＜報　告＞

A Study of Informed Consent in Nursing

看護におけるインフォームド・コンセントに関する一考察

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Ⅰ. Introduction

Informed Consent (IC) is commonly interpreted as "consent following sufficient explanation," or "explanation and consent." In the field of medical treatment and care, these words carry the meaning of providing information to the patient through full explanation, and obtaining that person's voluntary permission, with no coercion, after he or she understands and agrees with a given procedure.

After examining hospital and medical care facilities in Japan today, one cannot say that, in the areas of nursing care, tests and procedures, or surgery, patients are receiving full explanations, nor can one say that the practice of deciding a course of treatment or care is followed correctly after the understanding and agreement by the patient. Effort by the physician is required to build up a positive patient-doctor relationship where a comfortable atmosphere is created. Based upon confidence built by this relationship, a patient can be fully informed as to the appropriate course of treatment. The patients should receive explanations in language they can understand, and feel free to raise questions repeatedly when something remains unclear.

In this report, the authors intend to discuss, on the basis of actual cases, the role of nurses regarding informed consent.

Ⅱ. Cases

1. A case in which the patient was told she had cancer and needed emergency surgery.

Patient "A" was a 40-year-old female with uterine cancer who held a managerial position in a life insurance company. Her family included her husband (a regional government employee), a 17-year-old son, 14 and 8-yea-old daughters, and mother-in-low.

Condition: The patient had irregular bleeding for three years, and was initially diagnosed as having myoma uteri by her private gynecologist. During the three years she underwent regular examinations, she experienced occasional profuse bleeding, and, during each visit, her treatment consisted of prescription medications. Her persistent bleeding, occasional inability to work, and deteriorating lumbago prompted her to consult a second opinion at a University Hospital. She was examined, diagnosed there with uterine cancer, and underwent surgery.

The patient believed for three years that she had been suffering from myoma uteri. She had made regular outpatient visits to her private gynecologist. The abrupt change in the diagnosis to uterine cancer, coupled with emergency surgery, threw her into a state of

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confusion followed by days of deep depression. Her husband, after hearing the diagnosis from the attending physician and the word "cancer," equated cancer with death. He was also unable to properly perform his work.

The husband and wife, who were at the center of their family, were left in an extreme state of confusion. This had a profoundly negative effect on the entire family. They felt they no longer had a future and they were overcome with grief.

The root of this grief came from the gnawing anger and distrust the patient and her family developed toward her private gynecologist. Despite the regular outpatient visits during a period of three years prior to diagnosis of cancer, there had been no special tests or treatment. Then, suddenly being informed of uterine cancer and the need for emergency surgery, their anger turned into rage. In the area in which the patient lived, most people who transfered to the hospital at the Medical University were those with serious illnesses for which there is no prospect of recovery, or those on the verge of death. This also helped explain some of the extreme anger and grief of the patient and her family.

However, after the woman was admitted to the university hospital, they met a number of times with the primary care physician's nurse. The nurse listened to the fear and grief expressed by the patient and her family, and provided explanations regarding the treatment. This helped the couple to gradually regain their mental composure and helped them to understand the situation.

These discussions included:(1)explanations of symptoms and the disease, (2)the purpose and details of anticipated surgery, tests, and treatments, (3)the expected results and／or possible dangers of each, and (4)explanations of a differences between having and not having surgery. As a result, the patient and her family were able to understand the treatment plan, maintain their composure, and thus consent to surgery. Here the communication between the patient, her family and the medical staff, beginning with the attending physicians and nurses, was greatly improved. This improved communication led to a situation in which the participants (patients and family) were dealt with in human terms, producing a successful IC.

2. A case in which the patient was told he had liver disease, but his family was told that he had liver cancer.

Patient "B" was a 72-year-old unemployed male with liver cancer (with metastasis to the large intestine). His family included his wife (68 years old), his eldest son (45 years old), and his daughter-in-law (43 years old), and two grandchildren; one an 18-year-old college student and the other a 16-year-old high school student.

Condition: The patient had felt a constant general malaise and loss of appetite over the previous six months. As a result of various tests, he was diagnosed with liver cancer. It was explained to the patient that he had a liver disease that required medical treatment, and he was hospitalized. At the same time, his family was informed that he had advanced, inoperable liver cancer and he was expected to live only two to three months.

One month after entering the hospital, a constriction caused by the intestinal metastasis was discovered. Surgery was regarded as the best course of treatment. In response to the explanation of his doctor, the patient said, "I was told that treatment by a physician would be enough when I came to the hospital.I can't understand why you're now telling me I need surgery of the intestine. I'm going home." Moreover, the family's response was, "You said that he had cancer, and we don't understand why you want to operate on his intestine if he has liver cancer." The family said, "we're not experienced in these matters and we don't really understand your explanations. The only thing we can do is to leave everything to you and trust you'll do

what's best."

The nurse provided an additional explanation to the family. She mentioned that a metastasis of liver cancer (the primary lesion) had caused constriction of the large intestine and that with surgery on the large intestine (to remove the blocked section), this would allow the patient to be better able to pass feces. Together with the physician, the nurse explained in simple language to the patient (a second time) that the liver and large intestine are related organs that work together in the digestion and absorption of food. They mentioned that the proposed surgery was necessary to remove a malignant tumor that had formed outside the liver. As a result, the patient decided to undergo the surgery.

The key concept in this case points to the common perception that the "doctor knows best," which even now remains firmly rooted in the patient and his family. This so-called paternalism is based on the medical code of conduct that medical treatment is best left to the medical professionals and doctors. It is thought that they will choose treatment that is in their patient's best interest. When considering the levels of understanding of patients and their families, it is obvious that doctors should provide explanations with concern for the patient's condition, feelings, and present details in such a way that will be understood.

In current medical practice in Japan, the tendency is to explain the situation to the family without fully informing the patient when a disease is untreatable, such as in the case of patient "B", Mundtherapie. It is not the point of this paper to judge appropriate medical treatments for certain illnesses. Regardless of the prognosis, the patient and his or her family should be given a full explanation regarding questions posed by the patient – for example: "Why do I need intestinal surgery when I have a liver disease?" The nurse can play a key role in assessing the level of the patient's and family's understanding of the symptoms and treatment, their doubts and worries, unclear detail regarding the treatment plan, such as the expected course of treatment, the location of the treatment plan,and the people involved in the treatment plan can be explained by a nurse. Finally, she can help in assuring that the plan is discussed fully and clearly.

During the early discussions with the patient and family, the presence of a nurse, together with the attending physician, can be important in helping to prevent miscommunication and lack of understanding.

3. A case of lifestyle guidance for a patient with diabetes.

Patient "C" was a 55-year-old male employee (in a managerial position) with diabetes. His family included his wife (53 years old) and his eldest son (a 25-year- old office worker).

Condition: Hyperglycemia was indicated in a company health check, and the patient had undergone three weeks of educational hospitalization. Patient "C" had for some time felt a general malaise, but ascribed this to fatigue resulting from a hectic schedule which included long working hours and entertaining business clients with golf and other activities on weekends.

Patient "C" was a middle manager with a passion for his work. Most of his meals were eaten out and his lifestyle had an irregular schedule. The sudden diagnosis of diabetes left him in a quandary. Because hospitalization would disrupt his work and daily life, he was initially against the idea of entering the hospital. After the strong urging of his family and doctor, he finally agreed to an educational hospitalization.

The patient and his family were given nutritional and lifestyle guidance so that he could attempt to control his blood sugar, but first the patient and his family had to understand diabetes.

Next, education was presented concerning the prevention of complications and the need

to lower, control, and maintain his blood sugar during his irregular daily lifestyle. The instruction included changing his ideas toward eating, specifically, his unbalanced eating habits of always eating out.

During the patient's hospitalization, his awareness of his diabetes was raised, he was counseled by his doctor on eating and exercising, and he was given guidance to use in daily life. Before leaving the hospital, his knowledge about diabetes had increased enormously. He also learned how to modify his every day behavior so that he could continue to lead an active healthy life, while controlling his diabetes.

In this case, not only the patient but also his wife were deeply involved in receiving lifestyle guidance (because his wife coordinated the household). The patient knows it was best to avoid eating out, but in cases when it was unavoidable he tried to get a balanced meal. In addition, he began calculating his daily caloric intake because he had learned the seriousness and the possible complications associated with the disease. It is thought that the use of educational materials employing VTR and various other kinds of study equipment helped lead to success of his lifestyle training. The patient and his family learned very effectively, and explanations were given at the patient's level of understanding. This enabled he and his family to make their own decisions about their lifestyle and diabetes control. This shows the importance of a smooth IC process in the area of lifestyle guidance.

A nurse can assess what the patient and family think about with regard to lifestyle training, and any aspects they question or find problematic. This assessment information can then be supplied to the doctor, nutritionist, occupational therapist or other health care team members involved in the lifestyle training, so that full education can be provided to the patient.

4. A case involving nursing care assistance.

Patient "D" was a 75-year-old woman in rehabilitation for femoral neck fracture.

In spite of being in the rehabilitation stage of her treatment plan, the patient did not try to move on her own (perhaps because of the location of the fracture). After her first rehabilitation session in walking training (post operatively), she refused to take a shower. This event occurred during the summer, and afterwards the nurse explained to Patient "D" the necessity of showering. At first, the patient continued to refuse. The nurse continued to present the patient with the necessity for cleanliness and included showing in detail how showering could be accomplished. Eventually, the patient agreed to shower. Due to the nurse's explanation of the necessity of showering and the positive effects of the shower, the patient fully understood the reason for showering, and a collaborative treatment plan was achieved.

The role of a nurse, depending on the type of nurse (public health nurse or nurse midwife) utilized nursing methods that can include "caring for the ill or injured" and "providing care during medical treatment." Of the two, "providing care during medical treatment," or, phrased differently, providing assistance for daily life, may be a unique field to nursing. In the area of patient care, it has been a long nursing practice to explain details to patients, and to assist in the patient's understanding when providing care. This support is necessary even when IC itself is not at issue.

Among all medical professionals, nurses have the most bedside presence. Thus, they are also specialists in providing order and structure to daily life. They collect information, including the perceptions of patients and their families toward daily life, they detect problems (from a nursing standpoint), and then they plan, carry out, and evaluate the care that is required. These steps mean that the nursing process is utilized. The principle involved in appropriate I.C. and the nursing processes are analogous, and when utilized correctly, positive patient

and health-care-team outcomes can occur. In nursing situations, a carefully detailed explanation, adapted specifically to the patient's level of understanding, is needed. The knowledge the patient gains will allow him or her to invision an appropriate concept of self, and thus determine a suitable future course of treatment and action.

Ⅲ. Discussion

On the basis of four cases cited involving IC in the field of nursing, the roles of a nurse may be summarized as follows:

1. Helping patients in understanding themselves with their present conditions:

This means helping the patient understand what is happening at the present time and what is likely to happen in the future[1)~3)]. While listening to the patient, the nurse should accept the patient's feelings. The nurse should explain the situation as many times as necessary and in as many different fashions as needed. This explanation is done until the patient and nurse are satisfied that all people involved are fully informed and understand the treatment plan[4)].

2. Helping build the doctor-patient relationship:

Theoretically, IC has its foundation in "communication trust", and its maintenance between the patient, family, and, doctor. The support of the nurse in building a good relationship is essential for improved patient-physician communication[5),6)].

3. Determine the level of understanding of the patient and his or her family, and attempting to educate as needed:

This requires that the nurse assess whether or not the patient and family have accurately understood the physician's explanation. Hence, the nurse determines which areas, if any, which are lacking needed information knowledge. The nurse must then determine the following: what knowledge is deficient, who needs to be educated, who will perform the teaching, how the teaching will occur, and finally, when will the education transpire? Follow up supplementary explanations should be provided as necessary. Also, as needed during the course of treatment, the nurse should make additional requests to the physician or other professionals for further explanation and arrange these exchanges as necessary[7),8)].

4. Act as spokesperson:

The nurse must continually seek to obtain the latest information from the patient and family. If necessary, the nurse must act as a spokesperson for the patient and family in relating their needs and information to the physician and other medical practitioners.

5. Provide information:

The nurse should supply full and necessary information so that the patient is able to make his own decision. The nurse must also supply accurate information to medical practitioners in order to provide the most of an appropriate plan[8)].

6. Perform functions unique to nurses:

The first consideration of a nurse is to assist a patient in planning his/her daily life activities. This means providing the patient necessary support for his or her safety and comfort so that he or she can live in the way that suits him or her best. The nurse must also work in conjunction with the nursing process.

The previously stated six points demonstrate the required steps in the nursing process. This process is based on communication between the patient and nurse.

First, in the information-gathering stage, the nurse must ask the patient and family about their level of understanding concerning what the attending physician has explained to them. She must also ask whether they are satisfied with the explanation and what they are feeling. This stage must also include attempts to educated the patient in any areas where there is a lack of knowledge. The information gathered during this step should be presented to the physician and other medical care providers.

Next, in the assessment stage, the nurse must determine the amount and depth of

knowledge that the patient has truly understood and has agreed to. It's also the nurse's professional responsibility to determine whether the treatment plan is acceptable or not based upon each individual case. During this stage, the nurse must gain an understanding of which facts were not sufficiently explained, find any misconceptions in understanding, determine the level of the patient's understanding, and plan the best way to supplement or correct these defects. In this stage, specific methods should be used to devise a plan enabling repeated explanations. These explanations will allow the patient and his or her family to be fully informed, thus yielding an appropriate decision and plan of care (treatment or procedure)[9].

This plan should then be reflected in actual practice. Finally, the nurse must evaluate the results of the action, and whether or not the objectives have been met. If the objectives were not met, the nurse must determine the reasons and areas where the breakdown in understanding occurred. The nurse then returns to the information-gathering stage, and the nursing process is repeated as many times as is necessary for full comprehension[10].

If nursing, as Florence Nightingale defined it, means "organizing the life process so that it consumes the least amount of life energy,[11]" then IC and patient- physician communication parallel this quote. When executed correctly, the IC process can serve as an important support so that the life energy of the patient and family will not be consumed, producing a great order and comfort in the patient's life.

Using the preceding methodology, the nurses may fulfill the six steps described previously, and they may act more accurately as a coordinator. The role of nurses in setting the proper direction and tone in the hospital so that IC／patients-physician communication can function smoothly for patients and their families is a fundamental corner stone in nursing practice.

Ⅳ. Conclusion

We have discussed the importance of IC as well as the role of the nurse in this process. Team therapy, an approach of creating a team of specialists to meet the various needs of individual patients and families, is currently being actively promoted. In order for IC to function in the medical field, it is essential that the groups of professionals involved in patient care maintain close contact with one another and work together cooperatively. The principle idea far effective IC, from a nursing perspective, is not to have the doctors provide, exclusively, information to the patient, thus sometimes persuading the patient to give consent without full knowledge of the treatment plan. In this role, the nurse becomes the patient advocate, providing information and continued assistance, yielding an effective informed consent.

Furthermore, the nurse has another important role in "patient education," for, today, many patients and families still cling to the idea that all care and decisions should be entrusted with the attending physician. As nurses, we must educate patients with the meaning of IC in an understandable fashion.

It is the authors hope that this article precipitates active discussions and contributes to the growth of competent care in nursing.

References

1) Ministry of Health and Welfare Medical Affairs Bureau (translation) : U.S. Presidential General Report on Life Ethics. Sinohara Shuppan, 20-28 (1984)
2) Paul S.A., Charles W.L., (Sugiyama.H.Ed), Informed Consent, Bunkoudo, 176-191 (1994).
3) Mizuno,H. Informed Consent, Chuo Kourin-sha, 35-55 (1993).
4) Jogahana,H, Informed consent for the support of patient education, Nurse Date, 14, No.3, 79-82 (1993).
5) Hosino,K. Informed Consent, Maruzen library, 159-166 (1997).
6) Jogahana,H, Informed consent for the suport of patient education, Nurse Date, 14, No.4, 124-127 (1993).

7）Ministry of Health and Welfare Health Policy Bureau:Informed Consent for Greater Energy. Chuo Legislation Press, 56-77 (1997).
8）Jogahana,H, Informed consent for the suport of patient education, Nurse Date, 14, No.1, 63-67 (1993).
9）Sara,T.F. Ethics In Nursing Practice, ICN, 39-51 (1994).
10）Jogahana,H, Informed consent for the support of patient education, Nurse Date, 14, No.12, 103-130 (1993).
11）Florence Nightingale. Notes on Nursing — what is it and what is it not. Dover Publication Inc, New York, 8 (1982).