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Title	Informed Consent at the Time of Childhood of IDDM Patients
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Citation	看護総合科学研究会誌, 4(3), 63-69
Issue Date	2001-12-27
DOI	https://doi.org/10.14943/36811
Doc URL	https://hdl.handle.net/2115/38328
Type	journal article
File Information	4-3_p63-69.pdf



Informed Consent at the Time of Childhood of IDDM Patients

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Abstract

In the field of pediatric medical care in our country, it has never been clear what was explained by medical employees to children and how the children accepted it.

On this survey, interviews were carried out with nine male and female patients (from age 14 to 35) who fell ill with IDDM (Insulin-Dependent Diabetes Mellitus) in their childhood (younger than the age of 15) and who have come to hospital regularly. Questions were focused on these patients' memories of how they were informed of their conditions in their childhood, and what they should do to deal with it, to research how informed consent was conducted and how they recognized it in their earlier years. The results of this study were as follows:

1. Informed consent concerning the name of the disease, the condition of the disease, and treatment had never been conducted for children themselves when they fell ill with IDDM.
2. Life managements for IDDM patients, such as blood sugar measurement, insulin injections, urine sugar analysis, and diet cures, have been explained and taught since their younger ages whenever they fell ill with the disease.
3. Now as adults, recalling informed consent in their childhood, they all recognized the need of explanation to children themselves.
4. Their requests to medical employees in case of informed consent all concerned having suitable strategies of explanations of the disease and explanations of methods to deal with the disease in day-to-day living, for each according to personal need, in regard to factors such as age which would affect their ability to understand.

Key Words: Informed Consent, Care for IDDM Patient, Child Nursing

Introduction:

In the field of primary children's medical care in our country, it has never been clear what was explained by medical personnel to children and how the children accepted it. Though different children have different abilities of understanding and behaviors, each should have the right to be informed personally about what sort of medical care they should take, and in a proper way¹⁾. It is important for a chronic ill patient to take self-management techniques include an understanding of the condition of the disease and medical treatment corresponding to his/her developmental stage from the early period, and to control of the disease condition. Patients who fell ill with IDDM (Insulin-Dependent Diabetes Mellitus) in

their childhood need lifetime medical treatment and self-management techniques are important for the maintenance and improvement of the quality of life. However, it is difficult to do a clinical investigation for the children. Then, we investigated the informed consent which the patient of IDDM had received from their childhood by the following purposes.

Purpose:

It is the purpose of this paper to clarify how informed consent on self-management required for IDDM, it was conducted between medical personnel and IDDM patients who developed the disease and how they recognized it in their childhood. Informed consent indicated in this paper includes advice and facts explained by medical staff on factors such as the conditions of the disease and treatment, self-administered insulin injections, blood sugar and urine sugar measurements, diet, exercise therapy, and so on. However, because patients' memories from their childhood are predicted to have changed according to various factors such as the period of the treatment, their ages at that time, and the course of the disease, the results gained from this survey have their limitations. In addition, the limited number of subjects makes it difficult to generalize.

The definition of the term 'informed consent': In this survey, 'informed consent' was defined as "to obtain agreement based on sufficient understanding after full explanation and information being offered." In this case, 'informed consent' included not only the notification of disease names and medical treatment but also the overall information on medical and nursing care that would have been done for patients such as medical procedures, inspection and nursing.

Method:

This survey was carried out as shown below:

- 1) Period: August 19~27, 1999
- 2) Method: The procedure of the survey
 - ① We asked the director of the hospital, the chief of the nursing department and physicians to cooperate with this survey and obtained their consents.
 - ② Physicians were asked to explain to their subject outpatients using a request form for the patients.
 - ③ We obtained informed consents of subject outpatients who responded to our request.
 - ④ Interviews were carried out in a private room in the hospital with them. Interviews took 15~25 minutes and were recorded on tape with their consent (see attached data for the contents of questions).
 - ⑤ Interviews were conducted by 3 persons. The privacy of patients in this study was protected.

Results:

- 1) Outline of cases

The outline of cases is shown in Table 1. The cases consisted of 1 male and 8 females

from the age of 14 to 35 (Case D, 14, was accompanied by her mother). They developed the disease when they were 5~14 years old. Eight of them, excluding except case D, have been ill with the disease for over 10 years. Seven patients noticed subjective symptoms such as thirst, excessive drinking, excessive urination and weight loss, and their parents decided to seek diagnosis.

2) Explanation of disease

Nobody except case B, a nurse, sufficiently understood the term 'informed consent.' Only C and D received direct explanations from medical employees on disease names and the treatment progress. D and her parents received a comprehensible description by using "figures and pictures," reporting that terms for description were not difficult except those on the physiological function. Cases A, E, F, G, H and I did not receive descriptions at all (Table 2).

Now, as adults, they all thought, "Even children should receive explanations from medical employees," because "the explanation of disease is for benefit of them" and "children with IDDM will be able to understand if the explanation of disease is explained corresponding to their age." Six of them answered, "because they need lifetime medical care" and "because they cannot sufficiently manage themselves if they do not understand their conditions properly," which are typical reasons that chronic disease patients answer.

3) Medical treatment and self-management

All patients were sufficiently informed of examination and treatment. Seven of them received guidance on daily management of insulin injection, blood sugar measurement and urinalysis. D received the guidance using a videotape with her mother. A, C and F received the guidance from their parents, and G learned in a summer training camp for IDDM pediatric patients. H was not interested in his disease and did as medical employees told him to do. Regarding self-management, 5 patients started while they were hospitalized right after they developed the disease, and 1 patient after the first hospitalization. Case A gradually started self-management after the first hospitalization and completely acquired it within two years, F started in the sixth grade when she had a school trip, and G started in the third grade when she participated in the camp. The problems in self-management included ① how to treat themselves when they were in bad physical condition, ② how to treat themselves when they had low blood sugar, and ③ when and where they should have an injection.

The problems in medical treatment included ① the difficulty in managing physical exercises and diet, and ② mental pain caused from misunderstanding and prejudice of other people. However, only B and D consulted with their doctors about these problems.

On reporting to their schools, the parents of A, B, C, E, F and G reported on their pathology, and C submitted a medical certificate. H and I explained to their teachers by themselves when necessary, and told their friends about their disease. D's homeroom teacher and school nurse were told about her disease directly by her doctor in the hospital.

4) Method of informed consent

Six patients said that the explanation using the video tape and pictures was effective. Five patients concretely answered that "it was effective when the diet was explained in the

affirmative way of speaking, not negatively making them feel that they could eat only these foods" and "when the patient is a child, suitable strategies for how often and how they should be explained are necessary." Other opinions were that concrete numerical values and information should be given even for children, and that group education with the same disease patients and the opportunity to learn with their mothers were effective.

Discussion:

The play therapist and the child life specialist in Sweden and the United States do a mimetic explanation concerning hospitalization and treatment to the child on three years ²⁾. Moreover, 'assent', agreement to treatment given by a child or minor not old enough to give legally valid informed consent, is recommended to be taken in the child of 7-14 years old by the Medical society of Pediatrics in the United States³⁾.

In our country, it is general in the present pediatric medical treatment that the explanation is first done to the family when hospitalization and the operation are necessary for the child.

The survey of physicians in pediatric cancer to pass on the name of a disease to the child is only 10% or less and most of them have employed 'informed consent' for patients more than 10 years old⁴⁾. Another survey indicated that there were a lot of affirmative opinions after having explained the name of a disease had been explained to the child⁵⁾.

The subjects of this survey had not received information on the name and the state or the treatment of their disease at the appearance of IDDM in the childhood. However, whenever they developed the disease, they received explanations and guidance on self-management of IDDM such as blood sugar measurement, insulin injection, urine sugar examination and diet therapy from an early age. It is likely when they developed IDDM at the age of 10 or more, at the time of the first hospitalization, they had the ability to understand the explanation and to learn self-management.

Children with IDDM are required to master the methods of self-management, including insulin injection and blood sugar measurement and urinalysis as well as medical treatment including diet, physical exercises and cleanliness. In particular, as children older than 6th graders, 12 years old, are supposed to be taught to manage insulin injection, blood sugar measurement and urinalysis by themselves appropriate explanations about their pathology are necessary. In addition, lack of an explanation about their disease or subjective symptoms may cause anxiety and confusion when they have subjective symptoms, which might result in distrust of medical personnel and adults. To prevent these problems, it seems to be necessary that children understand sufficient explanations of their disease or symptoms by medical personnel.

Keith⁶⁾ wrote that "to transmit accurate information and not to increase patient's mental distress are not compatible" in cancer notification. Especially for patients with chronic diseases, descriptions suitable for their ages will be necessary when they are taught medical treatment or self-management, because daily self-management is necessary for patients with chronic diseases.

Subjects of this survey suggested that it was necessary for children to answer their

questions and reduce anxiety by giving effective explanations through visual tools and materials^{7,8)}. Recently, some medical institutions make booklets for kindergartens and elementary schools, which are offered for children and their families to read. Consequently, in explaining to children, a combined method with some tools and materials, not the one only method, is desirable and medical personnel should explain things, confirming whether they are understood by children.

In the case of informed consent for children, medical personnel are educated to have a responsibility for explaining clearly what children need in the medical treatment, making them understand it, and obtaining consent of practicing it according their ability after considering sufficiently the individuality of the patient, such as his/her developmental stage, character and living environment. To achieve this, nurses need to have close relationships with children and their families and try to play a role as a coordinator with other medical organizations and people concerned.

Conclusion:

In case of informed consent to IDDM patient, medical employees, especially nurses are thought to have a responsibility to conduct informed consent according to patients' individual needs, concerning explanation and treatment methods, after first thoroughly understanding individuality of the patient, such as his or her development stage, character and living environment. (This study, conducted jointly with E. Watanabe and S. Higashikawa.)

References

- 1) Onishi, H., Kiuchi, T.: *Shoni kango to play therapy 3 Nihon no Shoni kango to play therapy*, SHONI KANGO (THE JAPANESE JOURNAL OF CHILD NURSING), 21(4):496-503, 1997.
- 2) Ivonny L., von Euler M., Nomura M.: *Playtherapy; Hspital & Educatio Enviroment for Children* (Ed. By Nomura M), ketikugijutu, 1998.
- 3) Matsuda I. Yaku: *Shyoni iryo no seimeirinri* (Ethical Dilemmas in Pediatrics by Edwin N. Forman and Rosalind Ekman Ladd), Sindan to chiryo sha, 1998.
- 4) Saiki C. S.: *Shoni gan senmon i no truth-telling ni taisuru sisei—1: nitibei hikaku—* (The Attitude of Pediatric Oncologist Regarding Disclosing the name of Illness to the Children, part I: A Comparison Between Japan and the United States) SHONI HOKEN KENKYU (THE JOURNAL OF CHILD HEALTH), 57(4):590-597, 1998.
- 5) Oka T., Azuma H., Okuno A., et al.: *Byoumei setsumeigo no shonigankanji to ryosin no hannou*, SHONI HOKEN KENKYU (THE JOURNAL OF CHILD HEALTH), 55(2):328-330, 1996.
- 6) L. Keith Dipboye (Masaoka T. Yaku): *Informed Consent*, RINSHOKAGAKU (THE JOURNAL OF CLINICAL SCIENCE), 33(4):398-405-1997.
- 7) Horikoshi Y.: *Ketuyubyo ni kansuru kokuchi to informed cnsent*, SHONIKA (PEDIATRICS OF JAPAN), 26(4):93-99, 1994.
- 8) Tsunematsu Y., Kakei N.: *Gan no kodomo heno informed consent to open communication*, SHONIKA (PEDIATRICS OF JAPAN), 38(7):891-899, 1997.

Questions

1. On age and sex
2. On informed consent
 - Do you know the term informed consent' ?
 - Do you think that 'informed consent' is necessary ?
3. How old were you when you developed the disease and how did you come to be diagnosed ? (How many times have you hospitalized ?)
4. On your disease
 - How did you understand your disease at its first outset ?
 - Did you receive an explanation from a medical person ?
 - Did you receive an explanation with your parent(s) ?
 - Who did you receive an explanation from? Whose explanation was easy to understand ?
 - Did you understand ? Why didn't you understand?
 - What kind of explanation was easy to understand (including methods) ?
 - When did you come to rightly understand your disease ?
 - Do you think that even children should receive an explanation of their disease from medical personnel ? (Why?)
5. Have you received examination or treatment without receiving an explanation from doctors?
 - When and how did it happen ?
6. On management
 - Who taught you daily management of insulin injection, blood sugar measurement and urinalysis ?
 - From when did you come to manage yourself ?
 - Have you had problems ?
7. On your life as a whole
 - Have you had problems or things you don't like ?
 - What did you do at that time ?
 - Was your school informed of your disease? Who informed your school ?
8. When and what do you think should be explained to you ?
 - In your childhood
 - Now looking back at your past
9. What kind of explanation do you think is effective for children ?
10. What do you expect from medical personnel ?

Table 1. Outline of Cases

case	age/sex	job	diagnostic passage	appearance of disease
A	30 / F	housewife	subjective symptoms	8 years old (second grade of elementary school)
B	28 / F	nurse	subjective symptoms urine sugar	13 years old (first grade of junior high-school)
C	28 / F	medical person	subjective symptoms	12 years old (sixth grade of elementary school)
D	14 / F	student	urine sugar	12 years old (sixth grade of elementary school)
E	29 / F	design relation	subjective symptoms	10 years old (fourth grade of elementary school)
F	35 / F	housewife	subjective symptoms urine sugar	7 years old (first grade of elementary school)
G	29 / F	company member	subjective symptoms	5 years old
H	22 / M	worker	urine sugar	10 years old (fourth grade of elementary school)
I	28 / F	Housewife, part time worker	subjective symptoms urine sugar	14 years old (second grade of junior high-school)

Table 2. Explanation of Informed Consent (Question & Answer)

Question	A	B	C	D	E	F	G	H	I
1. Do you know the term 'informed consent' ?	×	○	△	×	×	△	△	×	×
2. Did you receive an explanation from a medical personnel?	×	△	○	○	×	×	×	×	×
3. Did you understand?	—	—	○	△	—	—	—	—	—
4. Did you receive an explanation from your parent(s) ?	?	×	—	—	△	△	△	△	×
5. Do you think that even children should receive an explanation of their disease from medical personnel?	○	○	○	○	○	○	○	○	○
6. Did you understand about disease on appearance of disease ?	×	×	×	○	×	×	×	×	×

※Answer : ○ : yes, △: a little, ×: no, ? :no remember.