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Secrecy and disclosure of diagnosis in a Japanese psychiatric apprenticeship



Joshua Breslau

My initial opportunity to consider the disclosure of diagnoses in Japanese psychiatry was a clinical interview (*mensetsu*) I observed while conducting fieldwork on the training of psychiatrists¹. I was observing a neophyte psychiatric resident conduct one of her first psychiatric interviews and it was perhaps the most difficult challenge she had yet faced. The patient was a young woman with a complicated history including some sketchy but frightening reports of physical violence in the home, stigmatization and bullying in school, and at least one previous psychiatric admission. She had appeared quite timid in previous brief encounters. In the early afternoon the resident, the patient and I sat down to talk in one of the small conference rooms of the psychiatric ward. To the resident's great surprise, as soon as we sat down the patient began speaking excitedly at a rapid pace about a wide range of issues, her troubled home life, her need to separate from her parents, and her hopes for the future. She spoke continuously for

over two hours, showing no signs of tiring. As the interview became more and more a monologue, the neophyte resident struggled to interject some simple questions; she wanted to get some basic information for the medical chart without losing the thread of the patient's ongoing stories. As she anxiously paged through the chart that was open on the desk in front of them, she inadvertently allowed the patient to catch sight of a previous doctor's report on her case. On the report, the diagnosis of schizophrenia (*seishin bunretsubyo*) was clearly noted.

Catching sight of this diagnosis in her chart, a diagnosis she had never been told directly before, the patient stopped in her tracks for a second. «Really, is that what I am?» Somewhat taken aback by this direct question, the resident answered noncommittally; «Well, that's what the letter says, but umm...» «I don't know», the patient interrupted. «My mom thinks it's more like manic depression». At this point, the resident was at a loss. She did her best to redirect the conversation, which quickly

¹ This paper developed from a talk given in March 1998 at a symposium at Harvard Medical School entitled «Practicing Medicine in Asia: Ethical Challenges». I would like to thank Arthur Kleinman for the invitation to participate in that symposium. I would also like to thank Mary-Jo Good and Tana Nilchaikovit for their encouragement to develop that talk into this paper.



returned to the patient's own speedy monologue as if nothing of particular interest had happened. For me, this inadvertent disclosure provided an opportunity to explore ethnographically how my physician informants thought about and managed disclosure as a practical issue of care and not simply the ideal forms in which they would like to practice. When I asked the resident afterwards what she thought about this disclosure of diagnosis, her response was in no uncertain terms, «That was my failure as a psychiatrist». Embarrassed and ashamed, she felt it was obvious that she had lost control of the interview and allowed a guarded secret to escape. She felt it her clinical responsibility not to disclose the diagnosis to the patient.

Secrecy, disclosure and medical power

Disclosure of diagnosis does not appear to present much of an interpretive or analytical challenge. Already with Talcott Parsons, non-disclosure was seen as symptomatic of the power asymmetry between doctor and patient typical of biomedical institutions (Parsons 1975). This asymmetry derived, according to Parsons, from the specialized expertise that underlies medical authority in the modern West. Doctors have access to technical knowledge and this knowledge gives them power in their relationships with patients, power that they guard and maintain by keeping diagnostic information secret. This view that secrecy derives from an excess of physician power has been followed in most subsequent research on this topic and in medical opinion (Stoeckle 1987). As expressed in a letter to the *British Medical Journal* in August 2000: «An essential part of the treatment of people who have schizophrenia must be to inform them of their diagnosis. Not to do so reverts to a time of medical paternalism (as in previous cancer care) where patients were not

allowed the basic ethical right to take part in decisions about their health care.» (Clafferty et al. 2000: 384) The view also involves an ethical evaluation of this practice and the outline of a path toward its amelioration: non-disclosure is wrong because it denies patients' rights to knowledge of their conditions, and diagnoses should be told to advance the cause of egalitarianism against traditional authoritarianism in the patient-doctor relationship. In Japan, the non-disclosure of diagnosis has been characterized by some commentators in precisely these terms. In the Japanese context, however, the association of modernity and progress with disclosure and egalitarian as opposed to authoritarian relationships has an additional dimension, a sometimes explicit comparison with idealized practices in the United States.

Ethnographic experiences like the above, however, motivated me to consider disclosure in a broader theoretical perspective by more closely investigating the pragmatics of diagnostic disclosure in Japanese psychiatry and examining these practices in the light of anthropological work on secrecy. How are diagnostic terms used in Japanese psychiatry more generally? When are diagnoses withheld from patients and what are the consequences of non-disclosure for relationships between patients and psychiatrists? Secrecy has almost always been understood as a strategy involving the exercise of certain types of power. Ethnographic research in a wide range of contexts, from secret societies in Africa to the military bureaucracy of the United States, have seen the production and maintenance of hierarchies as the key factor in institutionalized secrecy (Tefft 1980). Yet secrecy takes many different forms and is often double-edged, protective as well as abusive, liberating as well as confining (Bok 1983). One close study of doctor-patient interactions found strong evidence that patients actively participate in limiting the amount of information given to them by their doctors (Heath 1992). How can the withholding of a diagnosis from a patient be understood



as a strategy involving the professional power of the physician that Parsons and others see at the root of this problem? A closer ethnographic examination of these issues should take us away from the generalized prescriptions of medical ethics to the particulars of local settings of biomedical practice, as Kleinman has urged (Kleinman 1995).

The key theoretical difference between the approach here and that of Parsons lies in the understanding of science and professional expertise. Parsons saw the power of physicians as rooted in their possession of scientific knowledge and he considered this something peculiar to Western culture with its deep investment in science (Parsons 1975). In other words, authority stems from the truth of the knowledge that physicians possess. Current understandings of the sociology of science, however, have reversed this analysis, suggesting that the legitimacy of knowledge as truth depends on the authority of physicians and biomedical institutions more generally. The asymmetry between healer and patient, within the clinical relationship at least, is substantially more pervasive cross-culturally than is scientific credibility. This reversal is also truer to the ethnographic context of medical education. In the setting of an apprenticeship training program like that examined here, and like virtually all advanced training in biomedicine, the priority of authority over knowledge is built into the very structure of the institution. Residents acquire the skills of mature clinical practice only through their provisional adoption of the authoritative role of clinician.

This reversal of Parsons's account of knowledge and authority in the doctor-patient relationship has consequences for our understanding of the issues regarding secrecy and disclosure of diagnoses. Most importantly, it suggests that the social constitution of professional knowledge also be considered a culturally variable dimension of the power of physicians and a factor in their clinical strategies. In fact, in this paper I will argue that secrecy regarding some diagnoses in Japanese

psychiatry stems not from an excess of power possessed by Japanese psychiatrists but from the opposite, a weakness of professional standing within Japanese society more broadly.

Secrecy, as defined by Bok, is the intentional withholding of information (Bok 1983). This definition makes a clear distinction between secrecy and more general aspects of how the use of information is patterned or organized in the course of strategic social interaction. Anthropologists have focused on secrecy as a component of social action across a wide variety of cultural settings; as Hilda Kuper pointed out, secrecy is «present in different forms in every social system» (Kuper et al. 1995: 79; Tefft 1980). While small-scale societies have been the object of most analyses, secrecy has also become prominent in ethnographic accounts of the sub-culture of magic in contemporary England and biomedical practices such as cancer diagnosis and reproductive technologies (Petersen 1993; Piot 1993; Luhrmann 1989; Lasker and Borg 1989; Gordon 1990). While the fundamental interpersonal dynamic of secrecy may be universal, its particular use in varied institutional contexts is likely to differ. Secrecy in biomedical institutions, as we shall see, is not a survival from earlier forms of social organization, but a basic and necessary feature of everyday practice. In the terms posed by Giddens, biomedical institutions form part of a pervasive «sequestration of experience» into relatively sealed off sectors of social life (Giddens 1991). Secrecy is such a fundamental part of this system that it is easily taken for granted. Yet viewed in this light, practices of secrecy, of non-disclosure of medical diagnosis, are not merely manipulations of the doctor-patient relationship, but strategies for managing personhood and identity in particular contexts of power and knowledge.

The ethnographic research that provides the basis for this analysis was conducted over the course of two years, 1995-97, in a variety of Japanese post-graduate training programs in psychiatry. One particular cohort of residents



was followed closely during their entire first year of clinical training on the psychiatric ward of their university hospital. Throughout this year, observations of clinical work on the psychiatric ward were made several times a week, and interviews were conducted with each resident at three different points in time. The ethnography of this cohort of residents was complemented by participation in the life of the department over the entire course of the research. Several other training programs were examined through shorter visits during which residents were interviewed and observed. While not the main focus of this research, the issue of diagnostic disclosure was a prominent one both during the planning phase of the project and for the residents themselves during the course of their training. In this paper, I outline the uses of secrecy in Japanese psychiatry in more detail, then explore the particular context of the psychiatric apprenticeship for greater insight into the relationship between secrecy and medical authority. In the discussion that follows, I relate this analysis to the ethics of disclosure in the context of cultural differences within global biomedical institutions.

The uses of secrecy

The attitude of the resident who inadvertently leaked the diagnosis of schizophrenia to her patient is far from atypical in Japanese psychiatry. On the ward where she worked, non-disclosure was the norm. In a nationwide survey of psychiatrists conducted by the Japanese Association of Psychiatrists and Neurologists, only 7.3 percent of respondents indicated that as a rule they tell patients the diagnosis of schizophrenia (Committee on Concepts and Terminology of Psychiatric Diseases 1996). The overall situation, however, is much more complicated than an across-the-board avoidance of conveying diagnostic information to patients. I will explore two dimensions of

the maintenance of secrecy in greater detail. First, secrecy regarding diagnosis is part of a broader set of institutional controls, formal and informal, regarding access to medical information. Withholding of diagnostic information is often accompanied by selective disclosure to family members or other institutional actors. Secrecy regarding diagnosis is thus part of broader strategies for constituting the social position of patients and, in particular, shaping the social context of disability. Second, the withholding of diagnostic disclosure is not applied across the spectrum of psychiatric disorders. Rather, each major diagnostic category is associated with a typical strategy for clinical engagement, including a typical approach to the issue of disclosure. These diverse strategies enlist the power of psychiatry in different ways.

Secrecy in psychiatry

The withholding of psychiatric diagnoses occurs in a context in which virtually everything that happens, even the fact that a particular individual was there, is a tightly kept official secret. The confidentiality of medical information is essential to the privacy of medical treatment, and to the effective division between public and private aspects of individual identity. In psychiatry in particular, secrets must be kept vigilantly, against the efforts of other institutional actors to gain access to them and act according to their own interpretations of events. The stigma that attaches to the diagnosis of schizophrenia, for instance, attaches not only to the affected individual, but also to family members. When a person applies to be hired by a large company or enters into marital negotiations, companies that specialize in background searches will try to find evidence of mental disorder in his or her family (see for instance Rohlen 1974). The importance of secrecy here is attested by the results of surveys of attitudes towards the mentally ill; 50-70 percent of respon-



dents from the general population state they would not accept someone with a family history of mental illness as a potential marriage partner (Shiraishi 1994: 136-140). Even when physicians submit official reports to outside agencies, such as their patients' employers, they tend to keep the diagnosis of schizophrenia secret. An innocuous diagnostic term such as «dysfunction of the autonomic nervous system» (*jiristu shinkei shicho sho*) is often used to provide cover.

Moreover, when a diagnosis is withheld from a patient, it is often told quite directly to family members. The resulting situation is one where the patient is unaware of their own diagnosis while a tight ring of their closest relationships, family members and medical staff, are acutely aware of it. For many patients, this ring of secrecy may also constitute the boundaries of their world of everyday social interaction, as their range of activities becomes constricted with the progress of their disorder. Goffman described the moral career of disability in which a person is shielded from the social consequences of their own disability by a «protective capsule» formed by close family members (Goffman 1963: 32). He had children with disabilities in mind, for whom the family constituted their effective social environment. In the case of the adult mentally ill patient, the constitution of this protective capsule is much more complicated, but follows a similar logic.

Intentionality, diagnosis and disclosure

As one resident explained to me, the disclosure of diagnoses other than schizophrenia involves very different considerations:

«Well, for instance, it seems to me that the image of depression and the image of schizophrenia are completely different.

With depression, somehow, it's like it is easier for the patient to understand and accept. It seems easier to accept as one's own current condition, that kind of a bad condition. With schizophrenia, it doesn't feel that way at all, it seems incredibly difficult for the patient to grasp.

»It's the same with mania, it's easy to tell the patient. You can just tell the patient: "your feeling like that has no relation to your will, you've just become extremely excited." And really, that kind of condition, it's so hard you don't think there is anything you can do. More than just disclosing the diagnosis, it's if you can talk about it, if you can get acceptance. Though there are also times when you can't get acceptance.»

As this resident suggests, the patient's acceptance of the disorder is the critical factor determining the approach to diagnostic disclosure. Ethnographically, however, it is clear that the patient's awareness of their own condition is organized into psychiatric treatment in a different way when the patient has depression than when the patient has schizophrenia. Treatment approaches to depression presuppose the patient's awareness of themselves as having a disease, an agent within them causing their symptoms. One common approach, for instance, was to encourage patients to keep a diary of their daily life, recording their thoughts and feelings. The diary would then be read together with the psychiatrist. This approach, which has strong (and recognized) similarities with Cognitive Behavioral Therapy, also draws on diary writing practices common in Japanese elementary school education as well as Japanese psychotherapies such as Morita Therapy. It is not possible to use such a treatment without telling the diagnosis to the patient. From the perspective of clinical knowledge, however, it is ironic that depression is explained as a disease while schizophrenia is not.

Patients diagnosed as neurotic (*noiroze*) or hysterical (*hisuterii*) fall between the two extremes. It is not hard to understand the delicateness involved in disclosure of a diagnosis that implies that a



patient is quasi-intentionally the cause of his or her own symptoms. Disclosure of a diagnosis of neurosis is effectively a denial of a previously supposed diagnosis of another disorder, usually a more straightforward physical disorder. Disclosure with such patients is generally considered a matter of timing; telling a patient at the wrong time can be devastating, but telling at the appropriate time is an important clinical art. Consequently, on the ward where I worked, there are often disagreements among residents, and even among senior psychiatrists, about the best approach to take with a particular patient. In one case that became a major dispute, one resident told another resident's patient that her symptoms, which were being assiduously examined for their physical basis, were in fact psychosomatic. The key issue in determining the timing of disclosure is the «readiness» of the patient to be an active and aware participant in the already established treatment goals.

Secrecy in the making of psychiatrists

The work of residents, apprentices within the ongoing work of clinical treatment on the psychiatric ward, offers particular insight into the organization of secrecy and disclosure (Breslau 1999). Residents work at a remove from the frontline of psychiatry. They rarely interact directly with family members or other outside institutions. Rather, they take on patients who have been admitted for inpatient treatment by one of the senior psychiatrists, and they treat patients within the clinical framework constructed by that admitting psychiatrist. Thus, even when a patient is told their diagnosis, the resident is not the one to do it. The telling of diagnoses is reserved for more senior practitioners. As in the case described in the introduction, residents learn their clinical techniques by sitting with patients for open-ended interviews that are structured by the clinical decisions of their seniors.

This combination of openness and structure constitutes an essential part of the «curriculum» of the psychiatric apprenticeship. The patient's knowledge of their own disorder forms part of the structure within which residents learn to interact with patients and understand clinical syndromes. In other words, the awareness that patients are expected to have regarding their own disorder forms part of the basic core principles of clinical practice that residents must learn in order to advance towards mastery of their chosen profession. Patients often press up against this assumption by accidentally reading the diagnosis in the chart or, more frequently, by simply asking the resident what their diagnosis is. These moments are among the early challenges for residents, moments when they come up against the boundaries of their own expertise. As one resident explained to me:

«Especially, if you're telling someone it's schizophrenia (*bunretsubyo*), even to the family, it's a huge shock for them, you know. I've never done it myself and even if I were asked I'd probably say something like, "well, we don't have a clear diagnosis, we still don't really understand." If they really kept asking well, I'd consult with the senior psychiatrist, but I can't say whether we would say it or not. Disclosure, in particular, is something I don't do.»

Residents explain the non-disclosure of the diagnosis of schizophrenia in several ways. The first and most obvious explanation that they give is the intensity of the stigma associated with this disorder. Telling a patient that they have schizophrenia sounds to many like «telling them they no longer qualify as human», as one resident explained. Moreover, because of the stigma, telling a patient that they have schizophrenia is likely to increase their stress (*sutoresu*) at precisely the time they should be relaxing and focusing on recovery. Families, if told that a member has schizophrenia, are likely to write that person off, to assume that they will never get better. These are also the reasons commonly given by senior psychiatrists and representatives of the profession to



explain their hesitancy to disclose diagnoses (Committee on Concepts and Terminology of Psychiatric Diseases 1996). They form a kind of medical poetics, a theory of the medical impact of the procedure rather than the content of medical care². Residents also talk about a different aspect of this issue that is not part of the common discourse on disclosure. For them, telling the patient that they have schizophrenia would feel like an over-extension of their authority, an unwarranted imposition of their will on the patient. Their role should be that of listener. «It's no good if we come in from our side too strongly», as one resident put it. This feeling that disclosure, not secrecy, would be an over-extension of professional authority is part of the «experience of secrecy» that is not commonly captured in professional discourse (Bok 1983: 29-44).

The experience of secrecy for residents is double-edged. On the one hand, secrecy requires that they contain the authority that is invested in them as residents before they know how to manage it. The need to maintain secrecy forces them away from their reliance on specialized knowledge, into improvised conversational material as the main source of clinical interview techniques. In this sense, secrecy has a leveling effect, at least within the context of the doctor-patient interaction. On the other hand, maintaining secrecy is an essential part of their connection to the institutional context in which they are enmeshed and which they are trying to master. The fact that they have and hold medical secrets, of which a diagnosis is only the most obvious, marks their membership in the profession in which they hope one day to become competent and mature practitioners. Secrecy is a basic condition shaping how they must organize their personal knowledge and experience in order to advance to maturity as psychiatrists. In fact, maintaining secrets such as a diagnosis of schizophrenia can be seen as one of the many rites of passage that are built into the structure of apprenticeship in clinical medical training. The double-edged character of secre-

cy in psychiatric learning further complicates the standard sociological picture of the ethics of diagnostic disclosure.

Discussion

The view that non-disclosure of medical diagnoses is a paternalistic anachronism in medicine is simplistic. Secrecy with respect to diagnoses, as we have seen, takes place in a context in which many things are kept secret from many people. Indeed, secrecy at this broader level is integral to the entire institution of modern medicine. The withholding of diagnoses is not a consistent, across-the-board strategy of medical professionals, but part of a specific strategy for managing particular types of medical problems in particular cultural and political settings. In Japanese psychiatry, the diagnosis of schizophrenia in particular tends not to be disclosed to patients. Reticence towards the disclosure of this diagnosis to patients is generally explained by the intensity and far-reaching effects of the stigma that attaches to it. These effects are well documented and they extend beyond the patient to family members, even crossing generations. For psychiatric residents in Japan, to manage learning secrecy regarding the diagnosis of schizophrenia is a rite of passage that forces them away from reliance on technical professional expertise in their clinical encounters with patients. At the same time, through secrecy they are inducted into their profession. For residents, it is disclosure, not withholding, of diagnoses that feels like a misuse of professional power.

The key factor explaining differences in attitudes towards disclosure as between the US and Japan lies outside the patient-doctor interaction in the credibility of psychiatry in the society as a whole. In Giddens's terms, the relevant context is not social integration, the particular relationships between actors, but systems integration, the mutual relationships of

² Luhmann's (1989) ethnography of magic in England shows a «magical poetics» regarding the maintenance of secrecy in that context. Secrecy regarding magic has magical effects. Disclosing magic secrets depletes their magical power.



autonomy and dependence among groups or collectivities that constitute a society (Giddens 1979: 76-81). Japanese psychiatry lacks the autonomy in constituting its own objects, psychiatric diseases, that is securely possessed by psychiatric institutions in the US and other countries. The stigma attaching to the diagnosis of schizophrenia, the difficulty in having patients recognize themselves by this label, and the sense of imposition of medical authority in the disclosure of the diagnosis by residents all suggest this lack of autonomy. Lock argues that a similar weakness of medical institutions lies behind the non-recognition of the medical concept of brain death in Japan (Lock 2002). In this sense, it is the weakness of the psychiatrist, not his or her excess power, that accounts for the strategy of non-disclosure.

In her analysis of secrecy with respect to cancer diagnoses in Italy, Deborah Gordon argues that a diagnosis of cancer in this context would lead to a sort of social death (Gordon 1990). This insight has clear parallels with similar practices regarding schizophrenia in Japan. Schizophrenia is not a terminal illness, but it is profoundly disabling, even when the prognosis is quite good. A diagnosis of schizophrenia most often means a lifetime of dependence on family or the state. Being a schizophrenic is a social status, an institutionalized form of disability that persists throughout the adult life course. In this sense, the diagnosis of schizophrenia is a kind of social death, an end to all the expectations of future productivity and independence that underlie the identity of a young person. Disorders such as depression may be equally severe and equally perplexing with respect to understanding a person's intentions and actions, but patients are also likely to recover. The diagnosis of schizophrenia is withheld to maintain openness of the future in the face of a predicted downward course.

The key factor in shaping the strategy of maintaining secrecy of the diagnosis of schizophrenia, in contrast with other diagnoses, is the expected role of the

patients' awareness of their own condition in the course of treatment. The ability of psychiatrists to recruit patients to participate in their own treatment depends on the credibility of their knowledge outside of the medical context. This link between the identity associated with a disability such as severe mental illness and the legitimacy granted medical knowledge regarding that form of disability plays out in different ways in different settings, even when the underlying diagnosis is the same. The difference is apparent, for instance, in the way that patients organize themselves into advocacy groups. In the United States, mental health consumer groups incorporate the diagnosis of schizophrenia into their identities. In Japan, by contrast, such groups tend to be more focused on a traditional anti-psychiatry position that attacks the diagnostic label itself. In other words, the medical concept of schizophrenia can be seen as hegemonic in the US context, providing a taken-for-granted touchpoint for all arguments regarding mental illness. The ethical demand to disclose diagnosis is a function of this hegemony. The situation is quite different in Japan where the diagnosis does not have this authority. The practice of disclosure, as indeed the entire constitution of the identity of the patient, is correspondingly more discreet.

Through this paper I do not wish to suggest a particular ethical evaluation of particular practices of diagnostic disclosure or secrecy. Rather, I am trying to show how secrecy fits into a context in a way that differs significantly from the received view that disclosure is an essential component of egalitarian clinical relationships. To the extent that the ethical judgment relies on this received view, it should be rethought. These issues are all the more acute in the context of global biomedical institutions where local ethical standards are used as global yardsticks of evolutionary development. The globalization of biomedical institutions raises many such problems, and they should be examined ethnographically before simplistic ethical judgments are formed (Good 1995). While this paper is not meant as an



endorsement of any particular strategy with respect to diagnostic disclosure, I do hope to have opened the door to alternative understandings of the potential future of psychiatric institutions and the social situations of the mentally ill.

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Abstract

Secrecy and disclosure of diagnosis in a Japanese psychiatric apprenticeship

Discussions of disclosure of diagnosis have not examined the broader issues of secrecy that pervade medical practice. This paper examines the disclosure of psychiatric diagnoses in Japan, where non-disclosure of some diagnoses is widely supported by professional opinion. Ethnographic data is drawn from a study of an apprenticeship training program for novice psychiatrists on the psychiatric ward of a university hospital. The standard interpretation of secrecy as a symptom of excess power is challenged through an examination of strategies regarding diagnostic disclosure for different diagnoses and comparison with institutional secrecy in other ethnographic contexts, medical and otherwise. The relevance of close attention to such strategies for an understanding of global medical institutions is also explored.

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