Does Involuntary Treatment Scare People with Mental Illness Away from Treatment?

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Involuntary treatment, including outpatient forms such as assisted outpatient treatment (AOT) and conditional release, continues to be controversial among some people. In opposition to involuntary treatment it is commonly alleged that "involuntary treatment is traumatic and frightens people away from treatment" (Daniel B. Fisher, Letter, *Boston Globe*, Jan 1, 2013). When a reference is provided to support this allegation, the reference is invariably the "Well-Being Project" published by the California Department of Mental Health (The "Well-Being Project," California Dept. of Mental Health, 1989). Since this is the only evidence cited to support this allegation, it is worth a close examination.

It is assumed that between 40 and 50 percent of individuals with schizophrenia and bipolar disorder will oppose any treatment, voluntary or involuntary. These are the individuals who are unaware of their own illness – they have anosognosia – and thus see no need for any treatment. When these individuals become dangerous to themselves or other people, they are often involuntarily hospitalized and treated. It is also assumed that there is a group of individuals with severe mental illness who, in the past, may have been involuntarily hospitalized and treated poorly. They may have been treated disrespectfully and/or by mental health professionals who were not competent. Such things do unfortunately happen. Thus it is reasonable to assume that in any random group of individuals with severe psychiatric disorders, approximately half will be opposed to treatment.

The "Well-Being Project" was co-directed by Ron Schraiber, who had been diagnosed with paranoid schizophrenia and involuntarily hospitalized three times in California. When he was released he was one of the founders of the California Network of Mental Health Clients which was organized to oppose all involuntary treatments. The website of the California Network states as its basic principle that "the use of involuntary treatment such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination…CNMHC [California Network] members have unanimously endorsed this statement" (www.californiaclients.org/about/cnmhc).

What the "Well-Being Project" did was to survey 331 individuals who had been diagnosed with a mental illness, of which 320 were California Network members. All were living in the community and 87 percent had been previously hospitalized; no individuals who were in state mental hospitals were included. Thus the group surveyed was self-selected insofar as they had joined an organization that opposed all involuntary treatment. Within this group there was a further self-selection of individuals who volunteered to respond to Mr. Schraiber's survey. As the survey itself acknowledged: "Such samples are not entirely representative and these findings also cannot be generalized to the overall category of mental health clients."

This highly-select group of individuals were then asked to respond to the following question as part of a larger survey: Do mental health clients avoid treatment due to fear of involuntary commitment?

The respondents could only answer "yes" or "no," although answers to other questions were scaled 1 to 5 with intermediate possibilities, such as "occasionally." The result of the survey was that 47 percent of the individuals answered "no" and 52 answered "yes."

These are remarkable results but not for the reason that they are usually cited. When a group of highly self-selected individuals who had joined an organization dedicated to opposing involuntary treatment were asked to respond to a questionnaire co-directed by a man known to be strongly opposed to involuntary treatment, **only** 53 percent agreed that "mental health clients avoid treatment due to fear of involuntary commitment." This was not a scientific "research study," as it is usually represented, but rather a biased survey of no scientific merit. That it was carried out and published with California taxpayer funds is inexcusable.

What do we really know about the effects of involuntary treatment on individuals with severe mental illness? In fact there are several studies on this question, done scientifically and published in peer-reviewed journals. In most such studies, there is a significant number of individuals who oppose all psychiatric treatment, as would be expected. But there is also a significant number of individuals who have experienced involuntary treatment and who in retrospect, agree that it was in their best interest. **However, there is no published study which has shown that the existence of involuntary treatment scares people with mental illness away from treatment, other than the people who are opposed to all treatment, voluntary or involuntary.**

The following are some of the published studies on this issue:

- **2010:** A Norwegian study compared the outcome between patients admitted to psychiatric hospitals for their first episode of psychosis. 91 were admitted voluntarily and 126 involuntarily. At the end of 2 years following discharge there was no difference between the two groups on their adherence to medication.

  Opjordsmoen S, Friis S, Melle I, et al. A 2-year follow-up of involuntary admission's influence upon adherence and outcome in first-episode psychosis. *Acta Psychiatrica Scandinavica* 2010;121:371-376.

- **2009:** In England, 94 individuals "who lacked capacity to make treatment decisions" were admitted to a psychiatric hospital, and then assessed one month later or at discharge, if that came sooner. Among the 35 who regained the capacity to make treatment decisions, 29 (83%) answered yes to the question: "Were the right [treatment] decisions taken on your behalf?" Among the 49 who did not regain the capacity to make treatment decisions after one month, 20 (41%) answered yes to that question. Although almost two-thirds of the patients had been admitted involuntarily, "there were no clear differences in the views expressed about surrogate decision-making between those who were treated involuntarily under the Mental Health Act on admission compared with those who were treated informally."

  Owen GS, David AS, Hayward P, et al. Retrospective views of psychiatric in-patients regaining mental capacity. *British Journal of Psychiatry* 2009;195:403-407.

- **2006:** In New Zealand, 69 patients who had been on involuntary outpatient treatment ("Community Treatment Orders") for less than one year were queried about the effects of involuntary treatment. Among the 69 patients, 46 (67 percent) agreed that people on involuntary outpatient treatment "are more likely to take medication" and 47 (68 percent) agreed that they "are more likely to stay out of the hospital."

  McKenna BG, Simpson AIF, Coverdale JH. Outpatient commitment and coercion in New Zealand: A matched comparison study. *International Journal of Law and Psychiatry* 2006;29:145-158.

- **2005:** In New York, researchers conducted face-to-face interviews with 76 assisted outpatient treatment (AOT) recipients to assess their opinions about the program, perceptions of coercion or stigma associated with the court order, and quality of life as a result of AOT. After they received treatment, interviewed recipients overwhelmingly endorsed the effect of the program on their lives:

  - 75 percent reported that AOT helped them gain control over their lives
  - 81 percent said that AOT helped them to get and stay well
  - 90 percent said AOT made them more likely to keep appointments and take medication

  Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment (New York: Office of Mental Health, March 2005).

- **2004:** In North Carolina, interviews were conducted with 104 individuals with schizophrenia and related disorders regarding their feelings about involuntary (assisted outpatient) treatment. Such mandated treatment was regarded as being effective by 62 percent and as being fair by 55 percent of these individuals. Those who had awareness of their own illness (insight) were much more likely to regard mandated treatment as fair.

  Swartz MS, Wagner HR, Swanson JW et al. Consumers' perceptions of the fairness and effectiveness of mandated community treatment and related pressures. *Psychiatric Services* 2004;55:780–785.

- **2003:** In New York, 117 individuals with severe mental illness were followed up for 11 months after discharge from a psychiatric hospital. Those who perceived themselves as being forced to take medication ("high perceived coercion") were compared with those who did not perceive themselves as being forced to take medication. At the end of 11 months, there were no differences between the two groups in their adherence to medication.

  Rain SD, Steadman HJ, Robbins PC. Perceived coercion and treatment adherence in an outpatient commitment program. *Psychiatric Services* 2003;54:399–401.

- **1999:** In North Carolina, 331 individuals, 97 percent of whom had schizophrenia, bipolar disorder, or other psychotic disorders, were queried about the perceived effects of involuntary outpatient commitment. Among them, 83 percent said that "people under outpatient commitment are more likely to take their medication" and 77 percent said that they were "more likely to stay out of the hospital."

  Borum R, Swartz M, Riley S, et al. Consumer perceptions of involuntary outpatient commitment. *Psychiatric Serv*ices 1999;50:1489-1491.

- **1996:** In New Jersey, 30 patients who had been forcibly medicated during their psychiatric hospitalization were interviewed by telephone one to two weeks later by individuals who had not been involved in their treatment. Eighty-seven percent of the patients had been diagnosed with schizophrenia or bipolar disorder. Among the refusers, 30 percent recalled having refused the medication because they had believed there was nothing wrong with them, and 20 percent said they had refused because they had believed the medication was poison. Retrospectively, 18 patients (60 percent) said that having medication forced was a good idea, 9 (30 percent) disagreed, and 3 (10 percent) were unsure. Most of those who disagreed had either paranoid schizophrenia or bipolar disorder with grandiosity. The authors concluded that "forced medication frequently restores the capacity to make competent decisions and often results in a more rapid return of freedom to be discharged from involuntary hospitalization."

  Greenberg WM, Moore-Duncan L, Herron R. Patients' attitudes toward having been forcibly medicated. *Bulletin of the American Academy of Psychiatry and the Law* 1996;24:513–524.

- **1995:** In Maryland, 28 outpatients who "had felt pressured or forced to take psychiatric medications within the past year" were administered a questionnaire by their peers. Diagnostically, they were part of a larger group of users of psychosocial rehabilitation centers in which 52 percent of those with known diagnoses had schizophrenia or bipolar disorder. Only 2 of the 28 had actually been physically forced to take medication. In reply to questions about how they felt about having been pressured to take medications, 9 (32 percent) were positive, 9 (32 percent) expressed mixed views, 6 (21 percent) reported no effect, and 3 (11 percent) reported a negative effect. In addition, 12 patients (43 percent) said that "the experience gave them a sense that people were looking out for their best interest." The authors also noted that "only a few respondents said that past experiences of pressured or forced medication had had any effect on their subsequent willingness to take medication."

  Lucksted A, Coursey RD. Consumer perceptions of pressure and force in psychiatric treatments. *Psychiatric Services* 1995;46:146–152.

- **1991:** In Australia, 79 patients who had been placed under guardianship, 75 (95 percent) of whom had been involuntarily medicated, were asked to retrospectively fill out a

questionnaire. Eighty-seven percent of the patients had been diagnosed with schizophrenia or bipolar disorder. The results were as follows:

- Do you have a mental illness?
  - definitely/probably not: 47%
  - don't know: 9%
  - definitely/probably do: 44%
- How helpful was your guardianship?
  - very/fairly helpful: 45%
  - neutral: 21%
  - very/fairly unhelpful: 34%

There was a high correlation between patients who believed they had a mental illness and those who found the guardianship helpful ($p < 0.01$). The authors concluded that "although a majority of the patients were against enforced treatment in principle, often because they thought it conflicted with their civil rights, most found the actual experience, including medication, to be helpful."

Adams NHS, Hafner RJ. Attitudes of psychiatric patients and their relatives to involuntary treatment. *Australian and New Zealand Journal of Psychiatry* 1991;25:231–237.

- **1988:** In New York, 24 patients who had been involuntarily medicated with antipsychotic medication were interviewed at the time of discharge from the hospital. Sixteen (67 percent) were diagnosed with schizophrenia or bipolar disorder, and 5 more (21 percent) with atypical psychosis. Thirty-three percent of the patients said they had refused medication because they believed they had no need for it, 29 percent said they had refused medication because of "severe confusion or psychotic ideation," and 17 percent "stated that they did not know why they [had] refused medication." At discharge, 17 patients (71 percent) agreed that the decision to involuntarily medicate them had been correct and agreed with the statement: "If I become ill again and require medication, I believe it should be given to me even if I don't want it at the time." The 7 patients (29 percent) who disagreed scored high on measures of grandiosity, hostility, and suspiciousness; 6 of them had a diagnosis of bipolar disorder. The authors concluded that "it is impossible to avoid the conclusion that the treatment refusal of every patient in our sample was influenced by psychosis."

  Schwartz HI, Vingiano W, Perez CB. Autonomy and the right to refuse treatment: patients' attitudes after involuntary medication. *Hospital and Community Psychiatry* 1988;39:1049–1054.