

レディネスの構築

——日本における、発症前診断にかかわる
遺伝カウンセリングのプロセス——

岩渕亜希子、工藤 直志*

Constructing Readiness:
Process of Genetic Counseling Related to Presymptomatic Diagnosis in Japan

Akiko IWABUCHI, Tadashi KUDO

要 約

本稿は、遺伝カウンセラー（医師）へのインタビューに基づき、発症前診断にかかわる遺伝カウンセリングのプロセスがいかに遂行されているかを明らかにする。また、オーストリア、ドイツの遺伝カウンセリングとの国際比較を通じて、そのプロセスの日本における特徴を論ずる。グラウンディッド・セオリーを用いた分析に基づいて、遺伝カウンセリングのプロセスを示した。そこにおける中心的な現象は、「レディネスの構築」である。日本の遺伝カウンセリングのスタッフは、遺伝学的検査を実施することにもなっておりクライアントに生じる精神的、社会的な「リスク」を避け、クライアントの「本当の」自発的意思に基づいて遺伝学的検査を行うために、極めて慎重な態度をとっている。その慎重な態度のもとで、遺伝学的検査の結果とその影響を受け止める精神的、社会的準備を整えるための、クライアントとスタッフとの相互作用が「レディネスの構築」であると言える。検査にともなうリスクへの懸念、それに基づく慎重さ、慎重さをプロセスに反映したレディネスの構築は、日本の遺伝カウンセリングに特徴的な要素であり、新しい医療技術のもとでの医療者－患者関係の更なる検討を迫るものである。

キーワード：遺伝カウンセリング、発症前診断、レディネスの構築、慎重さ

Key words: genetic counseling, presymptomatic diagnosis, constructing readiness, cautiousness

*大阪大学大学院人間科学研究科

1 Introduction

The purpose of this article is to explore the process of genetic counseling regarding presymptomatic diagnosis in Japan using interview data. Genetic counseling is a new medical practice in the field of genetic medicine. Recently, as the number of genetic medicine departments increases, more and more genetic counseling is provided. However, standard procedures and ideas do not yet exist because it is a new area. In addition, there are many specific issues of genetic medicine and some of them involve difficult ethical problems, especially in the case of presymptomatic diagnosis. Presymptomatic diagnosis identifies gene abnormalities that may make a person susceptible to certain diseases or disorders (for example, Huntington's disease) before the appearance of symptoms. Genetic testing is required to establish such a diagnosis. Before conducting genetic testing, it is imperative to provide genetic counseling for individuals with possible gene abnormalities. The present study treats this process of this genetic counseling as a part of presymptomatic diagnosis. To establish and improve the method of genetic counseling, it is very important to understand present genetic counseling practices.

The general research questions applied overall were: (a) How do staff experience and manage the processes of genetic counseling? (b) How do they reach the decision to have clients undergo genetic tests? (c) Which factors influence their decision? Using these research questions, we examine clinical practice and central issues in the process of genetic counseling from the standpoint of medical staff including genetic counselors.

This study was undertaken as part of a larger research project investigating socio-cultural issues in genetic medicine (genetic testing and counseling) and presymptomatic diagnosis. This project comprised five types of study: (a) policy analysis, (b) preliminary interviews with experts, (c) social surveys, (d) qualitative research (ethnographic study), and (e) dialogues using NSD (neo-Socratic dialogues). This article is based on the results of (d).

This project compares Austria, Germany, and Japan. Its final aim is to propose feasible solutions to improve genetic medicine, especially presymptomatic diagnosis. We started this project in 2006 and have so far conducted a number of workshops in each country. This article reflects the discussions in the workshops, especially those in the final workshop in Vienna in July 2008, with special emphasis on the characteristics of genetic counseling in Japan.

2 Definition of Terms

For the purpose of this paper, the terms will be used according to, and in the context of, the following definitions.

Session and Process

Genetic counseling is a series of individual interviews conducted in a certain timeframe. We call each interview a “counseling session.” (This was called “consultation” in Hadolt and Lengauer (2007).) We call the total sequence of sessions a “counseling process.” (Hadolt and Lengauer (2007) refer to it as “genetic counseling.”) This process sometimes requires a long period, for example, of several months, though rarely more than a year from the first interview.

Clients and Staff

In this article, we use the word “clients” to mean individual persons who visit genetic counselors to talk about genetic diseases and genetic testing. Our research deals with genetic counseling related to presymptomatic diagnosis, so “clients” also refers to individual persons with potential genetic disease. In many cases, family members of clients take part in counseling and they are of course also clients of genetic counselors. However, we do not call their family members “clients.”

Although genetic counselors in Japan need not be doctors, most are doctors. Our survey showed that Japanese doctors provided genetic counseling, including psychological support, by themselves (Kudo et al., 2008). However, in the institutions where our interviewees work, psychological specialists always participate in counseling sessions, and doctors and psychological specialists always work as a team. This is an exceptionally well-developed system in Japan. We need to pay attention to this point. Because they always work as a team and interviewees talk about their cases as members of the team, we cannot cleanly distinguish individual interviewees’ behavior from team behavior. (This point is different from research in Austria. Using the method of participant observation, they can know the behavior of each subject directly.) Therefore, we treat providers of genetic counseling collectively and call them “staff.” If we need to talk about a specific person in the team, we use job titles such as “doctor” and “psychological specialist.”

3 Method and Data

Data Collection

A qualitative approach was selected to explore the phenomena surrounding genetic counseling because knowledge of this area was highly limited and it was very difficult to obtain data on the issue using the survey method. The use of qualitative methods permitted in-depth exploration of the challenges that staff encounter before and after offering clients genetic tests and during genetic counseling.

In Austria, participant observation was employed. That method makes it possible to know directly how each staff member behaves and speaks, that is, how they manage genetic counseling. But we could not employ this method. Generally speaking, it is more difficult in Japan for outside researchers to enter medical or clinical settings in order to conduct research. So we planned to interview some experienced genetic counselors. Firstly, we obtained permission for our research design from the Research Ethics Committee of the Osaka University Center for the Study of Communication Design. After obtaining written consent from interviewees, we started semi-structured interviews with each person individually. Interviews were conducted in Japanese and recorded with the permission of the subjects. In each interview, there were multiple. Each took about 2 hours on average. We asked interviewees in advance to remember and talk about impressive or difficult cases of presymptomatic diagnosis in their clinical experience. Although we basically let them talk freely, we confirmed the following points: (1) How do clients react to staff behavior? (2) What were the staff's feelings and thoughts during the genetic counseling? (3) What was discussed among staff in the process of genetic counseling?

Subjects

Our interviewees were experienced genetic counselors. We chose them because they conducted important practices in the field of genetic counseling in Japan and we could get in touch with them. The present paper uses only data from doctors out of all subjects because genetic counseling in Japan is conducted mainly by doctors. This focus will make our point clearer.

As a result, our present subjects comprised two doctors that had clinical experience in genetic counseling in departments of genetic medicine of university hospitals in Japan.

One doctor (Dr. A) was female and her specialty was pediatrics. She had more than 10 years of experience in genetic counseling and was then conducting two or three counseling sessions per day. Another doctor (Dr. B) was male and his specialty was neurology. His career as a doctor has spanned about 20 years. When the department of genetic medicine was founded in the university hospital where he worked 10 years ago, he started to perform genetic counseling related to neurologic diseases. However, he is not involved in genetic counseling now because of job relocation.

Data Analysis

Data analysis was based on the grounded theory approach (Glaser & Strauss, 1967; Saiki-Craighill, 2005, 2006). We also referred to the method of qualitative analysis in Ritchie, Spencer, and O'Connor (2003). Initially, we read the transcripts verbatim several times and picked up important ideas in line with sequences of events in genetic counseling. Secondly, each of us divided the transcripts into small pieces and labeled them (for example, "Approach from a staff member to a client" or "Influence of a client on a staff member"). We discussed and reached agreement on the size of pieces of transcript and label names. Thirdly, the pieces of transcript were sorted into groups by label. In each group, we studied each piece more closely and labeled them more specifically. These labels are "first-order concepts." For example, first-order concepts under the label "Approach from staff member to a client" were: "confirming clients' will regarding genetic testing," "testing the strength of clients' will regarding genetic testing," "showing the choice of not undergoing genetic testing," and so on. Fourthly, we studied the relationships among first-order concepts along the timeline of the counseling process, sorted them into groups of similar concepts, and labeled each group of first-order concepts. We call them "second-order concepts" or "categories." Using these categories, we stratified relationships among categories and made a chart of the counseling process, as shown in Figure 1. In this figure, categories are located in the boxes numbered 1 to 12.

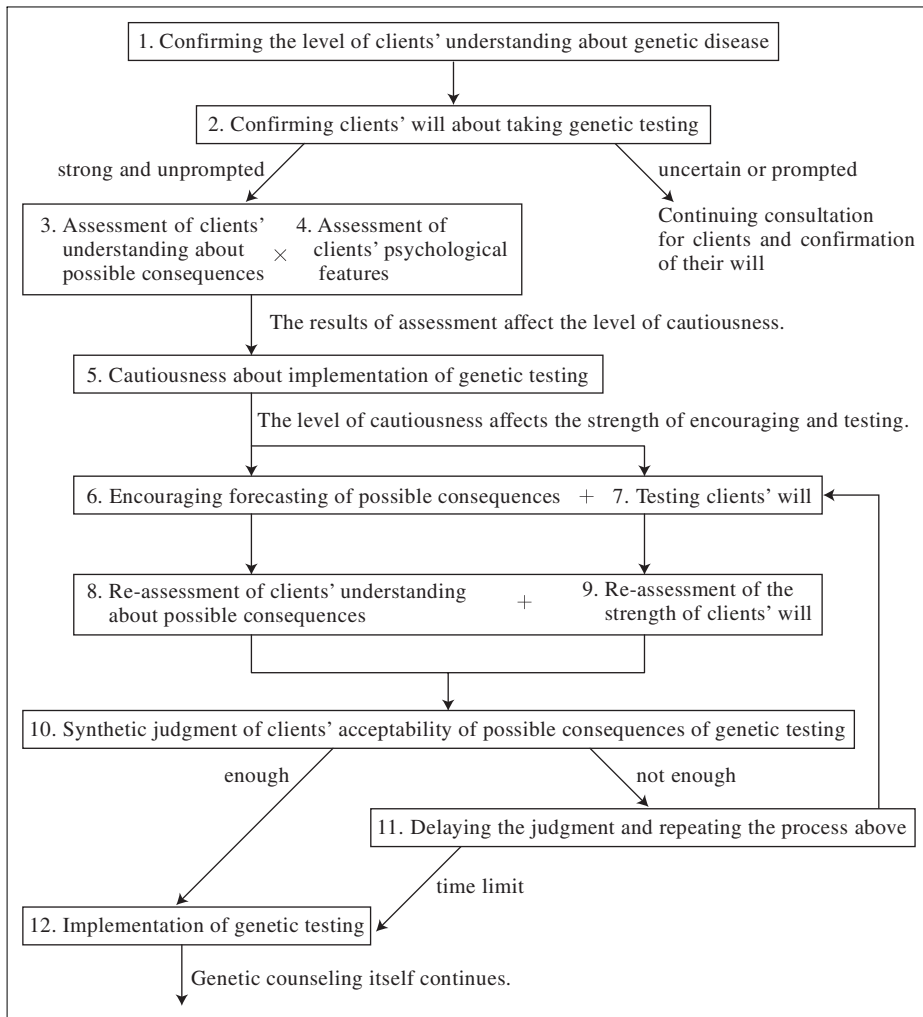


Figure 1: The Process of Genetic Counseling from the Viewpoint of Staff (from the first session to decision on implementation of genetic testing)

4 Process of Genetic Counseling for Presymptomatic Diagnosis in Japan

Process of Genetic Counseling

The department of genetic medicine usually employs an appointment system. The process of genetic counseling starts with a referral from another department in the same hospital or a direct call from the client. Basically, there is a common procedure for reception and the subsequent counseling process. For example, the department of genetic medicine of

Shinsyu University, which has an original guideline about presymptomatic diagnosis and is one of the most famous institutions in this area in Japan, has the following process: (a) appointment, (b) pre-counseling and examining the possibility of genetic testing, (c) staff conference and discussing ethical issues, (d) genetic counseling and genetic testing, and (e) follow-up counseling and/or medical treatment (Fukushima, 2001). So the point is not the procedure itself, but how to conduct the procedure.

In order to illustrate this point, we created Figure 1. The counseling process based on staff behavior and cognition is as follows: First, staff confirm clients' knowledge, understanding, and will about genetic disease and testing (categories 1 and 2). Second, staff assess clients' understanding about the possible consequences of genetic testing and psychological features (categories 3 and 4). These are at the stage of initial assessment⁽¹⁾. Third, based on the result of this initial assessment, staff make a judgment about the client's current condition and the judgment is shown in the staff's attitude of cautiousness (category 5). If the result of the initial assessment is good, staff become less cautious in the following process. But if it is poor, staff will be more cautious. Fourth, staff encourage forecasting of possible consequences and test the clients' will regarding undergoing genetic testing (categories 6 and 7). These are done in order to confirm more carefully and firmly what staff found at the initial assessment. Fifth, staff re-assess clients' understanding and will, checking the effect of the staff's approach in the fourth point (categories 8 and 9). Finally, staff judge whether clients are ready for the result and possible consequences of genetic testing or not (category 10). If they judge that clients are ready enough, they decide on implementation of genetic testing (category 12). In this case, genetic counseling will continue during and after genetic testing. However, if they judge that clients are not sufficiently ready, they delay the implementation of genetic testing and return to the approach in categories 6 and 7 (category 11).

Two Questions in Counseling Process

In the process of making Figure 1, we found that two questions were very important in the counseling process. One question is whether clients' will to undergo genetic testing is "genuine" or not (Q 1). Categories 2, 7, and 9 in Figure 1 are relevant to Q 1. Another question is whether clients are ready or not to face the result of genetic testing and its impact on their lives (Q 2). Categories 1, 3, 4, 6, and 8 are relevant to Q 2. In the counseling process, staff continue to ask themselves these questions expressly and/or implicitly. By studying how staff try to get answers to these questions and why staff ask

these questions, we can clarify the central phenomenon of genetic counseling in Japan.

So how do they ask Q 1 in the counseling process? First, staff ask this question of all clients. If clients have not yet decided whether to undergo genetic testing or not, staff naturally ask them Q 1. But even if clients have already decided to undergo testing with a strong will, staff still ask them Q 1. Of course, that clients hope to receive genetic testing is a necessary condition for conducting genetic testing. However, asking Q 1 is more than one stage of the procedure in genetic counseling in Japan, particularly in counseling related to presymptomatic diagnosis. It is succinctly expressed in the next point. That is, staff ask this question repeatedly. Of course, most clients have the will to undergo genetic testing when they visit counselors for the first time. So if staff ask them Q 1, most clients will answer “yes.” But staff do not assume that their will is “genuine” immediately.

Why do staff ask Q 1 in such a way, that is, ask all clients repeatedly? This does not mean that staff do not respect clients’ will, but that they determine clients’ “genuine” will very cautiously and carefully. This attitude comes from their following understanding: First, clients are sometimes unaware of their “genuine” will. For example, there are clients who confuse the will of their family members with their own will. In such cases, some clients are not sure about their “genuine” will and other clients say in the counseling session, “My husband (mother, mother-in-law, etc.) tells me to undergo genetic testing, but in fact I don’t want to do that.” Second, clients’ will can change in the counseling process even though their will is “genuine” at any point in time. Although this understanding comes from the clinical experience of staff, we can also understand it through our daily experience.

However, “genuine” will is not a sufficient condition for conducting genetic testing. Staff bring clients’ “readiness” into question using Q 2. They think it is very important to have clients feel ready to face the result of genetic testing and its impact on their lives. That is, “constructing readiness” is the central phenomenon in the counseling process related to presymptomatic diagnosis in Japan. In fact, Q 1 is part of Q 2 in this sense because uncertainty or lack of clients’ will mean that clients are not ready to undergo genetic testing. Then, what is “readiness” and how is “readiness” constructed?

Central Phenomenon: Constructing Readiness

From the perspective of staff, it is a necessary condition for conducting genetic testing that clients have constructed sufficient readiness before receiving it. What we mean by

the concept of “readiness” is as follows: First, clients understand the implications of both undergoing genetic testing and not undergoing it. Second, clients understand the possible consequences of genetic testing for their lives and family. And third, clients’ family members, especially key person(s)⁽²⁾, also understand such possible consequences.

“Constructing readiness” has the following meaning. First, it means activities that clients and their family perform to create “readiness” in this sense. Second, it also means all approaches that staff take to help clients and their families to construct readiness. However, because most clients do not have sufficient readiness and are not fully aware of the need for such readiness when they begin counseling, staff approaches allow for clients’ activities to start constructing readiness in many cases. So, third, this phenomenon essentially comprises cooperative activities among participants in genetic counseling although it begins only as a purpose for staff in the early stages of genetic counseling. As counseling interactions continue, “constructing readiness” becomes the common purpose for both staff and clients.

Why do staff make “constructing readiness” an important issue? Staff told us that, if clients are not ready, they cannot and should not decide whether or not to undergo genetic testing, because there is a strong possibility that clients and their families will face a “crisis” during the counseling process and after the implementation of genetic testing. Staff are very fearful of such a crisis. This strong “fear of clients’ crisis” is a remarkable characteristic of Japanese counseling staff. As mentioned above, because staff recognize that many clients are not ready, it is a very important and central action in the counseling process for staff to construct clients’ readiness. Even if clients seem to be ready in the early counseling sessions, staff do not believe it hastily. It is the same situation as with the case of clients’ will that we discussed above.

Then, what kind of “crisis” do staff expect? First, they expect the kind of crisis that occurs when clients receive a positive result of genetic testing without sufficient readiness. Because many clients hope to undergo genetic testing in order to show that they do not have a genetic disease, some of them do not entertain the possibility of a positive result at the early stage of their counseling. In the other words, they do not understand the possible consequences of genetic testing, and so they are not mentally prepared for a positive result. If they receive an unexpected result (it is often bad news for them), they will be terribly shocked. Staff indicated that a positive result sometimes led clients to a “catastrophic event” like suicide, attempted suicide, and depression or problems with family members such as divorce or wedding cancelation.

Second, staff also expect a crisis even if the result of genetic testing is negative. Tamai (2005) indicates that there are cases where clients show mental problems like depression after they get an expected (negative) result. Tamai showed four types of such risk: (1) depression by burden, (2) survivor's guilt, (3) disappointment, and (4) doubt (Tamai, 2005: 129). (1) In the case where the result of genetic testing is negative, some clients feel they have to support and care for other family members with genetic disease because they are "healthy." In addition, it is not uncommon to see clients who get negative results having to take the role of coordinator for family members and relatives around genetic disease issues (Tamai, 2006). This burden causes clients to become depressed. (2) In the case where there are family members with genetic disease, some clients who receive a negative result feel sorry that only they are healthy. Such guilty feelings are called "survivor's guilt" and sometimes cause depression, too. (3) Some clients have excessive expectations that if they receive a negative result, their lives will take a turn for the better. But because their lives naturally do not in fact change very much, they feel totally disappointed. (4) Some clients do not believe the negative result of genetic testing. They think that staff and their families are lying to them about the result because they care for the client. Therefore, they compulsively ask for the result of genetic testing many times or feel distrust against staff. This doubt and distrust also cause depression.

How do staff act to construct clients' readiness and avoid possible risk? Here, in order to show this, we use our categories in Figure 1 and specific examples from interviews. The stage of initial assessment (from category 1 to category 4) is preparation for constructing readiness in the following process. Most central categories for "constructing readiness" are categories 6 and 7. In the case where the result of initial assessment is poor, staff try to construct clients' readiness through these approaches, and in the case where the result is good, staff also try to ensure clients' readiness using them.

Category 6 (encouraging forecasting of possible consequences) has two sub-categories, that is, "encouraging forecasting of the possible result of genetic counseling" (category 6-1) and "encouraging forecasting of influences on their lives and family" (category 6-2). In one case of Dr. A, the client (young female) and her mother wanted to establish their "innocence (they were not genetically diseased)" for her husband's parents. In this case, they did not imagine how they would feel or how his parents would behave if the result was positive. They had been trying to undergo genetic testing. So Dr. A told them that "there is a possibility that you can't establish your innocence (6-1); please

think how your relatives would feel in that case, and how the relationship between you and your relatives would be affected by undergoing genetic testing (6-2). Sometimes not knowing is better for clients and their families.” In one case of Dr. B, it became a problem that the client (young male) had a brother who knew nothing about the possibility of genetic disease and the choice of genetic testing. Dr. B told the client repeatedly, “Your brother has the same risk as you. I think you had better tell your brother about this. Is it really good that only he doesn’t know about it? Please think again (6-2).” And in some cases, doctors also let clients imagine their lives after the onset of symptoms, including care for clients (6-2).

Category 7 (testing the clients’ will) has four sub-categories, that is, “presenting risk” (category 7-1), “proposing the advantages of not knowing” (category 7-2), “showing the choice of not undergoing genetic testing” (category 7-3), and “giving directive advice” (category 7-4). In one case of Dr. B, the client (young male) did not seem to sufficiently understand the possibility of genetic testing, but he had extremely strong will to undergo it. So Dr. B explained to him that some people were mentally depressed and had trouble socializing even if the result of genetic testing is negative, and that some clients committed suicide if the result was positive (7-1). As a result, this client decided to give it some time and think it over. In one of Dr. A’s cases, the client (young female) came to hesitate to receive genetic testing in the process of counseling. But her family members strongly recommended that she receive genetic testing. Dr. A advised her that she had the choice of not receiving it (7-3) and she should abandon the idea (7-4).

The actual actions that staff take to construct clients’ readiness are very individual and diverse. This is because what is needed for constructing readiness differs among clients. Of course, genetic counseling is conducted within a medical framework as a rule, but sometimes the issues that clients have are beyond the framework. These issues are often ethical difficulties. Fukushima (2001) pointed out that “case-based ethics” are important in dealing with ethical problems in genetic counseling. As a result, staff actions for constructing readiness look like a certain type of intervention. As we showed above, staff even suggest to clients that they should give up genetic testing if staff judge that it is necessary.

Characteristics of Genetic Counseling in Japan

Based on the discussion above, we can reveal five characteristics of genetic counseling in

Japan as follows. (1) Risk awareness about undergoing genetic testing: Staff estimate the risk of undergoing genetic testing as high; (2) Deep concern about clients' lives: Staff worry about the influence of genetic testing on clients' lives and relationships between clients and their families; (3) Cautiousness: Staff are very cautious about conducting genetic testing. This cautiousness comes from characteristics (1) and (2) that we indicated above. And this cautiousness results in the following two characteristics in their level of action; (4) Support that sometimes looks like intervention: Of course, they attach great importance to supporting clients' self-determination in undergoing genetic testing, and at the same time, they also place a very high premium on avoiding the negative consequences of clients' self-determination by anticipating the possibility of a crisis. Not only self-determination in undergoing genetic testing, but also its results are their prime concern. This generous support sometimes looks like intervention; (5) Absence of agreement on conducting genetic counseling: Staff actions show well that they do not encourage genetic testing. Among participants of genetic counseling, there is no "agreement" on conducting genetic testing in advance. Staff require all clients to rethink whether they should know and/or need to know that there is a possibility of onset of genetic disease.

Why is genetic counseling conducted in a distinctive way in Japan? In particular, how does cautiousness appear? On this point, we do not have enough evidence and we have to avoid linking such differences with "culture" without careful consideration. However, we do note that there are differences in the system that introduces clients to genetic counseling in Austria and Japan. In Japan, clients are invited to genetic counseling without detailed explanation such as, "Do you know what genetic counseling is? This gives you specialized counseling about genetic problems. Are you interested in it? Are you willing to try it? If you are, I will introduce you to it." So, many clients do not have enough knowledge about genetic counseling and testing at the first visit to genetic counselors. On the other hand, in Austria, the primary doctor explains what genetic counseling and testing are before the first session of genetic counseling. Therefore, Austrian clients can start to examine what the counseling and testing mean to their lives before counseling starts. However, most Japanese clients start to examine it in detail after starting genetic counseling. This is why Japanese staff are more cautious in confirming clients' knowledge and will and undergoing genetic testing. This difference in attitude reflects a structural difference. Of course, this is only one of the reasons⁽³⁾. To explore them is an issue for future research.

5 Conclusions

The present study has discussed the process of genetic counseling in Japan and its characteristics. We have already shown what is important for staff of genetic counseling in Japan and how their cognition is expressed in the process. We conclude that “constructing readiness” is the central phenomenon in the counseling process and a cautious attitude in constructing readiness is a distinctive characteristic of genetic counseling in Japan.

At the end of this discussion, we picked up two more issues as follows. What does it mean that “constructing readiness” is the central phenomenon in the counseling process in Japan? Genetic counseling as a medical practice has two aspects. One aspect is “information transfer,” that is, staff provide clients with their expertise⁽⁴⁾. Another aspect is “counseling,” that is, staff support the decision making of clients by promoting their ability to cope with their genetic problems⁽⁵⁾. The second aspect (counseling) may not always accompany the first aspect (information transfer), but the fact that “constructing readiness” is very central in the counseling process tells us that staff in Japan place more emphasis on the “counseling” aspect in their practice. A certain interviewee spoke about this point: “If we conduct presymptomatic diagnosis, we need preparation to take responsibility for supporting clients’ lives totally.”

Some people will criticize this attitude saying that such responsibility is beyond what genetic counselors can take or that it is just a particular attitude only in Japan. However, the increase of new technology and new medical areas are changing the existing relationship between medical staff and clients/patients. The growing importance of the role of genetic counseling in the medical field shows exactly that. Of course, to support clients’ self-determination is very important for genetic counselors and their colleagues. But the present study showed that in Japanese cases it is not the procedure itself but how to conduct the procedure of genetic counseling that is more important. The process of genetic counseling requires us reconsider partnership and cooperation between medical staff and clients.

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Notes

- (1) During the initial assessment, staff show clients that there is a very high bar for them to take genetic testing. For example, clients need to take counseling sessions at least several times, they need to take psychological tests, they need to invite their key persons to counseling sessions, and so on. Although we do not discuss it in detail in the present study, “showing a high bar” also reflects the cautiousness of staff discussed below.
- (2) Here, “a key person(s)” means those who can support clients during the process of genetic counseling and after conducting genetic testing. In many cases, spouses and partners are most important key persons. If the clients are single, their parents (in our research, they are mainly mothers) are likely to be key persons.
- (3) For example, Dr. A pointed out that there are no systems that support clients to live with genetic disease, especially after the onset of symptoms. The difference in support system also explains the difference in staff attitude between Austria and Japan.
- (4) Hadolt and Lengauer (2007) refer to “genetic counseling as a medical practice based on the particular expertise.”
- (5) Hadolt and Lengauer (2007) refer to it as “narrowly defined genetic counseling,” but it is different from our definition in two points. The first point is that, in the “counseling” we mentioned here, staff give suggestions or advice to clients about how to cope with their problems. The second point is that the ability to decide is important for clients but that it is just a part of the ability that staff intend to promote.

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