatment in order to complete POLST form.

Prognostic disclosure to minor patients

- Parents refused to let Jinho know about the situation because if he knew the situation, he would become discouraged and his condition would worsen sooner.
- After 2 days, Jinho suffered from dyspnea due to pneumonia and received iv fentanyl, but his consciousness was clear. The parents told the medical staff that they did not want to apply the LST to Jinho, such as ventilator, CPR, but they still objected to explaining the situation to him.
- The medical staff knew that because Jinho was conscious, the Decision Act required Jinho to take part in a decision. However, his parents were strongly opposed to it, and medical staffs were also worried whether it was a good thing or not.
- Jinho's pulmonary condition worsened the next day, and the doctors did not apply LST such as mechanical ventilator in accordance with the parents' decision, and he died on the day.

Prognostic disclosure to children & adolescents

1950-70s: Don't tell

- Diagnosis and prognosis could be wrong.
- It may be harmful to tell the truth.
- The child does not want to know because he does not ask.
- It is a burden on the family to inform the child of the facts.



1960-80s: Always tell

- Children are already aware of their own death.
- Mutual pretense is very difficult to stand.
- Children may be afraid to ask.
- Communicating honestly is helpful to a child in his / her end of life.



1980s-: Individual approach

- Identify wishes and expectations through sufficient discussion with parents
- Considering the patient's personality, current situation, etc.
- Determine to what extent the patient is currently understanding his / her condition
- Find a clue as to whether he/she wants to know information
- Careful consideration of family situation

- Most adolescents seem to be good at understanding prognosis and want to participate in decision making.
- However, 75% of the respondents said they wanted to know the situation, but 12% of the respondents said it was inconvenient to open communication when they were in the terminal state.

Prognostic disclosure to children & adolescents

▪ Ethical principles in pediatrics

1. Promote the well-being of child
2. Promote well-being of family
3. Respect parents as decision-makers for the child
4. Respect child's (developing) autonomy
5. Respect privacy of child
6. Respect the privacy of the parents and family
7. Allocate resources at your disposal fairly



Adolescents must be involved in decisions because decision-capacity is growing enough and often at the adult level before reaching the age of 18.

vs

Although adolescents' ability to understand is technically sufficient, it is necessary for parents to make decisions with long-term perspectives because they lack mature or life experiences.

Parents have an obligation to protect young people to make the best choices possible.

Prognostic disclosure to minor patients

- 제10조(연명의료계획서의 작성·등록 등) ① 담당의사는 말기환자등에게 연명의료중단등결정, 연명의료계획서 및 호스피스에 관한 정보를 제공할 수 있다.
 - ② 말기환자등은 의료기관(「의료법」 제3조에 따른 의료기관 중 의원·한의원·병원·한방병원·요양병원 및 종합병원을 말한다. 이하 같다)에서 담당의사에게 연명의료계획서의 작성을 요청할 수 있다.
 - ③ 제2항에 따른 요청을 받은 담당의사는 해당 환자에게 연명의료계획서를 작성하기 전에 다음 각 호의 사항에 관하여 설명하고, 환자로부터 내용을 이해하였음을 확인받아야 한다. 이 경우 해당 환자가 미성년자인 때에는 환자 및 그 법정대리인에게 설명하고 확인을 받아야 한다.
 1. 환자의 질병 상태와 치료방법에 관한 사항
 2. 연명의료의 시행방법 및 연명의료중단등결정에 관한 사항
 3. 호스피스의 선택 및 이용에 관한 사항
 4. 연명의료계획서의 작성·등록·보관 및 통보에 관한 사항
 5. 연명의료계획서의 변경·철회 및 그에 따른 조치에 관한 사항
 6. 그 밖에 보건복지부령으로 정하는 사항

○ 미성년자에 대한 연명의료계획서 작성 방법

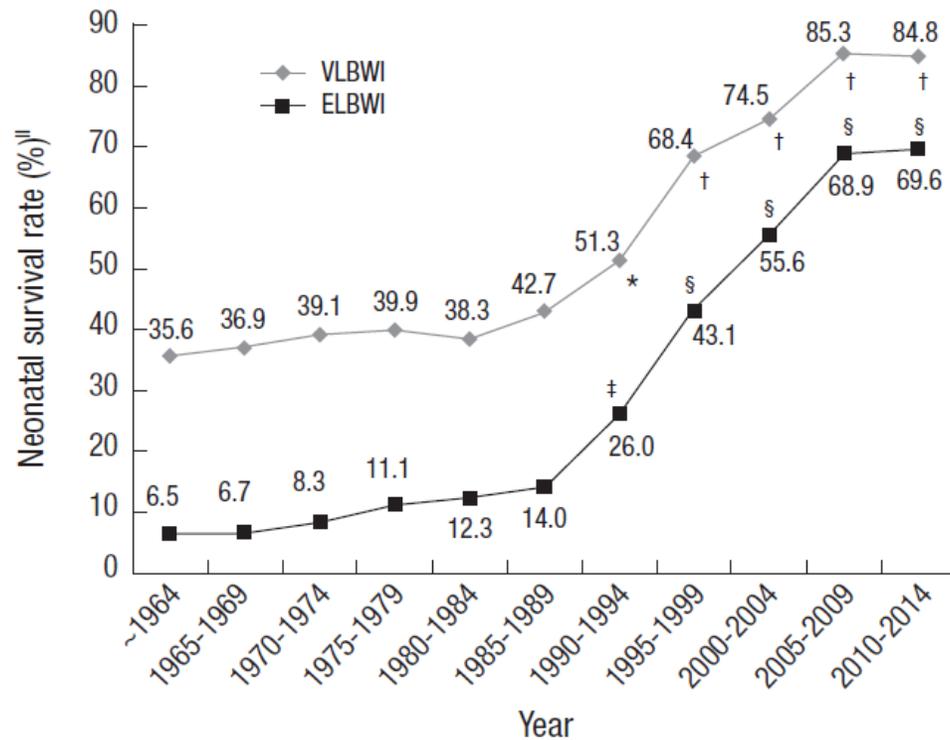
- 연명의료계획서 작성 전 설명하여야 할 사항에 관하여 해당 환자가 미성년자인 경우에는 환자 및 그 법정대리인에게 설명하여야 하고, 그 확인의 방법은 법정대리인 1명이 대표하여 서명을 하시면 됩니다. (환자 서명 불필요)

- In case of children and adolescents, individual approach is needed considering the situation of patients and family when discussing prognosis and life-sustaining treatment decision.
- Is it necessary to include individual approach to the law?– How to put it if necessary

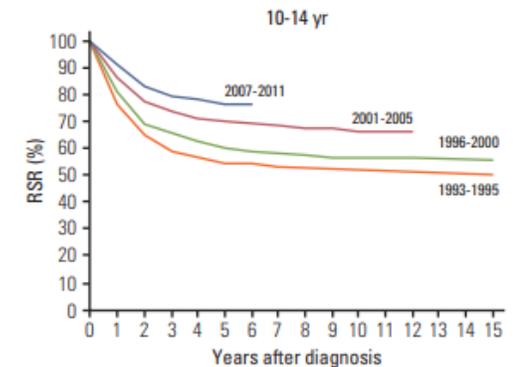
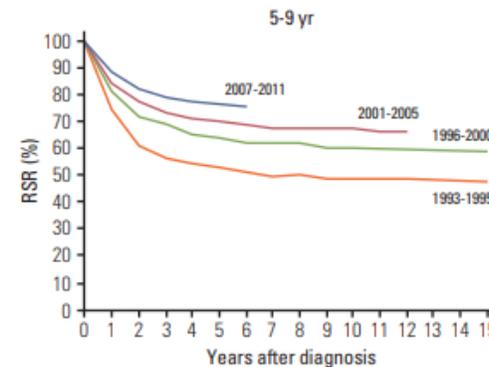
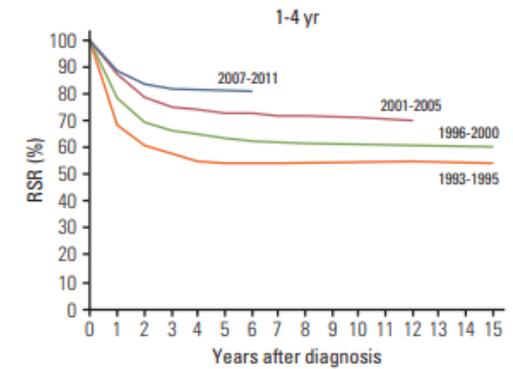
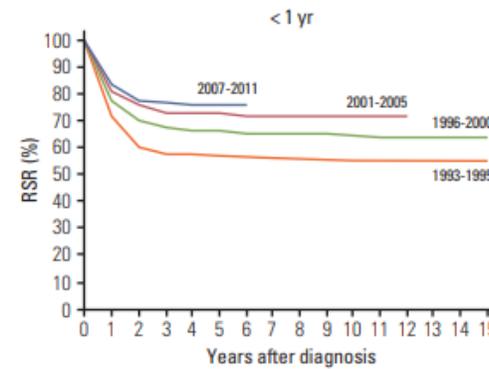
Summary

- 연명의료결정법은 생의 마지막 단계에 대한 자기결정권 보장을 처음으로 법제화하였다는 것과 불필요한 연명의료를 합법적으로 중단할 수 있는 절차를 보장하였다는 의미를 가지나 사회문화적 배경과 의료적 상황을 고려한 수정이 필요함.
- 의사표현을 할 수 없는 말기 환자의 가족이 미리 환자의 연명의료에 대한 결정을 할 수 있는 프로세스를 열어주어 존엄한 삶의 마무리를 보장하여야 함.
- 가족관계증명서의 확인은 불필요한 절차로 의도적으로 허위로 관계를 진술하였을 경우 의료진이 아니라 가족에게 책임을 묻는 형태로 논의되어야 함.
- 말기와 임종기를 구분하고 치료 결정의 범위를 '임종과정에 있는 환자의 연명의료 결정'으로 제한함으로써, 의학적 조건, 삶의 질, 환자의 선호, 배경적 상황 등을 고려하는 윤리적 의사결정을 쇠퇴 시키고 있는 점에 대한 논의와 검토가 필요함.
- 소아청소년에게 죽음이 임박하였다는 사실을 알릴 것인지를 결정할 때는 환자와 가족의 상황을 고려한 개별적 접근이 필요하고 의료진의 의사소통 기술이 매우 중요함. 이를 일률적으로 반드시 알리도록 한 법률이 적절할지에 대한 검토가 필요함.

Evolution of modern medicine: Improvement of survival rate of children with serious disease

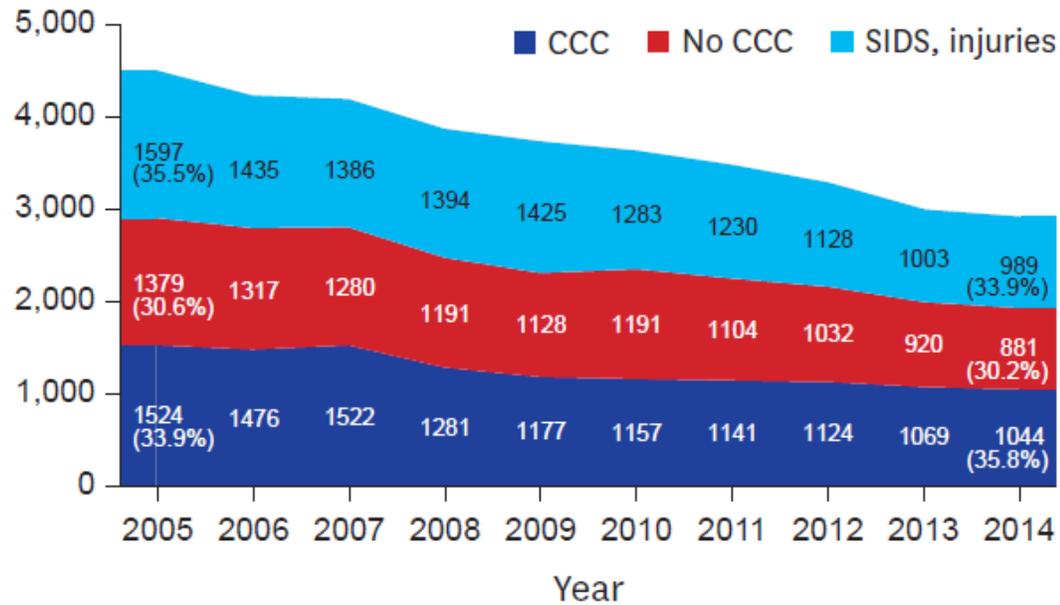


Survival rate of ELBW(<1kg)-VLBW(<1.5kg) infants in Korea
J Korean Med Sci 2015;30:S25-34



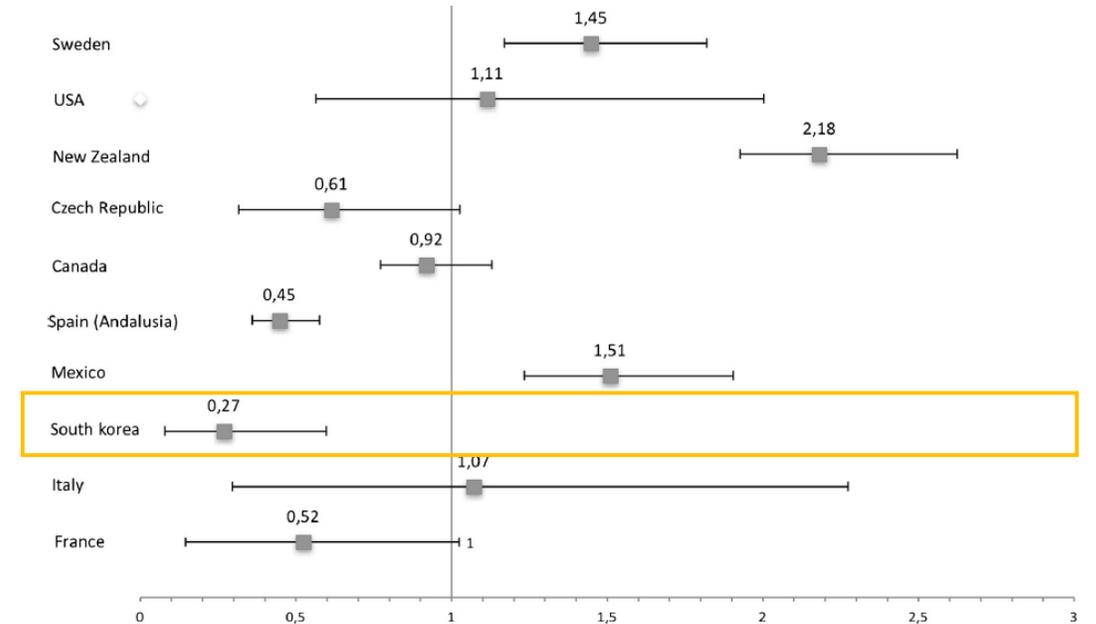
Survival rate of pediatric cancer patients in Korea
Cancer Res Treat 2016;48(3):869-82

Child Mortality in Korea



- Over 3,000 people under 19 years of age die each year in Korea
- Deaths with complex chronic conditions: 35.8%
 - <1: 41.3%, 1-9: 21.3%, 10-19: 37.4%

J Korean Med Sci 2018 Jan 1;33(1):e1



- 67.3% of children in Korea die in the hospital
- Complex chronic conditions: 85.5%

Eur J Pediatr 2017;176:327-35

Decision issues in children with serious illnesses

- **Limited quantity of life**
 - If death is imminent or premature death is anticipated
 - Hope for miracles
- **Limited quality of life**
 - How can we assess the quality of life of children?
 - Quality of life worse than death?
- **Patients with sufficient(?) decision-making ability refuse treatment**
 - Less common in children

Charlie Gard's parents say their 'beautiful boy' has died

Critically ill baby who became known around the world dies after being moved to hospice following long legal battle



▲ Charlie Gard, who has died aged 11 months, was diagnosed with a rare inherited disease in September 2016.

- London, Great Ormond Street Hospital
- At 8 weeks after birth, he was diagnosed with a rare disease and received supportive care such as ventilator. However, his brain, muscles, respiratory function deteriorated rapidly, and his heart, liver and kidney function were also damaged.
- The medical staff decided to withdraw life-sustaining devices, but the parents were opposed and went through legal proceedings.
- British courts and European Court of Human Rights have maintained the judgment of medical staff who have decided to withdraw LST.
- 자신의 의사를 표현할 수 없는 환자의 입장을 의료진이 대변하고, 이에 대하여 친권자가 동의하지 않아도 법원의 판단에 따라 그대로 진행한 사례.
- If it happened in Korea? In the US?

Case 1

- Preterm infant (GA 24+6wks, 710g) in NICU (Postmenstrual age 32+1wks)
- IVH at birth, diffuse cerebral injury
- She can open her eyes, but she has little response to painful stimuli and almost no movement. In addition, there is a possibility that the portable ventilator will be maintained in the future because the ventilator support degree is very high due to severe respiratory failure.
- The patient experienced several hypotensive shocks, but all the inotropics are stopped and her blood pressure is stable currently.
- The patient's parents asked the medical staff to stop the ventilator, saying that if the child's neurological damage was severe and the respirator had to be kept alive and live, it would only give pain to the child.

Case 2

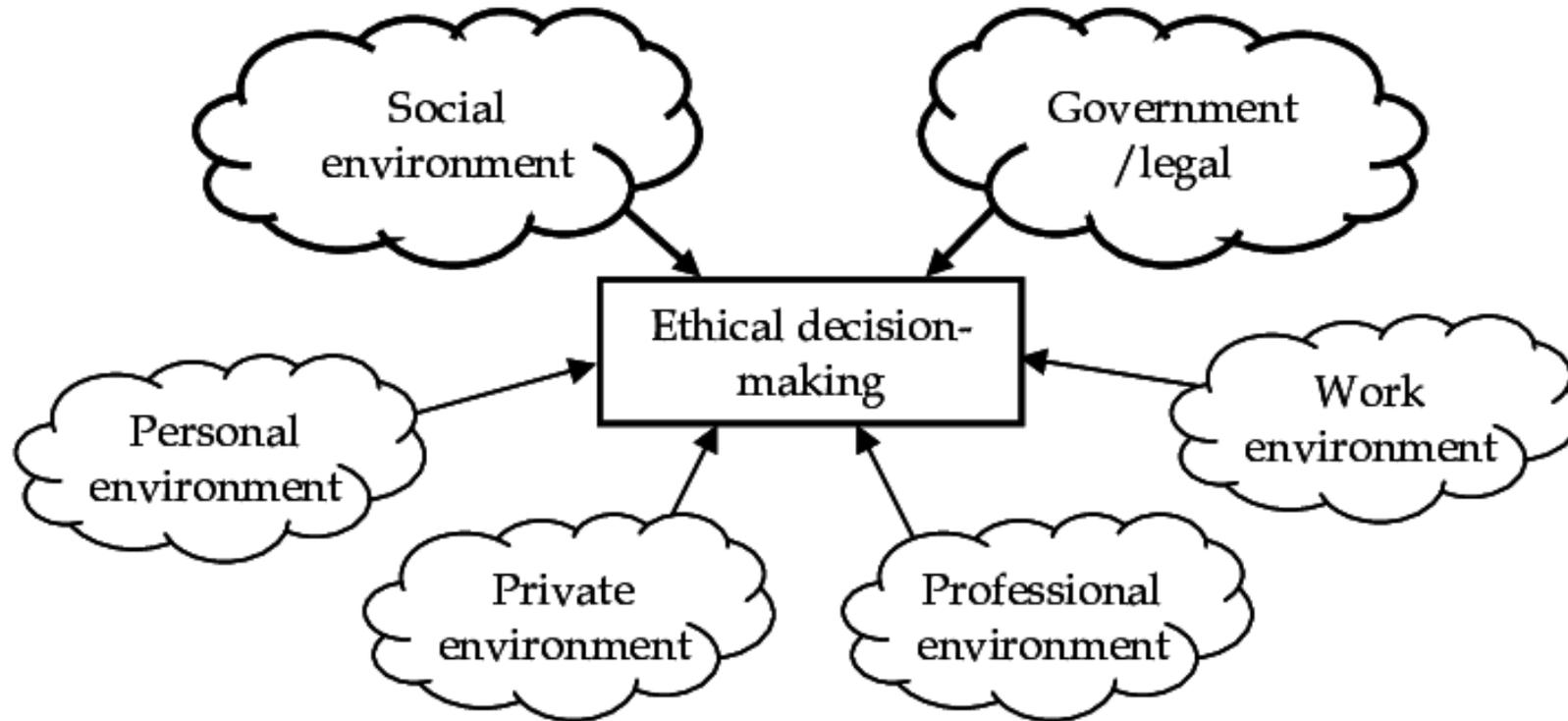
- GA 36+4wks, 2.9kg, currently in NICU
- The infant was admitted to the neonatal intensive care unit with a complex heart disease diagnosed at prenatal period. The right arm and left leg are half as short as the other.
- His heart disease requires two operations and medication. The probability of staying without serious complications immediately after surgery is more than 80%, but the complication after surgery is likely to occur in adulthood.
- Patients' parents refused surgery, saying that it is good for the patient to die easily without surgery, rather than letting the patient live with a physical disability with heart disease.
- The medical staff explained that the probability of success was high, but the parents made it clear that they have right to decide because they have to constantly take care of the patient's life after surgery.

Decision making in pediatrics

- Generally, the patient does not make decisions regarding treatment.
- The person making the decision can not be determined by the patient.
 - What is the scope of parental authority? (agreement vs permission)
- Because the patient has never been able to express his/her values with legal decision making ability, 'best interest' principle is taken into account first.
 - Discussing 'best interest' in the information inequalities related to complex medical situations
- The person making the decision has to consider the interests of the family as well as the interests of the patient.
 - patient's siblings
- Triangular relationship: patient- family- medical staffs



Factors affecting ethical decision making



Factors affecting ethical decision making – in Korea



[우리는 충분히 '돌봄' 받고 있는가](2)교통사고 당해도 입원 거부...“엄마들은 아들 자격도 없어요”

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입력 : 2018.03.09 06:00:03 | 수정 : 2018.03.09 08:16:06



• 중증질환 어린이 엄마들의 '빼앗긴 잠'



의료인 처벌규정 완화한 연명의료법 개정안

'환자 또는 가족 의사 반해 중단할 경우'에만 처벌...처벌 1년 유예는 불발

박진규 기자 승인 2018.02.22 18:47 댓글 0



Support for ethical decision making in pediatrics

- Establish and revise an institutional guideline on several issues, including the application and discontinuation of treatment
- Promoting awareness of medical staff, patients, and families about ethical issues in clinical practice
- Providing ethical counseling and deliberation on cases
- Encourage social change to create an environment where more ethical decisions can be made

Thank you for your attention

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