

\* This English manuscript is a translation of a paper originally published in the *Psychiatria et Neurologia Japonica*, Vol. 122, No. 7, p. 509-513, which was translated by the Japanese Society of Psychiatry and Neurology and published with the author's confirmation and permission. If you wish to cite this paper, please use the original paper as the reference.

## Debate

### Reading Ishizuka's article, "For Psychiatric Care that Talks about 'Heredity' in Inheritance and Diversity" - supplementing from the standpoint of patients and families

Ikuko NATSUKARI

Yakitsubenomichi Clinic

*Psychiatria et Neurologia Japonica* 122: 509-513, 2020

**Keywords** : patient, family, negative genetic factors, genetic inheritance, diversity

#### Introduction.

Ishizuka's article<sup>4)</sup>, published in Volume 121, Number 8 of this journal, develops a discussion based on the question, "Is the hereditary negative factor of mental illness a negative factor?" and points out the need to change the negative image of heredity associated with mental illness and to discuss heredity with patients and their families. The author, who has a mother with schizophrenia and has been a patient of psychiatry herself,<sup>7)8)</sup> asks how much psychiatrists listen to family history and how they utilize it for the

benefit of patients and their families. In this paper, we discuss the role of the genome in the pathogenesis of psychiatric disorders. In this paper, I would like to summarize the points that I feel are significant in the Ishizuka paper from the standpoint of the people concerned, and discuss the points that I would like to add to the Ishizuka paper.

#### I. The Significance of Ishizuka's Paper

1. The direction of "discussing heredity with the parties and their families" was indicated.

Until now, there have been some

papers in Japan that describe the relationship between psychiatric disorders and genetic disorders in a specialized manner, but there have been few papers that focus on how to discuss genetic disorders with patients and their families. Ishizuka's paper answers the author's question as a family member with a "genetic negative factor" for mental illness in an easy-to-understand style.

In particular, genetic counseling using family trees seems to be a useful method for patients and their families that can be used in general practice. The purpose of a family tree is not only to investigate the possibility of heredity. The Ishizuka paper describes a case in which the counselor and the therapist confirmed the fact that a relative, whom the counselor had interpreted as socially maladjusted, was working hard at a workplace with less interpersonal load while drawing a family tree, which led to a correction in the counselor's attitude toward mental illness.

2. Trying to change the image of "heredity".

Ishizuka's paper explains the history of the term "hereditary negative causation", including how the word genetics, originally a combination of the concepts of heredity and variation, became established in Japan as the translation "heredity", meaning

inheritance. In fact, this society has used the expression "negative genetic factors" until 2016.

The Ishizuka paper states that the negative nuance of the word "negative" cannot be overlooked, and then goes on to say, "Genetic factors in schizophrenia are not necessarily negative, but are known to be related to a wide range of individual qualities such as creativity and physical characteristics. At the very least, it is appropriate for us psychiatrists to take a neutral view of family history of mental illness as a category of diversity.

This text was a great opportunity for the author to reflect on the relationship between her mother and the author. The author's mother was a complete unknown, but she was a literary figure who devoted her life to novels and creative activities. Writing was not a hardship for the author either. The connection between her mother's extremely creative talent and the onset of her mental illness can only be imagined now, but at least it reminded me that such an inherited talent is not all bad.

In his article on "Psychiatrist's Privilege," Fukuda 1) states that there were requests from patients and their families not to use terminology that is not scientifically accurate. For example, "hereditary negative factors" is incorrect and should be replaced with

"family history," "genetic abnormalities" should be replaced with "genetic mutations and polymorphisms," "life difficulties" should be replaced with "life difficulties," "abnormalities in brain structure" should be replaced with "changes in brain structure," and "normal and abnormal" should be replaced with "physiology and pathology. He stated that the effort is easy to promote because he is a specialist.

Patients and their families are still suffering from prejudice against mental illness. We hope that psychiatrists themselves will recognize that the terminology they customarily use contributes to prejudice and consider reconsidering their terminology.

### 3. the point about accidental factors.

While there are various misunderstandings and taboos in the field of heredity, the Ishizuka paper clearly mentions "chance factors," or "luck," in the development of mental illness. Although the patients and their families do not often express the word "luck" out of a sense of modesty, they are probably the ones who know the most about the power of luck. The author also believes that "life is basically unfair.

Kasahara 5) says, "Front-line psychiatrists are the ones who know this 'cause of luck' the best. We average people have a little more bad luck than healthy people in heredity, family

relationships, ability, interpersonal relationships, and so on, but we are not so different. He quotes the sentence, "Isn't that what psychiatric cases are originally about?" to suggest a way of thinking about "luck factors" that clinicians vaguely feel but have not yet been able to sort out.

The Ishizuka paper also cites Tomasetti, C. et al.<sup>12</sup>) and states that it has been proven by biostatistical methods that chance, in addition to genetic and environmental factors, contributes greatly to the development of cancer, and that the majority of cases are "not the person's fault. We believe that psychiatrists' awareness of chance based on these findings, rather than mere consolation, will be beneficial to families who are prone to guilt.

At a lecture, the author was asked by a high school student who had a mother with schizophrenia who was refractory to treatment. "If you explain this disease as a brain disease, shouldn't psychiatrists be treating my mother's brain instead of just talking about it, since the brain is one of the organs? What does psychiatry treat when it comes to the brain?" He then asked, "Is schizophrenia inherited? He then asked, "Is schizophrenia inherited?"

The author could not answer either of his two questions clearly and confidently. It was painfully clear that, like the author before him, he was

uncomfortable with the author's answers.

The author did not intend to give him a literary answer such as "the risk of having a parent with schizophrenia is thought to be about six times higher than the general risk. 3) I was not going to give him a literature-based answer, because, as described in the Ishizuka paper, for the family, "there is only one choice: to have the disease or not to have it. The explanation that the prevalence of schizophrenia is 1% does not make much sense to the author or to the high school students. This is because the parents in front of them have already developed the disease, and for the family it is not 1% but 100%.

Genetic and environmental factors interact with each other, and chance factors also overlap. At present, how these factors actually interact is still only slightly understood scientifically<sup>2)10)13</sup>). Clinicians need to take this situation into consideration, including coincidental factors, and discuss it with patients and their families with humility.

## II. What I would like to add to Ishizuka's paper

1. What psychiatrists need to do to "prescribe hope" in listening to family history and talking about genes

In the Ishizuka paper, the author states, "I hope that psychiatrists will be

able to prescribe hope to the topic of inheritance and diversity of the genome," but as a patient and family member, I read the phrase "prescribe hope" with mixed feelings. As a family member of a patient, I read the phrase "prescribe hope" with mixed feelings. The author also states that "genetics is not all negative," but I wonder if psychiatrists themselves are really able to "have hope" in the first place.

It took several decades for the author to realize that genetic inheritance is not all bad. One of the reasons why it took so long may be that there was no one around to explain family history to the author "in a neutral way as a category of diversity. In this sense, increasing the number of psychiatrists who can talk about heredity would certainly be one solution.

However, the author believes that an even greater cause is the fact that "psychiatry is still unable to cure the symptoms of its patients. Even after she became a psychiatrist, the author kept her mother's existence a secret until she went public. When her family name was changed after her marriage, she even thought she would never remember her maiden name again. She did not want to "inherit" her horrible negative fate. The author came to this conclusion because her mother's symptoms were so severe that they affected the entire family. The onset of symptoms over decades, not

years, eventually led to the breakup of the family. For a significant portion of a person's life, symptoms must be endured in fear of prejudice. It was a "negative factor" in itself. "The author's true wish as a concerned family member was, "I would rather have a pill to cure my mother's disease than 100 supporters and people who understand her.

Then, I would like to consider why the author himself has come to accept it.

What contributed the most to the author's acceptance of the "negative factors" was the experience of listening to her and her family's stories hundreds of times after they were made public. The people in the family associations and parties did not deny the dark family history that had been hidden until now, but listened to it with warm eyes. It was a moment when many people recognized the author's history. People cannot move forward unless they are "approved". We cannot change the past, but we can change the way we look at the past. The author realized that it is important that the change is not prompted by someone else, but is a change that is born naturally in the speed of the person through storytelling. It is because of these changes that the author has come to believe that his life, which he thought was negative, has value.

Even if it is said that "genetic factors are not always negative," the author's

personal impression is that it may not be easy for patients and families suffering from ongoing psychiatric symptoms to accept. In addition, can psychiatrists, who have difficulty in dealing with treatment-resistant patients, accept the family history in a "neutral" way?

In order for patients, families, and psychiatrists to accept heredity in a neutral manner, they should be aware of the caring effects of narratives as experienced by the author. "Narrative is a process of accepting "environmental factors" and "chance factors" that were beyond the control of individual efforts as well as heredity.

At the same time, psychiatrists themselves need to become "psychiatrists who have hope for the future of psychiatry. In order to do so, they should repeatedly listen to the "stories" of the patients and their families, who are the "embodiment of the disease," and witness the changes that lead to their hope, not just medical knowledge. The author also believes that to become a doctor who can listen to others, "the first step is to have the experience of being listened to yourself. Psychiatrists, too, should have the experience of being listened to by others.

This attitude is not limited to genetics, but is universally necessary among psychiatric professionals. However, given the fact that the causes of

psychiatric disorders have yet to be identified and consist of the interaction of genetic, environmental, and chance factors, psychiatrists cannot confidently "talk about the involvement of genetics" based on scientific evidence. When asked about heredity by patients and their families, psychiatrists need to be humble enough to accept the fact that they cannot give a clear answer, and be objective enough to discuss the issue with the patients and their families, but this may be a difficult task. In the author's personal opinion, in order to be able to do difficult things well, it is necessary to experience the other person's position, that is, to experience being listened to. In other words, we need to experience being listened to. If possible, it would be even better if a genetic counselor were to be the listener.

2.The importance of psychiatrists' interest in understanding the pathogenesis of mental disorders through genetic disease research.

In recent years, an increasing number of patients and families have been diagnosed with developmental disorders. 22q11.2 deletion syndrome, a genetic disorder, is known to cause a wide variety of symptoms and to be associated with a high rate of developmental psychiatric disorders such as autism spectrum disorder, attention deficit/hyperactivity disorder,

and schizophrenia.<sup>3)6)9)11)</sup> We wonder how many psychiatrists are motivated to learn about these genetic disorders as they relate to the pathogenesis of mental disorders. Again, the author believes that what the patients and their families really want is a psychiatry that can "cure" them rather than a full range of services. Knowing the wishes of the patients and their families, psychiatrists should actively look into the literature on heredity. The author read the literature on genetics<sup>9)</sup> and was able to have hope that mental illness and neurodevelopmental disorders can be cured. It is important to be able to see even a small possibility in the future, even if it is not immediately realized. In order to become a psychiatrist who "prescribes hope," I think it is necessary to be interested in the latest knowledge about genetic disorders.

3.How to increase the number of psychiatrists who can explain genomics to patients and their families

The Ishizuka paper states that "there are clinical geneticists and certified genetic counselors in each region" and that it would be good if collaborative relationships such as requests for genetic counseling and consultation of cases could be built around these specialists. However, in reality, of the 1,334 clinical geneticists<sup>14)</sup> in Japan,

only 10 are psychiatrists (as of October 21, 2019). In reality, however, of the 1,334 clinical geneticists<sup>14</sup>) in Japan, only 10 are psychiatrists (as of October 21, 2019).

The author did not hear any explanation of her mother's disease from the viewpoint of "heredity" from her doctor, who only gave her a very general answer without any scientific explanation when she was over 30 years old, "Since you are over 30 years old, you should not be at risk (of developing the disease) anymore, right? This was an extremely generalized answer without any scientific explanation. Since there are late-onset schizophrenia as well, such generalizations cannot be satisfactory.

The situation is the same today as it was when the author received treatment as a patient, several decades later. In today's Japan, patients and their families are not allowed to choose their doctors. The patients and their families do not know clearly what the doctor in charge specializes in, what he or she is good at, or what he or she is not good at. If many psychiatrists had the kind of genetic knowledge described in the Ishizuka paper, they could share their knowledge and experience with other professionals and reflect it in treatment. However, with only 10 psychiatrists qualified as clinical geneticists in Japan, is such

collaboration possible?

If we really want to change psychiatry, we need to think about how to increase the number of clinicians who can talk about genetics among psychiatrists. If we really want to change psychiatric care, we need to think about "how to increase the number of clinicians who can talk about genetics" among psychiatrists, so that the patients and their families can truly benefit.

The author, from the standpoint of patients and their families, asked the president of the Japanese Society of Schizophrenia to hold a symposium on "Genetics" at the 2018 meeting. The symposium was realized, and the content was rich with a variety of speakers related to heredity, including geneticists, members of the 22 Heart Club (a family association for patients with 22q11.2 deletion syndrome), and the author. I would like to see a symposium with a "diverse" lineup of geneticists held at the annual meeting of this society. I believe that the accumulation of such symposia will foster the development of physicians who are interested in genetics. I believe that creating opportunities for patients and their families to participate in the creation of programs for the Annual Meeting will open up a broader field for psychiatry.

Conclusion.

"It is necessary to have a guide to navigate through genetic factors, environmental factors, and luck (chance factors) in order to live life. In order for medical professionals to understand this, it is necessary to listen carefully to the patient's life from the very beginning.

The author wanted a navigator to help her through life. The term "navigator" here refers to the role of a therapist who comprehensively understands the individual genetic, environmental, and coincidental factors of the patient, and provides easy-to-understand explanations and advice for the future.

We hope that psychiatry will develop so that patients and their families can receive satisfactory explanations at an early stage after the onset of illness so that they can lead a rich and valuable life thereafter.

There are no conflicts of interest to be disclosed in relation to this paper.

## References

- 1) 福田正人: 精神科医の「特権」に気づき役立てる. 精神経誌, 117 (5); 353-361, 2015
- 2) Fusar-Poli, P., Tantardini, M., De Simone, S., et al.: Deconstructing

vulnerability for psychosis: meta-analysis of environmental risk factors for psychosis in subjects at ultra high-risk. Eur Psychiatry, 40; 65-75, 2017

3) 石塚佳奈子, 尾崎紀夫: 精神疾患のジェネティクス—自閉スペクトラム症—. CLINICAL NEUROSCIENCE, 36 (2); 238-241, 2018

4) 石塚佳奈子, 尾崎紀夫: 「遺伝」を継承と多様性で語る精神科医療に—精神疾患の遺伝要因を当事者やその家族とどう話し合うか—. 精神経誌, 121 (8); 602-611, 2019

5) 笠原 嘉: 精神科における予診・初診・初期治療. 星和書店, 東京, p.122-123, 2007

6) 加藤秀一, 尾崎紀夫: 自閉スペクトラム症—診断上の留意点と, 発症メカニズムの最近の知見について—. 臨床神経学, 59 (1); 13-20, 2019

7) 夏苺郁子: 「人が回復する」ということについて—著者と中村ユキさんのレジリエンスの獲得を通しての検討—. 精神経誌, 113 (9); 845-852, 2011

8) 夏苺郁子: 人は, 人を浴びて人になる—心の病にかかった精神科医の人生をつないでくれた 12 の出会い—. ライフサイエンス出版, 東京, 2017

9) 名和佳弘, 久島 周, 尾崎紀夫: 既知の遺伝子疾患と関連する神経発達症・統



合失調症. 臨床精神医学, 48 (1); 53-61, 2019

10) Peh, O. H., Rapisarda, A., Lee, J.: Childhood adversities in people at ultra-high risk (UHR) for psychosis: a systematic review and meta-analysis. *Psychol Med*, 49 (7); 1089-1101, 2019

11) Schneider, M., Debbané, M., Bassett, A. S., et al.: Psychiatric disorders from childhood to adulthood in 22q11.2 deletion syndrome: results from the International Consortium on Brain and Behavior in 22q11.2 Deletion Syndrome. *Am J Psychiatry*, 171 (6); 627-639, 2014

12) Tomasetti, C., Vogelstein, B.: Cancer ethiology. Variation in cancer risk among tissues can be explained by the number of stem cell divisions. *Science*, 347 (6217); 78-81, 2015

13) van Os, J., Guloksuz, S.: A critique of the "ultra-high risk" and "transition" paradigm. *World Psychiatry*, 16 (2); 200-206, 2017

14) 臨床遺伝専門医制度委員会: 全国臨床遺伝専門医・指導医・指導責任医一覧  
(<http://www.jbmg.jp/list/senmon.html>) (参照 2019-10-21)