







## Review Article

# Epidemiology of child mortality and challenges in child death review in Japan

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## Abstract

We performed a retrospective survey and verification of the medical records of death cases of children (and adolescents; aged <18 years) between 2014 and 2016 in pediatric specialty training facilities in Japan. Of the 2,827 registered cases at 163 facilities, 2,348 cases were included. The rate of identified deaths compared with the demographic survey, was 18.2%–21.0% by age group. The breakdown of deaths was determined as follows: 638 cases (27.2%) were due to external factors or unknown causes, 118 (5.0%) were suspected to involve child maltreatment, 932 (39.7%) were of moderate or high preventability or were indeterminable. Further detailed verification was required for 1,333 cases (56.8%). Comparison of the three prefectures with high rates of identified deaths in Japan revealed no significant differences, such as in the distribution of diseases, suggesting that there was little selection bias. The autopsy rate of deaths of unknown cause was 43.4%, indicating a high ratio of forensic autopsies. However, sufficient clinical information was not collected; therefore, thorough evaluations were difficult to perform. Cases with a moderate or high possibility of involvement of child maltreatment accounted for 5%, similar to previous studies. However, more objective evaluation is necessary. Preventable death cases including potentially preventable deaths accounted for 25%, indicating that proposals need to be made for specific preventive measures. Individual primary verification followed by secondary verification by multiple organizations is effective. It is anticipated that a child death review (CDR) system with such a multi-layered structure will be established; however, the following challenges were revealed:

1. The subjects of CDR are all child deaths. Even if natural death cases are entrusted to medical organizations, and complicated cases to other special panels, the numbers are very high. Procedures need to be established to sufficiently verify these cases.
2. Although demographic statistics are useful for identifying all deaths, care must be taken when interpreting such data.
3. Detailed verification of the cause of death will affect the determination of subsequent preventability. Verification based only on clinical information is difficult, so a procedure that collates non-medical information sources should be established.
4. It is necessary to organize the procedures to evaluate the involvement of child maltreatment objectively and raise awareness among practitioners.
5. To propose specific preventive measures, a mechanism to ensure multiprofessional diverse perspectives is crucial, in addition to fostering the foundation of individual practitioners. To implement the proposed measures, it is also necessary to discuss the responsibilities and authority of each organization.
6. Once the CDR system is implemented, verification of the system should be repeated.

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This article is based on a study first reported as "Waga-kuni ni okeru shouni-shibou no ekigaku to chairudo-desu-rebyu seido deno ken-shou ni okeru kadai (A Committee Report: Epidemiology of Child Mortality and Challenges in Child Death Review in Japan)" in *J. Jpn. Pediatr. Soc.* 2019; 123 (11): 1736–1750.

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Efforts to learn from child deaths and prevent deaths that are preventable as much as possible are essential duties of pediatricians. Pediatricians are expected to undertake the identified challenges and promote and lead the implementation of the CDR system. This is a word-for-word translation of the report in *J. Jpn. Pediatr. Soc.* 2019; 123 (11): 1736–1750, which is available only in the Japanese language.

**Key words** cause of death, child abuse, child mortality, review.

## Background

Sufficient verification of the cause of death has great significance in reducing the number of preventable deaths. In particular, it is the responsibility of our society not to allow the unnecessary death of children. Sufficiently discussing each case of the unfortunate death of a child is a minimum courtesy for the child who died as well as one of the greatest forms of grief care for the bereaved family.<sup>1</sup>

In several countries around the world, including North America and Europe, child death is legally verified and various measures are taken. Furthermore, the World Health Organization (WHO) has emphasized the importance of such verification and provided guidelines for constructing the system.<sup>2</sup> Meanwhile, the medical examiner system has been only partially implemented in Japan, and this system is qualitatively different from coroner/medical examiner systems that serve in the UK and USA, and there is no system to perform death verifications at multiple organizations in Japan.<sup>3</sup> Finally, the Basic Law for Child and Maternal Health and Child Development, Article 15-2 states: “In the event of a death, national and local governments shall establish systems for the collection, management, and utilization of information related to the cause of death, organize the database, and take other necessary measures.” In addition, the subsequently enacted law, the Basic Act on Establishing Verification of Cause-of-Death, states the following in Article 2 of the Appendix: “The government . . . shall examine the mechanisms of collection, management, and utilization of information regarding the cause of death in the event of a child death . . .” Thus, it is important to design an appropriate system.

The Committee for Child Death Review of the Japan Pediatric Society has raised the importance of the verification of child death,<sup>4</sup> termed it “child death review (CDR),” and has repeatedly discussed the possible format regarding the contents and system design. To practice this, we performed a verification survey on child deaths in selected areas in Japan in 2011 and reported the outcomes.<sup>1</sup> In this study, a retrospective survey of the medical records indicated that preventable deaths potentially existed at levels similar to those reported in studies from other countries.<sup>5,6</sup> Based on this, our committee suggested that CDR should be part of the basic responsibilities of pediatricians, and maximum efforts should be exerted to incorporate CDR into the pediatric medical care system.<sup>7</sup> Thus, in collaboration with the study group of “Study on feasibility examination of the registration and verification system for child death cases” (group leader, Fumitake Mizoguchi) of the Project for the Basis of Raising the Next Generation of Babies and Infants to Adolescents and Young Adults through Health

Research and Development under the Ministry of Health, Labor, and Welfare’s Health Labor Sciences Research Grant system, the committee planned a study seeking a more efficient way to conduct a wide-range survey of child deaths covering the entire country of Japan.

If the CDR methodology, particularly the issue related to verification, is clarified by this study, it will essentially become the basic material for designing the administrative project and should greatly contribute to child welfare in Japan.

## Subjects and methods

To delineate the circumstances surrounding child deaths in Japan, particularly the verification of the cause of unknown death, possibility of the involvement of child maltreatment (e.g., abuse), preventability of death, and specific measures, we conducted a survey according to the following procedure.

Survey period: Between January 1, 2014 and December 31, 2016.

Survey subjects: Those who died during the survey period and aged <18 years at the time of death.

Survey methods: A questionnaire survey was conducted for the representatives of pediatrics at pediatric specialty training facilities to determine whether they could participate in this study (preliminary survey). We issued an access code to the encrypted online survey to the facilities that confirmed their ability to participate and requested them to provide information about survey subject cases. The cases for which entry was started were considered to be registered cases and were included in our analysis (primary survey). Of these, cases in which entry was completed to the last item were subjected to further analyses (secondary survey). In addition, for areas that desired to implement verification and established a multi-organizational verification system, the statistical data of that area was lent and the verification was entrusted. After that, the interview survey was conducted of the verification results (tertiary survey; Fig. 1). The contents of the first and second surveys were as follows:

### Surveys of applicable cases

Basic patient information (e.g., age at the time of death, family structure); birth history, family history, and past medical history (including immunization history and health checkup history); history of present illness; circumstances of death (how the child was transported to hospital, and the contents and results of the medical examination and tests), and information about death certificate; presence or absence of

response to abuse; presence or absence of autopsy and imaging examination at the time of death and the results.

### **Survey on hospital systems**

Presence or absence of abuse response committee.

### **Evaluation by investigators**

Based on the above contents, those who administered the questionnaire (investigators) at each facility evaluated the following four items and added them to the survey results: reclassification of the cause of death (degree of unknowingness if cause of death is unknown), possibility of involvement of child maltreatment, preventability, and preventive measures (if there are proposals and their effectiveness). The evaluation contents were regarded as the primary verification results in subsequent analyses.

### **Data organization**

Regarding the questionnaires, those who did not intend to register were excluded. In addition, all information that could be used to identify individuals in the description contents, such as proper nouns (including individual and facility names (excluding injury/disease names)) and dates (including date of birth/date of onset/date of death) were deleted.

### **Secondary verification**

In areas with research-allotted facilities where multi-organizational verification meetings could be held, statistical data regarding the cases in the area was borrowed, and the secondary verification was entrusted. For cases in other areas, the committee conducted the secondary verification.

### **Ethical matters**

This study was planned as a multi-organizational collaborative epidemiological study with the Maebashi Red Cross Hospital and Japan Pediatric Society as the central study facilities and the hospitals in each area as research-allotted facilities, joint facilities, or collaboration facilities. The approval was obtained from the ethical review boards at the central study facilities. In addition, the procedures stipulated in the “Ethical Guidelines for Medical Research involving Human Subjects (Ministry of Health, Labor and Welfare and Ministry of Education, Culture, Sports, Science and Technology)” were performed at the other participating facilities.

## **Results and discussion**

### **Number of responding facilities (preliminary survey)**

Of the 508 pediatric specialty training facilities, 266 (52.4%) responded that they were able to participate. Of

these 266 facilities, 36 were research-allotted facilities (intended to coordinate verification in the area), 36 were joint research facilities (conducted both verification and analysis in the facility), and 194 were collaborating facilities (only provided information to the central study facility; Fig. 2). A total of 68 facilities answered that they were unable to participate.

### **Number of child deaths (primary survey)**

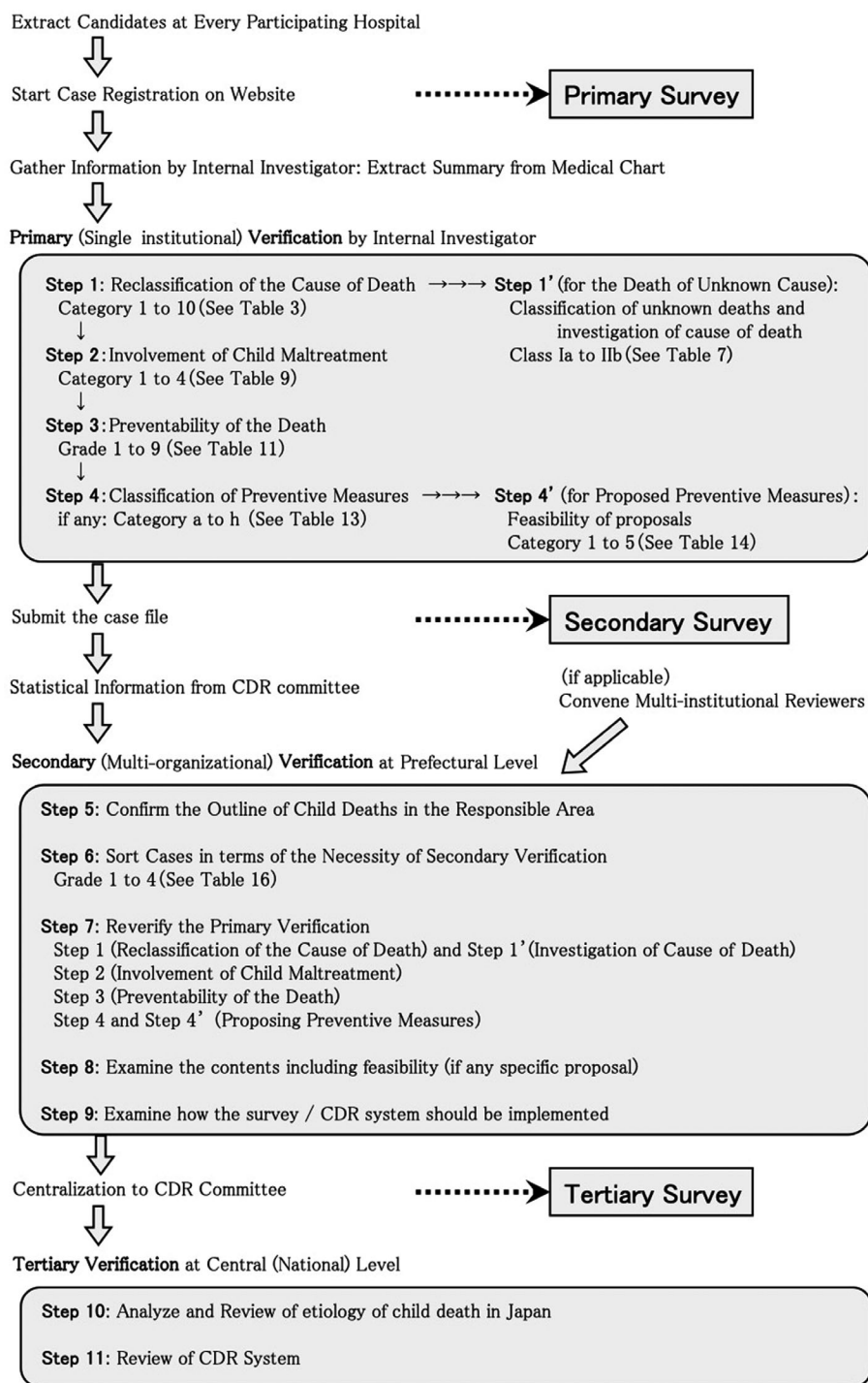
Of the facilities that were able to participate (266), 1–132 cases were registered per facility (median 9) at 163 facilities, resulting in a total of 2,827 cases. Cases with obvious entry mistakes and those that were not supposed to be registered were excluded to obtain the registration number (primary survey). Selection of the cases for actual registration among the target cases was left to each facility, and they were guaranteed the freedom of not registering particular cases, such as those that were subjects of another verification and those that hesitated in providing information to the study.

### **Breakdown of child deaths (secondary survey)**

Of the cases described above, the questionnaire was answered to the final item, and registration was completed for 2,348 cases at 148 facilities. These cases were subjected to the secondary survey (Fig. 3). According to the official statistical data from the demographic survey,<sup>8</sup> the number of child deaths by age group in Japan during the survey period was 5,924, 2,269, 1,303, and 1,411 (at age 0, 1–4, 5–9, and 10–14 years, respectively); the number of deaths between 15 and 17 years was not published. Compared to these numbers, the percentage of child death cases that were the subjects of the secondary survey (hereinafter referred to as “grasped rate,” the percentage of the number of responses to this survey to the number of official statistics) was calculated to be in the range of 18.2%–21.0% (Table 1 and Fig. 4).

Based on the result of the secondary survey, 1,015 cases (43.2%) were determined as ineligible for further variation because they were deaths from clear internal factors. For the remaining 1,333 cases (56.8%), a more detailed verification was desired for the following reasons: (i) deaths due to external factors or unknown causes (638 cases, 27.2%), (ii) moderate to high possibility of involvement of child maltreatment (118 cases, 5.0%), (iii) moderate or high, or undetermined preventability (932 cases, 39.7%; some are overlapping; Table 2).

In the future, it is estimated that, using the CDR system, death cases from undoubtful internal factors will be entrusted to medical verification within organizations, such as hospitals, and other cases will be prioritized as subjects for secondary verification. Even in this case, more than half of the cases of child deaths will be targeted for verification, i.e., a total of 10–300 cases per prefecture per year need to be verified. It will be a challenge to establish a system that can handle such a large number.



**Fig. 1** Study flowchart. CDR, Child Death Review.

### **Step 1: Reclassification of cause of child death**

The investigators assigned a cause of death reclassification code (Table 3) to each case based on medical records, considering the cause of death disease, name stated on the death certificate. Based on the methods by Pearson *et al.*,<sup>9</sup> all applicable categories were first listed, and then the highest

category (with the smallest number) was extracted similar to that of the previous study.<sup>1</sup> The number of deaths, as reclassified, was as follows: “Chromosomal, genetic, and congenital anomalies” 567 (25.5%); followed by “Perinatal/ neonatal events” 340 cases (15.4%); and “Sudden unexpected and unexplained deaths” 325 cases (14.6%). Distribution of cause of death reclassification by age group is shown in Table 4.

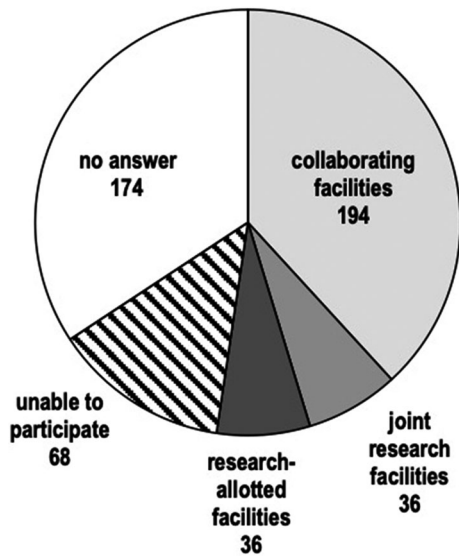


Fig. 2 Pie chart representing the number of responding facilities.



Fig. 4 Age distribution of respondents (by age range).

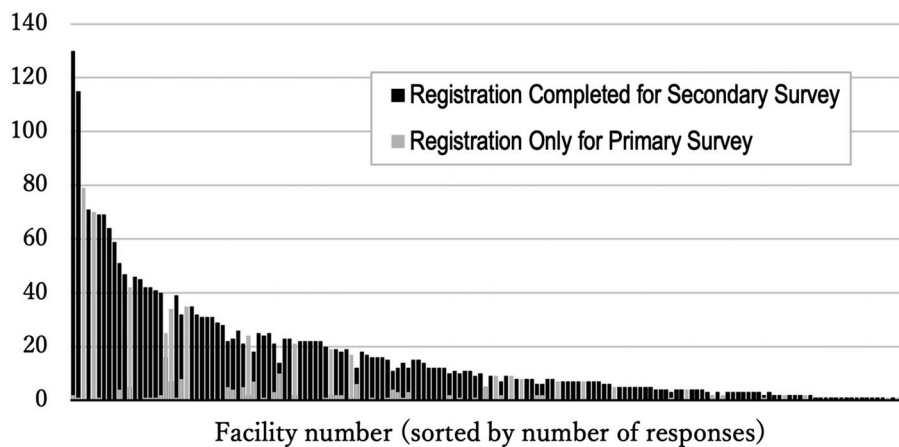


Fig. 3 Number of child deaths per facility (number of responses). (■), registration completed for secondary survey; (▨), registration only for primary survey

**Table 1** Breakdown of respondents by age group

Age group	Male	Female	Non-entry	Official statistics (Identification rate)
0 years	684	551	10	5,924 (21.0%)
0 days	112	82	0	-
≤1 week	111	106	0	-
≤1 month	64	72	2	-
≤3 months	170	140	5	-
≤12 months	227	151	3	-
1-4 years	229	209	4	2,269 (19.5%)
5-9 years	157	100	3	1,303 (20.0%)
10-14 years	141	113	3	1,411 (18.2%)
15 years or older	89	55	0	-
Total	1,300	1,028	20	-

**Table 2** Causes necessitating detailed verification

Necessity of detailed verification	
Verification not necessary	1,015 (43.2%)
Verification necessary	1,333 (56.8%)
Cause of death: External factors or unknown cause	638 (27.2%)
Abuse: Moderate to high	118 (5.0%)
Preventability: Moderate to high or cannot be determined	932 (39.7%)
Total	2,348

In the present study, the subjects were limited to the cases at pediatric facilities of a certain scale, participation of each facility was voluntary, and selection of cases for registration

was up to each facility. Thus, the grasp rate of the survey to the total number of deaths remained at approximately 20%. There is the possibility that a certain selection bias may have occurred during the information collection stage; for example, “cases with no doubts, which are easy to answer” or “cases

**Table 3** Reclassification of the cause of death while focusing on preventive intervention

Category	Name and description of category
1	<b>Deliberately inflicted injury, abuse, or neglect</b> This includes suffocation, shaking injury, knifing, shooting, poisoning, and other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death
2	<b>Suicide or deliberate self-inflicted harm</b> This includes hanging, shooting, self-poisoning with paracetamol; death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children
3	<b>Trauma and other external factors</b> This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in preschool children, anaphylaxis and other extrinsic factors. Excludes deliberately inflicted injury (category 1).
4	<b>Malignancy</b> Solid tumors, leukemias and lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, hemorrhage, etc.
5	<b>Acute medical or surgical conditions</b> For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy
6	<b>Chronic medical condition</b> For example, Crohn's disease, liver disease, neurodegenerative disease, immune deficiencies, and cystic fibrosis, even if the final event leading to death was infection, hemorrhage, etc. Includes cerebral palsy with clear postperinatal cause
7	<b>Chromosomal, genetic and congenital anomalies</b> Trisomies, other chromosomal disorders, single-gene defects, and other congenital anomalies including cardiac
8	<b>Perinatal/neonatal event</b> Death ultimately related to perinatal events, for example, sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, and posthemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause and includes congenital or early onset bacterial infection (onset in the first postnatal week)
9	<b>Infection</b> Any primary infection (i.e., not a complication of one of the above categories), arising after the first postnatal week or after discharge of a preterm baby. This would include septicemia, pneumonia, meningitis, HIV infection, etc.
10	<b>Sudden unexpected, unexplained death</b> Where the pathological diagnosis is either sudden infant death syndrome or unascertained, at any age. Excludes sudden unexpected death in epilepsy (category 5)

with much concern, which are likely to raise problems," may have been particularly selected. We therefore extracted prefectures with a high identification rate and compared them with the national data. Comparison of the cases of children younger than 15 years of age, which were extracted from the survey results with the sum of the number of deaths in the four age groups, 0, 1–4, 5–9, and 10–14 years, in the official statistics<sup>8</sup> revealed that the grasp rate was high in the following order: Kagawa prefecture (97.0%), Aichi prefecture (91.3%), Gunma prefecture (79.4%), Oita prefecture (70.3%), and Niigata prefecture (55.0%). Of these, the top three prefectures (Kagawa, Aichi, and Gunma) were extracted as a high-grasp-rate group (grasp rate of 88.4% for cases of children younger than 15 years), and the distribution of cause of death reclassification were compared with that of the entire survey results (Fig. 5). Although there were some differences, they were not significant, indicating that the selection bias was negligible, such as "only certain types of deaths were selectively included in or excluded from the survey." Results therefore suggested that the study reflects generally accurate epidemiology.

#### **Step 1': Classification of unknown deaths and investigation of cause of death**

In the cause of death reclassification of Step 1, the age distribution of 326 cases of "Sudden unexpected and unexplained

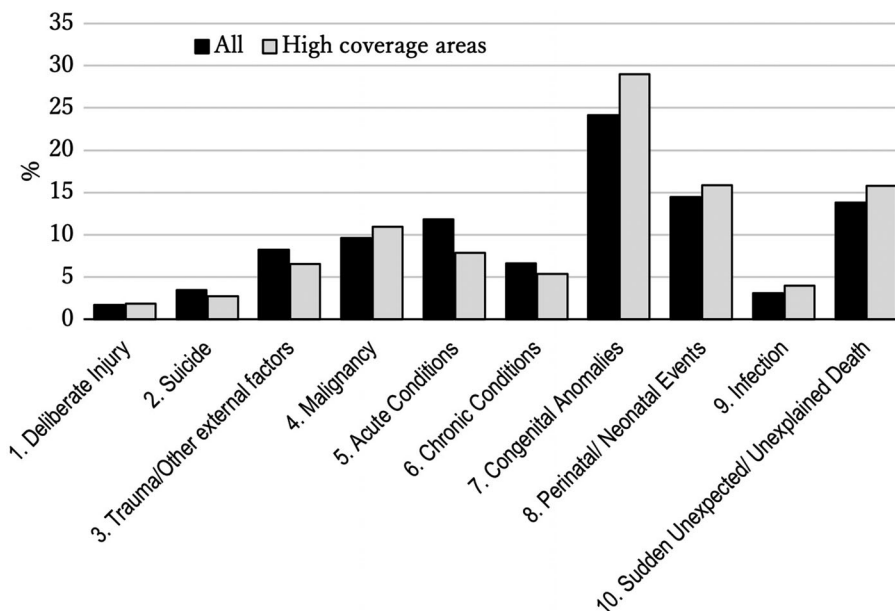
death" was shown in the previous section (Table 4). Of the cases classified as "Unknown deaths" for the "Type of cause of death" in the death certificate, etc. (death certificate/post-mortem certificate), 70 cases (22.4%) were reclassified as cases other than "Sudden unexpected and unexplained death" in this survey, and conversely, 83 cases (4.1%) of those that had been classified as cases other than "Unknown death" for "Type of death" were newly reclassified as "Sudden unexpected and unexplained death" (Table 5). It was confirmed that the interpretation of the official statistics based on death certificates requires attention when they are incorporated into the CDR.

Autopsy in children was performed in 401 cases (17.1%) in total. The number of each autopsy type was as follows: pathological autopsy in 188; forensic autopsy in 194 (judicial autopsy in 125, investigation-method autopsy, conducted based on the cause of death and background investigation in 45, administrative autopsy in 22, and consented autopsy [a type of forensic autopsy based on the consent of the bereaved] in 2); and an unknown type of autopsy or with no description in 19. Among these, the autopsy rate in "Sudden unexpected and unexplained death" was 43.3% (141/326 cases), 89.4% of which were forensic autopsy cases. In contrast, the autopsy rate in cases other than "Sudden unexpected and unexplained death" was 13.2% (258/2,022 cases), 69.0% of which were pathological autopsy cases, showing a significant difference

**Table 4** Results of reclassification of the cause of death and comparison by age group

Category	(Total)	0 years	1–4 years	5–9 years	10–14 years	15 years or older
1. Deliberate injury	39	18 (1.5%)	7 (1.6%)	7 (2.8%)	6 (2.4%)	1 (0.4%)
2. Suicide	81	0 (0.0%)	0 (0.0%)	3 (1.2%)	41 (16.3%)	37 (14.7%)
3. Trauma/other external factors	193	26 (2.2%)	52 (12.2%)	48 (19.0%)	35 (13.9%)	32 (12.7%)
4. Malignancy	226	17 (1.4%)	56 (13.1%)	60 (23.8%)	66 (26.2%)	27 (10.7%)
5. Acute conditions	278	96 (8.0%)	78 (18.3%)	50 (19.8%)	34 (13.5%)	20 (7.9%)
6. Chronic conditions	156	35 (2.9%)	48 (11.3%)	29 (11.5%)	30 (11.9%)	14 (5.6%)
7. Congenital anomalies	567	427 (35.4%)	102 (23.9%)	20 (7.9%)	13 (5.2%)	5 (2.0%)
8. Perinatal/neonatal events	340	325 (27.0%)	8 (1.9%)	7 (2.8%)	0 (0.0%)	0 (0.0%)
9. Infection	73	24 (2.0%)	24 (5.6%)	9 (3.6%)	12 (4.8%)	4 (1.6%)
10. Sudden unexpected/unexplained death	326	238 (19.8%)	51 (12.0%)	19 (7.5%)	15 (6.0%)	3 (1.2%)
Non-entry	69	39	16	8	5	1
Total	2,348	1,245	442	260	257	144

Parentheses represent percentage for the corresponding age group.



**Fig. 5** Results of reclassification of the cause of death, and comparison between high identification rate areas and the nationwide data for Japan. (■), all; (□), high coverage areas.

(Table 6). Although cases of “Sudden unexpected and unexplained death” had a significantly higher forensic autopsy rate, the reason for this was not clarified in this study. It is possible that, as a result of reporting abnormal deaths to the police, the percentage of forensic autopsy cases turned out to be high. However, as shown in other studies, it is also possible that there was no other way to answer but the cause of death was unknown because the response to this survey was solely based on clinical information, which reflected the difficulty in disclosing forensic autopsy results to physicians.

There are cases where the cause of death cannot be medically determined other than “unknown” even after conducting sufficient investigations. However, in general, there are “Don’t know” cases for which the cause of death could be determined if a more comprehensive investigation were to be

**Table 5** The number of deaths with unknown cause and comparison between official statistics and the results from this study

Type of cause of death on Death certificate, etc.	Reclassification of the cause of death	Total		
		Unknown (including SIDS)	Other	
Type of cause of death on Death certificate, etc.	12. Unknown death	243	70	313
Type of cause of death on Death certificate, etc.	1.~11.	83	1,952	2,035
Total		326	2,022	2,348

conducted; these coexist with “Can’t know” cases for which the cause of death cannot be identified even after a highly detailed investigation. To clarify the level of investigation that was conducted to identify the cause of death for each case, the investigators therefore determined the degree of unknowingness of the cause of death according to the classification (Table 7) of a previous study<sup>1</sup> that was conducted in accordance with the proposal by Blair *et al.*<sup>10</sup> (Table 8 and Fig. 6). In autopsy cases, the ratio of class Ia cases corresponding to “Can’t know” is large, whereas in non-autopsied cases, the ratio of class IIb cases corresponding to “Don’t know” is large. However, as there are considerable numbers of class Ib and IIb cases among autopsy cases, it is presumed that there may be an issue as to whether or not on-site inspection information, which was necessary for clinical perspectives, was properly communicated, apart from the problem of whether sufficient investigation of cause of death was conducted. If this was the case, it is the limitation of the method of “death verification solely based on clinical records as an information source” in this study, which indeed indicates the necessity of seeking an alternative information source for verification of unknown deaths. If there is no chance to summarize existing information in a clinical situation, therefore, the prospective CDR must be developed to include such a function.

### Step 2: Child deaths that can be associated with child maltreatment

According to a previous study,<sup>1</sup> the investigators evaluated the possibility of involvement of child maltreatment based on records (such as medical histories using the revised standard of the category classification)<sup>11</sup> (Table 9) proposed by “Guides for Child Abuse Response and Medical Diagnosis for Doctors Responding to Child Abuse,” a product of the Health Science and Labor Research. The number of cases classified into each category was: 1,518 cases (64.7%) in Category 1 as

**Table 6** Presence or absence of autopsy and the type of autopsy performed

	Unknown death (including SIDS)	Other
Autopsy performed	141	260
Pathological	10 (7.1%)	178 (68.5%)
Judicial	70 (49.6%)	55 (21.2%)
Investigation method (new method)	42 (29.8%)	3 (1.2%)
Consent	2 (1.4%)	0 (0.0%)
Administrative	12 (8.5%)	10 (3.8%)
Unknown	5 (3.5%)	14 (5.4%)
No autopsy performed	112	1,635
Unknown	66	79
Non-entry	7	48
Total	326	2,022

“no possibility of involvement of child maltreatment,” 336 (14.3%) in Category 2 as “low possibility of involvement of child maltreatment,” 71 (3.0%) in Category 3A as “moderate possibility of involvement of child maltreatment,” and 19 (0.8%) in Category 3B as “high possibility of involvement of child maltreatment” (Table 10 and Fig. 7). There were total 118 cases (5.0%) in “Category 3A or higher” that specifically required verification regarding the involvement of child maltreatment, which is a similar number to those of several previous studies.

In addition, according to previous study results, it was pointed out that the possibility of involvement of child maltreatment tended to be undervalued in cases such as those where the investigator was engaged in the medical care as an attending physician. It is therefore necessary to develop a more objective methodology by third-party evaluation and engage in creating awareness to minimize subjectivity among practitioners.

### Step 3: Preventability of child deaths

Based on the survey results and judgments so far, the investigators evaluated the preventability of each case according to the classification used in a previous study<sup>1</sup> (Table 11). There were 198 cases (8.6%) classified as A: “Preventable,” 377 (16.4%) as B: “Potentially Preventable,” 1,372 (59.5%) as C: “Unpreventable,” and 357 as D: “Unable to be determine Preventability” (15.5%; Table 12). The percentage of “Preventability of A and B,” considered to be preventable deaths, was 25%, which was close to the values of previous studies.<sup>1,6</sup>

Preventability varies depending on the cause of death, so preventability was computed using the cause of death reclassification item (Fig. 8). Preventable death cases (A and B) equaled 224 cases of deaths from exogenous factors (“deliberate injury,” “suicide,” “trauma/other external factors,”) and 117 cases (35.9%) of deaths from endogenous factors (“4. Malignancy” to “9. Infection”). In other words, the preventability of death cases from endogenous factors is less than that of death cases from exogenous factors; however, the actual number of cases that are preventable is approximately the same because of the several parameters of death cases from endogenous factors. For unknown deaths, “unable to determine,” 36.5% was the highest, and this was due to insufficient investigation of cause of death or unclear results.

### Step 4: Proposal for preventive measures and Step 4': Effectiveness of preventive measures

Based on the results so far, we questioned if there were any measures that investigators could propose for each case, and if such measures were present, which of the following categories would they be classified: “establishing the cause of death investigation system,” “preventive measures for abuse/abuse-related death,” “preventive measures for accidents,” “preventive measures for suicide,” “establishment of perinatal-

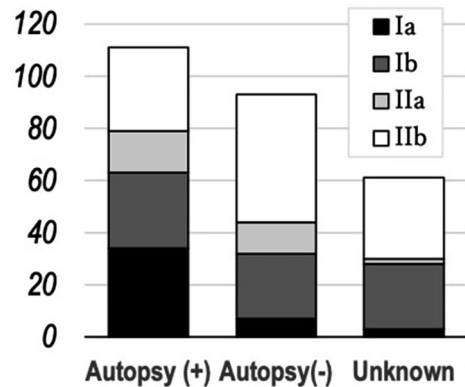


**Table 7** Classification criteria for the unknown cause of death

		Satisfy all the following
Class Ia	Unknown child death due to which a comprehensive investigation was performed, including typical SIDS cases	Clinical features: No problems in the medical history (including growth and developmental history), and no abnormalities in the perinatal period. No abnormalities in family history. Circumstances: Death scene investigation did not yield a causal relationship with death (e.g., sleeping environment is safe). Autopsy: No macroscopic or histopathological findings indicating pathological conditions that could be fatal Negative for any of following tests: Toxicological, bacterial, imaging, vitreous humor tests, and metabolic disease screening.
Class Ib	Unknown child death with possibility of SIDS, no comprehensive investigation performed	Satisfying most of the criteria of general SIDS and the above-described Class Ia criteria. No comprehensive death scene investigation performed or missing any of the following tests: Toxicological, bacterial, imaging, vitreous humor tests, or metabolic disease screening.
Class IIa	Unknown child death satisfying Class I criteria except the requirement shown on the right	Clinical features: Abuse-related death was excluded but the presence of siblings or close relatives with diagnosed hereditary diseases; or previous history of infant death associated with the same caregiver, regardless of blood relationship; or past events during the perinatal period such as premature birth, even in the absence of medical problems. Circumstances: When physical mouth-nose obstruction due to suffocation cannot be excluded or death due to neck compression cannot be excluded. Autopsy: Cases where problems in growth or development were observed, although they were unlikely to have contributed to death. Cases with severe inflammatory changes or abnormal findings on histopathological examination, although they were not the obvious cause of death.
Class IIb	Unknown child death that cannot be classified	Cases not satisfying criteria of Ia, Ib, or IIa. No definitive diagnosis as internal or external causes of death could be made. Cases with no autopsy performed were also included in this class.

**Table 8** Classification of unknown causes of death and whether an autopsy was performed

	Autopsy performed	No autopsy	Non-entry/ unknown	Total
Unknown death	141	112	66	326
Ia	34	7	4	45
Ib	29	25	27	81
IIa	16	12	2	30
IIb	32	49	35	116
Non-entry	30	19	5	54
Not an unknown death	260	1,635	127	2,022



**Fig. 6** Classification of the unknown causes of death and whether an autopsy was performed. (■), Ia; (▒), Ib; (░), IIa; (□), IIb.

neonatal medical service delivery system,” “establishment of pediatric medical service delivery system,” “child-rearing support measures,” and “others” (Table 13). There were 1,552 (66.1%) no-response cases, and even for the 796 cases (33.9%) who responded that there were measures they can propose, the column for specific contents was mostly left blank. It is difficult to propose specific measures at the investigators’ level, and it was inferred that developing the foundation to derive proposals is a critical issue for an effective CDR.

At the same time, we questioned the feasibility of the each content of the proposals, following Table 14 according to the previous study.<sup>1</sup> Proposals were categorized as follows: “Preventable and feasible” amounted to 166, “Preventable but difficult to realize” to 102, “Difficult to prevent but feasible” to 184, and “Difficult to prevent and difficult to realize” to 212 (Table 15). Death cases for which preventable and feasible

**Table 9** List of possible categories and criteria for child abuse

Categories	Category name and details
1. No possibility	A group where possibility of death due to abuse/neglect is excluded Cases definitively judged as an accident with third party witnesses. Cases medically and completely consistent with internal pathology and without social risk.
2. Low possibility	A group where possibility of accidental death or death due to internal factors is high, but the possibility of death due to abuse cannot be excluded. Cases presenting with medical conditions generally consistent with the situation of injury as reported by the caregiver, but without witnesses. Cases medically explained as internal conditions but with some social risk.
3A. Moderate possibility	Cases with the possibility of accidental/internal death but with clinical suspicion or possibility of abuse death. Abuse is clinically suspected, but its possibility cannot be judged to be obviously higher than accidental/internally-caused death. This includes accidental death due to inadequate supervision or internal death due to poor management. Cases with unknown cause of death of a sibling or with high social risk but unclear cause of death are also included in this class.
3B. High possibility	Cases in which the possibility of accidental/internal death cannot be denied but with clinically higher possibility of death due to abuse. Cases that present with pathology that cannot be explained as accidental/internal factors and death due to abuse is strongly suspected but cannot be definitively established. Cases of accidental and internal death in which social intervention was started due to continuous supervisory neglect or medical neglect. Cases of accidental death due to inadequate supervision or death due to delay in medical consultation are included in this class if the level of negligence is extremely high. Cases in which cause of death is unclear with extremely high social risk, such as when multiple siblings have died or with a history of parent-child separation (except for a short-time or temporary separation) are included in this class.
4. Definite possibility	Cases judged to be death due to abuse/neglect Cases with a third-party witness to the action leading to death, cases with confession of abuse, cases of death that cannot be medically explained except by abuse. Neglect-related deaths are included in this class if the caregiver deliberately neglected to provide care that lead to life-threatening situations, apart from death due to direct damaging actions.

proposals could be made were highly preventable. Conversely, difficult to prevent death cases for which only largely unfeasible proposals could be made for prevention or for which no such proposals could be made (unpreventable) were considered to have low preventability.

The ratios of preventable (regardless of feasibility) and feasible (regardless of the preventive effect) proposals were calculated for each category (Table 13). Preventive measures against deaths from exogenous causes, in other words, accident prevention, suicide prevention measures, and abuse/abuse-related death prevention measures had higher ratios of preventable proposals in that order, and the feasibility of the proposals was also high. Feasible measures were easily proposed for the child-rearing support measures, establishment of the pediatric medical service delivery system, and establishment of the perinatal–neonatal medical service delivery

system, although the preventive effects were limited. Most of the respondents were pediatricians, and it was inferred that the results reflected the contents of their daily work. Multiprofessional discussions are essential for more diverse prevention proposals in the future.

#### **Steps 5–9: Multi-organizational verification**

Multioorganizational verification covered a wide area at prefecture level, assuming the following purposes: (i) objectively review individual verification results, generalize the obtained lessons and proposals, and return them to the area; (ii) grasp and extract the cases that passed through individual verification to prevent occurrence of unverified cases; (iii) cooperate with the existing third-party verification held separately in the area or more specialized verification; (iv) gather area

**Table 10** Distribution of possible child-abuse, actual numbers by age group

Maltreatment category		0 years	1–4 years	5–9 years	10–14 years	15 years and older
1	1,518 (64.7%)	836	268	167	162	85
2	336 (14.3%)	159	69	31	49	28
3A	71 (3.0%)	42	15	5	8	1
3B	28 (1.2%)	22	3	2	1	0
4	19 (0.8%)	10	1	5	3	0
(3A–4 repost)	118 (5.0%)	74	19	12	12	1
Non-entry	376 (16.0%)	176	86	50	34	30
Total	2,348	1,245	442	260	257	144

**Table 11** Classification of preventability categories. Referring to the following standard, A, B, and C were further subclassified into nine levels of high, moderate, and low. Those that could not be determined were classified as “O. Classification not possible”

Preventability 9-level evaluation	A: Preventable			B: Potentially preventable			C: Unpreventable		
	1 Highest	2	3 (High ←	4	5	6	7 → Low)	8	9 Lowest

Grading preventability.

A. Preventable

a. Where there were identifiable failures in the child’s direct care by any agency, including parents, with direct responsibility for the child.

b. Where there were latent, organizational or other indirect failure(s) within one or more agency, including parents, with direct or indirect responsibility for the child.

c. Where there was a failure of design, dilapidation of barriers or inadequate maintenance by agencies with responsibility for public safety (e.g., rail maintenance leading to Hatfield rail disaster).

B. Potentially preventable

a. At a higher level than the agencies with direct or indirect responsibility for the child (e.g., political violence, war, terrorism, crime and if the child is the victim of homicide).

b. Where no agency, including parents, was involved directly or indirectly with the child.

c. Where intrinsic factors (e.g., an acquired disease with a known high mortality such as meningococemia) were the principal factors leading to the death.

d. Where there were potentially modifiable factors extrinsic to the child.

e. Where the causal pathway leading to the death could reasonably be traced back to antepartum or intrapartum obstetric events.

C. Unpreventable

a. Death caused by unmodifiable factors extrinsic to the child (e.g., lightning strike, earthquake).

b. Death due to undiagnosed, asymptomatic conditions presenting with a lethal event (e.g., hypertrophic obstructive cardiomyopathy).

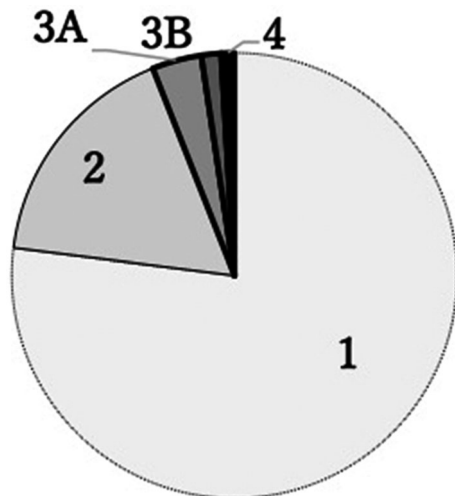
c. Planned palliation for unpreventable, incurable disease or anomaly (e.g., Leigh disease).

information and transfer it to the central department; and (v) monitor the validity of the proposal contents in the area and maintain the effectiveness of the CDR system itself.<sup>7</sup> Our committee named the meeting described above the Child Death Overview Panel, and content of its structure and its discussion contents were investigated in an exploratory manner in this study.

If a research-allotted facility requested information, and a non-profit organization with no conflict of interest comprising multiple organizations/professions (hereinafter, a verification organization) was formed with the purpose of verification in

the responsible area, our committee borrowed unlinkable and anonymized statistical information. The contents of the verification meetings provided to the verification organization, and if consulted, our committee requested the verification organization to follow almost the same methodology after discussion. (Fig. 1. Downstream of the multi-organizational verification [secondary verification] is shown in the shaded part in the center). In other words, we showed the flow by giving examples as follows: (i) confirming the outline of child deaths in the responsible area (Step 5); (ii) based on the borrowed statistical information, sorting each case to be classified in terms of the necessity of secondary verification (Table 16; Step 6); (iii) re-verifying the primary verification results centered on the cases classified as Grade 1 as “cases that are subject to secondary verification with priority.” Where detailed verification by professionals in a certain field is separately required, append a note describing it (Step 7); (iv) Where specific proposals are given, examine the contents including feasibility (Step 8); and (v) based on the discussion described above, examine how the survey has been so far, and how the CDR system should be implemented in the area mentioned (Step 9).

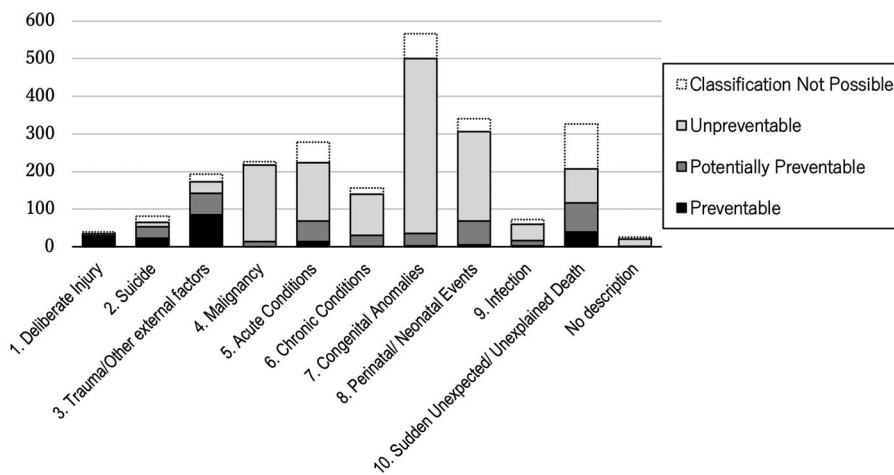
There were seven applicable prefectures, and the composition of the meetings is shown in Table 17. Of these, in three areas where the meetings were entrusted to a conference related to child deaths that was in progress prior to this survey study, meetings were scheduled to be regularly held after the conference. Other areas also answered that they considered to continue holding meetings in the future.



**Fig. 7** Distribution of possible child abuse.

**Table 12** Results of preventability triage

Nine-level classification of preventability			(Accumulation %)	Endogenous factors	Exogenous factors	Unknown
Preventable	1	80	(3.5%)	25 (1.5%)	134 (42.8%)	39 (12.0%)
	2	35	(5.0%)			
	3	83	(8.6%)			
Potentially preventable	4	48	(10.7%)	208 (12.7%)	90 (28.8%)	78 (23.9%)
	5	129	(16.3%)			
	6	200	(25.0%)			
Unpreventable	7	169	(32.3%)	1,215 (74.1%)	48 (15.3%)	90 (27.6%)
	8	162	(39.3%)			
	9	1,041	(84.5%)			
Classification not possible	0	357	(100%)	192	41	119
Non-entry		44				
Total		2,348		1,640	313	326



**Fig. 8** Results of preventability classification after re-classification of the cause of death. (■), classification not possible; (▒), unpreventable; (□), potentially preventable; (■), preventable.

**Table 13** Classification of prevention proposals based on contents and feasibility of proposals

Classification of preventive measures	Total	Preventable (%)	Feasible (%)
a. Establishing a cause of death investigation system	49	18.4	20.4
b. Preventive measures against abuse/abuse death	45	48.9	53.3
c. Accident preventive measures	190	52.1	53.2
d. Suicide preventive measures	54	51.9	53.7
e. Development of medical perinatal/neonatal care delivery system	177	11.9	31.1
f. Development of pediatric medical care delivery system	189	24.3	35.4
g. Childrearing support system	50	26.0	40.0
h. Other	133	21.1	33.1
Total	887	30.0	39.5

For each participating organization, we did not distinguish between attendance representing the organization and individual attendances. Attendance therefore did not necessarily mean

that “multiple organizations were working on the CDR project” in these areas. Because this is a medical study, even if there may be cases where the foundation of cooperation as an organization is difficult to systemize, it is important to have a thorough discussion between the parties that are involved regarding which organization should have which responsibilities and what authority, when building the CDR system as an administrative project in the future.

The outline of meeting contents is shown according to the flow of the multiorganizational verification presented in Figure 1 (Table 18).

The area statistics of Step 5 were presented at the beginning of the four verification meetings. It was revealed that the existing official statistics alone are not sufficient, and the epidemiology of child deaths from a different perspective other than official statistics was revealed in this study. The best approach to death cases that could not be grasped by the method used in this survey was examined. One important use of multi-organizational verification is to grasp the cases passing through individual verification to prevent the occurrence

**Table 14** Classification of the effectiveness of preventive measures

Classification	Outline
Category 1	The possibility that the death was preventable is high. Obstacles: Barriers to the implementation of preventive measures for this type of death are low, and implementation is highly realistic.
Category 2	High possibility that the death was preventable, but barriers to the implementation of preventive measures for this type of death are high, and implementation is not realistic.
Category 3	While the possibility that the death was preventable is not high, the implementation of preventive measures for this type of death is highly realistic, i.e., the implementation of preventive measures will not result in a certain effect in the short-term, but results are expected to be obtained by long-term implementation.
Category 4	The possibility that the death was preventable is not high. Furthermore, the implementation of preventive measures for this type of death is not realistic, i.e., implementation of preventive measures will not result in a certain effect in the short-term and the effects of long-term implementation are unclear.
Category 5	There is almost no possibility that the death was preventable.

**Table 15** Distribution of the effectiveness of preventive measures

Effectiveness of preventive measures		Case preventability		
		High	Moderate	Low
1. Preventable, feasible	166	102	52	9
2. Preventable, difficult to realize	102	34	49	9
3. Difficult to prevent, feasible	184	21	87	62
4. Difficult to prevent, difficult to realize	212	6	75	118
5. Impossible to prevent	131	2	4	117
Non-entry	1,616	62	132	1,067
Total	2,411	227	399	1,382

of unverified cases. Exploring the method of investigation to this end was pointed out as future task.

Classification of Step 6 was clearly conducted according to Table 16 in four areas. However, the subjects were selected for detailed verification in some way also in other areas. Such “triage” work is indispensable for the most effective verification within a limited time, as in the present circumstances. As described above, it is essential to allocate an appropriate amount of time for effective verification in an optimal CDR system.

Reverification of Step 7 was performed for selected cases. In this study, one of the important issues was to seek a way to conduct verification under strict time constraints, rather than how to verify each individual case carefully. To this end, we limited the time for verification even for Grade 1 cases (handled with priority), meaning that the median time per case was 12 min (5–45 min). Individual case verification at a medical facility (primary verification) involved: “discussing cases for relatively long hours” to “create new preventive proposals” “from a standpoint closer to persons involved” while “capturing the specific characteristics of the case” and “using as much information as possible”. In contrast, it was confirmed that multi-organizational verification at a prefectural level (secondary verification) involved: “selecting preventive

**Table 16** Necessity classification of multi-organizational verification

	Necessity of verification
Grade 1	The primary verification result identified new issues that should be verified by multiple organizations, or that there is some concern. The case should be subjected to secondary verification at the multi-organizational verification meeting with priority.
Grade 2	The primary verification result is generally valid but there are few new contents that should be verified by multiple organizations. Determination of whether the primary verification result is right or wrong is performed at the multiorganizational verification meeting, and if any issues are raised the case may be subjected to secondary verification.
Grade 3	The result of primary verification is entirely valid, and it is expected that at the multi-organizational verification, approval of the primary verification result would occur.
Grade 4	The result of primary verification is clearly inaccurate or incomplete. It is difficult to conduct effective secondary verification in its present form.

proposals” and “identifying the greatest common factors between the cases,” which contribute to society more in general “within a limited time” and “from an objective and comprehensive perspective” should be emphasized (Fig. 9). To establish effective secondary verification, sufficient primary verification is an important precondition, and it may be necessary to entrust further detailed verification separately to a specialized panel as necessary.

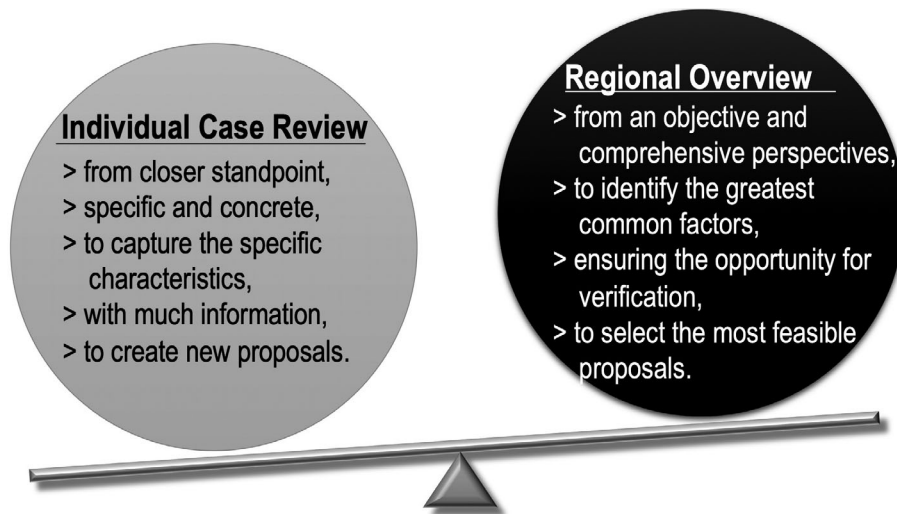
Step 8 is the part where specific proposals are given to appropriate departments/organizations to put them into practice to ensure the avoidance of arguing for argument’s sake. However, the verification in this study is medical research, and administrative organizations were under no obligation to realize the proposals. In future, when the CDR is implemented as a social system, it will be necessary to carefully formulate which department is to have what responsibility if the measures are to be successfully implemented.

**Table 17** List of multiorganizational verification meetings held so far and their composition

	Main constituent of the meeting	Number of participants (number of people)	Clinician	Forensic doctor	Police	Prosecutor	Child consultation center	Health center	Administrative
Gunma	Abuse network project	>40	○	○	○	○	○	○	○
Aichi	Prefectural Medical Association	>40	○	○	○	○	○	○	○
Kagawa	Voluntary organization → Transferred to the Pediatric Society Local Association	23	○	○	○	○	○	○	○
Mie	Voluntary organization	21	○	○	○	-	○	○	○
Chiba	Voluntary organization + Faculty of forensic medicine	23	○	○	-	○	○	○	○
Kyoto	Voluntary organization	21	○	○	-	-	○	○	○
Ibaragi	Voluntary organization	15	(n.a.)						

**Table 18** Multiorganizational verification meetings held so far and their verification status

	Step 5 (Area statistics)	Step 6 (Sorting)	Number of Subjects	Step 7 (Reverification)	Detailed verification cases (number of cases/length (min))	Step 8 (Proposals)	Step 9 (System)
Gunma	○	○	105	○	6/90	△	○
Aichi	○	△	114/257	○	7/90	○	○
Kagawa	○	○	69	○	4/60	○	○
Mie	-	○	38	○	3/20	△	○
Chiba	○	○	110	○	3/60	○	○
Kyoto	-	△	4	○	3/45	△	○
Ibaragi	○	△	30	○	3/90		



**Fig. 9** Comparisons between Individual Case Review (held as the primary verifications) and Regional Overview (held as the multi-organizational secondary verification).

Step 9 is an examination of the CDR system itself, including the implementation system described in this study. This time, the common challenge concerning how to establish a CDR system in

each area was discussed for all regions. In the future, even once a stable system has been implemented, it will be necessary to repeatedly verify the system and continue to evaluate its effectiveness.

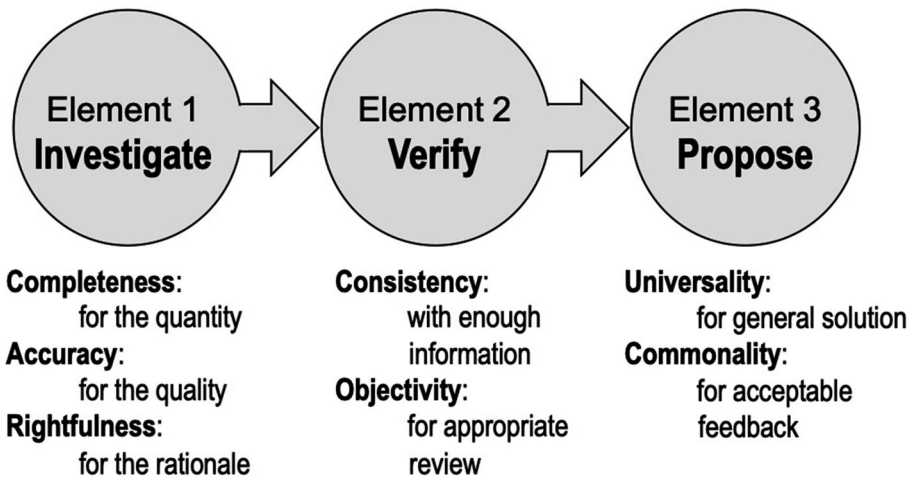


Fig. 10 Three elements of the Child Death Review (CDR).

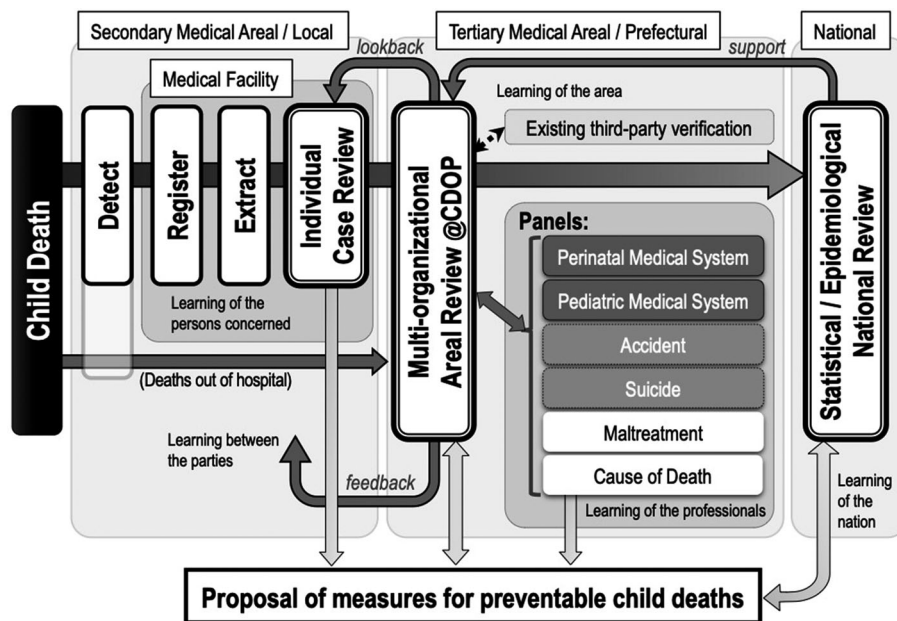


Fig. 11 A conceptual model of the Child Death Review (CDR) system proposed by the Committee for Child Death Review/Verification of the Japanese Pediatric Society.

**Conclusion**

In this study, unlinkable and anonymized medical information was gathered and analyzed. When entering questionnaire data, certain retrospective evaluation was conducted on each individual case, regardless of the scale, which ranged from investigations by individual investigators to multioccupational investigations. If we consider this retrospective evaluation as primary verification, our addition of secondary verification through the collection and analysis of the results of primary verification has enabled us to provide important basic information about the situation surrounding child death in Japan, which had not been fully clarified.

An effective CDR is expected to: (i) be based on thorough investigation, (ii) gather clinical knowledge by sufficient verification, and (iii) be linked to specific proposals (Fig. 10). Regarding “sufficient verification,” in the proposal regarding the CDR system that should be established in Japan, our committee previously proposed a multilayer structure consisting of individual verification conducted at each medical organization or at the level of secondary medical area, multiorganizational verification conducted based on the individual verification results at the level of tertiary medical area or prefecture, and further statistical epidemiological verification to be conducted summarizing these verification results at the national level (Fig. 11).<sup>7</sup> When applying the methodology of this study, step

by step, to the structural diagram, the steps of extracting medical records and the entry of judgments of Steps 1 to 4 in the survey form correspond to the stage of “registration of death cases and performing individual verification” in the diagram. Likewise, the step where the statistical information obtained was discussed in Steps 5 to 9 in several areas corresponds to “multi-organizational verification” in the structural diagram. It is necessary to further summarize the results and examine how to implement statistical and epidemiological verification at a national level.

As described above, this study realized the specific proposals<sup>7</sup> of our committee, and proved that the structural diagram demonstrated in the proposals functions well.

The primary limitations of this study include the possibility of selection bias due to the voluntary nature of participation, the limited number of facilities and cases, one-sided and limited data due to medical records being the only source of information, and concerns about the accuracy and comprehensiveness of the cases because cases were included where the investigation of the cause of death was insufficient. There were also limitations related to the analysis methods for verification, in that primary verification relied on the subjective judgment of the investigator, only one cause of death was specified, and preventability was also classified into a semi-quantitative index. Secondary verification was performed while investigating the discussion contents, and one of the future tasks will be to accumulate sufficiently structured verification. Finally, regarding the proposals, it is not only medical professionals who will need to be involved but the consensus and cooperation of many organizations will be indispensable for the implementation of these specific measures. However, given that this was a medical research study, it was difficult to obtain active involvement from potentially important partners other than medical scientists.

Despite these limitations, this is an important study as we provided those medical organizations that completed the questionnaires with an opportunity for primary verification. At the same time, we explored empirically what type of secondary verification may be possible based on the information derived from medical organizations.

The CDR system has attracted a great deal of interest from the general public in Japan and has become a topic of discussion in the media. Its importance has at last now come to be recognized in law. Currently, the implementation of the CDR system is in an exploratory stage, and details of how it should be established in Japan have not yet been determined. It is necessary to develop investigations and verification continuously while also addressing the problems identified in this study.

Reducing preventable deaths is one of the most important duties of pediatric medicine, and the CDR is of great significance in this regard. Pediatricians, who stand at the forefront of pediatric medicine and also confront many cases of pediatric death, have a duty to share this idea widely and support the efforts to implement the CDR system, both from an academic perspective and as practitioners of clinical medicine. It

is also desirable that pediatricians coordinate with diverse occupations within their region and act as leaders for the CDR scheme.

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## Disclosure

The authors declare no conflict of interest.

## Author contributions

A.N. and F.M. contributed together to the conception and design of the study. A.N. and T.O. contributed to the analysis of the data. Y.A., K.I., S.S., Y.K., M.K., and A.O. contributed to criticizing the study design, analysis, and the manuscript. All the other members of the CDR committee (A.N., F.M., B.A., A.I., Y.I., Y.U., M.U., Y.O., M.O., K.K., J.K., Y.K., A.K., Y.K., N.K., A.S., M.S., T.T., Y.N., Y.N., Y.M., N.M., K.Y., Y.K., M.K.) contributed to the acquisition and analysis of the data. All authors read and approved the final manuscript.

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