

## Prognosis in Schizophrenia and the Role of Subjectivity

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It is a little like the “Have you stopped beating your wife?” problem. Language contains assumptions and sets the context, a context from which it is almost impossible for the person to escape. The group that sets the context rarely notices that it is a context, rather taking it for granted as reality. Until around the 1970s, in most parts of the United States, the context for understanding mental illness was psychoanalytic theory and anyone who did not accept that was either “resistant” or did not know enough. Now, the context is often represented by words like “progression of the illness,” suggesting as it does a fixed evolution and implying a mainly biological substrate. But I would like to shift the focus to a related question. That question is whether a field that systematically ignores a considerable amount of data can be considered an adequate science. There has been a major failure to consider adequately patients’ subjective experiences in research, theory, and practice. We have also failed to be guided sufficiently by those experiences to develop new research questions and areas of investigation.

The prognosis of schizophrenia (the word “prognosis” to me having a more open-ended realm of possible implications than “progression”) has been a major issue in defining the disorder originally called dementia praecox<sup>1</sup> and is addressed again in this issue.<sup>2–7</sup> Although symptom and biological variables are obviously important in understanding prognosis, another area of data, the subjective experiences of persons with schizophrenia, is often ignored. Yes, there are problems with the measurement of subjective experiences. Yes, there is a long history of data on subjective experiences being given questionable interpretations and being accepted with minimal caution. There is also, in contrast, a history of “we do it already” (pay attention to subjective experiences) and, conversely, a long history of considering subjective data as irrelevant. Are patients’ experiences of their own efforts, their own will power, their feelings beyond those considered by us as symptoms not that important to understanding schizophrenia, to understanding its prognosis for example? Do we consider those experiences adequately already? I do not think so.

About 15 years ago, a schizophrenic patient in a follow-along study we were doing with repeated interviews asked me during one of these, “Why don’t you ever ask

me what I do to help myself?” I am still trying to answer that question fully. She was raising the question of subjectivity. She did not consider herself merely a helpless victim of illness, an object for whom her own feelings and actions were irrelevant to her course of disorder and improvement. She was asking why I, why we mental health professionals, do not include those aspects of subjectivity in our concepts and theories, our actions, and our research. As far back as 1807, Main de Biran<sup>8</sup> raised a closely related issue; although he put it more positively, he noted that in spite of the importance of traditional science and its emphasis on objectivity, when one is dealing with human beings we also need to consider subjectivity and to include it in our theories and methods.

So why did my research patient have to raise that question again? I think that it was for many reasons but partly because we in the mental health field still struggle to be accepted as a “real” science like the physical sciences and we try to limit ourselves to imitating their methods. Also of course, subjectivity is so difficult to study in a way that is acceptable to the principles of the physical sciences.

That patient reported many things she did to help herself diminish her symptoms. As we began asking other patients, they too reported examples of their decisions, intuitions, and desires to take various actions (eg, decide to go for a walk when the voices got worse, ask friends whether something strange is happening when the delusions of reference got stronger). And then there was the patient with a major thought disorder who had to tell me the same thing at 3 different follow-up interviews before I “heard” her. “But Doctor Strauss, as I told you before, I have to work in a confusing job [as a secretary at a busy office] because that *makes* me organize myself.” In taking as an example, the question of prognosis in schizophrenia, once one has the idea that people think they might “help themselves,” one can then begin to move in more traditional scientific directions and ask the relevant questions systematically.<sup>9</sup>

But beyond the feelings that generate action, other aspects of subjective experiences also appear important, eg, those aspects related to feelings of personal worth. Many patients say, “The most important thing in my improvement was someone who took me seriously.” In one instance, it was a patient’s mother, in another a social worker, and in another a friend. These are statements

one hears commonly—if you ask the questions and are interested in answers that fall outside our usual domain of scientific concerns. They are also statements one hears in other cultural settings.<sup>10</sup>

But even when a patient recounts what he or she does or feels, or when patients do not try to help themselves but are eager to learn what others do, do these things really help? Do they make a difference to course and outcome? The frequency with which such statements based on feelings are made strongly suggests that they reflect a real and important phenomenon, that, eg, a person's own role is of some help in reducing symptoms, and that such a success, even if temporary or partial, enhances self-esteem. This may then improve relations with other people and generate further efforts of focusing one's actions in important ways. In one microexample of such a process,<sup>11</sup> a patient reported how even simple experiences of will and efficacy were important. Having previously been devastated by her sense of helplessness and inadequacy during a psychotic episode, she found that the simple sequence of wanting to hear a program on the radio, turning on the radio, and finding the program she wanted was extremely helpful for her.

It is also possible that the opposite process occurs, that failure to act on one's behalf, or having the belief that such action is impossible, or the lack of being taken seriously by others can have a strongly negative impact on course and outcome. This appears also to be true for the loss of hope fostered, eg, by being told by a psychiatrist ignorant of the data showing the diversity of course and outcome in schizophrenia "that you have a disease called schizophrenia, you will have it all your life." The message often given to patients, that they have little or no ability to impact the outcome beyond taking medication, may devastate a person's identity and sense of efficacy.

As part of these sequences, the context within which one lives, including life events, obviously plays a major role in a person's gaining a positive subjective sense of self and of the possibility of improvement.<sup>12,13</sup> Life context features, for example, include material resources such as a place to live and money for expenses, employment, the formal and informal health systems, and significant others.<sup>14</sup> In one instance, for example, while doing interviews in a longitudinal study in which I was not the principle investigator, I was asked to interview a woman with schizophrenia who would meet me at the health center of a major university. I arrived at the scheduled time, asked the receptionist for the woman, and a young woman appeared who introduced herself to me as the person I was scheduled to see. The woman looked so "with-it," so alert, so normal, and well dressed that I was certain that the head of the project had made a mistake in diagnosis (why are other people so often wrong?) but went ahead anyway, led by the young woman whom I will call Shirley, to a room where we could talk.

She recounted her history. Two years earlier, she had been living on the street, hallucinating, and certain that evil forces were working against her. She had become progressively more disturbed over several months. Then, a man befriended her whom she felt was not trying to exploit her, and she began to feel that perhaps it was worthwhile to do something to see if she could have a better life. She went to a treatment center where she made a connection with a social worker and where she also received antipsychotic medication. Shirley improved somewhat but soon reached a plateau at which she was living indoors but still with some symptoms and little desire to move on further. She told the social worker whom she knew quite well by now that more than anything she wanted to be reunited with her daughter who had been taken from her when Shirley had started to become ill.

Over the next few months, the social worker found a way to "stretch the truth a bit" with the authorities so that Shirley could be reunited with her daughter. Shirley told me that she was so impressed that the social worker would extend herself like that for her that she found the will to get ahead further with her life. She applied to University, was accepted, attended, and did well, and that was how I was seeing her now. I had to accept on further inquiry that the investigators had been correct about the original diagnosis and that it was I who had been wrong. The sequences involved in the experience of "someone who cared" (in this case 2 people) and the related change in feelings and actions of the patient and her subsequent course were striking indeed.

Elsewhere it has also been described how more adequate attention to subjective experiences of patients can be important for diagnostic validity and for insuring better treatment alliance, both important for more effective treatment and hopefully for better prognosis.<sup>15,16</sup> And, of course, because biological variables may be related to prognosis, it is essential to recall that everything "mental" has a biological correlate and that subjective experiences at all levels are intimately tied to biological phenomena.

Clearly, to proceed from individual examples to a more convincing scientific demonstration of validity, research and better methods of study are required. These have been difficult to develop, and in spite of diverse efforts the establishment of links between the more subtle aspects of subjective experience and course of disorder or improvement have made only limited progress. One valuable approach has been to recognize what a small sample of patient experience we are seeing by limiting our contacts to seeing patients in our offices or in hospitals.<sup>13</sup> Seeing patients in other contexts often demonstrates the competences of people with severe mental illnesses and raises the question of explaining how it is possible that competence and illness in mental functioning

coexist. Another methodologic approach has been to utilize the vast knowledge of the arts in understanding subjectivity, especially the theater in which theater professionals spend their lives learning what is like to be “in someone else’s shoes.”<sup>13</sup> This approach has suggested, eg, the degree to which being treated as someone who is hopelessly defective can destroy hope and possibilities for the person diagnosed with schizophrenia to make efforts toward improvement.

Further study may require not only new techniques but also new conceptualizations for considering subjective experiences. It is helpful in contemplating such efforts to recall that for understanding the functional biology of the brain, it was not just a matter of someone sitting down and saying, “I wonder how serotonin (for example) works.” Years and many millions of dollars were required for developing the questions to be asked and the scanning equipment and techniques required. Developing more adequate concepts and methods for understanding subjectivity would require time and methodology as well, and very limited efforts have been made in this regard in comparison to those put into understanding biological processes.

So do the subjective experiences of patients make a difference to prognosis? There are many reports to suggest that they do. It is difficult at this point to know for certain, but we will never find out if we continue in our science to act like Geppetto in the Disney version of Pinocchio. When, toward the end of the movie Pinocchio appears to have been killed but awakens, now a human being, he sees Geppetto and asks why he is crying. Geppetto says, “Because you’re dead Pinocchio.” To which Pinocchio responds, “No I’m not.” Geppetto, not looking up, “Yes you are” and then Pinocchio, “But father, I’m alive see, and I’m real, I’m a real boy.”

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