

## The Patient's View: Issues of Theory and Practice

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**Abstract** Almost all the knowledge now produced about psychiatry includes what is called “the patient’s or client’s perspective.” This paper analyzes how this notion has been framed in the discourses on mental health over the last two decades, particularly in mental health research and in anthropology. The very concept of the “patient’s perspective” is a social and historical construct. Despite its remarkable prevalence, the notion remains vague. Mental health research pictures it as a stable attribute of the individual. Anthropologists integrate the contextual nature of the patient view; but they still largely envision the psychiatric patient as a rational actor producing narratives based on common sense. However, in psychiatric practice, the client’s perspective is not something the patient individually produces; it is rather shaped by and in a context. To explore this process, my research investigated interactions between staff and patients in a French community mental health center, and showed that the client’s perspective is the result of a collective process. Further analysis demonstrates that eliciting or producing the patient’s view is sometimes considered a therapeutic goal in itself, since being granted the status of a rational and narrative actor gives access to the most valued model of care, one that is based on partnership. Being an outcome that is negotiated between patients and care providers, the “patient’s view” then becomes a new resource in mental health settings.

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Statement on ethics: The research conducted for this paper followed the ethical guidelines of the University Paris 5. After being presented with the objectives of the study and informed of their right to withdraw from the study as well as of the rules of confidentiality, the staff members and the residents separately gave their oral and written consent.

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## Introduction

What is the patient's perspective? What is the patient's subjective experience? These and similar questions are now common and even unavoidable within the field of psychiatry in Western countries. The patient's point of view is everywhere: anthropologists study "illness narratives" (Izquierdo and Johnson 2007; Kleinman 1988; Mattingly and Garro 2000); governments emphasize the protection of patients' rights (JORF 2002; USDHHS 1999); clinicians want to know the patients' opinion and illness experience (Lillrank 2002; Waserman and Criollo 2000); social scientists and journalists wonder about the patient's subjective experience (Angermeyer and Klusmann 1998; Becker 1998; Busfield 2000; Schneider and Conrad 1983); and sociologists and clinical researchers include the patient's view in their assessment of medical practices (Aranda and Street 2001; Cook and Wright 1995). Almost all the knowledge now produced about psychiatry, as well as in other fields of medicine, includes what is called "the patient's (or client's) perspective."<sup>1</sup>

A variety of reasons is given by authors to justify the inclusion of the patient's view. They are quite heterogeneous. Some underline the quest for more refined information, or the need to provide a balanced assessment by taking into account the opinion of all actors (Cook and Wright 1995). Other arguments are moral rather than pragmatic: they suggest that there is an intrinsic importance in being attentive to what a patient thinks because it ensures that he or she is treated humanely, as a person (Barham and Hayward 1991), or they argue that for patients who come from socially and economically marginalized groups, consideration of the patient's perspective is particularly important, as it grants them access to the sphere of legitimate discourse (Kuipers 1989; Williams and Healy 2001). In both mental health and anthropological literature, then, there seems to exist a strong expectation, sometimes an obligation, that mental health services take into account the patient's perspective. Thus, advocating for the patient's perspective takes place within a larger discourse on the appropriate way to conceive of mental illness and of mental health care.

I would like to challenge the universality of the patient's view and its appearance as being self-evident. In doing so, I intend to question how the patient's view is socially produced and how its use is defined in practice, paraphrasing what Desjarlais (1994: 887) suggests about the notion of experience. I believe clinical and anthropological literature to share two assumptions regarding the patient's view, namely, that it is inherently present and that to elucidate it is empowering, and that both should be challenged. An historical and cultural construct, the patient's view also emerges attached to its context: a context that I would suggest is not external

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<sup>1</sup> On the sensitive topic of the patient/care provider relationship, the very terms employed are infused with meaning. Various terms have been proposed and used in the last decades to name the individuals who receive care from psychiatric services, each of them referring to a political stance toward psychiatric treatment (McLean 1995). In the French context, however, there has been remarkably little debate on this issue, and care recipients are still widely called "patients," or sometimes ex-patients.

but consubstantial. At first glance it would seem that to express his or her opinion, a patient only needs to be given a space. Yet, in psychiatric practice, as in other fields of medicine, “space” is not the only thing that is required. Ethnographic data show that the patient’s view is necessarily shaped by specific social interactions.

How has the interest in the patient’s perspective become so pervasive and how is it used in the literature? In order to answer this first question, I examine the way the patient’s (or client’s) perspective has been framed in discourses on mental health over the last two decades, focusing on mental health research and anthropology. Then I turn to psychiatric practice in France to understand how patients’ views are constructed and challenged in the therapeutic process.

### **The Pervasiveness of the Patient’s View in Theory: A Literature Review**

#### “The Patient’s View Is Stable and Empowering,” or Is It So Clear? A Literature Review

Although the idea that there is such a thing as the patient’s perspective and that it should be taken into consideration may seem obvious today, analysis of the mental health and anthropological literature shows that it is clearly an historical product. Furthermore, it also appears to be a social and cultural construction (Hacking 1999; Weinberg 2005), with varying degrees of pervasiveness.

The perception of the patient’s words has greatly evolved in the course of the 20th century (Armstrong 1984), an evolution related to a shift in the medical gaze. Michel Foucault (1963) described the emergence of a medical gaze at the end of the 18th century that reads the patient’s body in order to identify signs leading to the disease. Around the 1950s, medical perception extended to include the patient not as an object of inquiry but as a source for eliciting subjective experience (Arney and Bergen 1983; Baszanger 1991). Also around this time, references to the need for assessment and outcome measures to take into account what is called the patient’s view can be found (LeMoigne 2005). However, the process of actually incorporating it has been slow, and 25 years ago it was still relatively uncommon to ask patients for an evaluation of their care (Armstrong 1984).

How is the patient’s view integrated in today’s psychiatric research literature? Outcome measures incorporate the hypothesized effects of patients’ view on their behavior: patients’ dissatisfaction with their treatment may affect their compliance. These studies use a wide range of notions to characterize the patient’s view: attitudes, perceptions, preferences, wishes, goals, needs, expectations and, more recently, satisfaction and quality of life (e.g., Noble et al. 2001). These various aspects of the patient’s view are then interpreted using behavior models about health and illness. The complexity of these models and the particular variables they include depend on the authors’ therapeutic orientation. As a consequence of this process of measurement and recording, the set of opinions that make up the patient’s view becomes a new objectified variable. The patient’s view, according to these studies, becomes a set of answers to standardized questions that are transformed into discreet variables. As appears in Rhodes’ (1984) critique, the authors of these

studies “consider beliefs to be like ‘things’ which people ‘have’ as they have other traits” (68). In other words, the patient’s view is considered to be a stable attribute of individuals, born within the individual. Sociologists also point out that this conception allows researchers to combine an experimental design that largely reasons in terms of cause and effect with the imperative of taking into account the “patient’s subjectivity” (Busfield 2000).

An examination of the evolution of quality-of-life measures illustrates the trend toward objectifying subjective dimensions of illness (Benamouzig and Velpry 2001). When these measures were introduced in the 1960s for policy planning and cost reduction purposes, data collected by care providers or the investigator included only objective quality-of-life criteria. These ranged from global mortality or survival rates to indicators of the ability to function in daily life; they did not depend on the patient’s appreciation of his or her quality of life. Today, almost all measures include subjective dimensions of quality-of-life criteria, and the data are collected, at least in part, directly from the patients (Corten 1998). Interestingly, this shift has been incorporated in psychiatry with a delay (Atkinson and Zibin 1996). This may be due to the fact that, in psychiatry, what a patient says may be considered a symptom of mental illness instead of an opinion to be incorporated into health care planning. Even today, many assessment tools in psychiatry combine evaluations of the outcome by the staff as well as by the patient.

The incorporation of the patient’s and then the client’s perspective, which has been established over the last 30 years, has not been limited to mental health researchers’ assessment tools.<sup>2</sup> The self, the individual and the subjective experience are of interest in many areas of knowledge-production about psychiatry.

In the last 25 years, medical anthropology has thoroughly explored this area (Velpry 2003). Researchers who emphasize the cultural, in addition to the biological, dimension of mental illness describe the cultural specificity of mental illnesses in the Western world through the study of illness experience (Good 1977; Kleinman 1980, 1988; Littlewood 1990; Velpry 2006). However, the way these two dimensions connect and participate in shaping mental illness has been debated (Velpry 2006; Young 1981; Zempleni 1988). *Making It Crazy*, a pioneering ethnography on outpatient psychiatric treatment by Sue Estroff (1981), is one of the first studies to explicitly emphasize the patient’s view. In the following years, a field developed around issues of experience, the self, narrative and identity. Authors have increasingly described their interest in the client’s perspective with reference to the subjective experience and the self (Corin 1990; Estroff 1989; Good et al. 2001; Leibing and Cohen 2006; Saris 1995; Strauss and Estroff 1989), sparking philosophical debates on the nature and access to this “self” and on how the notion of person is used (Heinimaa 2000; Lovell 1997). The necessity of an epistemological discussion has drawn some authors to use narrative theory, thus shifting their interest toward “illness narratives” (Estroff et al. 1991; Hydén 1997; Mattingly and Garro 2000). Narrative theory and references to identity have become

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<sup>2</sup> This trend is noticeable in medicine in general, as well as in other social realms. In this respect, integrating the consumer’s perspective has become a social imperative that extends well beyond psychiatry.

central interests in the field of medical anthropology, with some authors considering the role of narrative in identity construction (Somers 1994).

In anthropology, the patient's perspective has been described as context-dependent. Contrary to the assumptions made for mental-health research protocols, social scientists do not assume that a person's point of view is a stable, individually produced attribute. As anthropologists have shown, it is necessarily produced by, as well as expressed in, a context (Biehl 2005; Lovell 1997). Furthermore, anthropological approaches identify subjective experience as part of a political stance, thus framing the client's perspective in terms of power and politics (Littlewood 1990; McLean 1995). According to this frame, attention to subjective experience of mental illness is alleged to help psychiatric clients' collaboration with the staff and involvement in their treatment process; to incorporate a concern for the client's experience is thus considered a path to rehabilitation and empowerment. This way, subjective experience acquires a political meaning. The work of some anthropologists is directed toward improving mental health treatment by better informing physicians and policy makers (Rosenfield 1992, 1999), while others assume that the patient, once empowered, will act as a force for change (McLean 1995). When investigating the work of such anthropologists more closely, conflicts between the political meaning of the patient's view and its conceptual framing appear. For the reader of their works, it seems that both the informing and the empowering character of the patient's view tends to obliterate its contextual nature. Quite often, then, when the patient's view is referred to, it is considered a stable attribute of the individual, something the patient carried all along without having an opportunity to express it. For some researchers the patient's view has also become an imperative; in her critique, Butt (2002) underlines how the "suffering stranger" has become a recurrent figure in anthropology. She argues that this figure is used for the purpose of a wider theoretical agenda, one of defense of social justice. According to her, such a rhetorical use of these "individual voices and stories" reduces the richness of human life to a moral model, thus denying them "a place to act" (17).

Although by introducing the effect of context, the anthropological framework begins to more profoundly characterize the patient's view, the notion remains vague. Desjarlais (1994) has noted that "experience, it seems, is a crucial element of contemporary academic thought; to try to write about humans without reference to experience is like trying to think the unthinkable" (886). Even if many authors seem to put subjective experience at the core of their research, they usually seem to consider it a neutral and common-sense notion, one that does not need to be defined theoretically or empirically. As Desjarlais claims,

In listening to the debates sparked by these different orientations [of analyses of experience], one gets the sense that everyone knows what is meant by experience. Yet it is rarely defined and, when it is defined, it involves a generic 'we'.... Yet despite its apparent necessity, as something that can and must be thought, its universality remains in question. We must ask if experience is as essential or as commonplace as it [is taken] to be. (887)

I think this investigation of the notion of experience could start with the notion of the patient's view, which is usually either equated with the patient's experience or considered as a point of access to at least part of what the patient experiences.

In the literature, mental health research and medical anthropology each promote a version of the patient's perspective. Their understanding of the notion differs; in the first case it is an individual attribute, while in the second it is context-dependent. However, in both cases, this understanding is assumed to rest on common sense. Analyzing interactions during focus groups, Lehoux et al. (2006) argue that "the patient's view is the result of context-dependent social interactions that need to be scrutinized." To really understand what the patient's view is, I suggest we investigate the role of the context in its shaping.

Ethnographic data I gathered in psychiatric settings show that patients do not spontaneously create a "view." Rather, the patient's view is something that has to be produced jointly with the participation of the staff. In these interactions, at least two main processes are required for a patient to express an opinion. First, patients have to "know" what their opinion is and how to express it. For example, when the first program assessment forms designed to be completed by the patient were introduced, the staff had to "teach" patients how to express their opinion (R. Bebout, personal communication, September 2002). Second, professionals have to recognize what the patient says as an opinion rather than a symptom of mental illness.

I would argue that in the study of this process of construction, psychiatry is not one example among others but, rather, constitutes a privileged setting from which to exercise the scrutiny Lehoux et al. call for. Because mental illness is deemed to impair the very capacity to have and express a view, in a psychiatric setting, what the patient says either may contribute to the shaping of "a view" or may be treated as a symptom and included as part of a clinical assessment. Each side of the alternative entails a different power relationship between patient and care providers. The coexistence in psychiatric practice of two paradoxical conceptions of the patient—the first in which the patient is seen to be capable of having a view, and the second where the patient is considered incapable of fully understanding and expressing his or her own inner world—makes the process of shaping the patient's view more visible.

Under these conditions, the patient's view becomes less self-evident and new questions appear: How does one come to have a point of view? What is a point of view? Who determines what constitutes a point of view? Of what use is it to have a point of view? Does everyone have a point of view? To explore these issues, I now turn to an analysis of psychiatric practice based on my ethnographic fieldwork.

### **The Elusiveness of the Patient's View in Practice: Ethnography of Psychiatry in French Public Psychiatric Services**

Carla<sup>3</sup> is a woman in her 50s who is considered to have a severe psychotic disorder.<sup>4</sup> She has been independently managing her daily life for many years, with the help of

<sup>3</sup> All names used in this paper are pseudonyms.

<sup>4</sup> This is how Carla's care providers refer to her disorder. I don't refer here to a DSM IV diagnosis, since the staff very seldom used it.

a guardian, while being treated as an outpatient at a community mental health center. She is currently living in supported housing, which means that she rents an apartment from the mental health center, which provides her with material and moral support. She recently inherited money and, as a result, has the financial capacity to buy an apartment. As moving out of supported housing is one of the expected goals of the residents, the topic is often introduced in support-group discussions by Carla's care providers. Every time this occurs, Carla invariably says that she wants to buy her own place. Yet, care providers are convinced that she does not "really" want to live on her own and that she is actually too scared to try.

What is Carla's view in this case? If, in a literal sense, Carla's point of view is what she expressed to the group, then it would be that she wants to buy and move into her own place. In any other context this would automatically be called "her opinion" or "her view." In a psychiatric context, there is another interpretation of what Carla wants, and it emerges from the staff's own interpretations. What is remarkable about the staff's opinions is that they assume their interpretation to be not an alternative view of what Carla should do, but her "real," unexpressed, point of view. In other words, they know what her "true" opinion is, despite what she says. This substitution is made possible by the differential legitimacy of the patient's versus the care provider's word in the psychiatric context. What is Carla's perspective: Is it the one she expresses or the one that the staff legitimizes?

In psychiatric practice, then, more than in other fields of medicine, the patient's view, because of his or her pathologies' symptoms, is not a straightforward notion but one that is embedded in a relational context and that raises the issue of the capacity for rationality. In the next section, I examine the extent to which there is a patient's view, and how it is developed through interaction, using a supported housing program for people with mental illness as an example. The housing program is linked to a community center whose model of care advocates autonomy and personal change. In this model, the development of the patient's view is an expected outcome of the treatment and, at the same time, one of several frameworks structuring patient staff relationships. It becomes apparent that in this context, the patient's perspective is a co-construction that takes place as patient and professional negotiate a therapeutic model. As I will explain, this treatment model is an important part of the context of psychiatric practice. This leads to a new question, which is addressed in the final part of this paper: Is the patient's view specific to a certain conception of mental illness and its treatment?

## Background and Method

Over the course of the year 2003, I conducted ethnographic fieldwork in a French public supported housing program for mental health patients. The French deinstitutionalization movement was initiated some 50 years ago. As a part of this process, the country was divided into 70,000 territorial units called *secteurs* (catchment areas). Each *secteur* offers a range of public mental health services including a community mental health center, hospital beds and programs such as day centers, crisis centers and supported housing. When the reform was created, emphasis was put

on accessibility and continuity of care and a unique, multidisciplinary team assigned to each *secteur*. Implementation of the reform has been a long and, in large part, voluntary process, resulting in heterogeneous modes of implementation at the level of the *secteur* throughout the nation. However, a few common features of psychiatric practice in the French public services can be identified: although each patient is treated by a multidisciplinary team, the patient is usually referred for care by a psychiatrist and very rarely by social workers. This, and the fact that psychoanalysis and institutional psychotherapy<sup>5</sup> have been and still are very influential, may be one of the reasons why programs that would call for the strongest involvement of social work, such as psychosocial rehabilitation,<sup>6</sup> are relatively underdeveloped in these services. Psychiatric patient movements remain similarly underdeveloped in comparison with the North American system;<sup>7</sup> they are quite recent and still not wholly integrated into the French mental health system. Therefore, whereas in North America various terms have been proposed and used in the last decades to name the individuals who receive care from psychiatric services, each of them referring to a political stance toward psychiatric treatment (McLean 1995), in the French context there has been remarkably little debate on this issue, and care recipients are still widely called “patients”—especially in psychiatric settings.

Although the fieldwork for this research consisted of attending various therapeutic group meetings of patients and staff, as well as staff meetings and repeated interviews with patients, I here rely only on data gathered at supported housing program patient group and staff meetings. Patients in this program live in individual or shared apartments. All of them have to attend a weekly group meeting, which is led by two staff members and where daily life issues are discussed. My observations show that the discussion of these issues involves learning to express feelings and opinions and constitutes an occasion to work collectively on the construction of patients’ views. The interpretation of what patients say in the group, and how their views are subsequently negotiated, has consequences for what the clinicians think the patient can or cannot do, obtain, or expect.

### Is There More Than One Patient’s View? The Patient’s Perspective in a Model of Care

Carla’s example makes it apparent that if a statement is not recognized as valid by the professionals, it will be attributed not to the patient’s insight but, rather, to the illness.

<sup>5</sup> Institutional psychotherapy appeared in French psychiatric hospitals after the Second World War, and aimed at transforming the hospital itself into a therapeutic tool. The term has been used for very diverse experiences, which share a strong reference to psychoanalysis, especially Jacques Lacan, and to group therapy.

<sup>6</sup> Psychosocial (or psychiatric) rehabilitation refers to a great variety of treatment programs; all emphasize recovery and aim at restoring an optimal level of independent functioning in the community. Although the reference to psychosocial rehabilitation has greatly expanded in North American mental health services as well as in Europe in the last decades, its influence is still limited in the French public psychiatric sector.

<sup>7</sup> This statement is by no means a judgment. It is based on complementary research I carried out in Washington, DC.

In the psychiatric context, the staff sometimes believe that they are better able than the patient to know and express the patient's perspective. This points to a critical aspect of psychiatry: what a patient says in a psychiatric setting may be called either the patient's view or a symptom of mental illness. It opens two questions: First, how does this process of qualification occur? Second, what is at stake in this process?

When Oscar, a resident, describes a mouse that often visits him, is it an actual mouse? When Charles, another resident, complains of the smell of Chinese food coming into his apartment in the mornings, is it real or delusional and thereby attributed to the resident's racial/ethnic prejudices? These questions were raised by the staff during their bimonthly meeting and fostered discussion. Both Oscar and Charles were considered "covertly delusional," to a degree varying over time. By "covertly delusional," the staff refer to patients who appear "normal" and well functioning in superficial conversations, but who are revealed to have delusional thinking in more profound exchanges. The nurse who had heard Oscar describe the mouse perceived him as being quite convincing. The psychologist noted that the building was known for being poorly maintained. Another nurse gave contrasting examples of delusional statements repeatedly made by this resident. About the smell of Chinese food complained of by Charles, various staff members remembered a few occasions when they had noted the resident's racial prejudices. The psychologist also pointed to the fact that this kind of food odor was unlikely to appear in the mornings. Considering all these elements of each statement's context, the mouse was considered to be real and the smell to be delusional. As a consequence, the staff acted to get Oscar to use a mousetrap, while the staff's image of Charles as "covertly delusional" was reinforced. Yet, in the literal sense, both these statements can be defined as "patients' views." What is remarkable about these two examples is that there is no way to determine the veracity of the statements without additional information, yet a judgment has to be made nonetheless.

When a statement made by a patient is not interpreted as a view or opinion, there are two alternative interpretations: professionals may consider the statement to be delusion, as in Charles' case, or simply an impractical goal, as it appears to be in Carla's example. Common discourse used in medical settings usually attributes a lay view, as opposed to a medical view, to the patient. Depending on the particularities of patients' mental states, their lay views may also be categorized as "crazy," which effectively disqualifies and discredits these views. At least at some moments, a mental patient may be considered not to have (or to have lost) the very capacity to express something that would be accepted as a point of view.

Before examining how these interpretations take place within a model of care, I describe with more precision how I define the different categories of statements patients make, and the corresponding types of patients as they are categorized by psychiatric practice. As I have shown in the first part of this paper, mental health research and medical anthropology delineate two conceptions of the patient's perspective, which refer to a specific understanding of the patient. In their study designs and discussions, mental health researchers conceive of the client as a largely rational actor, able to engage in the management of his or her illness in partnership with the staff, and to express natural opinions that staff are able to easily access. Medical anthropologists imagine a narrative actor, willing and able to constitute his

or her identity through narrative. Together, these two conceptions shape the patient as a rational and narrative actor. This understanding of the patient can be found in the categories used by the staff in psychiatric practice. As I will show, this idea of the patient can be found in the supported housing program's model of treatment: the patient as rational and narrative actor is an explicitly expected therapeutic outcome. Yet such a conception only partially meets how psychiatric clinicians view the patient. It is not adapted to incorporate any statement that is considered "psychotic," delusional or impractical. Since it appears that in psychiatric practice not all patients have a view at all times, the idea of the patient as a rational and narrative actor stands as an ideal. The irrational patient is not excluded from the model of care, but becomes part of it. This patient should be assisted in reaching the ideal of the rational and narrative actor to the extent that the staff believe he or she is capable.

Each of these understandings of the patient, rational or irrational, influences the way in which patients and professionals interact in the clinical setting: a patient stating an opinion, like the fact that there is a mouse in his apartment, is considered to be a rational and narrative actor, and interactions with professionals will take place in a partnership model where patients and professionals collaborate in managing the illness. Conversely, a patient describing a delusion, like Chinese food smell coming into his apartment, will be treated as a "psychotic" actor. "Psychotic" is a term used among staff members to describe a patient whose life patterns are strongly deviant (like staying in bed all day, never cooking, not having personal relationships, etc.) as a consequence of mental illness. In these cases, for clinicians, psychiatric treatment is based on putting aside what the patient says and deciding on the appropriate action. At such moments the patient's perspective cannot exist in psychiatric practice. When evoked by staff members, the two modes of interaction between staff and patients I describe here do not pertain to a theoretical discourse on psychiatric treatment. Rather they constitute "situated concepts" (Floersch 2002), in the sense that their definition incorporates a situated knowledge developed by the staff that stems from practice. Interestingly, the two situated concepts Floersch defines in his study of a case management program in Kansas are very similar to the ones I just described. On the one hand, case managers "do with" consumers when they consider them to be "high-functioning." On the other, they "do for" consumers who appear to be "low-functioning." This correspondence between my findings and Floersch's is even more striking given how much the two settings diverge organizationally as well as in their theoretical references (Velpry 2006). It leads to the hypothesis of a certain stability of some "modes of doing good" (Pols 2003) for care providers in psychiatry. Returning to Carla's housing plans, the consequence of the disqualification by the staff of her statement that she wants to live on her own clearly materializes in the staff's attitude. By concluding that what she says is not really what she wants, the staff avoid assisting her in her plans toward independent living, and decline to offer material or moral support for her efforts. Furthermore, they do not consider this goal to be part of the therapeutic project. Therefore, how a patient's words are qualified determines how the patient will be taken care of.<sup>8</sup>

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<sup>8</sup> The nature of the interaction between patient and staff is unstable, meaning that interpretation is an ongoing process (Velpry 2008).

These two understandings of the patients are also appreciated and valued differently by the staff and by society at large. Psychiatric practice requires constant balancing between the two poles of collaboration and of assistance. What I argue below is that the two poles are united through making the narrative and rational actor the main therapeutic goal. In psychiatric practice, one of the justifications for action is to enable patients to participate in a collaborative model of care. The support group is a good place to observe this process since it gathers care providers and patients around the discursive material of expressed views.

### The Patient's Perspective as a Collective Project

In the support group I observed, all the participants appeared to be working collectively to construct the patients' status in the interaction. This construction occurs through the way care providers "hear" what patients "say." Formally, the patient is given a status of partner, that is, of an agent, in the group. However, since a goal of the group is also for the care provider to exert a therapeutic intervention (e.g., to get the patient to change his or her behavior or outlook), the patient is an object of the interaction at the same time that he or she is an agent of it. This double position leads to conflicts, which arise most clearly around the interpretation of the patient's words, or the construction of specific viewpoints.

How do group participants work collectively at constructing views? The support group is a place where each resident<sup>9</sup> learns to express feelings and opinions. In the supported housing group, residents come to discuss their living situations, their daily activities and recent events in their lives. Specific topics are diverse: from plumbing problems to the news to description of future projects. The intervention on the part of the staff members (psychiatrist, psychologist, or nurse) can consist of encouraging the residents to express or formulate an opinion through recurrent questions. Sometimes this is done by "correcting" or consolidating existing opinions expressed by the residents. When a resident expresses something in the group, be it a perception, an opinion or an attitude, it will be responded to by all members (staff and residents). This generally leads to an interpretation and qualification by staff members of what is said and done.

The criteria used to qualify a statement have a normative dimension; the values of the group members, both resident and staff, are used to judge residents' expectations of what daily life should be. Residents in the group are expected to adopt these values. However, the way in which this normative dimension is incorporated by the participants is complex. Both the staff and the patients are conscious of an ideal of social and personal well-being, which consists of the individual's ability to take care of him- or herself, willingness to live a productive or at least an active life and recognition of the existence of an illness and the necessity of treatment. The actual expectations of the staff combine these features with what they assume to be each patient's personal limits, which are usually understood to result from the patient's illness. Normative expectations will be modified depending

<sup>9</sup> Here and throughout the paper, "resident" refers to patients living in supported housing.

on assessments of the patient's capacity. Before examining the role these expectations play in the interpretation of the patient's statements, I look at the way they appear in the group's discourse.

Speech is quite free in the group. Residents can and do express opinions that they know oppose staff ideas. During one session, for example, Oscar advocates smoking marijuana as a legitimate form of self-medication: "Weed will cure me. I need to stay in bed and concentrate to get better." Commenting on his statement, the two staff members bring up arguments against his practices, but without going further into the critique and with no apparent intention to convince Oscar. In general, residents maintain their opinions even when they contradict the common-sense values held by staff members. Discussing tobacco consumption, a psychologist asks the smokers among the residents if buying cigarettes would remain a priority were the price to rise so high as to endanger their budget balance. They all say they would keep buying cigarettes without a second thought, even if it is clear to everyone that this is not the "expected" answer. Indeed, the staff members do not comment on this deviation from the expected answer. In the whole discussion, then, the staff members have not explicitly stated what the normative behavior is. Rather, through their questions, they have given the residents an opportunity to express conformity to, or acceptance of, these norms, an opportunity that has not been taken. It should be noted that the fact that the residents do not respond adequately to the staff's expectations does not mean that they are unaware of them. Discussions in the group thus convey normative statements, yet the staff members never make it explicit that they expect the residents to conform to or accept them. Rather, they seem to be waiting for the day when the residents will spontaneously converge with their normative views.

Most often, the work on behavior, especially on lifestyle, occurs through this pattern of implicit expectations. The expectations appear through certain repetitive, even ritualized questions and through emphasis on the desirability of conformist behavior. "To do something with your day" is an example of expected behavior. During group sessions, the question "What did you do this weekend?" is a ritualized one. The way residents answer is ritualized as well, as appears in my fieldnotes:

Bérénice (a psychologist) asks if someone went out last weekend. Walter says he went out with friends, to see a soccer game. Maurice says that he didn't go out and adds that he has a lot of things to do at home, like reading or listening to music. Serge says that he didn't go out, Charles says so too, as well as Carla, who smiles as she says so. Bérénice tells her she should go out when it's so nice outside. Carla answers that she looked at the sun, but didn't feel like going out. Mélanie says that she went out each day. Bérénice insists for a few minutes that one should go out when it's sunny, rather than staying at home. She is not addressing anyone in particular.

This particular exchange takes place every session; every time it follows approximately the same lines and includes the same protagonists. In this sense, it is ritualized. The scheme adopted here shows how a normative expectation (here, "to go out on the weekends") is stated as a general opinion. The recurrence over time of the question ("What did you do this weekend?") indicates the psychologist's

expectation of the residents having done something, since it would be a positive sign of a clinical evolution. Yet, even if the residents are aware of this expectation (as shown, for example, by Carla's smile), they most often give the "wrong" answer that they did not go out.

By answering "no," the residents participate in a ritualized exchange with the staff without completely playing the game. Changing habits is another object of attention for staff concerned with daily life. Every year, Paul goes on vacation for 4 days, at the same place and on the same dates. During a session, a staff member asks him if he wouldn't for once like to leave for longer. Paul says, "No, I wouldn't like to." When Bérénice asks him why, he gives different answers successively. He says first that it is too expensive, then that he has medicine to take, then that he doesn't want to be away for too long, and, finally, that he just doesn't feel like it. Paul's answer seems to show his understanding that he should justify his actions to the staff. In contrast, Carla, when asked this kind of question, just smiles and says no, she doesn't feel like it. By doing this she appears to refuse the kind of discussion proposed by the staff, feeling that she has the right to keep her private life and reasons for her decisions to herself. While Paul and Carla react differently to this intrusion on their lifestyles, both are aware of the normative implication of the question, and of the fact that they deviate from this norm.

The existence of this game probably explains the ritualized role of the exchanges in the group. It has become so ritualized, in fact, that similar topics are sometimes introduced by residents as well as by staff. Some do it often and spontaneously, narrating their week or describing recent news. It is certainly the case that the degree to which residents reveal private aspects of their lives depends on what they want to share. Yet, regardless of what exactly is revealed, for everyone, the feeling of intimacy and inclusion in the group depends on the definition of a patient role through ritualized and stereotyped comments.

The description of how normative expectations are formulated in the group shows that the interpretation of a statement as a point of view takes place within a larger effort to affect patients' behavior. The goal of interventions made by the staff is not only to assess the patient's capacity to present him- or herself as a rational and narrative actor, and thus capable of having a point of view, but also to help the patient become such an actor, within his or her assumed limits. Therefore, going back to the central question, the patient's view appears to be an expected result of the group rather than an attribute of the patient. The shaping of the patient's viewpoint is negotiated through the way the patients talk and the staff listens. I now turn to an exploration of this specific relationship that shapes the patient's view, and of how the collective production of the patient's view relates to the notion of autonomy.

### Negotiating a Perspective: A Narrow Path to Autonomy

It is true that in the supported housing program we try to develop autonomy, but it is a structured autonomy, not a variable one.

Staff member

To explain the way a relationship geared toward producing a rational and narrative patient is negotiated between patient and staff, I need to enlarge the scope of analysis. Within the support group, the therapeutic intervention focuses on behaviors that take place outside the group. The preceding analysis of the discussion group has revealed the conditions for the construction of a patient's view and the normative dimension of the group. However, the support group is part of a set of interventions that constitutes the supported housing program. Other interventions include home visits and help with daily activities as necessary. An important difference between these activities and the support group is that they act directly on behavior through coaching. This combination of tools, namely, coaching and talking, comprises the therapeutic model of the program that I now describe in more detail.

The supported housing program I studied can be conceived of as a space where residents and staff work together. While they share common goals (to control residents' illness and to manage their daily life, financial resources and social relationships), the means they use may diverge widely (Velpry 2006). For the staff, these means consist of a process of profound personal transformation for residents, which they have to accept as well as appropriate. Therefore, the supported housing program, as a therapeutic process, is centered on engaging and supporting residents through change. This change focuses not only on behavior but on development of notions such as autonomy and responsibility through verbal exchange. Residents are expected to take responsibility for their lives, or at least for their expectations. The delicate part of the therapeutic intervention, therefore, is that the care provider must both alter the resident's behavior and allow their relationship to evolve from that of assistance to collaboration. In order to meet these two goals, the balance between "doing for" and "doing with," to use Floersch's words, is constantly reassessed.

A successful intervention will replace a regime where interventions are imposed on the resident with one of collaboration between care providers and residents. With this evolution, the status of the resident in the relationship is transformed, as is the extent to which the care providers will intrude in the resident's private life. If we take the example of housecleaning, in a "regime of imposition" (doing for), care providers may themselves clean the residents' apartments, while in a "regime of collaboration" (doing with), they will not. At most they may advise the resident that he or she should clean up the house; whether the resident actually does is his or her responsibility. The position of the resident is different in the two regimes. In the transformation of the resident's status, how his or her statements are interpreted is crucial. This is especially true in supported housing, where a large part of the interpretation of a resident's behavior in daily activities occurs through the resident's description during the group of what he or she does rather than by direct observation. It is important how what the patient says organizes and structures the therapeutic framework: the patient's words are clinical material that providers use during treatment. It is apparent that by changing the regime from imposition to collaboration, and thus modifying the patient's position in his or her relationships with care providers, the status of discourse and the definition and limits of therapy are altered.

During staff meetings, care providers determine residents' capacity for autonomy and responsibility, which allows them to select the appropriate regime of intervention; this has important consequences for therapeutic decisions. In the following cases, we see how interactions are adjusted when new residents resist the existing therapeutic framework proposed by the staff. Although part of this framework consists of instilling autonomy, the staff members remain the ones to judge whether a behavior qualifies as a sign of autonomy. Hence, in some instances, patients showing their autonomy in daily life management, in particular, at the domestic level, constitute a form of resistance. This is especially the case when the autonomy asserted is not the outcome of the therapeutic process and therefore has never been directly controlled by the staff members.

Norbert pictures himself as an independent person, one who has always succeeded in meeting his basic needs whatever the circumstances. He was admitted into the supported housing program after hospitalization left him without a housing solution. For Norbert, the constraints of the admission process were hard to get through because they conflicted with his conception of personal independence, an independence he particularly wanted to prove to care providers. Meanwhile, for the staff, Norbert's acceptance of the admission process was considered part of the therapeutic process. When Norbert viewed accessing this apartment as "a leg up," he was referring to socioeconomic hardship rather than a hardship resulting from his mental illness. Following this logic, he was happy to be visited by psychiatric nurses but handled them like social visits. Therefore, instead of letting them in for a discussion of his personal and housing issues, he used to cook lunch and invite them to eat with him as guests. This inability to take staff's expectations into account made it difficult for the staff to frame their interaction in a way they found acceptable. In other words, by maintaining his behavior, which was perceived as a complete lack of recognition of the therapeutic context defended by the staff, Norbert was asking them to treat him as a very special patient. Because care providers had known Norbert for several years, they accepted a larger margin of deviance from him than from other residents.

At this point, the evolution of the situation was undetermined. For it to go Norbert's way, Norbert would have to truly assert and prove his capacity for autonomy, by, for example, demonstrating that he had found the job for which he routinely said he was actively searching. Since various aspects of his behavior became more and more bizarre, his statements were increasingly interpreted as delusional in discussions between staff members. In this context, elements of his situation, such as the fact that he faked taking his medication and paid his rent irregularly, were newly incorporated into the staff discussions as clinical material, adding to their eventual assessment of him as being in an active period of his illness. This interpretation was confirmed when, following a violent crisis at his apartment, Norbert was readmitted to the hospital. At the next staff meeting, the decision was made to exclude Norbert from the program. This was a very unusual decision; when hospitalized, residents were usually kept in the program until plans for their release could be discussed. In Norbert's case, however, it was considered by the staff the logical conclusion to a string of factors that were now all pointing to Norbert's incapacity to live independently at that time. What should be noted, however, is that

had Norbert shown a greater ability to manage life on his own, which the staff had come to expect from him, all these factors would not have been considered indicative of illness. This example emphasizes the contextual nature in which staff members consider residents capable of autonomy.

Christophe's case contrasts with Norbert's because, although a similar conflict of interpretation emerged, the negotiation between resident and staff was a success. In both cases, the conflict rests on the resident's initial claim to manage his life independently. Christophe's claim focused on the apartment. When interacting with the staff, he refused the patient/care provider framework and acted in a framework that emphasized a renter/landlord relationship. This behavior was very offensive to the staff because he undermined the therapeutic framework of their actions. The psychologist remarked during a staff meeting: "Last night, Christophe came to the center at 6 pm and asked for X [a patient]. We couldn't believe it.... Then he said he needed us to change the bulb in the kitchen. I felt like we were a real estate agency. I can't find the therapeutic project here."

Like Norbert, Christophe violated the rules for resident behavior and almost explicitly asked for special treatment that would recognize his autonomy in daily life management. But Christophe didn't refuse the rules imposed by the staff: he paid rent and wasn't violent; rather, he displaced them by trying to establish cooperation on the basis of housing. This may explain the numerous discussions among staff members that centered around how to decide whether Christophe's behavior was pathological or normal, and if and how they should reassert their therapeutic role:

*Psychiatrist:* Christophe is still acting normal, it is just that sometimes he says things that are off track. Or would it be a "*folie des grandeurs*"?<sup>10</sup>

*Psychologist:* I wonder what the therapeutic project is. Or is it only housing?

*Nurse:* He doesn't have the notion of therapy.

*Psychologist:* Is his story about volunteering with older residents true?

In this discussion among staff during a meeting, we see that everything Christophe says, as well as his daily activities, comes to be questioned. Yet, after a series of similar incidents, each party adjusted his or her expectations and behavior. The staff still refused to play the role of the landlord with Christophe, even though this role may be predominant with other residents who don't ask for it but are considered unable to take care of their housing tasks. Yet, they accepted that he addressed them as landlord and stopped interpreting these attempts as pathological. Rather, they tried to see them as an effort toward achieving more autonomy. Christophe, for his part, accepted that he must "treat them as care providers," as he formulated it. By this, he meant that he tried not to feel rejected or insulted by their refusal to act as his landlord and, instead, blamed it on their medical ethos. In Christophe's case, his ability to adjust his behavior to the staff's expectations is partially what allowed a successful outcome: his allowing the staff members to occupy the therapeutic role as they felt they had to lessened the staff's expectations

<sup>10</sup> "*Folie des grandeurs*" refers to grandiose delusions and is used as a synonym for megalomania.

for Christophe's behavior and gave him the feeling that he indeed had more autonomy.

These two examples illustrate a tension intrinsic to psychiatric interventions: on the one hand, the goal of the therapist is to help patients to live independently, without therapeutic support. To achieve this, staff place strict rules and limits on behavior and accept a narrow margin of deviance. Here, the therapeutic goal of the program is for residents to "learn" to live by themselves in their own place. Yet, to reach this goal, care providers require that residents increase their autonomy progressively. If a resident is acting in a way that is considered too autonomous too quickly, staff may read the behavior through a clinical lens and define it as pathological. Inversely, if patients are too conformist, they will be deemed passive. In the supported housing program, then, the negotiation centers on the limits of autonomy.

## Conclusion

The patient's view has become unavoidable in every discourse about psychiatry. This emphasis on the patient's perspective is the product of an historical and cultural evolution. Today, mental health research treats the patient's view as a stable attribute of the person as well as a tool of empowerment. It considers the notion to be evident and natural. Ethnographic data presented in this paper show that the patient's perspective is a more complicated notion than often appears in the discourse of mental health professionals.

First, the patient's perspective is not independent of the psychiatric context, where it is sometimes even considered a therapeutic goal in itself. Observations in a support group of patients in psychiatric care show that the patient's view is not a given but a construct that results from participation in the group. Second, the perception of the patient as a rational and narrative actor is in conflict with another version of the patient, less present in the discourse but observable in practice: one that I have called the "psychotic" actor. From there it appears that to be granted a legitimate and rational "point of view," a patient has to walk a fine line between showing autonomy and conforming to the staff's ideas on the limits of the patient's capacities. If patients are "too independent," they risk being discredited as "irresponsible." If they don't show enough independence, they will appear too passive and therefore "too sick to get well." In this sense it is a normative notion, normative being used in a nonpejorative sense. Finally, the "patient's view" is negotiated as a result of the therapeutic process and constitutes a resource to be used in interactions in medical settings, for both patients and care providers. As a resource, it permits patients to be attributed status and credit in discussions with staff members. The more patients' actions correspond with provider views, the less their behavior and words risk being interpreted as symptoms of mental illness.

Anthropologists have developed an interest in the patient's perspective as well. Attempts to frame it as context-dependent have shifted attention to the narrative identity of the client and its empowering effects, thus focusing again on the individual. My goal in this paper was not to show that emphasizing patient

empowerment and the patient's view is wrong. Rather, I have emphasized that the patient's view is not a stable, individually produced attribute, waiting for a venue for expression. I have argued that attention to the context should consist in focusing on the process of production of the patient's view in mental health settings. Negotiated between patients and care providers, the "patient's view" becomes a new resource: it gives the patient status and credit in the discussion, and greater freedom of action. Therefore, it seems more accurate to conclude that the inclusion of the patient's perspective in psychiatric practice does indeed change the way negotiation is conducted, regardless of whether it does or does not liberate the patient.

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