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**Special Feature Article**

# Significance of Case Reports for Patients: Investigation from the Standpoint of the Patient and Their Family Including Cases for Which Consent was Difficult to Obtain

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## Abstract

In some cases, the ethical considerations concerning obtaining patient's consent for case reports could be considered "cumbersome ethical restrictions" that "oppose scientific freedom." However, the author believes that assuming the patient's consent is provided based on their trust in their attending physician, a case report can act as an important bond between the patient and the physician. Patients and families are often willing to cooperate generously to enable progress in the field of psychiatry due to trust in the field. Hence, the patient's consent is essential on principle.

However, forensic psychiatry, child abuse, and genomic medicine, the three fields covered in this special edition, differ greatly from routine healthcare. In routine healthcare, it is often difficult to maintain the patient-physician relationship on an equal footing; hence, it is preferable that the patient and physician engage in "shared decision making" through mutual effort. However, in the above three fields, the existing power gradient, whether towards the legal defendant, between parent and child, or as a person with expertise in genetics and genomics, makes it even harder to maintain equality than in routine healthcare. Moreover, strict patient confidentiality requirements make it even more difficult to obtain patient's consent. Despite this, etiologies in patients in these fields often involve complex interactions among the neuropathology, environmental factors, and surrounding social structures of psychiatric disease; thus, case reports in these fields are believed to serve an important role in psychiatric research.

The author's discussion focused on the "significance of case reports for patients themselves" from the standpoint of patients and their families, including patients whose consent is difficult to obtain. In recent years, there is a new trend of "academic presentations being given by patients or their families." In addition to contributing knowledge towards advancements in medicine, case reports should also be meaningful for the patient. They should be conducive to the patient's recovery and non-traumatizing to the patient without aggravating existing stigmas. However, such positive outcomes of case reports can only be founded on the patient's trust in their physician. Academic associations should realize that changing times demand developing new guidelines in line with these new trends such as open access or Participatient study.

**Keywords**：ethics, patients, family members, case reports, patients' consent

## Introduction

Patients and families are eagerly awaiting elucidation of the pathophysiology of mental disorders and development of therapeutic drugs for them. Recovery is important, but it is not easy for those with severe symptoms to live with dignity despite their symptoms. The most important solution to the social problem of physical restraints under involuntary hospitalization, even before the shortage of medical personnel, is to improve symptoms with treatment, and so isolation and restraints will no longer necessary. Therefore, research to elucidate the pathophysiology of diseases must be promoted.

Researchers must reaffirm the importance of Article 8 of the Declaration of Helsinki (revised in 2013). Omori 9) states: ""The main goal of medical research is to obtain new knowledge, but this goal must not take precedence over the rights and interests of individual subjects. When there is an unresolvable conflict between the conducting of research and interests and rights of patients, medical research must back down. I 6) expressed my thoughts on consent from the standpoint of patients and families in this issue of the journal. If consent is disregarded, the trust between patients and physicians, which is of the utmost importance for the purpose of academia to pursue the truth, may be undermined. The Ethics Committee of the Japanese Society of Psychiatry and Neurology (hereafter referred to as "JSPN") has prepared "Guidelines on Privacy Protection in Journal Publication and Conference Presentations Including Case Reports" 8), but some believe that requiring consent adhering to these guidelines will impoverish clinical practice and research. 3) From the standpoint of a patient and their family, I suggest that you use your imagination and think about what it would be like if the patient, who is the subject of the case report, were a member of your own family. How many of us would be able to bear the thought of our own and our family's unwanted secrets being made public without our knowledge or permission? The author's basic idea of consent is the above. Harming patients' feelings by reporting cases is not an acceptable act of a person involved in medical care.

In this article, based on the author's concept, the consent of a patient is discussed from the standpoint of patients and families involved in three difficult cases of: forensic psychiatry, child abuse, and genomic medicine. In recent years, a new trend has begun to emerge in the form of academic presentations given by patients or their families from the standpoint of research on the parties concerned. The paper discusses how JSPN should respond to such trends and the new era of open access from the viewpoint of the meaning of case reports for the parties and their families.

## I. Difficulty in Obtaining Consent

### 1. Crime and Child Abuse

When a crime or case of child abuse is considered to have mental illness as its underlying cause, the person involved is often someone who has no access to medical care and fallen outside the safety net. Although the causes of these incidents are complex and it is difficult to predict whether they could have been prevented if they had been under medical care, it is clear that dealing with those who are not connected to medical care is an urgent issue for psychiatric care today. Case reports from a psychiatric perspective are extremely important in order to promote reform of medical and social systems regarding the care of untreated patients. However, it is not difficult to imagine that there are many patients who hesitate to have the details of their cases published in academic presentations or articles. Above all, the Personal Information Protection Law includes not only the secrets of the person concerned, but also the secrets of all those concerned, but the issue of all those concerned has not been given much thought. The author's thoughts from the standpoint of the patient's family are described below:

1) Family Thoughts in the Judiciary

The author is also a member of a family association, and crime is a concern that is familiar to the families of patients with mental disorders. When a person with a history of psychiatric hospitalization commits a crime, it is widely reported in the mass media and speculative diagnoses are circulated on the Internet, and it is sometimes written that the family is responsible for the person's crime and that it was caused by family relations without any evidence. Unable to seek help from a third party, the family tries to cope alone and becomes isolated. Within the confines of the home, the patient commits acts of violence against the family, and some cases of family violence against the patient have resulted in death.

It is natural for the family to worry that if the paper is published, the public may hold the family responsible and limit their daily lives, and if the sentence is reduced, the reverse discriminatory criticism may occur, saying: "patients with mental disorders are not guilty of anything they do", and they may be slandered, saying: "such criminals should stay in jail forever because mental illness cannot be cured." While we want to be as unobtrusive as possible, we also hope that the public will be given a correct explanation to rectify these distorted reports. The desire for a correct explanation is the same for me as any member of the public. I hope that each case will be scientifically and medically verified as much as possible because I am concerned that: "it is unclear how much of a case is due to psychiatric symptoms from the trial results alone" and "preventive measures cannot be taken until the cause of the case is known."

However, in the judiciary, there is a power gradient between the defendant and prosecutor. For the sake of their respective interests, not all facts are necessarily presented in court. If this is the case, then, based on the principle that academia strives to seek the truth, psychiatry should be the field to investigate and publish the truth about the motives and background of a case.

In order for no one to be hurt by a case report, a trusting relationship is required so that consent can be obtained for a psychiatric evaluation. In the case of Norio Nagayama, who is known for the Nagayama standard for the death penalty 1), the psychiatrist established a psychotherapeutic relationship with Nagayama at the appraisal session, which led him to confront the case. Nagayama has matured and grown enough to do this on his own, but it is believed that the psychiatric involvement of his expert brought him to this point. Although the verdict itself reflects a prosecutor's tactics, past precedents, and public opinion, and the results of psychiatric examination do not directly lead to the verdict, in psychiatry, the relationship between the defendant and expert witness is one of the achievements. Based on the role of academia in the search for the truth, in case reports, it is necessary to obtain the defendant's consent from a neutral standpoint, not to denounce him or her, not to traumatize him or her by presenting the case, and not to promote stigma. The defendants may experience emotional pain and trauma by facing the truth in the wake of the case report. If they are unable to endure this, we should refrain from getting them to talk and asking for their consent based on the principle that: "no one should be hurt by a case report."

Some medical professionals wonder: "Is there any possibility that the presence or absence of consent could bias the published information and distort the science?" It is natural for scientists to be concerned about such a possibility. Nudeshima 7) states: "If the desire to conduct science is the essence of science, then ethics is the principle of restraining that desire." It is ethical to curb the desire to "publish about the patient" if the case report may cause pain or trauma to the patient, and if such a situation cannot be avoided.

The desire for the "pursuit of science without distortion" must be curbed.

2) Family Feelings in Child Abuse Cases

In child abuse cases, there is an overwhelming power gradient between the abusive parent and abused child. Even in non-abuse cases, the parent is in an overwhelmingly strong position with respect to the child, which is common to the power gradient between the defendant and prosecutor described in 1).

I have spoken about my background on many occasions with the goal of making psychiatrists aware of the reality of children raised by parents with mental disorders. However, most of the people who attended were non-professionals or medical personnel such as nurses and social workers, and psychiatrists rarely came to listen. Some parents with mental disorders have abused their children, such as pointing a knife at them or bathing them in cold water in winter. Nowadays, more and more people who were these children are speaking out as adults, and some cases have already been presented in private forums. In most of these cases, the parents as patients are untreated or have discontinued treatment.

In principle, however, it is impossible for a person in the position of a child to present a case report at an academic conference without the consent of the parents as patients. In fact, the more "non-consenting" parents often raise their children in a poorer way, and some are not convinced from the child's point of view. The author received the following comments: "I would rather not present at an academic conference than be bound by the conference's code of ethics." "I feel uncomfortable and hesitate when I am treated as a researcher because I am presenting at a conference." "I hope the academic society understands what it means for the parties to speak." "I just want medical professionals to know how hard it is for a child to live with parents with mental disorders, but it's hard when they expect my presentation to be academic." "All rights should be protected equally, shouldn't they?" "Education and welfare have the idea of 'the best interest of the child', but not academic societies?"

From the child's point of view, it is natural to feel this way. On the other hand, after disclosing about my mother and myself, I came into contact with many researchers and clinicians, and my thoughts about "research" are now changing. In addition to the importance of narrative, I began to look at meta-analytic studies and realized that some facts can only be understood by translating a large number of cases into numbers. Mental disorders are "syndromes," and symptoms and diagnostic names overlap, indicating a variety of conditions. In addition, the social status of the family in which the incident occurred, and the social conditions of the society are added, resulting in a process that leads to the abuse of the child. In this regard, the author's case represents only a small portion of "children with parents with mental disorders." We must avoid publicizing these cases as if they were representative examples, biasing the "image of mental illness," whether good or bad, and promoting stigma. There are cases in which children raised by parents with the same mental illness are well-adjusted in society, and it cannot be said that they are necessarily prone to a bad situation. The issue of target bias must be carefully considered, as people with a good prognosis tend not to (want not to) speak up in psychiatric care, and as a result, the voices of those who are dissatisfied with their care are more prominent.

Kumagaya 4) states: "In ordinary society, there is an overwhelming power differential between a doctor and patient, or a parent and child, and fair and equal communication is not possible. I believe that presenting in academia, which is a ‘place to seek the truth,’ will increase the possibility of telling the ‘truth’ even in relationships where there is a power gradient." In such cases, the parties concerned are also required to "tell the truth," which is quite difficult for them to do. The purpose of my own disclosure was "to let psychiatrists know the reality of the child so that they could improve their practice," but after several years of disclosure, I have finally come to realize that behind this, "lusantimania toward parents and psychiatry" was lurking. This is my truth.

It is not possible to gain the consent of parents for a publication or article that is intended to denounce them. It is necessary for academia to pursue the truth in a neutral way and for the parents involved to be able to tell the truth. This is the same as in the case of justice. Kuroda 5) conducted a questionnaire survey of parents who were in prison for child abuse, and stated that the respondents sent him comments, such as: "Answering the survey helped me see how I was feeling." This may be the result of efforts, such as: "conducting the survey as a neutral academic, putting safety first in terms of consent, prioritizing the protection of collaborators' interests, and carefully explaining concerns about personal information." The respondents' honest, answers based on trust may have allowed them to face themselves "without trauma."

2. Consent in Genomic Medicine

Although genomic medicine seems to have nothing to do with crime and abuse, from the perspective of "not causing new psychological trauma by reporting cases," it may include problems common to crime and abuse.

Currently, advances in genome analysis technology have revealed that genomes are involved in almost all diseases in some form or another. Genome analysis research is indispensable for the future, even if it does not immediately lead to the benefit of those concerned. The author hopes that the pathophysiology of mental disorders will be elucidated through the advancement of genomic medicine, and that mental disorders will become "curable diseases," and this is also the wish of all patients and their families. Current psychiatric treatment is based on a lack of understanding of the cause of the illness, and patients are treated in a "don't know until you try" situation. In addition, people feel fear when the cause is unknown. One of the reasons why people consider mental illness to be "dangerous" is because "the cause is unknown," so clarification of the pathophysiology is necessary to overcome the prejudice.

On the other hand, the image of "mental illness and heredity" from the perspective of patients and their families is not good even today. Also, medical practitioners do not have a good image of heredity, as symbolized by the term "negative hereditary trait," which has been used for a long time. As genome analysis progresses, the "possibility of future disease occurrence" will be revealed, and patients and their families are likely to be concerned that this will be detrimental to their marriages and employment opportunities. Even if the family agrees to a case report, relatives and others in the same village often oppose it, and there is a high bar for obtaining their consent. This is the same as in judicial psychiatry and child abuse.

Ishizuka 2), a clinical geneticist, states: "It is appropriate for us psychiatrists to view family history of psychiatric disorders neutrally as a category of diversity." The marked specialty of genomic medicine, as in forensic psychiatry and child abuse, tends to create a power gradient between the parties involved. The author believes that the neutral attitude of "seeking the truth" is the value of academia and a solution to the power gradient.

In addition, in order to dispel the long-standing prejudice against heredity that has spread among patients, their families, and the public, clinicians, who are the closest to the patients, should first recognize the importance of genomic medicine. It is necessary to explain to patients and their families in a neutral way that genome analysis can lead to significant benefits, such as a better understanding of the disease, prevention, and early and appropriate treatment. A patient's understanding of the disease may be improved if their own doctor talks about genetics. Fusar-Poli, P., et al.10) examined the relationship between psychiatric disorders and "environmental factors" throughout the life cycle, starting before birth. I spent my adolescence worrying about the choice between "heredity or environment" and was never given an explanation by anyone, and believe that it is necessary for clinicians to have a neutral acceptance of "both heredity and environment" in this way. The number of clinical geneticists who support such a view should increase among psychiatrists. General psychiatrists also need to read the literature on genetic disorders that are included in intractable diseases, and be aware of the possibility that patients with intractable diseases with identified genomic variants (e.g., 22q11.2 deletion syndrome) may consult them in their daily practice. An environment in which patients and their families can discuss genetic issues with their attending physicians without hesitation will, above all, reduce genetic prejudice and promote cooperation between patients and their families in genome analysis. Although not all psychiatrists need to have a high level of expertise in genetics and genomics, there should be a genetic specialist nearby to whom patients can be referred if they seek genetic counseling. We believe that only by making various efforts to expand the entry points for genomic medicine and deepen the understanding of genetics in psychiatric disorders will it be easier to obtain the consent of the patient.

## II. Meaning of Case Reports for Patients

Keeping in mind the principle that "case reports should not cause new psychological trauma," we would like to consider "the meaning of case reports for patients" not only for forensic psychiatry, child abuse, and genomic medicine, but also for case reports as a whole. When consenting to a case report, what feelings do patients have when they give their consent? Some may want to "contribute to the advancement of medicine" or "be helpful to the attending physician," while others may simply give their consent in a businesslike manner. As the physician explains the case report to the patient, the patient may reflect on his or her symptoms and progress. Some may be hearing the whole story of their disease for the first time. Given this, the decision to consent is not an easy one. Sometimes, the patient consents once and then reverses the decision, and the opposite situation can also occur.

Medical progress and respect for the patient and family as individuals are not issues that can be weighed in the same way. If each side argues about the legitimacy of the other, they will go round and round in circles. Medical progress has been possible only with the cooperation of research participants. The author agrees with Omori's view that when the usefulness of personal information conflicts with the protection of individual rights and interests, medical research has no choice but to back down.

Here, I would like to consider the meaning of case reports for the parties concerned, aside from the purpose of medical progress.

As mentioned above, my case reports on my mother were motivated by my resentment toward my parents and psychiatry. I have had a lot of people listen to my story through the publicity, and it has been a great acknowledgement of my own truth. Being able to honestly face the truth led me to take a step back and rethink the parent-child relationship and psychiatry from a new perspective. This process led to my recovery, freeing me from the pain and stigma of the past. Norio Nagayama must have gone through such twists and turns before finally accepting his own view.

The author believes that situations in which patients are asked to give their consent, as well as situations in which patients and their families present their research at academic conferences as part of the research on the parties involved, are very stressful for the patients and their families. However, if the patients and families can finally face the truth with honesty, even if it takes time, such case reports will contribute to their recovery. This is the author's view of the importance of case reports for those involved.

It is necessary for medical staff to accompany the patient with the understanding that various processes are necessary in the patient's mind before he/she gives consent. It is through such an attitude that a relationship of trust can be established. There may be cases in which a patient wishes to make a presentation even though he or she has not yet come to an honest feeling. Such a presentation would amplify their pain. For cases in which the pain seems intolerable, it is necessary to give consideration from the standpoint of psychiatry.

From the standpoint of case reports that lead to the recovery of patients, we should not view the ethical code as a cumbersome administrative procedure or a violation of academic freedom. In the era of open access, new ethical guidelines are needed to ensure that case reports promote patient recovery, are trauma-free, and do not cause bias.

## Conclusion

This article discusses "difficulties in obtaining consent for case reports" common to the three areas of forensic psychiatry, child abuse, and genome medicine, from the viewpoints of patients and their families. I believe that the purpose of psychiatry and psychiatric research is "to improve the biosis, lives, and livelihoods of patients and their families. It is necessary to understand the feelings of the patients and their families who are hesitant to give consent to case reports, although they are eagerly awaiting the development of medical research, elucidation of pathological conditions, and discovery of new drugs. It is desirable to forge a relationship in which recovery is promoted through discussion between medical staff and the patient, and through obtaining the patient's consent based on trust. This is the purpose of medical progress, and it is also another meaning of case reports.

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