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The right to choose treatment-without-treatment: respecting civil rights or an unprecedented manifestation of 'reverse stigma'?

Perspective

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Abstract

Recently the Norwegian Health Minister ordered the creation of medication-free treatment wards as a result of the lobbying by patients' groups and activists. The idea behind this is that patients should have the right to choose their treatment, but for the first time, with this arrangement, the user/patient does not choose between treatment options; he literally determines by himself what efficacious treatment is. In our opinion this is another step towards a 'reverse stigma' which denies patients the right to be considered as such and eventually kicks them out of the health care system, deprives them of the right for proper treatment and care and instead puts them at the jurisdiction of the much cheaper and ineffective social services.

Summations

- Treatment of severe mental disorders especially psychosis without medication is of unproven efficacy since they are not adequately researched under double blind and placebo-controlled conditions.
- While the right of the patient to choose between treatments is accepted as the standard, on the contrary the right of the patient to determine what constitutes treatment heralds the acceptance of post-psychiatry as mainstream practice.
- Wards without medication as a principle, could mark the emergence of a 'reverse stigma' that is patients are not considered as such and conveniently are deprived of the right for proper treatment.
- Should such medication-free treatment options of unproven efficacy be available for other groups of patients (e.g. cancer)?

Considerations

- There is considerably low acceptance of medication treatment for mental disorders both among patients and lay persons but also among mental health professionals.
- There is a growing demand by patients and the general public to take part in the diagnostic treatment decision-making. Involving the patient in decision-making includes fully respecting his/her choice.
- While such demands should be respected, the question to which extend responsibility could be shared is of outmost importance. The ethical dilemma for the psychiatrist starts when patients might demand unconventional or unproven treatment options.

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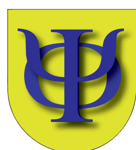

Since 2011, the Norwegian Health Minister was 'advising' the regional health authorities to create medication-free wards, but without any such wards being created. In 25 November 2015, he went one step further and issued a directive, ordering its four regional health authorities to create these wards. The idea behind this directive was that patients should have the right to choose their treatment, and that care should be organised around that choice. The whole issue was accompanied by statements like that of Magnus Hald, chief of psychiatric services at the University Hospital of North Norway: 'We have to consider the patient's perspective as equally valuable as the doctor's perspective', but the picture was perfectly captured by one phrase in an

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interview by Anne Grethe Terjesen, chair of LPP, a national association for families and carers in mental health: 'If treatment had been very good, it would have been more difficult (to persuade the minister to push towards the creation of this kind of wards)' (1). In our opinion this clearly means that no matter how efficacious a treatment is, this was never the point; instead the point was to abolish medication treatment for mental disorders.

Around the world and also in Norway there is a strong trend to have 'user councils' and to pay attention to the 'voice of the users'. Recently the legislation has further pushed towards respecting the choice of the patient (2). Although this is a legitimate idea, in the case of medication-free wards, in our opinion, its materialisation is misleading and potentially dangerous not only for the health of individual patients but for public health in general. This is because it is no longer a matter of choice of treatment option; this is a legitimate demand from the side of the patient. However, with initiatives like the one under discussion, the user/patient determines what constitutes treatment options from a variety of options with unproven efficacy but with significant sociocultural load and support. The key point is what the word 'treatment' stands for, and what the debate really concerns. A more recent evolution in the anti-psychiatry movement concerns a revisiting of the separation between biological psychiatry and the psychological component of Psychiatry. Peter Roger Breggin (1936) in his book 'Toxic Psychiatry' (1993) argues against neurobiology and in favour of psychosocial interventions in a humane context (3).

The Health Minister's resolution was the result of lobbying by the Fellesaksjonen for Medisinfrie Behandlingsforlop (Joint Action for Drug-Free Treatment in psychiatry). This group was unhappy with in compulsory treatment in Norway, including outpatient commitment orders (4,5) whose efficacy was questioned (6). The number of compulsory admissions was stable between 2000 and 2010 (7) but varied widely within the country (8) and this raised a number of questions.

Instead of focussing against compulsory treatment which would had been difficult to do, these groups, instead chose to push towards 'civil rights' and the 'right to choose treatment'. This is not radical in principle, since every patient has the right to accept treatment or not (except for compulsory cases); the difference here is that the user/patient has an opinion of an equal value with his psychiatrist concerning what constitutes treatment and what is best for his health. In other words, the user/patient does not choose between treatment options; he determines the options themselves. This is a radical and qualitative change, it poses the question whether individual psychiatrists are involved in systematic malpractice and another issue is whether we are going to see a radical change also in the way the insurance compensates or covers the costs.

According to its President at that time, Anne Kristine Bergem, 'The Norwegian Psychiatric Association has decided not to express one opinion on the subject, and is of now trying to keep an open mind' (9). This resolution stands until today although critique from Norwegian concerning this kind of treatment settings psychiatrists appeared (10). The same time, a non-profit organisation, Stiftelsen Humania (http://www.stiftelsenhumania.no/), organised a public debate on the usefulness of psychotropic drugs as if this should be the question for a lay persons' referendum.

It is known that currently there is much debate on the usefulness of antipsychotics (11–16). But, although extreme voices do exist, until now this concerned the limitations and the problems of their use rather than their core usefulness. During the last couple of decades there seems to be a fierce debate on the usefulness of psychotropic medications, mainly antidepressants but recently this included also antipsychotics. The much older debate on antidepressants teaches that the dispute is continuous, ever-emerging, ideologically driven (17) and does not respect the analyses and the data of those people who argue against medication treatment themselves (18). This conflict has also spread in the social media (19) and it seems to be a revival of the bitter conflict between biological psychiatrists and psychoanalysts of the 1940s and 1950s on electro convulsive treatment. It is extremely interesting that the media and opinion leaders arrived at sharply contrasting conclusions when interpreting identical and always positive results after meta-analyses of antidepressant trials (17,20–25).

The issue can be framed with only a few words and it should be made clear: antipsychotics and antidepressants clearly work according to double blind placebo controlled data. Their efficacy is far from perfect and much better treatment options are needed. However, this is not the case concerning all 'alternative' treatments since no other therapeutic option, including all psychotherapeutic methods, has been tested under similarly stringent conditions and versus an appropriate placebo. In this frame, it is peculiar that while nobody would ever dare to ask for a 'psychotherapy-free' treatment environment, many argue for 'medication-free' treatment wards.

All the above together set an environment within which Psychiatry is called to abandon its scientific and medical orientation and adopt an approach based on a holist individualised assessment of the person and the interpretation and understanding of his condition (26). No matter how appealing this is, it is in sharp contrast with the accumulated evidence during the last decades of scientific research.

In our opinion all the above are probably another step towards a new kind of stigma. It is not the first time, since during the last few decades, mental health issues are often relabelled as 'psychosocial issues'. This could constitute a 'reverse stigma' which denies patients the right to be considered as such; it eventually kicks them out of the health care system, and deprives them of the right for proper treatment and care and instead puts them at the jurisdiction of the much cheaper and 'politically correct' but ineffective social services. This was recently also the case with rising deaths by suicide in Europe, which were widely considered to be the direct consequence of increasing unemployment acting as a generic risk factor on the entire population rather than failure of the mental health care system and social security to protect specific patient groups (27).

While anti-psychiatry was the driving concept a few decades ago, today its main arguments have collapsed, and now most movements criticising psychiatry talk about a 'post-psychiatric' approach (28). Essentially they suggest being open-minded to a variety of perspectives but in real this 'open-mindness' means rejecting the scientific method which poses rules and methods and tries to clarify which perspective is valid and which is not. In addition these movements push of a central position of service users in the decision process and the recognition of ideological implications of psychiatric practice (29). This is a wider phenomenon in medicine today, that particularly in chronic illness, the patient himself is the 'expert' in his own symptoms and illness experience. Of course this is in direct conflict with the 'evidence-based approach' which is also pushed forward today (30).

These movements reflect the fact that a lot of patients have an unsatisfactory experience from mental health care and often from their contact with mental health professionals both in terms of time allocated but often also in terms of attitude and behaviour.

It is unknown where this trend will eventually lead. The memories of Villa 21 (31) are still recent and the short-to-

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medium-term results of such 'experiments' can be easily foreseen. But the real question is quite different: Are we going towards a world where the way to deal with mental disorder is at the absolute discretion of the individual patient while the psychiatrist acts as only one out of many advisors with radically different backgrounds? Are we designing a future for mental health where science has the same stature with folk remedies, lay and cultural beliefs as well as politico-ideological approaches?

In our opinion this will be a stigmatising environment, a modern revival of the medieval world, where mental patients will suffer far more and left alone without any investment from the part of the society in their global health and in their lives. A new 'reverse stigma' worse than the 'traditional' one will emerge.

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