Positive Impact on Patient Engagement
-What I Have Undergone as a Bereaved Family-

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IMS Rehabilitation Center Tokyo, Katsushika General Hospital

Chairman of NPO “Kakehashi (Bridge)”,
-connecting patients, families and medical staff

April 13, 2018
My Son’s pathology from Initial Consultation to Death

<Initial Visit for Medical Consultation>
Emergency room $\rightarrow$ Treatment (enema) $\rightarrow$ Home $\rightarrow$ Symptom become severe

<2nd Visit for Medical Consultation>
Return to Clinic (waited more than 20 minutes) $\rightarrow$ Examinations (X-ray, CT) $\rightarrow$ Treatment (enema) $\rightarrow$ Examinations (blood collection) $\rightarrow$ Infusion $\rightarrow$ Blood test result (waited for approximately 2 hours) $\rightarrow$ Hospital admission $\rightarrow$ Vomited blood / CPA approx. 2 hours later without physician’s visit to the ward $\rightarrow$ Code Blue (emergency medical treatment) $\rightarrow$ Confirmed Death
Onset of disease / Hospital visit
⇒ Admission ⇒ Sudden death
a month later, there was
a sudden notice
A whistle-blower reported to several newspaper companies
↓
Medical record disclosure
→ The hospital explained:
“We did our best.”
↓
Media Coverage
<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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</thead>
<tbody>
<tr>
<td>January 11, 1999</td>
<td>Accidental mix-up of patients undergoing surgery (Yokohama City University Hospital)</td>
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<td>February 11, 1999</td>
<td>Infusion of the wrong drug (Tokyo Metropolitan Hiroo Hospital)</td>
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<td>March 2001</td>
<td>Declared to be the “Year to Promote Medical Safety” and recommendation “Coalition of Healthcare Professionals to enhance Patient Safety”</td>
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<td>April 2001</td>
<td>Establishment of the Medical Safety Promotion Office, MHLW</td>
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<tr>
<td>March 9, 2003</td>
<td>Sudden death of my son (Riki) due to medical accident</td>
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<td>September 2003</td>
<td>Jikei University School of Medicine Aoto Hospital Incident</td>
</tr>
<tr>
<td>April 2004</td>
<td>Supreme Court decision on the Tokyo Metropolitan Hiroo Hospital. “Article 21 of the Medical Practitioners Act”</td>
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<tr>
<td>April 2004</td>
<td>Joint statement of Japanese Society of Internal Medicine, the Japan Surgical Society, the Japanese Society of Pathology, and the Japanese Association of Medical Sciences “Notification of Medical Practice-related Patient Deaths ~ Toward the Establishment of a Neutral Specialized Agency ~”</td>
</tr>
</tbody>
</table>
Accommodation with the Hospital and Onwards

<table>
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<tr>
<th>Date</th>
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<tbody>
<tr>
<td>January 2004</td>
<td>Reported the incident to police.</td>
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<td>September 2005</td>
<td>Settled with the hospital.</td>
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<tr>
<td>October 2006</td>
<td>Court finalized a decision not to charge the attending doctor.</td>
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“Medical Safety Promotion Week” was established in the hospital, the week falls on before and after the anniversary date of my son’s death. The hospital organizes a training seminar for medical safety every year on the week.

Change in feelings against the hospital — Nurse’s apology on the third year anniversary of death

Lecture was given by the bereaved family in the seminar in 2007

(A face-to-face dialogue between the bereaved family and the hospital staff realized for the first time, which led to a good relationship.)
"Our mission is to disclose information and think together"

Shinkatsushika Hospital, located in Katsushika-ku, Tokyo, with 176 beds

Yoichi Shimizu (became Hospital Director in 1999, Cardiology)

▼ “The hospital director is responsible for medical safety.”
▼ “Patients are ultimately asked to participate.”
▼ “To hide one lie, thousands of other lies are necessary, and consequently, those concerned may become defiant.”
▼ “I may also turn around, depending on the circumstances. That’s why I need Ms. Toyoda to oversee us.”

Ikuko Toyoda (employed in 2004, Safety Manager)

▼ Lost her son (Riki-chan; at the age of 5) in March 2003. Misdiagnosis and handoff error  Cover-ups
▼ “There should be no more victims or second victims. I don’t want anyone else to suffer as I did.”

Yomiuri Newspaper dated August 3, 2004
Shinkatsushika hospital (at that time)
Patient Support Office
Medical Safety Management Office

Training to promote the dialogue among medical professions & staffs. This training subsequently became NPO “KAKEHASHI (Bridge)”

【Full-time】One medical safety manager
【Full-time】One medical dialogue facilitator
【Interlocking】Nurse · MSW · Medical Division

【Where the patients and family support office locates】
1st floor, management building: in “Body Learning Center.”

【Patient Counselling Counter: Library Hours】Mon-Fri: 9:00 to 17:00
Sat: 9:00 to 12:00  *except holidays and Sundays
※ We have comment boxes in hospitals / clinics
   Answers are posted on the notice board
   (We also support staffs)

Importance of face-to-face talk
- Listen to the voice of the patients (listen)
- Sympathize (imagine)
- Make an effort to have a dialogue (Communication)
Received the first “a New Form of Healthcare”

Sponsorship

November 25, 2007
Road to Establish a Medical Accident Investigation System

April 20, 2007 to December 1, 2008

“Panel on method for investigating deaths associated with medical treatment” - meeting were held 17 times


December 2007  Panel on Medical Dispute Solution “System for Identifying Causes of Medical Practice Related Deaths” Organized by Liberal Democratic Party


June 2008  MHLW “Outline of the Bill to Set up a Medical Safety Investigation Committee (provisional title)”
June 2008  Democratic Party of Japan “Draft Proposal for the Bill to Partially Revise the Medical Service Act etc. for the Provision of Information on Medical Care, Promotion of Counseling/Support and Proper Solution of Medical Disputes, and Prevention of Recurrence of Medical Accidents etc. (provisional title)” (commonly called “Patient Support Act Bill”), “System for Identifying Causes of Deaths (including Disability) Resulting from Medical Accidents etc. (Draft)”

August 2008  Established the “Medical Safety Liaison Council from the Patient’s Perspective.”

December 2008  Started distribution of leaflets and a campaign to collect signatures for the “Desire for Early Establishment of a Medical Accident Investigation Agency.”

October 2008  Worked on compiling “Major Opinions Received on the Third Draft Proposal and Draft Outline and Current Opinion of the MHLW.”

January 2009  Started operation of the “Obstetric Medical Compensation System.”
This council was founded in 2008 to collaborate the bereaved families of medical accident victims, the citizens, the medical practitioners who are making active effort towards medical accidents reduction and health care quality and safety improvement.
Campaign for early establishment of medical accident investigation agency

“Bereaved families collected signatures 100 times in ten years”

“Strong hope to Prevent Medical Accidents”
Activities Undertaken so far to Establish a Medical Accident Investigation System

March 2010  Established the “Liaison and Adjustment Council of Agencies for Alternative Medical Dispute Resolution (ADR).”

June 2010  Established the “Panel on Autopsy Imaging that Contributes to the Identification of the Cause of Death.” - July 2010  Submitted the report.

August 2011  Established the “Panel on No-fault Compensation System that Contributes to Improvement of Health Service Quality.”

February 15, 2012 to May 29, 2013  “Panel on Medical Accident Investigation System” - 13 meetings were held.

May 2013  MHLW “Discussions on Basic Policy for Medical Accident Investigation System”
Symposium to Establish the NPO “Kakehashi(Bridge)”
May 27, 2012

(Photographed by Ms. Yasuko Jinbo)
With the aim of building a mutual trust relationship between medical staff and patients/family, we provide support and enlightenment to medical staff to facilitate communication and dialogue.

By learning from the feelings of patients/family members who encountered medical accidents, we contribute to the improvement of the future medical safety and quality.

Patients/family members who encountered medical accidents and involved people provide opportunities for healthcare professionals and citizens to think about the importance of dialogue between patients/family and related persons to restore the post-accident mutual trust relationship.

<Background>

May 2006: Started workshops aiming to facilitate dialogue between staffs in Shinkatsushika Hospital.
September 2008: Due to the needs, we established “Kakehashi(Bridge) Study Group for Dialogues Leading to the Trust Relationship with Patients/Family” and expanded the workshops outside the hospital.
2011: Conducted workshops to train patient-supporting staff (in-hospital supporting staff) in Tokyo, Osaka, and Sapporo.
April 2012: Established the NPO Corporation with the focus on education projects for training of medical dialogue facilitators.

*April 2012: During the revision of the medical service fees, an additional incentive for a well-organized patient support system was adopted.
Well-organized Patient Support System
(Additional incentive for a well-organized patient support system: From April 2012)

I. Guideline for Medical Dialogue Facilitators

1. Positioning of medical dialogue facilitators at medical institutions

A medical dialogue facilitator is authorized by the supervisor of each medical institution to serve as a person who plays a role in coordinating the patient/family support system and facilitating dialogue between the persons involved, and responds to inquiries/consultations etc. from the patient/family systematically in collaboration with the medical safety manager, each department of medical services, and administrative departments based on the instructions of the supervisor.
Medical dialogue facilitators training by NPO bridge

Three-day training focused on group discussion of case study to earn basic knowledge of medical safety, communication, law and dialogue.
Patient stories, rather than data, are considered to have significant meaning in the US medical setting.

At Ms. Sorrel King’s house (Baltimore)

May 9, 2008

At the Josie King Foundation office

Ms. Sorrel King’s book titled “Josie’s Story” [Eiji Press]
From 2009
National Hospital Organization
Kanto Shinetsu Group Seminars for Training of Supervisory Doctors
“Communication Education Aimed for Patient Safety”
IMS Rehabilitation Center Tokyo, Katsushika General Hospital
Workshop Co-sponsored by the World Health Organization (WHO)
Quality of Medical Care at Hospitals and Patient Safety Management Course
Held every March from 2016

At Katsushika Royal Care Center, Shinkatsushika Royal Clinic
From 2017
Curriculum of the
Department of Medicine,
International University of
Health and Welfare

◆ Medical Professionalism I
(Basic)
First-year: Medical Ethics and
Medical Safety
Participation of Patients/Family (Bereaved Family)

Hisashi Katsumura
Member in charge of Arrangement/Administration/Recurrence Prevention for the Obstetric Medical Compensation System

Hiroyuki Nagai
Member in charge of Administration, Medical Accident Investigation/Support Center, Medical Accident Investigation System

Masakazu Miyawaki
Member of the Liaison and Adjustment Council of Agencies for Alternative Medical Dispute Resolution (ADR)

Ikuko Toyoda
Member of the Cause Analysis Committee, Obstetric Medical Compensation System
Member of the General Research Committee, Medical Accident Investigation/Support Center, Medical Accident Investigation System

Junko Kitada
Member of the Cause Analysis Committee, Obstetric Medical Compensation System

Ayako Kawada
Expert Advisor for the Obstetric Medical Compensation System
Seven Things That Should Be Kept in Mind by Medical Dialogue Facilitators

1. Stay in touch with the pain/suffering of involved persons with empathy
Malpractice deeply hurts the feelings of patients/family and healthcare providers. Medical dialogue facilitators therefore have to consider the feelings of persons involved to the greatest extent.

2. Listen to stories of involved persons and think together
Medical dialogue facilitators should first devote their full attention to “listening” to understand the feelings of persons involved. They should then support the patients/family and healthcare providers, and think together about what they are going to do, rather than giving proposals and/or advice.

3. Sincerely respect the patients, their family, and healthcare providers
What is important for medical dialogue facilitators is to sincerely respect and try to understand the feelings of patients/family and healthcare providers. Medical dialogue facilitators should not control their feelings. It is necessary to undergo training to acquire such skills, but the final result should not be copybook skills (listening and/or paraphrasing techniques).
Seven Things That Should Be Kept in Mind by Medical Dialogue Facilitators

4. Try not to cover others’ roles but help them to face the facts
Medical dialogue facilitators should not stand in for “victims/victimizers,” e.g., offer an apology on someone’s behalf. What medical dialogue facilitators need to do is to help patients/family and healthcare providers face the fact and organize an environment that makes it possible for them.

5. Act beyond an “impartial/neutral” position
Being neutral is a measure to gain trust from patients/family and healthcare providers; however, hospital staff may not seem to be “impartial/neutral” on some occasions. Medical dialogue facilitators have to build a trust relationship by remaining on the side of the sufferers depending on the situation.

6. Not getting involved in, but work together on the investigation of malpractice analysis
Medical dialogue facilitators should not get directly involved in the investigation of the malpractice analysis but have to collaborate appropriately.

7. Gain a small trust to grow into a big trust
There is no single correct answer or measure to deal with malpractice once it has occurred. Medical dialogue facilitators then need to help build a process whereby a small trust can be gained and then grown into a big trust through truthful dialogues between patients/family and healthcare providers.