

Online Appendix-A

Consent Form

Title: Participant observation study of informed consent for outpatient chemotherapy

To the director of the hospital,

I have been given an explanation according to the explanatory document about the above study. Having fully understood the explanation, I gave my consent of my own free will to participate in the following option of research (Please tick either for the relevant box below):

- I shall give my consent to respond the questionnaire only.
- I shall give my consent to cooperate the participant observation and the questionnaire.

*I understand that even if I consent to participate in the study, I am free to withdraw my authorization at any time.

*I received a copy of the signed consent form.

■ Date of consent: _____ / _____ / _____ (Year/ Month/ Day)

Participant (patient in person): _____ (Signature)

■ Date of explanation: _____ / _____ / _____ (Year/ Month/ Day)

Physician providing explanation: _____ (Signature)

Researcher providing explanation: _____ (Signature)

Online Appendix-B

An example of an 800-word description of an informed consent consultation:

Case No. 12, a lung cancer patient with low motivation.

Before the informed consent consultation: Delineation from field notes.

The patient (Mr. E) was a 60-year-old lung cancer patient who had experience of inpatient chemotherapy at a university hospital. He came alone into the outpatient chemotherapy unit from the hospital ward. He met with the oncologist and the observer for the first time. When the observer asked him to participate in this study, he seemed to be cranky, made an intimidating face, and turned his name card back to front. The observer's first impression of him was that "he will never accept my proposal and never listen to me."

Introduction (*Ki*) stage: The patient was having a defensive attitude.

Dr: On the day of a drip, I'd like you to measure your blood pressure and your weight at Reception [i.e., the waiting room] like just now.

Pt: Yes.

Dr: And

Pt: Mmm (coughs).

Dr: If you didn't measure your temperature at home, I'll give you a thermometer, so please say if you need one.

(Doctor notices the patient's name card is back to front)

Dr: Err, it's back to front (laughs).

(Doctor approaches the patient and is trying to take out the name card from the case).

Pt: Mmm (coughs).

Dr: Well, in the waiting room it can be back to front.

Pt: Mmm (coughs).

Dr: Well, when you're having the drip, I'd like you to show [the front side] to the front. Because even if Mr. E falls asleep during a long drip, the nurse will recognize that you are Mr. E, and she can change over to the next [visiting patient]. Please cooperate.

Development (*Shou*) stage: The patient happened to mention the needle-injection pain.

Dr: When you had a drip, I saw that your card [i.e., electronic medical chart] said, it was painful where the needle was inserted. Did you have any pain?

Pt: (1.0-s pause) Well, that was a physical thing. (laughs) The needle wasn't inserted properly.

Dr: Ah (laughs).

Pt: It was painful.

Dr: Ha ha ha.

Pt: I think that was probably the reason.

Dr: Today, how was it? Today's drip?

Pt: (1.0-s pause) Today, I had no particular problem.

Dr: You didn't have any problem?

Pt: Yes.

Dr: There are some patients who complain of pain along the vein with this medication. But, as you say, it depends on how the needle is inserted. That's why it might have been painful. If you had no problem today, I think we can say there's no problem. If you come to Outpatients.

Pt: Yes (small voice).

Dr: At the beginning, if it often happens, I'll have to get them to deal with it.

Turn (*Ten*) stage: When the patient began to talk about himself, the oncologist seized the opportunity.

Dr: That's everything I wanted to say, but do you have any questions?

Pt: Well, let me think.

Dr: Aha.

Pt: I mean, (1.0-s pause) aside from this, Can I go back to work? When will that be? Well, 6 months later I suppose.

Dr: (1.0-s pause) Aha.

Pt: I don't exactly know. (2.0-s pause) Can you give me your opinion?

Dr: What were you doing until you were hospitalized?

Pt: I was working.

Dr: Aha, you were, weren't you?

Pt: Yes.

Dr: The reason I've been treating you as an outpatient is that I believe in letting people work if they are able to work.

Pt: Yes.

Dr: (0.5-s pause) Honestly speaking, when you're hospitalized, you get weak.

Pt: Yes.

Dr: So, really, I'd like you to let you leave the hospital as soon as possible. Leaving the hospital is, basically, getting back to the normal routine.

Pt: Mmm (coughs).

Dr: I think so.

Conclusion (*Ketsu*) stage: The patient confided in his doctor.

Dr: What do you do for a living?

Pt: I'm a security guard in a supermarket.

Dr: If that's a place where there are a lot of germs, it wouldn't be a good idea. But I'd like you to go back to work as usual if possible.

Pt: Ah, I see.

Dr: But, since you were hospitalized for a long time, I honestly think it's a bit tough to go back to work suddenly.

Pt: Umm (laughs).

Dr: I think it'd be good if they could shorten your working hours. That might be difficult in today's working environment. I think that basically you can go back to work as usual.

Pt: Ah, I see. (4.0-s pause) Fortunately, I got a message saying, come back as soon as you can.

Dr: Yes.

Pt: Even in today's hard world.

Dr: Yes, really.

After the informed consent consultation: Delineation from short interview and field notes.

The observer asked the patient (Mr. E) to provide free comment on the dialogue. He responded (in a very free translation, for sense rather than literal meaning of the

words), “I could basically understand the things [the doctor said]. I could get the answers I wanted, and avoid hearing the doctor say what I did not want.”

The observer also asked the oncologist to provide free comment on the dialogue. The oncologist responded, “Although his face was stiff at the beginning, it was nice to hear his story at the end. To be honest, I did not expect you to get his permission for participant observation, hahaha.” Moreover, the oncologist mentioned his father, who had kept working despite enduring health problems—as the patient wished to do.