Running title: Gøtzsche, Systematic violations of patients’ rights

Systematic violations of patients’ rights and lack of safety:

cohort of 30 patients forced to receive antipsychotics

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Similar work has not been submitted elsewhere. We deal with administrative issues in another paper (our ref. 8, expected to be accepted very soon).

**Abstract**

We assessed the records for 30 consecutive patients who had appealed decisions about forced medication with antipsychotics to the Psychiatric Appeals Board in Denmark. In all 21 cases where there was information about the effect of previous drugs, the psychiatrists stated that antipsychotics had had a good effect whereas none of the patients shared this view. The harms of earlier or currently used antipsychotics did not seem to have played any role for the psychiatrists’ decision-making. The legal requirements for using force to protect the patients’ health were never met and less intrusive treatments than antipsychotics, e.g. benzodiazepines or psychotherapy, were never mentioned as options. The power imbalance was extreme, the patients felt misunderstood and ignored, their legal protection was a sham, and the harm done was immense. Forced medication must be abandoned.

**Introduction**

Forced treatment with psychiatric drugs is highly controversial. It violates basic human rights and discriminates against psychiatric patients. The United Nations Convention on the Rights of Persons with Disabilities has therefore called for abolishment of mental health laws that permit forced treatment (1).

As we shall discuss further below, the benefits from antipsychotics are so doubtful and the harms so pronounced that it is not clear that forced treatment is in the patients’ best interests (2-6). In Norway, forced drugging is only allowed when, with “high probability, it can lead to recovery or significant improvement in the patient’s condition, or if the patient avoids a significant worsening of the disease.” Other countries have similar laws, and the Norwegian Ombudsman concluded in December 2018 that the Psychiatry Act had been violated in a concrete case because the randomised trials showed that the probability of achieving the intended improvement was low (7).

In an earlier cohort study of 30 patients, we showed that the Psychiatric Appeals Board in Denmark focuses on uncontroversial issues that are easy to check when patients appeal forced treatment orders (8). It seems mainly to have a cosmetic function, rubber stamping the views and arguments forwarded by the psychiatrists.

As the Psychiatric Appeals Board consistently avoided dealing with issues of crucial importance to the patients, we decided to study these in detail, in the same cohort of cases (8).

**Methods and materials**

In Denmark, a patient can complain about forced medication to the Psychiatric Patients’ Complaints Board, and if the decision is upheld, the patient can appeal to the Psychiatric Appeals Board whose decision is final.

The Appeals Board granted us access to the records for the 30 most recent consecutive patients subjected to forced medication. We needed to sign a confidentiality agreement and to read the material and extract data during visits to the offices of the Appeals Board. We were not allowed to make photocopies or to reveal the identity of patients, psychiatrists or departments. Permission from a research ethics committee was not required.

All the material handed out to us was on paper. It consisted of selected parts of the patients’ files, their complaints to the board (in two cases, psychiatrists complained that their decision about forced treatment had been overruled by the Complaints Board), the medical certificates, the expert assessments by psychiatrists, and meeting notes.

We extracted data between 30 January and 24 April 2018. For data extraction, we used a form with subheadings where we noted why the patients refused treatment with antipsychotics, benefits and harms of previous drugs, any mentioning of less intrusive medicine than antipsychotics or psychotherapy, signs and symptoms of psychosis, indirect coercion, motivation to take the medicine, expert assessments, and whether the patient was being ignored. When in doubt, we consulted each other and often also a psychiatrist who participated in some of the data extraction sessions.

Our main objectives were to assess if the arguments for using force were reasonable and evidence-based and took the patients’ views into account, including their previous experiences with antipsychotics, and if the patients were being treated with respect and dignity.

**Results**

The median year of birth for the 30 patients was 1970 (range 1935 to 1996) and 16 were males.

No respect for lack of benefit or harms of previous drugs

In all 21 cases where there was information about this, the psychiatrists stated that previous antipsychotics had had a good effect whereas none of the patients shared this view. Even for a patient whose psychosis had worsened, the psychiatrist noted that the treatment was effective, and when a high dose had not worked for another patient, a further dose increase was nonetheless deemed “absolutely necessary.”

All improvements were ascribed to the drugs, also in a case where it took a “long time” before any change was observed. We did not find any comments about a possible spontaneous improvement.

In three cases, the patients had not taken antipsychotics before, and in ten cases, we did not find any information about previous harms.

The harms of earlier or currently used antipsychotics did not seem to have played any role for the psychiatrists’ decision-making, not even when they were serious.

An expert confirmed our suspicion that a patient had developed akathisia on aripiprazole but on the same page, the expert – a high-ranking member of the board of the Danish Psychiatric Association - recommended forced treatment with this drug even though it was stopped because of the akathisia. Another patient suffered from uneasiness, ”inner cramps” and involuntary movements on zuclopenthixol, which might represent akathisia or tardive dyskinesia, but even though the Appeals Board noted this, it was not opposed to forced treatment with this drug. A third patient had tongue protrusion, but it was not mentioned that it could be a harm from antipsychotics (tardive dystonia).

A fourth patient had clear signs of tardive dyskinesia including ticks, odd facial movements, and twisted and involuntary movements confirmed by a physiotherapist, but this diagnosis did not appear anywhere in her file. A fifth patient highly likely had tardive dyskinesia but the psychiatrists ascribed her symptoms to her disease. We suspected tardive dyskinesia in yet two more patients who were nonetheless forced to take antipsychotics.

Four patients described that the drug made them lethargic, e.g. “the brain dries out” and “you might as well remove my brain.”

Feeling unsafe

In five cases, the patients expressed fear of dying because of the forced treatment: “the drugs kill you;” “Either I kill him, or he kills me with his shitty medicine;" “my father died because of intoxication with psychiatric drugs.” Another patient did not tolerate the medication and was very scared that the staff might kill her. Yet another patient, who had received clozapine earlier, said, ”I don’t want to die.” On admission, she was in treatment with dangerous polypharmacy consisting of clozapine tablets, aripiprazole depot injections and sertraline, plus tizanidine, clonazepam, and promethazine as needed for sleeping problems. A sixth patient felt very unsafe, but the staff did not ask why, even though she had spoken about being abused.

Tranquillizing the department by tranquillizing the patients

In five cases, the explicit purpose of forced treatment was to prevent the patients from disturbing the staff and other patients. A statement like, “We would like to help her with a tranquillizer as needed,” raises the question: for whom? Two of the patients did not have convincing signs of an acute psychosis but one of them received an injection of depot zuclopenthixol, which seems to be a disproportionate use of force for a noise problem.

Less intrusive treatments never used

Benzodiazepines or psychotherapy were never mentioned as options. Only in one case was there any indication that a patient might have received psychotherapy: “Continues talks with a psychologist.”

Seven patients asked for a psychologist, but this seemed not to have been granted. In one case, the psychiatrist argued that the patient’s condition was too poor for her to benefit but added that his judgment “of course can be discussed.” He noted that the patient looked down on psychiatry and had said that it did not offer psychotherapy, but he did not see the irony that he had just confirmed this himself. The patient was described as being “condescending and provocative when the staff gives her the drugs,” but she did not tolerate them, not even at low doses: ”I shall get my poison.”

Psychoeducation was mentioned three times but had another purpose, e.g. “to motivate for a life-long drug treatment,” which we find totally unacceptable given these drugs’ very serious long-term harms (4,6-9.

Questionable diagnoses of delusions

We had reservations about the psychiatrists’ diagnoses of delusions in nine cases. When a patient rejected olanzapine totally, this was called a persecutory delusion, and another patient who became ”hotheaded and difficult to communicate with” as soon as an antipsychotic was mentioned, was called “paranoid and conspiratorial about how we rally against him.” The patient mentioned above with clear signs of tardive dyskinesia was said to have psychotic misconceptions about the ”postulated side effects.” When a patient on voluntary admission mentioned that she was served meat during her last hospitalization even though she was a vegetarian, this was interpreted as a delusion.

A patient was said to have several delusions about hospitals and apparently also about drugs, as he would only take supplements and homoeopathy. His own view was that he had become psychotic because of the medicine. This might be true (6,9), and it is not a delusion to be afraid of hospitals or use alternative medicine.

A patient was diagnosed with religious delusions because he had said that Jesus could remove a cancer without leaving scar tissue. It is not accepted practice to diagnose delusions in people because of their religious beliefs.

A patient with known bipolar disorder who had not been in contact with psychiatry for ten years was admitted after a stressful period where she had been harassed by a neighbour. This was called a delusion with no insight into the disease. Based on the colourful descriptions of her behaviour, including that she was ironic and bothered other patients, it is difficult to judge whether she was delusional. No examples were provided of her alleged private logic (which many people have) or the alleged paranoid interpretations.

A patient who wanted to complain about being subjected to forced medication was called delusional because his file stated that force was not applied. However, force is often applied indirectly, and the patient file belied the diagnosis of delusion: “Is offered olanzapine 20 mg again and agrees to take this under force.”

"The patient still has no disease insight and says that her feelings disappeared after she tried to take medication." It is well-known that psychiatric drugs often make people emotionally numb (5,6,9). This fact cannot be used to diagnose a delusion (no disease insight).

Case stories about lack of respect for patients

A patient who did not want a sedative and had not bothered anyone was given an injection with 10 mg diazepam by the chief psychiatrist who argued, in contrast to the notes in the patient’s file, that the patient had been uneasy, had severe anxiety, and had a ”certain aggressive potential” (which, if true, was understandable, given how badly the psychiatrist treated him). The psychiatrist also argued that the patient “had severe catatonia, a potentially life-threatening condition.” When he was overruled, both by the expert assessment, the Complaints Board and the Appeals Board, he described this as ”a lack of insight into the psychiatric sphere of action.” When the patient developed headache on haloperidol, he doubled the dose of haloperidol injections without giving any reason, although headache is a well-known harm of this drug.

A patient who would rather go to jail than get drugs, and who had become lethargic while receiving three antipsychotics plus additional drugs, was said not to have experienced “inappropriate side effects.” Even though he was not psychotic and was massively treated already, the psychiatrist found it advisable to intensify the treatment and did not consider if the patient’s aggression might be caused by the drugs or the additional forced treatment he was subjected to.

A patient who firmly refused to take drugs was “offered” a haloperidol tablet as a sleeping pill even though its sedative effect is poor, and when she lashed out at the hand of the caregiver who gave her the pill and shouted that the staff should leave her room, she was judged to be in an “affective state.” When they had left, she became calm, but a plan was made that if she was not asleep around midnight, but was pained, uneasy, shouting and outwardly reacting, she would be treated with haloperidol, possibly as an injection “to maintain a sufficient sleeping pattern.” The medical certificate noted that a less intrusive treatment than antipsychotics would be inadequate but there was no explanation why, and the expert resolved that she was treated to preserve her health.

A patient who refused to take drugs because they did not work and because he had suffered multiple harms on olanzapine including weight increase, tiredness, lethargy, nausea, stomach pain, dry mouth, difficulty watching TV, and possibly also akathisia or tardive dyskinesia, was very agitated on the forced admission. Otherwise, he was quite peaceful and did not appear to be psychotic, e.g. it was possible to have conversations with him about “neutral subjects.” The expert resolved that he needed drugs to preserve his health even though it was obvious that the psychiatrists destroyed his health. It was also incomprehensible to us why he was hospitalized for a very long time. After three months, he was clearly burdened with being hospitalized, and after four months, he was said to have no realization of his need for treatment. It seemed to us to be the other way around: The psychiatrists had no realization of his need to be medicine-free.

A patient admitted voluntarily asked for 2.5 mg olanzapine, and when the psychiatrist talked about 10 mg and a long stay at the ward, he became angry. Already one day after his voluntary admission, he was told that if he refused, he would get an injection. The Appeals Board approved the use of force because the patient had threatened to kill staff and was extremely devaluing towards the chief psychiatrist and in serious affect several times when the psychiatrist tried to return him to his room. There were no reflections if his behaviour might be a result of the way he was being treated.

"The patient has been dismissive and refused to talk to doctors but is kind to nursing staff ... she gets very angry when we try to motivate her; will not say why she refuses to take drugs but asks me to try them for myself.” The patient informed the Complaints Board that the arguments used to compel her were all false and inadmissible. We agree. Earlier, the dose was reduced because of sedation, and she had experienced tremor of the hands and neck, which could be due to tardive dyskinesia, but according to the notes, she was well on zuclopenthixol.

A manic patient who had threatened to kill people received an olanzapine injection when he started to shout and threaten. The nursing records were revealing: “The patient says that it is through contact with staff he feels pressured and becomes upset … the patient has been threatening and noisy, but the staff has been able to correct him."

A patient with a verdict confining him to a forensic psychiatric hospital indefinitely did not respond to the medicine and was bothered by harms even on small doses, but the psychiatrist’s reaction was to increase the treatment. The patient was described as “quarreling, provocative and speaking in a condescending tone,” but he and his brother felt it was the staff that was provocative. The patient had "catatonic movements in the form of strange and sudden movements," and when he deteriorated following pressure from himself and the family to reduce the dose, this was explained by his disease even though catatonia might be a drug harm.

About a patient who refused to take olanzapine because it had no effect, the psychiatrist opined he was “well treated with olanzapine” and that “the effect of the drug is well documented.” He furthermore noted that the patient “sees the forced interventions as themes for the upcoming patient complaints board meeting." Such arrogance is not helpful for patients.

A patient who said that the dopamine hypothesis about schizophrenia doesn’t hold; that he had experienced serious harms on antipsychotics and did not want them; and that he had experienced a good effect of benzodiazepines, was subjected to forced treatment with an antipsychotic. On this treatment, he developed seizures and was unable to think.

A homeless patient, not previously known to psychiatry, said that she did not need to be medicated because she did not present a risk to others and was not uneasy. She was forcefully treated with a “tranquillizer” (olanzapine) because she was said to be increasingly rutted, uneasy and pained. When she got very upset over the use of force, she was put in belts.

A young woman reported that she was sexually abused as a child and had cut off contact with her family. She was admitted voluntarily, and when she could not be discharged, she became strongly agitated, shouted and felt threatened by a male patient. She was forcefully treated with 20 mg olanzapine two days later. A week later, the diagnosis schizotypy was changed to schizophreniform psychosis. It was not considered if her behaviour and symptoms might have been caused by the staff or the medication.

**Discussion**

The power imbalance and abuse we found was extreme. The psychiatrists did what they wanted to the patients and consistently ignored their wishes, traumas and other experiences. It was outright dangerous what some patients had to endure and very reasonable that some of them were afraid they might get killed by the drugs that were enforced upon them.

The patients are defenceless in such a system. All the way up to and including the Psychiatric Appeals Board (8), the psychiatrists’ views and decisions were being supported and the various experts paid lip service to the law. For example, one noted: “It was not acceptable to dose this way … but my assessment is of an academic character.” The expert reports were brief summaries of the cases that did not contribute anything substantial.

Habitual lying

A patient who perceived herself traumatized and not having "biological schizophrenia" found it unbelievable that she would not be heard, but that the Appeals Board would make a decision based on what was submitted to them.

In the US, it has been documented that psychiatrists, with the full understanding and tacit permission of the trial judges, regularly lie in court to obtain involuntary commitment and forced medication orders (10). Psychiatrist Fuller Torrey, likely the most prominent proponent of involuntary psychiatric treatment, has said that it would probably be difficult to find any American psychiatrist who has not exaggerated the dangerousness of a mentally ill person’s behaviour to obtain a judicial order for commitment (10). Quoting another psychiatrist, he has also said that this lying is a good thing: "Confronted with psychotic persons who might well benefit from treatment, and who would certainly suffer without it, mental health professionals and judges alike were reluctant to comply with the law."

However, the professional, "We know what is best for you," attitude is not only fallacious; it also leads to habitual lying and to ignoring the law and the patients’ basic rights. This is horrific, not least because it leads to thousands of deaths every year and likely millions of cases of serious brain damage worldwide, including tardive dyskinesia (6).

There is no sound scientific basis for the use of antipsychotics. All the placebo-controlled trials are biased because the conspicuous side effects mean that the trials were not effectively blinded (6). Furthermore, some or all patients were already in treatment before they were randomised (11), which means that patients in the placebo group are harmed through withdrawal symptoms. Even though the trials are seriously biased (6) and though it is easy for scores to improve quite a bit if people are knocked down by a tranquillizer and express their abnormal ideas less frequently (4), the trials have not found a relevant effect. The minimal improvement corresponds to about 15 points on the Positive and Negative Syndrome Scale (PANSS) (2), but what was obtained in recent placebo controlled trials in submissions to the FDA was only 6 points (3).

In Denmark, compulsory hospitalization or detention, which often leads to compulsory medication, may only take place if the patient is insane or in a similar state, and it would be irresponsible not to deprive the person of his liberty for the purpose of treatment because 1) the prospect of cure or a significant and decisive improvement in the condition would otherwise be significantly impaired; or 2) the person presents an imminent and significant danger to himself or others (12). The legal protections for people diagnosed as mentally ill are clearly illusory and the system meant to protect them is a sham. Condition 1) is never met, and condition 2) can only be met if the patient becomes so overdosed that he turns into a zombie. As an example, a patient who had developed psychosis two years earlier had never received antipsychotics and did not want them, but the Appeals Board argued that she would be able to improve significantly and decisively with treatment. Antipsychotics cannot accomplish this.

Another aspect of lying is that what is written in the patients’ files might not be correct and changes might have been introduced later to cover up for fatal mistakes (13). One of the patients noted that the psychiatrists do not listen and write something else in the file than what actually happened.

Antipsychotics are nothing but major tranquillizers, which was their original name, and if the staff have not been able to calm down a patient in an acute situation, benzodiazepines seem to be more effective than antipsychotics (14). It is a clear violation of Danish law that the patients were never offered benzodiazepines because forced medication should be with drugs with the fewest possible adverse effects (12). When we have asked, during our many public lectures about psychiatric drugs, all patients have said they would rather have a benzodiazepine than an antipsychotic next time they developed a psychosis. Hence, both the law and the patients are being ignored.

The abuse of diagnoses

We had reservations about the psychiatrists’ diagnoses of delusions in nine cases. There is an element of Catch-22 when a psychiatrist decides on a diagnosis and the patient disagrees. According to the psychiatrist, the disagreement shows the patient lacks disease "insight," which is a proof of mental illness.

The abuse involves psychiatrists using diagnoses or derogatory terms for things they do not like or do not understand. When patients did not like psychiatrists, the drugs, or being confined to a psychiatric ward, their defence reactions were often used against them. One of us once joined the chief psychiatrist on his round, and after having talked to a patient that appeared to be completely normal, the psychiatrist said that he was delusional because he had gone to the internet and claimed that antipsychotics were dangerous. A chief nurse said the same, also about a patient who had carefully studied the harms of antipsychotics.

The patients or their disease were blamed for virtually everything untoward that happened. We did not see a single admission that it was the psychiatrist or other staff that had escalated a situation by their insistence that the patients be treated with drugs they did not tolerate or did not want, or by other forced measures. When a patient was put in belts for five weeks and was angry after this, it was not ascribed to the fixation but to his mania. The psychiatrists did not seem to have any interest in traumas, whether they were previous one or caused by themselves.

Non-compliance with the psychiatrists’ ideas can lead to punishment in other ways. A patient had been discharged from a psychiatric centre in the community because she had refused drug treatment. Many patients have described such experiences when they do not want pills, also when they see psychiatrists in private practice: “Well, then I cannot help you!” (6).

When the patients stopped their antipsychotics after discharge because they didn’t want them, the curious term “medicine failure” was used (in ten patients). Before having consulted a psychiatrist, we thought it meant that the drug did not work, but this term is used when the patients do not take their drug.

A similarly misleading term is, “treatment resistant,” which psychiatrists use when a drug does not work. Again, it puts the blame on the patient who is perceived to have a particularly nasty form of the disease, although the drugs are to blame because they do not really work for anyone.

Withdrawal reactions were not taken seriously, and we did not see this term being used even though many patients suffered from them. The psychiatrists focused on the patients’ current condition and apparently did not consider that the re-emergence of psychosis could be a harm of the antipsychotic rather than a psychosis that would have occurred anyway at this point in time.

Several patients had previously stopped taking the drug every time after discharge, and for one of them, the Complaints Board emphasized that this had rendered her seriously psychotic but did not consider that it could be an abstinence psychosis, i.e. a harm of the drug. At the board meeting, the patient’s counsel informed the board that the patient could not tolerate drugs, but to no avail. As always, the expert resolved that she was treated to preserve her health.

Another patient received aripiprazole on “vital indication” because of catatonia, and the drug had “a pronounced effect … already after the first injection.” The patient was considered to have no disease insight because he did not believe he suffered from catatonic schizophrenia, but that the symptoms were side effects of the drug. Since he responded so promptly to the drug, the patient was probably right and suffered from withdrawal symptoms. He was informed that his life would be endangered if he did not get the medication but when he appealed to the Complaints Board, they nonetheless stopped the drug while the complaint was being considered.

Is psychiatry in a state of madness?

An anonymous person once said that, “Insanity is doing the same thing over and over again and expecting different results” (15). One of us tweeted about this in 2019: “Psychiatrists increase the dose, change to other drugs or use more than one drug of the same type. When drugs don’t work, they should be stopped. And psychiatrists should be stopped.” Four of the responses were: “My loved one is experiencing akathisia and his consultant thinks that treating akathisia with yet a different antipsychotic is the right way to go?;” “Feels like we don’t have a choice and hardly any support to taper,” “A medication I went on caused psychosis. To treat the psychosis, the dose kept getting increased. I became a monster, and I lost everything;” “Another definition of madness is administering poison and expecting your victim ‘to heal.’"

Psychiatrists often say that patients lack insight into the disease, but what about their own lack of insight? Doing the same thing over and over again and expecting different results is what they do all the time, and it includes ignoring what they do not want to see. One of the patients in our sample said that the psychiatrist forced her to take olanzapine to treat the psychosis, even though she maintained that the drugs she had received through 31 years had destroyed her life.

It took psychiatry 20 years to recognize tardive dyskinesia as a iatrogenic illness (9), even though it is one of the worst harms of antipsychotics and affects about 4-5% of the patients per year (16), which means that most patients in long-term treatment will develop it. In 1984, Poul Leber from the FDA extrapolated the data and indicated that, over a lifetime, all patients might develop tardive dyskinesia (9). Three years later, the President of the American Psychiatric Association said at an Oprah Winfrey show that tardive dyskinesia was not a serious or frequent problem (17). A particularly virulent form is tardive akathisia where the patient is driven by a torture-like inner agitation that compels them into moving their hands and feet nervously or pace frantically about in an effort to relieve the distress (18). Tardive psychosis, also called supersensitivity psychosis, is another common iatrogenic harm that is largely ignored (5).

Limitations

The information we had access to was biased in the patients’ disfavour and scant as well. We suspect that there were many more substantial problems than those we uncovered. We did data extraction under difficult circumstances and therefore not in duplicate, by two independent observers. We tried to compensate for this by extracting verbatim quotes from the material we reviewed and by consulting each other when the text was ambiguous.

**Conclusions**

The power imbalance was extreme, the patients felt misunderstood and ignored, their legal protection was a sham, and the harm done was immense. Forced medication must be abandoned.

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