Revised Organ Transplant Act and Pediatricians

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Abstract

Organ transplants in children are expected to increase in number following the enactment of the revised Organ Transplant Act that enables pediatric organ transplants. However, there are various obstacles in the actual medical practice in the pediatric field. The revised Act was enacted in the midst of calls to improve the pediatric emergency medical system and the pediatric intensive care system, putting greater demands on those active in the field. It is considered that the exclusion of abused children and the provision of satisfactory terminal care will lead to transplantation medicine.

In particular, to exclude abused children properly, it is important to comply with the manual stipulated in the guideline when making a diagnosis and when excluding abused children, as well as to establish a system and cooperate with official organizations including child consultation centers and the police when investigating the personal history of children.

Considering that organ transplants are only performed by a limited number of medical professionals at pediatric departments in organ donor facilities, an increased burden on them will be inevitable. There is an urgent need for official support to improve the current system at each medical stage leading to organ transplantation.

Key words Pediatric intensive care, Legal diagnosis of brain death in children, Child abuse, Support system for the family

Introduction

The number of patients in a very serious condition is usually small in pediatric emergency medicine, as was shown by 2008 survey on the current situation of pediatric emergency medicine at emergency care centers across the nation conducted by the special committee for pediatric emergency medicine of the Japanese Association for Acute Medicine; the number of children taken to hospital by ambulance was 5.7% of that of adults, the number of children with cardiopulmonary arrest on arrival was 2.3%, and the number of children admitted to the ICU was 2.4%. In other words, the number of out-of-hospital brain deaths in children is estimated to be small although a certain proportion of children become brain dead due to underlying disease (congenital anomalies etc.).

In order to transfer a small number of these brain-dead children from emergency medicine to organ transplantation medicine successfully, a more mature view of pediatric transplantation medicine must be nurtured, not only in the pediatric medical community, but in society as a whole. To this end, problems and challenges found at each step, i.e. pediatric emergency medicine, pediatric critical care, and pediatric transplantation medicine, must be discussed by policy makers, people on the front line of medical practice, and the general public, and then national consensus must be achieved.

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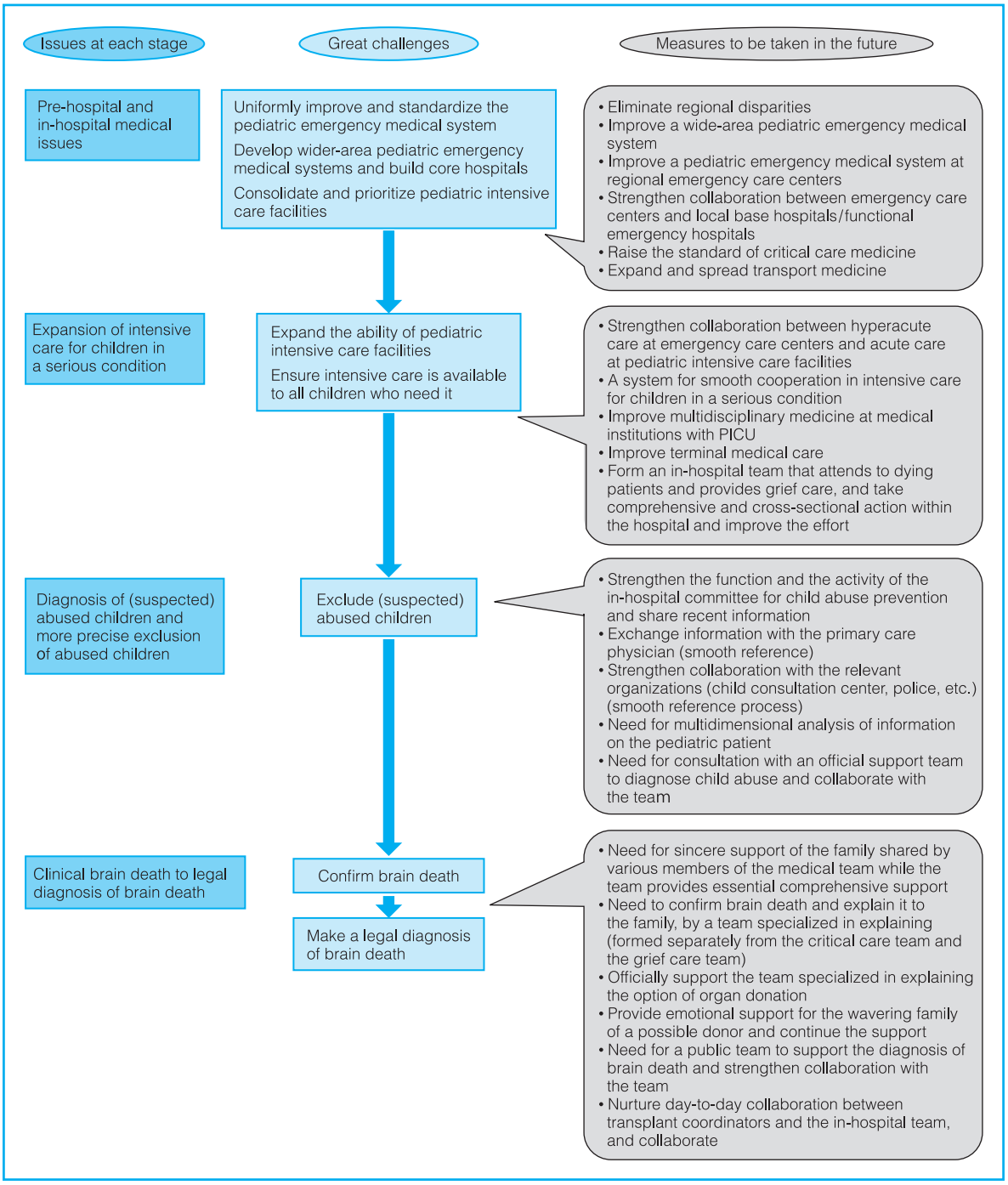

Fig. 1 Issues at each stage of pediatric emergency medicine on the way to pediatric organ donation

After the revised Organ Transplant Act took effect, organ transplants from adult donors who had not declined organ donation have been conducted with family consent/written consent form, and the number is steadily increasing. It is necessary to streamline the system in pediatrics as soon as possible to realize a bright future for children who have no other way to live but through organ transplantation.

Table 1 Items concerning the handling etc. of abused children

1. A system required for facilities dealing with pediatric organ donation
   (1) A necessary in-hospital system including a child abuse prevention committee is established to handle abused children.
   (2) Manuals etc. concerning the handling of abused children are prepared.
2. Confirmation of the presence or absence of a suspicion of abuse
   (1) If signs of abuse are detected in a child, determine whether or not there is a suspicion of abuse in an in-hospital system of handling abused children.
   (2) If it is suspected that the child is abused, report to the child consultation center as well as the police to cooperate with these organizations, and continue to handle the child in the in-hospital system.
   (3) Then, if a suspicion of abuse of the children is excluded for medical reasons, communicate that information to the relevant organizations and consider whether or not handling of abused children is necessary.
3. Handling of a case leading to organ donation
   (1) If the physician etc. intends to tell the family about the opportunity of organ donation etc., share information with the abuse prevention committee beforehand and seek any necessary advice.
   (2) If organs are to be removed from the child, an in-house organization such as the institutional ethics committee makes sure that the procedures described in 2 and 3 (1) above are properly followed, and determines whether or not the organ removal is appropriate.
   (3) If the child dies during the process of making a diagnosis of abuse, organ removal may not be performed.
   (4) Even if the institutional ethics committee etc. excludes any suspicion of abuse of the child and determines that organ removal is appropriate, cooperate with investigative organizations in case such procedures as autopsy are taken.

[Extracted and modified from the guideline for the operation of "the Organ Transplant Act" (partial amendment, July 17, 2010).[1]]

The Sections Related to Pediatrics in the Revised Organ Transplant Act

The revised sections related to pediatrics in the guideline for the operation of "the Organ Transplant Act" are "Concerning the expression of intention etc. not to donate organs," "Concerning the expression of intention by mentally retarded persons etc.," "Items concerning the coverage of the bereaved and the family," "Items concerning the facilities dealing with pediatric organ donation," "Items concerning the handling etc. of abused children," "Items concerning the diagnosis of brain death in terms of the removal of organs," etc. Among them, the handling of abused children is of great concern, and therefore appropriate measures should be taken to avoid confusion in medical practice.

Issues concerning Pediatric Organ Transplantation Medicine on the Front Line of Pediatric Emergency Medicine

There are many issues to address to provide proper pediatric organ transplantation medicine. We need to discuss these issues at each stage of medical care. (**Fig. 1**)

Improvement and uniformity in pediatric emergency medical system (especially for children in a serious condition)

Inadequacy of the pediatric emergency medical system has emerged as a social issue over the past dozen years. However, the problem has not really been solved although various proposals have been made. Regional disparity is increasing and local residents are not satisfied with the system. In particular, the emergency medical system for children in a serious condition is inadequate as has been pointed out based on the very high mortality among children aged 1 to 4 years in Japan among advanced countries.

"The review session on emergency medical system for serious pediatric patients" of The Health Policy Bureau, the Ministry of Health, Labour and Welfare reported in FY 2008 that the Pediatric Emergency Center (tentative name) should be added to medical facilities specialized in pediatric care in order to expand acute pediatric intensive care, and in addition, hyperacute pediatric intensive care should be expanded at emergency care centers across the nation. That is, it recommended a plan whereby serious pediatric patients can receive the first treatment (hyperacute treatment) at the nearest emergency care center to stabilize the condition, and are then

transferred to a medical facility with pediatric intensive care unit (PICU) to receive critical care (acute treatment).

There is a need to expand the pediatric emergency medical system as a whole with the focus on children in a serious condition, especially to eliminate regional disparities and construct a nationwide uniform system. To this end, it is essential to enhance emergency transport medicine for children, and to strengthen collaboration between the following facilities in a wide-area pediatric emergency medical system: core hospitals, emergency care centers, and medical facilities specialized in pediatric care with PICU.

Expanding ability of medical facilities with pediatric intensive care unit

In addition to improvement of the medical system itself, other improvement is necessary in software, including multidisciplinary medical care at medical facilities with PICU and medical support for terminal patients. In fact, it is essential to form an in-hospital team that attends to the dying and provides grief care, and to improve the team performances, and comprehensive and cross-functional activities of organizations within a hospital should be encouraged as the foundation.

In any case, it is ideal to provide quality emergency care for all children, and more medical facilities with PICU should be available nationwide. If parents are not satisfied with the emergency medical care provided to their child in a serious condition as a result of a sudden injury or disease, they will not be able to accept the brain death of their child.

Exclusion of (suspected) abused children

Abused children may be the biggest issue associated with the legal diagnosis of brain death prior to organ transplant at the front line of pediatric emergency medicine. Various problems are expected to derive from the issue.

In "Items concerning the handling etc. of abused children" (**Table 1**)[1] of the guideline mentioned earlier, the establishment of in-hospital organizations such as a child abuse prevention committee and the preparation of manuals are clearly stated to constantly update information on the early detection and prevention of child abuse. However, it is impossible for such an in-hospital committee alone to make a (suspect) diagnosis and a definite diagnosis of child abuse unless there is very clear evidence of abuse and a confession of the abuser. The ultimate purpose of conventional medical responses for abused children has been the safety and protection of the children, even if it could be over-diagnosed. Therefore, it will be extremely difficult to determine that an accident without any witnesses is not associated with child abuse under the current circumstances.

In fact, the medical diagnosis of abused children is different from the social diagnosis/recognition. If a medical professional suspects the existence of abuse and the family still strongly requests organ transplant, the guideline does not clearly state who should, in what way, take the initiative to decide whether or not to perform the transplant.

Furthermore, the guideline says "After that, if suspicion of abuse is excluded for medical reasons (Item 2 (3) of **Table 1**)," you cannot be sure whether the child was abused or not unless a medical professional speaks out in the first place. It is also difficult to obtain and investigate objective information such as personal history of the child when time is very limited. Therefore, child abuse is unlikely to be excluded for medical reasons, but it may be overlooked.

It is considered that it is difficult to make a legal diagnosis of brain death, except in case the child evidently became brain dead as the result of an accident with witnesses. In order to strictly select organ donors, the "flow chart" and the "check list"[2] in the "Manual for excluding abused children from brain-dead organ donors" need to be fully utilized and complied with. The manual was prepared in a study "Review of the criteria for legal diagnosis of brain death in children" (author: Fujiko Yamada) as part of a special research project, "Study on the diagnosis of brain death in children and organ donation, etc." supported by the Ministry of Health and Labour Sciences Research Grant in 2009.

Another problem may be the protection of medical professionals who continue to claim suspicion of abuse when there is no social diagnosis/recognition of such abuse, and the problem has not at all been solved yet. Needless to say, protection of families who refuse organ donation are not reviewed or even mentioned. They may receive negative reputation depending on the trend of public opinion.

It is also reasonable to exclude children if

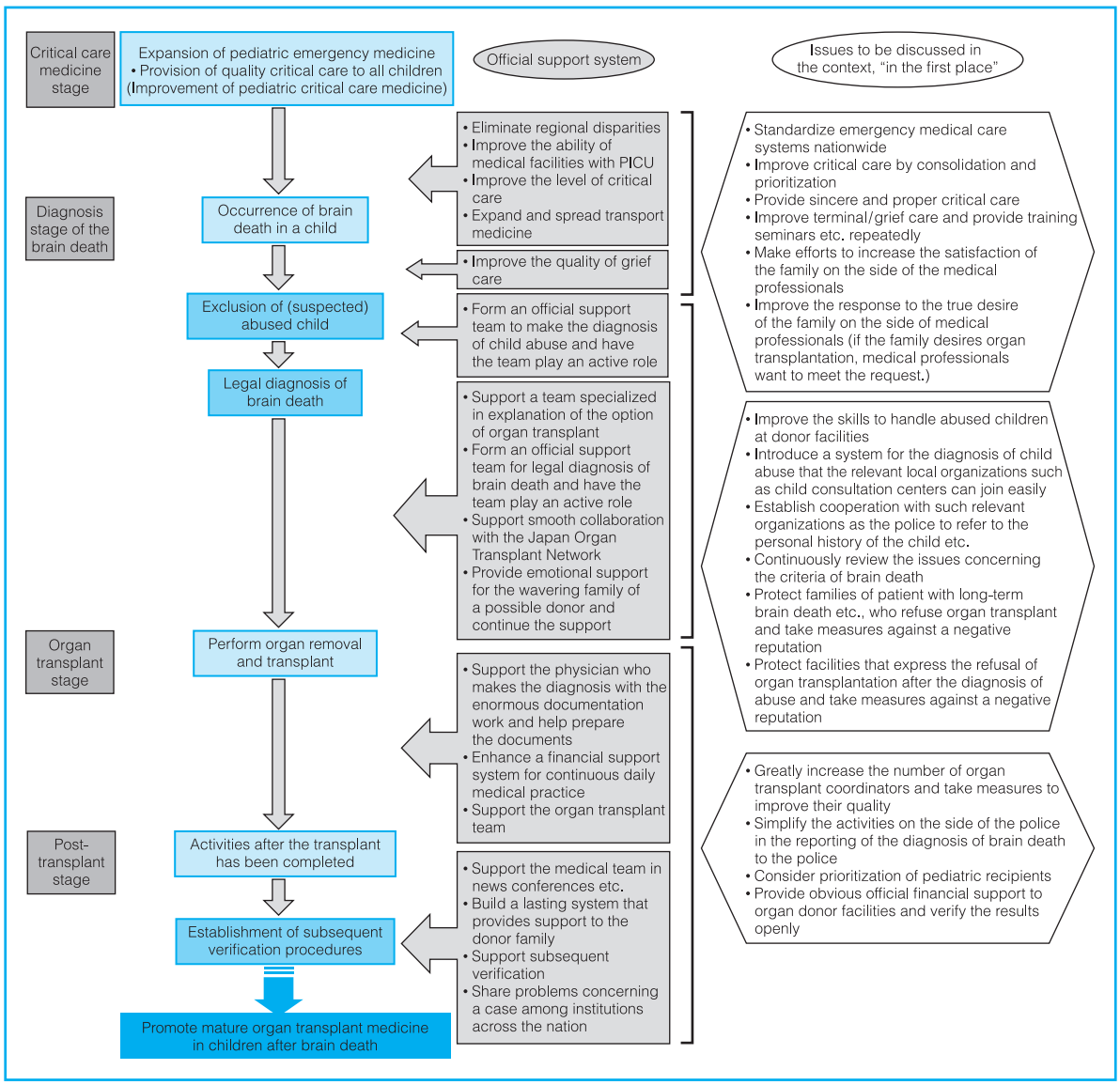

Fig. 2 Need for an official support system at each stage of organ transplantation in children after brain death

abuse is current, but there is this statement in the guideline, "Concerning confirmation of whether or not abuse was suspected." Although it sounds to refer to children with a history of abuse, the guideline is not very clear about it. In addition, it is extremely hard to identify a history of abuse in a child without any superficial scars (some scars may not be obvious after a long time), which often occurs with abuse by another blood relative than the parents or a parent who had left the family, or with sexual abuse that the child did not confess. It is also uncertain whether or not the relevant organizations and the police will respond rapidly and accurately to a reference from a medical facility. Without a clear written policy on the establishment of cooperation among these organizations, the ability of individuals would be very limited, and there would be regional disparity in the cooperation, as well as confusion in the medical practice as a result.

Taking these circumstances into account, it is impossible for an in-hospital committee for child abuse prevention alone to make a diagnosis or a judgment. It is essential for the relevant aca-

demic societies, in an effort to establish an official diagnostic system , to build "an official support team for the diagnosis of child abuse" on official request from the Ministry of Health, Labour and Welfare. In this way, organ donor facilities will be able to consult the team from the initial stage of making the diagnosis of brain death or to ask the team to make a diagnosis.

Legal diagnosis of brain death in children

At the stage of legal diagnosis of brain death, not only is an in-hospital diagnosis committee including at least one pediatrician among its members essential, but the existence of and the support from an official support team for the diagnosis of brain death is essential. Another in-hospital organization than an in-hospital diagnosis committee is also indispensable to extend support to donor families, and its activity will truly have the most important role in organ transplantation medicine. The future challenge lies in how the role should be expanded.

The legal diagnosis of brain death is a declaration of death. It may be ideal for the medical care team in charge of the child to handle the situation sincerely at each stage, but it may also be necessary for the entire medical staff to face the family of the child with integrity. A key person should be designated to take charge of the series of stages, and it should be a pediatrician who is the closest to the child and the family. Support must be continuously provided to the donor family, even after the death of the child, and continuous cooperation with the Japan Organ Transplant Network must be established for this purpose.

Terminal Stage Unique to Children

When a child in a serious condition as a result of a sudden illness or an accident becomes brain dead, it may be quite unexpected for the family. The family definitely needs time to undergo the proceeding psychological process in the following order: shock, denial, grief and anger, adaptation, and recovery. Just like the inner struggle of the family of a patient with an intractable/chronic disease associated with a poor prognosis needs a more sensitive attitude from medical professionals, it is important how medical professionals face with the family by the time of acceptance of the brain death. It is their sincerity that will enable the family to prepare for the option of organ donation within the limited time after brain death. To realize more mature organ transplant medicine in children, terminal care and grief care should be improved, and a thoughtful, compassionate attitude and support by medical professionals are required.

Conclusion

There are innumerable practical problems to solve on organ transplant after brain death in children, and more problems and challenges may develop while performing it. As pediatricians, all of us sincerely want to achieve the true and serious desire of the families. To respond to the desire of the families for organ transplant, we need to work out appropriate measures by considering how the problems and challenges should be overcome. However, it is impossible and too burdensome for medical professionals and donor hospitals to achieve this alone. The need to establish an official support system is urgent (**Fig. 2**).

In order to achieve more mature organ transplant medicine in children, further discussion mainly among medical professionals at the front line is necessary for national consensus building, and elaborate measures and policies through public and private cooperation are also necessary.

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