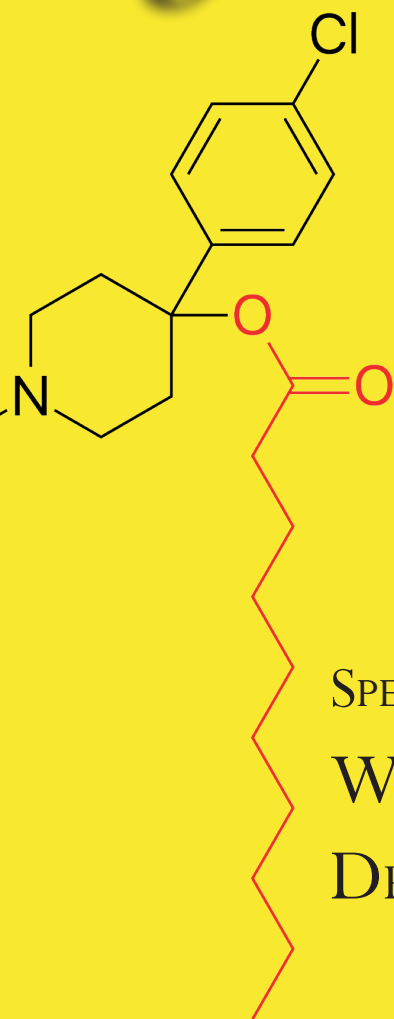


JCPCP

The Journal of Critical Psychology,
Counselling and Psychotherapy

Volume 20, Number 4, Winter 2020



SPECIAL EDITION:

WITHDRAWAL FROM PRESCRIBED
DRUGS

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Special Edition: Withdrawal from Prescribed Drugs

Edited by Peter Lehmann

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The Journal of Critical Psychology, Counselling and Psychotherapy

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Dr. Caligari reflects back and looks forward

David L. Richman M.D.

David L. Richman M.D. is a Board-Certified Psychiatrist (American Board of Psychiatry & Neurology), who went to The New York University School of Medicine, graduating in 1970. After working in a community clinic (La Clinica De La Raza) he worked for Kaiser-Permanente (a non-profit Health Maintenance Organization) in Northern California as a psychiatrist/psychopharmacologist from 1992-2008. He is a co-founder of Madness Network News.

ABSTRACT: This article explores the fallacy of psychiatric diagnosis, the dangers of psychopharmacology, withdrawal and a sense of missed opportunity in relation to alternatives to mainstream psychotropic medication.

KEY WORDS: Philadelphia Association, LSD, Withdrawal, Deprescribing

Before writing the preface for a forth-coming book about the withdrawal of psychiatric drugs edited by Peter Lehmann and Craig Newnes, I started by reading Peter's book *Coming Off Psychiatric Drugs* first published in 1998 with a 4th English E-edition in 2020. I had not known of Peter Lehmann and I was also not aware of his work on psychiatric drug withdrawal. His book was filled with powerful first-person accounts of heart-rending personal trials and tribulations within the world of psychiatric drugs with a focus on the oft-ignored issue of drug withdrawal and with reports of professionals, working in psychotherapy, medicine, social work and natural healing how they help in the withdrawal process. It led me to resources I was also unaware of such as the International Institute for Psychiatric Drug Withdrawal (IIPDW), and the many people internationally grappling this issue. Peter Lehmann's summary chapter was a serious and well researched attempt to provide an overview of the various categories of psychiatric drugs, withdrawal practices and resources. Then I reviewed the proposed table of contents for his new work and its expanded individual chapters on the various categories of psychiatric drugs, the look at professional and self-help strategies, and various approaches to the multitude of problems that can occur in an attempt at drug withdrawal. There is still a dire need for education and the provision of both avenues of support and specific tools and approaches to this complex issue. I applaud Peter and Craig for their efforts.

After reviewing Peter's work, I did an Internet search related to psychiatric drug withdrawal to see what is currently found in the English language. Not surprisingly most of the references were outside of the more traditional sources in the medical-psychiatric-scientific literature. Here is a summary:

- Peter Breggin M.D. — *Your Drug May be Your Problem, How and Why To Stop Taking Your Psychiatric Medications*, 2007 with David Cohen Ph.D.; *Psychiatric Drug Withdrawal: A Guide for Prescribers, Therapists, Patients and Their Families* - 2013. An excellent book by a medical iconoclast.
- Robert Whitaker - journalist. *Mad in America, Anatomy of An Epidemic, The Case for Psychiatric Drug Withdrawal* - Oct. 2016. And in a review of his work this quote stood out: "Whitaker is not anti-psychiatrist. He is anti-bullshit."
- Laura Delano - Her horrific story of entanglement in the world of psychiatric drugs was told in a New Yorker article titled "The Challenge of Going Off Psychiatric Drugs", April 20, 1999. Laura started the "Withdrawal Project", Inner Compass Initiative. Working to help others avoid a story like hers.
- Will Hall - another survivor who felt compelled to write: *Harm Reduction Guide To Coming Off Psychiatric Drugs*, 2012. "Psychiatric Medication Withdrawal: Survivor Perspectives and Clinical Practice." *Journal of Humanistic Psychology*.
- Dr. Yolanda Lucire (Forensic Psychiatrist). "Withdrawal Resources For Coming Off Psychiatric Drugs" - a website with many good resources.
- *Medicating Normal* - This is the title of a recently completed documentary about one family's struggle that has a website with many excellent resources about psychiatric drug withdrawal and related issues of how "science" and so-called chemical imbalances are used by Big Pharma.
- In *Psychiatric Times*, a throw-away newsletter, April, 2018 the article: "Online Communities For Drug Withdrawal: What We Can Learn" we have an exception to the standard psychiatric point of view which tends to ignore such self-help approaches or just sees them as an interference with the current standard practices.

Who is Dr. Caligari?

I am a Board-Certified Psychiatrist (American Board of Psychiatry & Neurology), who went to The New York University School of Medicine, graduating in 1970. I then did an internship and Psychiatric residency in Northern California where I had moved. After working in a community clinic (La Clinica De La Raza) for many years, I started working for Kaiser-Permanente (among the largest non-profit Health Maintenance Organizations in the USA) in Northern California as a psychiatrist/psychopharmacologist from 1992-2008. From the mid-1970s and onward, to be a psychiatrist meant you managed the prescribing of psychiatrist drugs, and the therapy was left to lower paid mental health professionals. This trend has only sped up to the present day, so a psychiatrist practicing

only psychotherapy is a rare bird indeed in the USA. Thus, there are many pressures subtle and not so subtle to prescribe, not to *not* prescribe.

The overall context in which the prescribing of psychiatric drugs occurs could not be more complicated if one considers factors from one's genome to personal and familial history and the overall life situation and stressors in which personal problems evolve and lead to a consideration of drug therapy to manage such complex problems. And it is still worth pointing out that unlike every other branch of medicine where there is a scientific basis for diagnosis and treatment, e.g. Covid-19 caused by the SARS-Cov2 coronavirus which can be clearly identified by culturing the virus or with tests like PCR (polymerase chain reaction); all psychiatric diagnoses are descriptive and a "diagnosis by exclusion"; meaning you exclude a scientifically based diagnosis like a brain tumor. There is no test to confirm a psychiatric diagnosis. Even with the advances of brain sciences, there may never be simple diagnoses for problems that involve mind, body and spirit in the 21st century world.

Since my retirement I have kept my medical license active on a volunteer basis only and besides being my neighborhood emergency coordinator (earthquakes, wildfires and now Covid19), I have not practiced psychiatry since 2008. It was in 1970 while doing an internship at San Francisco General and also volunteering at a "free clinic" that my wife Sherry Hirsch and I first connected with Wade Hudson, Leonard Frank and others and started Madness Network News (MNN) "All the fits that's news to print". The name is a reference to Ronald D. Laing's and David Cooper's Philadelphia Association of London and their "Network Newsletter" which I experienced in London in 1969 as they were trying to create alternatives to the psychiatric establishment with therapeutic places like Kingsley Hall - see the book *Two Accounts of a Journey Through Madness* by Mary Barnes and Joseph Berke. We published "The Madness Network News Reader" in 1974. We then also founded NAPA (The Network Against Psychiatric Assault). NAPA was based on our mutual experiences and concerns about psychiatry and its real potential for abuse, from the point of view of patients, professionals, and family members. The name was a play on the Napa, California state psychiatric hospital of the same name.

I started to write articles for MNN in 1971 about psychiatric drugs and drugging under the pen name 'Dr. Caligari' from the classic German silent film. In the film, Dr. Caligari is either a mad scientist with his somnambulist Cesare (comparable to a drugged patient) carrying out violent acts at Caligari's behest or the benevolent 'Alienist' (prior term for psychiatrist) director of a psychiatric hospital. One aspect of the articles I wrote had to do with withdrawal from psychiatric drugs. In 1984, MNN published my "Psychiatric Drugs" booklet and I wrote an unpublished manuscript "Tranquilizing Madness". During my career as a practicing psychiatrist/psychopharmacologist, I faced the Sisyphean task of trying to care for and help people while Doing No Harm. I worked hard to educate people, to look head on at the difficult decisions in using or not using psychiatric drugs in order

to help manage the complex personal, familial, cultural, life and human problems at hand, and to be as compassionate, caring and understanding as I could be. It's also important to not just stereotype all psychiatrists and mental health professionals as Dr. Caligari or Nurse Ratched (the tyrannical nurse in *One Flew Over The Cuckoo's Nest*). Most are serious professionals trying to help people however misguided their ultimate effects might be.

There is so much that could be said about starting, not starting, stopping psychiatric drugs. Withdrawal can occur or be needed for many reasons including: a serious adverse reaction, significant and disturbing side effects, lack of effect, avoiding long term damaging effects, trying to figure out if a drug is really needed or if an acute problem has passed, and the list goes on. The use of psychiatric drugs entails the withdrawal reactions of various types as well as the side effects, adverse reactions, potentially life-threatening problems like anti-psychotic induced neuroleptic malignant syndrome (NMS), and long-term risks of anti-psychotics like tardive dyskinesia. One rule of thumb was that the faster a drug is absorbed and then metabolized and excreted, the more likely a withdrawal reaction (the drug half-life). Examples include minor-tranquilizer/sedative-hypnotic/benzodiazepine drugs like Xanax (alprazolam¹), or the anti-depressant Effexor (venlafaxine²). However, there are very significant individual differences, genetically determined and involving the liver's enzyme systems for drug metabolism. When I was practicing there was no way to test for those who might be slow or rapid metabolizers. Lithium is the exception as an inorganic element which is not metabolized and it is the kidney that regulates the excretion and removal from one's system. There are now genetic tests available (not cheap) that can determine these individual genetic differences. I don't know how widely used they are, but they can help to determine a person's unique profile and affect potential starting doses. In an ideal medical world, anyone potentially going on a psychiatric drug would be tested before medications are started.

However, unlike an antibiotic affecting a relatively simple organism, and where everyone will get the same standardized dose; when it comes to human brains there is an enormous variability in one's response to any psychoactive drug! And this is above and beyond simple liver metabolism and blood levels of the drug. So, whether it is alcohol, narcotics, cannabinoids, psychedelics, psychiatric drugs, etc., there is no simple way to predict a person's sensitivity and the drugs ultimate effects. Only by an actual trial of the drug, using a test dose in your own biological system can you begin to figure this out.

1 Note by the editors: Marketed as Adco-Alzam, Alprax, Alprazolam, Alprocontin, Alzolam, Anxital (0.50mg), Apo-Alpraz, Atrest, Azor, B-Rest, Copax, Gerax, Kalma, Manorest, Pacyl, Panix, Saturnil, Xanax, Xanor, Zacetin, Zolam, Zopax, Zoralam.

2 Note by the editors: Marketed as Alventa, Apclaven, Dalium, Depefex, Deprevix, Efegen, Efevelon, Efexor, Effexor, Elify, Enlafax, Gen-Faxine, Illovex, Ireven, Majoven, Myprax, Neurofax, Odivem, Politid, Sentosa, Sunveniz, Tonpular, Vedixal, Venaxx, Vencarm, Venex, Veniz, Venlablue, Venladex, Venlafaxina, Venlafaxine, Venlafex, Venlalic, Venlasov, Venlex, Venlift, Venlofex, Venlor, Vensir, Venzip, Vexarin, ViePax.

There are also the effects of age, gender, ethnicity. The adage for the elderly had always been “start low and go slow” as far as drug dosing, but I think it is applicable still today for all who might use psychiatric (or any psychoactive) drugs even if one gets genetic testing of drug metabolism. Ask anyone who has ended up with problems or an emergency room visit after using edible marijuana products to begin to appreciate individual response patterns and the potential for unanticipated outcomes. Know the drug, know your own responsiveness as much as you can and yes, start low and go slow.

Reading Peter Lehmann’s book *Coming Off Psychiatric Drugs* will give you many first-hand accounts for the many problems that I also saw that can occur with psychiatric drugs. The withdrawal reactions were potentially horrendous (a non-medical term, however still apt), and often led to a cessation of any attempt to continue the withdrawal. It soon became obvious that for such drugs extremely slow and totally individualized drug tapers were needed with a great deal of structure, patience and individualized titration of progressively smaller and smaller doses with a systematic trial and error process a necessary component after an initial withdrawal schedule is made. And given the common practice of polypharmacy (using multiple psychiatric drugs, there is also no simple formula for which drug to begin withdrawal from when multiple meds are being consumed. In my MNN Dr. Caligari writings and the 1984 drug booklet (“Dr. Caligari’s Psychiatric Drugs”), I outlined a 10% generic formula for drug withdrawal schedules. Of course, 10%-steps are not to be understood as a rule of speed, but only as a proposal. In essence, when considering withdrawal, with whatever dose a person was on, start by reducing the dose by 10% and then after some period of time, say 1-2 weeks or longer, evaluate any problems. Separating drug withdrawal from any return of prior problems or a brain supersensitivity and related symptoms created by the use of the drug and exposed during drug withdrawal is not necessarily easy, to say the least. Going as slow as a person needed (weeks, months or even years), returning to the last dose when feeling stable if problems emerge before re-starting gradual dose reduction, etc. were all strategies. At times it required the mechanical process of going to the lowest dose of the drug manufactured and then cutting pills into quarters, and other such unorthodox ways to individualize progressively smaller doses. Dealing with tablets with hard coatings, capsules, etc. and limited dose ranges manufactured were among the problems. I was glad to read in Peter Lehmann’s book and other sources of ways now being used or suggested to manage this better such as tapering strips or working with pharmacists to hand tailor small drug doses and decrements. Another option was converting such a short acting drug like Xanax with a short half-life to a drug with similar properties or nearly identical properties but with a much longer half-life that would by its chemistry leave the body and brain much slower such as Klonopin (clonazepam³). That is

3 Note by the editors: Marketed as Aklonil, Clonam, Clonax, Clonazepam, Clonotril, Easyfeel, Klonopin, Lonazepam, Naza, Paxam, Rivotril, ZEE.

not to say this obviated all problems, which it didn't, as prolonged or just "long" enough use (which can vary enormously from one person to the next) and physiologic dependence are never simply solved for all kinds of reasons.

This is just one, albeit a very important, aspect of drug withdrawal, but all drugs in many different ways regardless of their half-life have by their nature an impact on the neurotransmitter systems of the brain (serotonin, dopamine, norepinephrine, etc.) and use over time can create problems when discontinued and by how they are discontinued. And all of this is occurring in the complex context of human beings and the human condition. Given all of this, the need for education, support on many levels, cooperative problem solving, etc. becomes a needed part of the entirety of helping someone to enter the process of withdrawal. I am glad that people like Peter Lehmann, organizations like IIPDW and others have been attempting to rectify what had been an enormous vacuum.

Today, even though I have not actively practiced medicine since 2008, I do follow the medical-psychiatric literature from a distance and in fact not much has changed in the world of psychiatric medications. More "me too" drugs (drugs that are derivatives of the same basic chemical formula and with similar or identical drug effects and properties) in most all categories of psychiatric drugs; aside from the use of ketamine⁴ for treatment-resistant depression - to say nothing of tools like transcranial magnetic stimulation (TMS), not to be confused with ECT (electroconvulsive therapy / electroshock) which should be relegated to the dust bin. We can do better!

During my entire career from 1975-2008, the greatest source of frustration for me was the total inability for me, or anyone, to legitimately continue the early legacy of the use of psychedelics (LSD, psilocybin, mescaline, ayahuasca, etc.) and related drugs like MDMA (ecstasy), and to pursue the legitimate medical and personal use of cannabinoids like THC (tetrahydrocannabinol) and CBD (cannabidiol). These were the pharmacological avenues I felt most helpful for me personally, and I and many others thought had enormous potential for beneficial use. The fact that marijuana and cannabis products are still a Schedule 1 drug in the USA ('no medical value and high potential for abuse') along with heroin, LSD, ecstasy, psilocybin, etc.), and despite all the states that have legalized it and overwhelming support for the decriminalization, only indicates how absolutely outdated our U.S. federal policies are. Only now through the work of groups like MAPS (Multi-Disciplinary Association for Psychedelic Studies) with private! money have clinical trials and a push for FDA (U.S. Food and Drug Administration) approval of psilocybin, MDMA, etc. occurred in the USA. LSD is still too hot to handle, unfortunately.

What has that got to do with psychiatric drugs withdrawal? Well given the reality that a one-time planned, supervised/guided and managed experience and follow up with psilocybin, for example for Treatment Resistant Depression or end of life emotional distress

4 Note by the editors: Marketed as Anket, KET, Ketalar, Ketamin, Ketamine, Ketavit, Kety, Rekita.

(whatever you might label it as) might be all a person needed, along with emotional support (as a simple term for many complex sources of support), to move through one's emotional impasse/struggles and find a way to 'Change Their Mind' (homage to Michael Pollan's book *How to Change Your Mind*). So perhaps finding alternatives may eliminate prolonged drug use, dependence and, voila, withdrawal concerns. Given our current reality, I'd say we ALL are looking for support and help these days. And minds, brains, spirits, souls, hearts are all interconnected. In other words, how do you help people in the grips of difficult life situations (or however you want to identify this kind of human suffering) without a potentially unhealthy, but very seductive dependence on a medication route? So, finding alternatives of various separate and overlapping approaches (and not just pharmacological) become potential paths of relief as opposed to an unhealthy dependence on the psychiatric drugs approach. Problems identified as Psychiatric are an interconnected web of all the complexity of life, from our genes to our neurophysiology to our persona, our life story, our society, culture, and the world we all live in.

During my years practicing as a psychopharmacologist I constantly faced the conundrums and difficult decisions inevitably present around the use of psychiatric drugs and did my best to care for people. But there is no cookie cutter approach in this arena. You can't just say No to any and all use of psychiatric drugs as the way to avoid concerns like dependence and withdrawal. Not everyone has necessarily been damaged by psychiatric drugs and like any tool it can be used constructively or destructively, but looking at the balancing scale of constructive vs destructive for any person is not just a simple objective evaluation (much more could be said about this). What is the legitimate use of lithium, atypical anti-psychotics, anti-depressants, psychostimulants, sedative-hypnotics? What about cannabinoids, psychedelics, substituted amphetamines like MDMA, ayahuasca, mescaline? There is no simple answer, but one can go just so far towards optimizing health and wellbeing and managing life's problems with any exogenous substance.

Covid-19 has led to this being a familiar refrain but applicable in so many ways:

Stay Safe!

The patient voice: Antidepressant withdrawal, medically unexplained symptoms and functional neurological disorders

Marion Brown and Stevie Lewis

Marion Brown is a retired psychotherapist and researcher/campaigner/petitioner on behalf of patient self-help peer group recovery and renewal: Scottish petition: Prescribed drug dependence and withdrawal. @recover2renew mmarionbrown@gmail.com

Stevie Lewis is an expert patient and researcher/campaigner for recognition – and for support services. Petitioner Welsh Petition: Prescribed drug dependence and withdrawal stevie.lewis2017@btinternet.com

ABSTRACT: Prescribers' lack of recognition of antidepressant withdrawal has led patients experiencing withdrawal symptoms to be diagnosed as having Medically Unexplained Symptoms (MUS) or Functional Neurological Disorders (FND).

KEY WORDS: SSRI, Drug Dependence, Misdiagnosis, Lived Experience

We joined forces as petitioners to our respective Governments' Public Parliamentary petitions, where we registered ongoing concerns about lack of recognition and support for those struggling with prescribed drug dependence and withdrawal. The full record of the Scottish Public Petition PE01651 (The Scottish Parliament, 2017a) from 2017 and the Welsh Public Petition P-05-784 (Welsh Parliament, 2017) from 2017. A huge body of patient experience evidence and evidence from other sources has been published for these two UK petitions.

What became clear as knowledge progressed was the potential for misdiagnosis. Marion Brown witnessed this first-hand with her therapy clients and Stevie Lewis experienced it in her personal dealings with the UK National Health Service. Prescribers' lack of recognition of withdrawal has led patients experiencing withdrawal symptoms to be

diagnosed as having Medically Unexplained Symptoms (MUS) or Functional Neurological Disorders (FND).

Today we know from the 2019 Public Health England review of the evidence of 'Dependence and withdrawal associated with some prescribed medicines' (Taylor et al., 2019) that a high proportion (around 1 in 4) of us are taking antidepressants and other drugs, for example, neuroleptics, associated with dependence and withdrawal 'as prescribed'. Neuroleptics and mood stabilizers, which also can lead to physical dependence and withdrawal symptoms (Cosci & Chouinard, 2020), have not been considered in this review. But it is accepted at least that antidepressants, especially SSRIs and SNRIs, affect the central nervous system, are dependence-forming and cause effects, adverse reactions and withdrawal. It is vital that we gain an understanding and appreciation of the relationship between these drugs and apparently unrelated, 'unexplained' and often misdiagnosed 'symptoms', yet we see little evidence of this being acknowledged, and certainly not explored.

Back in June 2017, in her opening statement as Petitioner for the Scottish Petition, Marion Brown encapsulated the experience of so many of her clients:

"I am here today to represent many people in Scotland who are not well enough to be here in person. Some courageous individuals have provided clear evidence to the committee on the terrible suffering that is being endured as a consequence of taking antidepressants and/or benzodiazepines, as prescribed by their trusted doctors..."

Clinical trials of medicines are usually carried out over relatively short periods. Patients may be prescribed these medicines over very long periods, perhaps in combination with other medicines. We have found that individual reported patient experience is frequently ignored, put down and disbelieved by clinicians. The clear medical guidance is that benzos should be prescribed for a very short time only, but that is not happening. There is substantial evidence for prescribed benzo dependence and withdrawal issues going back decades. In contrast, medical guidance for antidepressants is that they should be taken for at least six months, and then they are commonly prescribed indefinitely.

There are now many people who have been on antidepressants and/or benzos for twenty years or a lot longer. Long-term harm is now clearly apparent. Safe tapering after different periods of prescribed treatment is fraught with difficulties for patients. The very few - mostly online - support groups that exist have for years been informally gathering evidence on a trial-and-error, ad hoc, patient-report and patient self-help basis. That genuine experiential patient learning and sharing has been largely dismissed, disregarded and even denigrated by the medical profession.

Now that there is a great deal of patient communication via online social media, as well as extensive internet availability of research and medical information, patients often come to know much more about their own conditions than their doctors possibly can. When patients try

to discuss what they have learned, doctors patronise them and say that they should not believe anything that they find on Facebook or the internet. Those patients find themselves perceived by their doctors as troublesome and difficult heart-sink patients, and acquire psychiatric diagnoses such as personality disorders and medically unexplained somatic, functional or conversion disorders.”(The Scottish Parliament, 2017b)

In her written testimony to the Welsh Petitions Committee (P-05-0784), Stevie Lewis stated:

“There is a feeling and evidence from the lived experience of patients that, rather than educate NHS employees about the serious effects that occur when starting, changing, or stopping drugs which cause dependence, particularly antidepressants, NHS staff are being educated to look for and diagnose Medically Unexplained Symptoms (MUS) or Bodily Distress Syndrome (BDS). This is despite the fact that the patient in question is taking a drug that causes dependence. This fact is ignored or overlooked.”(Welsh Parliament, 2017)

Surely, we should be considering the effects of prescribed drugs - especially antidepressants (where physiological effects seem to have been largely overlooked) - that are designed to cross the blood-brain-barrier and act on the central nervous system (CNS) and to alter the functioning of the all-important autonomic fight/flight/freeze response? The amygdala, a collection of cells near the base of the brain, exerts effects on all the bodily systems (gastrointestinal, cardiovascular, endocrine, musculoskeletal, etc.) if necessary readying for fight/flight/freeze, as well as focusing attention on threats and escaping from any identified threats. In the case of antidepressant adverse reactions and withdrawal this can result, via interoception (sense of the internal state of the body) of a person's own malfunctioning bodily systems, in an overwhelming instinct to escape from one's own body - and sometimes life-threatening akathisia.

The two public petitions provided an extraordinary resource: a multitude of stories given as written evidence to the petitions committee members, who wanted a better understanding of the problems that Marion Brown and Stevie Lewis were describing. Their 2020 research paper “The ‘Patient Voice’: patients who experience antidepressant withdrawal symptoms are often dismissed, or misdiagnosed with relapse, or a new medical condition” (Guy et al., 2020), written together with Anne Guy and Mark Horowitz, draws on this patient evidence. It was commissioned by the All Party Parliamentary Group for Prescribed Drug Dependence and it tracks systemically 158 collated patient accounts of the aetiology of the development of all manner of prescribed drug-related symptoms which have been variously misdiagnosed as ‘relapse’, other illnesses, ‘unexplained symptoms’ or ‘functional’ disorders. The paper highlights eight ‘failure points’ where the system has led to exacerbation of the problems, for patients and prescribers and concludes that:

“Several points for improvement emerge: the need for updating of guidelines to help prescribers recognise antidepressant withdrawal symptoms and to improve informed consent processes; greater availability of non-pharmacological options for managing distress; greater availability of best practice for tapering medications such as antidepressants; and the vital importance of patient feedback.” (Guy et al., 2020)

Their research included 158 people and showed that:

“In this sample, 25% of patients with antidepressant withdrawal presenting to their GP were diagnosed with MUS, a ‘functional neurological disorder’ or ‘chronic fatigue syndrome.’ Many of the signs and symptoms associated with these medically unexplained disorders, captured in the often used PHQ-15 (Patient Health Questionnaire Somatic Symptom Severity Scale – M.B. & S.L.), overlap with the symptoms of antidepressant withdrawal, including insomnia, feeling tired, nausea, indigestion, racing heart, dizziness, headaches and back pain.” (ibid.)

Antidepressant research studies have for 3 decades used the DESS scale (Discontinuation Emergent Signs and Symptoms Scale, undated)—which clearly lists the physical somatic symptoms (also found in the PHQ-15 [Anonymous, undated]) in addition to other ‘affect’ symptoms (included in the PHQ-9 Depression and GAD-7 General Anxiety Disorder Patient Health Questionnaire (PHQ) Screeners (Pfizer, undated). This begs the question why these known multiple antidepressant ‘discontinuation emergent’ physical/ bodily symptoms came to be incorporated into tools to encourage prescribers to consider Medically Unexplained Syndromes (MUS) and overlook antidepressant withdrawal? The Royal College of Psychiatrists estimate:

“About 1 in 4 people who see their GP have such symptoms (...). In a neurological outpatient setting, it is 1 in 3 patients or more (...). Another common term is ‘functional’ - the symptoms are due to a problem in the way the body is functioning, even though the structure of the body is normal.” (RCPsych, 2015)

There is much debate around the classification of ‘unexplained’ physical symptoms; for example, Rosendal et al. (2017) say:

“Recent studies on BDS (Bodily Distress Syndrome - M.B. & S.L.) suggest that central sensitisation not only results in multiple symptoms; it may also prompt several specific symptom patterns described by arousal and/or exhaustion symptoms. These symptoms cluster in four groups: 1) cardiopulmonary/autonomic arousal symptoms (palpitations/heart pounding, precordial discomfort, breathlessness without exertion, hyperventilation, hot or cold sweats,

dry mouth), 2) gastrointestinal arousal symptoms (abdominal pains, frequent loose bowel movements, feeling bloated/full of gas/distended, regurgitations, diarrhoea, nausea, burning sensation in chest or epigastrium), 3) musculoskeletal tension symptoms (pains in arms or legs, muscular aches or pains, pains in the joints, feelings of paresis or localized weakness, backache, pain moving from one place to another, unpleasant numbness or tingling sensations), and 4) general symptoms (concentration difficulties, impairment of memory, excessive fatigue, headache, dizziness)." (Rosendal et al., 2017)

As Stevie Lewis stated to the Welsh Petitions Committee in her correspondence from November 27, this classification by Rosendal and colleagues "... *provides the most comprehensive list of my withdrawal symptoms that I have seen in one place.*" The striking similarities and relationship to CNS and autonomic arousal/exhaustion strongly suggest that these 'medically unexplained/functional/somatic symptoms' and 'bodily distress' etc., are connected to the wide ranging serotonergic effects of antidepressants and how the body tries to adapt (via all-important homeostasis) to any such changes.

Patients with "functional" symptoms make up a growing number of referrals to neurology. It has been known for decades that antidepressants cause neurological problems (for example, Foster & Lancaster, 1959; Haddad et al., 2001). One has to ask why does patient experience tell us that neurologists are as blind to, or as dismissive as prescribers of, the possibility that drugs that are designed to alter the functioning of the central nervous system could be the very reason that the nervous system is now presenting as malfunctioning. We were alarmed to see the British Medical Journal 'Practice Pointer' from October 2020 encouraging General Practitioners to 'recognise and understand' Functional Neurological Disorder (FND) (Stone et al., 2020), as well as the related article in the Scientific American "Decoding a disorder at the interface of mind and brain" (Kwon, 2020).

We responded via Rapid Responses to the British Medical Journal's "Recognising and understanding functional neurological disorder" (Brown, 2020a, 2020b) as did Jill Nickens (2020), co-founder of Akathisia Alliance for Education and Research. The collective concern is that prescribers are being further guided to 'misdiagnose' and overlook the vitally important emerging and developing signs of serious prescribed drug effects (including sometimes life-threatening akathisia) - and that this can lead to avoidable harm, chronic illness, disability and deaths. The following questions do not feature in the list of questions suggested by Jon Stone and his colleagues (Stone et al. (2020):

- What is the person's medication history - from the very first prescribed medications, and then over the long term?
- When did the 'unexplained'/'functional' symptoms first become apparent, especially in relation to prescribed medications (i.e. the possibility of adverse medication effects or withdrawal)?

Via the written evidence to the public petitions and through online social media platforms, many examples can be found of patients who were prescribed drugs which can cause dependence and withdrawal (particularly SSRI and SNRI antidepressants) whose lives have been devastated by neurological malfunctions, especially relating to movement. Stevie Lewis' own experience of a movement disorder, together with those of other people, is described by her in an article for Rxisk, an independent drug safety website to help weigh the benefits of any medication against its potential dangers (Lewis, 2020) and in a follow-up article by David Healy (2020).

The impact of prescribed drug withdrawal being swept under the carpet for the past 20 years has had profound consequences for both the UK National Health Service (NHS) and individual patients. For the NHS, the cost of misdiagnosis and over-prescribing must be huge - not to mention the costs of treating illnesses that arise as adverse effects of psychotropic drugs. This is the case for health care systems in other countries, too. Work is underway to establish those figures. For individuals, they have had to live with the ramifications of being told that they are more ill than they thought they were. They are told they have 'relapsed', they have Medically Unexplained Symptoms (MUS), Functional Neurological Disorders (FND), Bodily Distress Syndrome (BDS), chronic fatigue, irritable bowel, and a range of other diagnoses. When in reality a simple reinstatement of the drug and a long slow taper could result for many in the well-being they were originally seeking when they visited the doctor in the first place.

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Highlighting individuality requires tailored prescribing during recovery

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ABSTRACT: Reducing psychotropic drugs, namely antidepressants and antipsychotics, is challenging. It is an integral part of recovery if psychotropic drugs were needed during the mental crisis. Individualizing the reduction steps in terms of dose and speed makes reductions easier and more successful, yet the demands on the person remain high and crises in the reduction process or after discontinuation are possible.

KEY WORDS: Rebound Phenomena, Deprescribing, Antidepressants, Antipsychotics

Processes of reduction and cessation of psychopharmaca (deprescribing), namely antidepressants and antipsychotics, are highly individual. They cannot be done according to the book, but require individual solutions. This has three reasons:

1. Neurophysiological adaptation to the drug used varies from individual to individual, resulting in individually different reduction or withdrawal symptoms;
2. The reduction of medication also reduces its possible positive effects, which requires increased individual management of one's own mental condition;
3. People are different both in terms of their symptoms in times of crisis, possible psychosocial impairments outside the crises and in terms of their respective vulnerability to mental crises.

Accordingly, they need their own individual forms of coping. These general statements already illustrate the individuality of the challenges to be met in reduction processes. They are not already mastered because there are good reasons from long-term

studies that suggest that taking antidepressants for years increases the risk of further depressive episodes or that taking high doses of antipsychotics reduces the chances of a better recovery in the long run. Recovery, as well as group effects as shown in studies, must be achieved individually. And sometimes these group effects are invalid for an individual.

In our paper we will focus on the reduction of antidepressants and antipsychotics. From our years of experience of psychiatric monitoring of such processes we can say that the challenges during reduction are similar in many ways for antidepressants and antipsychotics. The farmer's rule applies: You have to do it slowly, and you have to do it in small steps. During the reduction process, the intensity of symptoms can be reliably controlled only by the size of the reduction step and the speed of its succession. This implies the need for individual prescriptions if the pharmaceutical industry does not offer liquids or very small doses of a particular drug, or if the person is unwilling or unable to prepare small doses of a particular drug himself (for example, using the water solution method).

Nevertheless, reduction of antidepressants and antipsychotics have important differences. This refers in particular to the last crumbs of medication. While some individuals benefit from a long-term individual minimum dose of antipsychotics, this appears to be very rarely the case with antidepressants. In an ideal world, antidepressants would generally be used only in severe crisis phases for a few months (i.e. in severe depression), whereas antipsychotics would sometimes be used also at a minimal dose for years after a severe crisis (i.e. after a severe psychosis, which subsided only with the use of antipsychotics). We report five cases that have taken very typical courses from our clinical experience and illustrate the variability of reduction courses.

Antidepressants

Antidepressants are mainly used in depressive or anxiety disorders. They can be of help in severe depressive episodes and severe phases of anxiety disorders. However, antidepressants cannot solve psychosocial challenges to recovery. Their main effect is a special kind of emotional numbness, both for negative and positive emotions. This particular type of emotional distancing is helpful during severe periods of affective mental crises, but not really helpful in regaining a satisfying way of life in the long term.

Deprescribing antidepressants is challenging on its own, since adaption/habituation of the human brain on the cellular level occurs when they are used regularly. Withdrawal symptoms are many and varied (Davies & Read 2019). Some are new and unknown for the person (i.e. flu-like symptoms, muscular pain, brain zaps, agitation). Others remind of the affective symptoms which gave reason to start the medication in the first place (i.e. anxiety, suicidal ideation, depressed mood). They begin a few days after reduction and often last for weeks, often increasing and decreasing in intensity in waves during this phase. Sometimes these symptoms show up again after a few weeks or months of better health. They should then be addressed as rebound-symptoms, even if they appear

to be “the original disease.”

However, since long-term studies have shown antidepressants to be relevant risk factors for ongoing and/or repeated depression, we are rather convinced that they are usually rebound phenomena (Hengartner et al. 2018; Ten Have et al. 2017). These withdrawal symptoms have both an individual expression and an individual time course. Typically, they run similarly at each reduction step, so that the person concerned can adjust to them at the next step. We cannot reliably say whether a gentle approach to reduction fundamentally prevents persistent withdrawal symptoms, as they occur at least in individual cases. However, our clinical experience shows that withdrawal symptoms are milder and cease, albeit perhaps only after many many months, if the reduction steps are chosen small enough.

Case 1 (easy reduction)

Mrs. H. suffers from a complex posttraumatic stress disorder with flashbacks, avoidance behaviour and enhanced excitability. For years she used an antidepressant (escitalopram¹), which she found relieving. After she had developed a way of dealing with her symptoms that was suitable for everyday life, supported by many years of psychotherapy, she decided to discontinue the antidepressant.

She undertook this without closer consultation with her treating therapist and abruptly discontinued the medication. A few days after discontinuation, flu-like symptoms began, associated with increased suicidal thoughts and muscle pain, as well as increased restlessness. She decided to pay off these symptoms. Because she associated them with discontinuation, she was able to separate them from her psychic symptoms. In addition, they remained at a tolerable level. After two weeks, the symptoms began to subside and eventually stopped altogether. She now had the impression of being more alive and sensitive again, and also had to readjust the way she dealt with her symptoms. Now, years later, in retrospect, she classifies the time with the antidepressant as a “*time under a lid*” in which her feelings and impulses were as if cut off and muffled. Even though she is not symptom-free, which is understandable given the complexity of her various traumas in childhood and adolescence, she experiences herself as more content and stable since the medication was successfully discontinued.

Case 2 (difficult reduction without persistent symptoms)

Already early in his youth, Mr. H developed depressive symptoms, which were caused

1 Note by the editors: Marketed as Ciprexal, Cironex, Citomyl, Citraz, Depsit, Dexanil, Dolin, Ecinil, Ec-Pram, Escipra, Esciprex, Escitalopram, Escitalpro, Escitotab, Escivex, Escivriens, Esetam, Esipram, Etalopro, Lepax, Lexapro, Loxalate, Marprem, Morcet, Nodep, Pramis, S-Oropram, Zitolex; component of Anxifree, Escitacalm Plus, Etlaam DS, Etinex-LS, Etipax forte, Etizola Plus, Fluwic-ES, O-Anxit Plus, Prasilife Plus, Stalowl plus.

by traumatization and exclusion experiences as well as an early life history that hardly provided any support. Over the years, Mr. H had several severe mental crises, including psychotic and, above all, suicidal crises. A depressive mood persisted throughout his life. During these years, Mr. H received many different psychotropic drugs, finally sticking to one antidepressant (sertraline²), which he experienced as somewhat helpful. He called this pill his “*kiss my ass pill*,” which made him immensely indifferent. This, he said, was pleasant in terms of his discomfort, but creepy given the lack of zest for life and the feeling of being out like a zombie. In this way, he was able to successfully hold a job in a sheltered field for years.

Many years later, after finding a new treating psychiatrist, he was offered the opportunity to accompany him in a reduction of this medication as well as with psychotherapy. Mr. H decided to take advantage of this opportunity and began to reduce the medication. In 10 mg increments, the original 100 mg dose was reduced over 2 years using custom-made capsules, with several weeks of increase in anxiety, thin-skinnedness, suicidal ideation, and also trauma-associated voice hearing after each reduction step. In addition, various physical symptoms persisted. Over the course of just over two years of reduction, life history issues reemerged, allowing personal development to resume and ultimately resulting in psychotherapy. This has still been ongoing for 1.5 years after the end of the reduction. In retrospect, Mr. H wonders why this was not offered earlier instead of sedating him with medication. He had the impression of having been immobilized for years, also in his personal development.

Antipsychotics

Antipsychotics are mainly used for psychotic disorders. They can be helpful in psychotic episodes and also to reduce vulnerability to psychosis (so-called relapse prevention). However, antipsychotics cannot solve the psychosocial challenges in recovery. Their main effect is to provide a kind of blunting or distancing from an overwhelming “too much” in the sense of being overwhelmed and uncertain of meaning in a given situation. Especially the latter is the great challenge during psychosis. Neurophysiologically, this effect is achieved by blocking dopamine-2 receptors in the mesolimbic system (Seeman et al. 2005). This effect is accompanied by a number of side effects, such as cognitive impairment, drive reduction, and depressivity, as well as physical side effects such as sexual or motor dysfunction. This particular form of “artificially grown thicker skin” is helpful for many during psychotic episodes.

2 Note by the editors: Marketed as Aurolift, Depreger, Eleva, Ertalin, Inosert, Lumaz, Lustral, Retalin, Seratine, Serdep, Serenata, Seretral, Serimel, Serlan, Serlife, Serlift, Sermax, Sertra, Sertralin, Sertraline, Sertzol, Setrof, Setrona, Stimuloton, Tatig, Xydep, Zolid, Zolof, Zosert, Zotral, Zylin; component of Alarm-Forte, Relax-S, Serxanti, Sinaday.

In combination with the psychological side effects, however, the reduced perception of one's own feelings and needs significantly restricts one's life options in the further course. Thus, antipsychotics, especially in high doses, contribute significantly to the fact that recovery processes are not as successful as they should be in view of the psychosocial help landscape (including all forms of self-help) (Wunderink et al. 2013; Harrow 2015). A major problem for antipsychotics is adaptation/habituation of the human brain at the cellular level when they are used regularly. Based on evidence from animal models and post-mortem studies, tolerance to antipsychotics can be expected to develop within months, involving an increase in dopamine-2 receptors and an increase in the relative rate of dopamine-2 receptors in a supersensitive state (Seeman 2011). Subsequently, the altered neuronal networks respond with rebound phenomena when the constant ingested dose of antipsychotics is reduced or discontinued (Chouinard et al. 2017).

Although withdrawal symptoms typically occur during reduction (e.g., concentration problems, irritability), the reduction itself is often not very problematic at first, because the person in question experiences fewer negative side effects anymore. Often, they can simply think better again and feel more active. But after a few days or weeks, the openness to stimuli and the inability to switch off can become increasingly problematic. Not infrequently, these complaints increase, leading to insomnia and even psychotic experiences. In our clinical experience, such supersensitivity psychosis is very often the result of a reduction that is too fast or too large. However, it can also be an indication that the dose has fallen below a critical lower limit. The latter, however, seems conclusive to us only in the case of already very small doses and very slow previous reduction. Unfortunately, despite extensive clinical experience, even we cannot reliably predict what step size and step sequence can be safely taken and up to what dose a person can safely reduce.

In the best case, the small psychotic crises that occur after reduction steps are such that the affected person can still be reached in contact with familiar persons in such a way that the issues at stake in this psychotic crisis can be addressed quite directly. In this way, the real-life subtext of the psychotic experience – typically involving no longer perceived (= split-off) emotions in relationships – can then serve as an anchor for the socially shared reality of the here and now, allowing the psychotic experience to subside without increasing antipsychotic medication. However, if the reduction steps are too large, the psychotic dynamics are often so great that this is not successful, sleeping pills not sufficient and – whether as a reintroduction or continuation of medication – a significantly higher dose for some time cannot be avoided. In this respect, in our psychiatric accompaniment, we advocate relatively small steps and occasional longer dose plateaus in the course of reduction. The idea is that in this way the person concerned notices the longing tensions within him if they are becoming too large and unbearable, when the medication-induced thicker skin becomes too thin (Schlimme et al. 2018).

Case 3 (intermittent use of antipsychotics)

In her 40th year of life, Mrs. H. had a first psychotic episode with a longer stay in a psychiatric hospital. She was treated with antipsychotics and diagnosed with “schizophrenia.” She suffered side effects from the antipsychotics but was discharged from the hospital with a recommendation for further antipsychotic treatment. Psychotherapy was not recommended. Because of the side effects (mainly decreased liveliness, agitation, and weight gain), she rapidly discontinued the antipsychotics within a few weeks of discharge and felt more or less normal after discontinuation. About six months later, she had a second psychotic episode – which was most likely at least partly rebound or supersensitivity psychosis – with a second admission to a psychiatric hospital. The second episode was interpreted by the treating physicians as evidence of the diagnosis as well as the need for lifelong antipsychotic treatment.

This happened two more times in the following years. After the last episode, she realized – so informed by ongoing discussion in ex-user groups – that rapid reduction of antipsychotics was dangerous, and she reduced her antipsychotic medication much more slowly over about a year last time. She remained more or less stable for at least a year before she felt her psychosis creeping back to her. She restarted antipsychotic treatment with the medication she had been on during her last outpatient treatment (quetiapine³) and quickly increased the dose to 250 mg. She also voluntarily readmitted to a clinic, and the acute psychosis resolved within a month.

After discharge, she saw a new psychiatrist, reduced the medication even more slowly over 1.5 years, with individual prescriptions below 25 mg in the latter stages. During this time, she did couples therapy with her partner and psychotherapy for herself to better understand the mental grammar of her psychotic experiences and her vulnerability to psychosis. She also reevaluated her experiences with various antipsychotics during her various inpatient stays and decided on perphenazine⁴ 8 mg as a crisis medication in case psychotic experiences recurred. Nine months later, she experienced mild sensory delusions. In our sessions, she was able to reevaluate these symptoms according to her earlier findings about her psychic grammar, which led to a decrease in her sensitive delusions. She has now been living without antipsychotic treatment for over two years. She is still willing to use antipsychotic medication in the future in case of an emergent psychosis.

Case 4 (maintenance low-dose use of antipsychotics)

3 Note by the editors: Marketed as Adequet, Alvoquel, Atrolak, Biquelle, Brancico, Conquet, Dopaquel, Geroquel, Ketipinor, Kizofrin, Mintreleq, Noletil, Notiabolfen, Pequit, Placidin, Psyquet, Psyquit, Quentiax, Quesery, Quetapel, Quetapil, Quetex, Quetiapin, Quetiapina, Quetiapine, Quetoser, Qusel, Serez, Seropia, Seroquel, Setinin, Sizonorm, Socalm, Sondate, Syquet, Tevaquel, Truvalin, Zaluron, Zimbiquet.

4 Note by the editors: Marketed as Perphenazine.

Mr. U. suffered his first psychotic episode in his early twenties including an inpatient stay in a psychiatric hospital as well as a given diagnosis of “schizophrenia.” He had five following psychotic episodes under ongoing medication which was escalated each time he had a new psychosis. Other ways of therapy were not offered, but he had a more or less good recovery. He was employed and got married in his early thirties. In his midthirties he suffered severely from side-effects of his current medication olanzapine⁵ 20 mg, namely weight-gain, diabetes and extremely reduced liveliness.

Being newly married and wishing to found a family he decided to restart his treatment schedule, opted for psychotherapy and slow reduction of his medication. Using individual prescriptions he managed to reduce his medication to a dose of 1.2 mg olanzapine in 10%-steps every six to eight weeks. During this time he subsequently deciphered the mental grammar of his psychosis and his vulnerability for psychosis. This psychotherapeutical process was heavily fueled by the reduction since his mental condition became more and more overt with lower doses. After he reduced below 5 mg he started to experience his marriage as being too close and very challenging for himself, but he wanted to continue his life closely together with his beloved wife and his newborn child at any cost. The psychological preconditions for this dilemma and thus his high vulnerability to psychosis were clearly rooted in his upbringing. However, living with his family subsequently overstepped his mental coping abilities and lead to a further psychosis.

During his inpatient stay his medication was escalated up to 20 mg olanzapine. After demission he re-evaluated the course of his medication with his psychiatrist/ psychotherapist. He concluded that this dilemma became unbearable after he reduced his medication below 2.5 mg olanzapine and that he would have to divorce from his wife if he wanted to live with less medication. Consequently, he decided to reduce his medication up to this point, to stay on this low-dose and to accept the side-effects. Again he reduced his medication using individual prescriptions from 10 mg olanzapine downwards. He is now for many years on olanzapine 2.5 mg paying a heavy price with weight-gain and diabetes. But he is still living with his wife and two children.

Case 5 (complete cessation of antipsychotics)

In her early twenties, Ms. T experienced a first psychotic episode and was hospitalized for five months. She was discharged to a home for the mentally ill on 18 mg perphenazine and a year-long rehabilitation employment program. She experienced herself as cognitively impaired and had reduced liveliness and drive. She remained hopeful of recovery, began

5 Note by the editors: Marketed as Dopin Tab, Hiolanz, Jolyon-MD, Joyzol, Jubrexa, Lanazyp, Lanopin, Olancer, Olancor, Olankline, Olanzaccord, Olanzapin, Olanzapine, Olanzavita, Olanzine, Olax, Onzapin, Ozapram, Prexolan, Rolyprexa, Tevatiapine, Tolanz, Xepat, Zalasta, Zolanz, Zozapin, Zypadhera, Zypine, Zyprexa.

psychotherapy, and in parallel reduced her medication with individual prescriptions by 2 mg about every 6 weeks. At a dose of 14 mg, she got back in touch with her inner needs and resumed social life. She was dating – which was quite overwhelming at times – and made plans to leave rehab and return to her former job as a veterinary assistant.

At the 10 mg dose, she felt cognitively fit enough to put her plan into action, moved out of the home for the mentally ill and into a shared apartment, resumed her job and a relationship with a former boyfriend. She continued to reduce her medication and was more and more able to decipher the mental grammar of her psychosis and her vulnerability to psychosis. Old conflicts resurfaced in her relationship, but she was able to regulate her urge to want to help others better and focused instead on her own needs, especially her need for autonomy. Still, she remained tense and dissatisfied inside.

It took her almost a year to come around to separating from both her boyfriend and her job as a veterinary assistant. For financial reasons, she had to move back in with her mother, a difficult relationship. During this time, she reduced her medication to a dose of 2 mg and planned to receive inpatient psychotherapeutic treatment at a specialized clinic for three months. At the clinic, she discontinued her medication with individual prescriptions in 0.5 mg increments and worked intensively on her abilities to better balance closeness and distance in relationships. After discharge from the clinic, she stayed with her mother, went on long hikes, continued her outpatient psychotherapy, and reconsidered her mental state and life aspirations. She decided to become a tattoo artist. She also began a new relationship, allowing herself much more freedom in this relationship and being much more aware of her needs. After completing her training as a tattoo artist, she now works freelance and lives in her own apartment. She has now been off antipsychotic medication for almost three years.

Conclusion

From our experience, the five case studies demonstrate very well the diversity of reduction processes for both antidepressants and antipsychotics. They show that the use of antipsychotics and antidepressants does not simply reduce symptoms. Rather, they present those affected with new challenges in dealing with their mental crisis and their vulnerability to crisis. This primarily concerns the side effects of the medication, but also personal development during the medication period. In particular, however, this is necessary in order to deal with the crisis experienced, the experiences made here and the background of crisis vulnerability. This concerns both life-historical and biological backgrounds as well as the mental habits and patterns that have grown out of them. In the process, these issues, which are usually associated with intense emotions, resurface in the course of the reduction. The psychological backgrounds of the mental crisis become (more) perceptible again and thus also more visible in relationships, in behavior and ultimately for others. It is necessary to face all these issues, to accept the mandate for personal development they

contain. In the interaction with the social environment it is important to find a co-creative way to recovery. This indicates that reduction is not a technical process, even if it may seem so at first. Rather, it is an integral part of recovery (Schlimme et al. 2018).

In our experience, the course of reduction processes cannot be predicted from the clinical situation. Even if the reduction steps are done slowly and with small doses, a guarantee of successful completion of the reduction until discontinuation is not possible. However, reduction processes are less painful and less crisis-prone if the dose steps are individually adapted. In this respect, individual prescriptions during reduction – at least during the last phases when the last crumb of the drug is taken – are often indispensable for us. Slow reduction also offers the advantage that the person in question grows along mentally and psychosocially (which, in the best case, also includes those around them).

Nevertheless, from our experience, some general statements can be made about the likelihood of successful reduction until tapering off:

1. A short duration of use is best. If the drug was only used for a maximum of 6-8 weeks, for example during a crisis, the reduction is typically successful. It should then rather be done quickly in a few weeks to months, also in order not to provoke neurophysiological adaptation processes too much during the reduction period;
2. The first reduction is the easiest. Each subsequent reduction tends to become more difficult, although we do not know exactly whether this is a kindling effect or why this is so. From our point of view, this does not mean that reuse of antidepressants or antipsychotics in later crises should be avoided as a matter of principle. It does mean, however, that the reduction should be as gentle as possible so that later reductions are not further complicated by kindling effects;
3. Discontinuation cannot be forced. Even if the goal of freedom from medication is individually comprehensible and can be well argued according to studies, freedom from medication does not seem to be achievable for some individuals without a persistent mental crisis condition, especially after a long period of use or repeated prolonged use. Whether this mental crisis condition can be assessed as tolerable in everyday life, for the person in question but also for his or her affected environment, is typically not up to us as professional companions. However, we can stay on board if the person in question wishes to do so and if basic requirements for contact can be met. And we can try not to make the situation any more difficult than it already is.

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Minimum dosage and monitoring of neuroleptics

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ABSTRACT: This paper is about how neuroleptics can be used in the lowest possible dose if for some reason it is not possible to stop taking them altogether.

KEY WORDS: Dopamine, Psychosis, Schizophrenia, Open Dialogue

Experiences described as psychotic can have a wide variety of causes and explanations. What the experiences usually have in common is an increased release of dopamine in the anterior, so-called presynaptic, part of the dopamine receptors in a region below the cerebrum. This increased dopamine release ends when a psychotic episode subsides, even without the administration of neuroleptics. About 70% of so-called schizophrenias, for example, progress in such episodes and 20% have only one episode over their entire lifetime. We do not yet know the mechanism that leads to a cessation of this increased release of dopamine and thus to the spontaneous remission of psychotic conduct.

A variety of biological and social factors can be involved in the overactivity of the dopamine system. Among the social factors, the following have been identified in scientific studies so far: early experiences of loss, sexual, physical and emotional trauma, neglect, growing up in cities, social hardship, social rejection, harassment suffered especially in the reference group in adolescents (so-called bullying) and migration.

Neuroleptics block dopamine transmission. The common and intended mode of action of all neuroleptics is a blockade of the postsynaptic portion of the dopamine D2 receptors. Neuroleptics thus have no influence on the increased dopamine production and release associated with psychoses. Accordingly, they do not have a so-called healing effect at the biological level, but often cause further unfavourable changes in the brain and body; these changes usually increase duration of neuroleptic use. Neurobiological researchers have described their effect in this way:

“Thus, these drugs may effectively silence the problem without correcting the underlying impairment. The analogy might be with a broken radio that is giving out white noise. Turning down the volume will remove the immediate problem (and the distress which it causes), but will not fix the underlying malfunction.” (Barkus et al., 2014)

Neuroleptics, however, cannot suppress symptoms in about 20% of patients, who are then referred to as non-responders. Nevertheless, these patients may receive neuroleptics - almost always permanently. In most cases, it would be desirable to accompany and support the people - if they agree - together with their important caregivers intensively at home via a multi-professional team trained and experienced in ‘Open Dialogue’ (Home Treatment). Experts by experience should also be team members. If this is not sufficient, round-the-clock support in a small Soteria facility would be an option (Aderhold et al., 2007). (See, also, Emmanouelidou, this issue.)

Approximately 40% of so-called first episode patients (Bola et al., 2009) could then manage without neuroleptics altogether, and with experienced teams presumably even more (Seikkula & Alakare, 2007; Seikkula et al., 2011). Additionally, they could then do so largely in the long term, according to the common findings of studies to date. Only a few of those people described as psychotic would then have to be treated in a hospital.

If the conditions are favourable, it can also be possible for people with a first psychotic episode to cope with their problems themselves via self-help, support from relatives and friends, or by making use of psychotherapeutic measures. These moves should prevent entry into the psychiatric system. Due to a persistent lack of such humane treatment efforts, people with psychotic experiences rarely find any meaningful help - except for pharmacological treatment. It is only much later, when symptoms have intensified, that they may seek or be taken to a psychiatric clinic. It would also be essential that such people are first shielded from overwhelming stimuli, personally accompanied if possible, so they can later experience an appropriately stimulating social environment, and can engage in meaningful physical activity.

The greatest possible personal approval of a drug and a positive experience of its effects are then essential. Both enhance efficacy and reduce undesirable effects. Conversely, negative experiences related to taking a medication lead to a reduction in effectiveness (Rief et al., 2016) and to sustained rejection (Van Putten et al., 1981). The reality of an acute ward unfortunately rarely meets the requirements of a positive experience. With no physical illness such distress-reinforcing institutional conditions would not be accepted, or would have long since become a scandal. (It is self-evident to me that the sustained rejection of neuroleptics can also be justified and need not be seen as a sign of psychiatric illness).

Because neuroleptic treatment is unnecessary for most people seen as psychotic

and can often have damaging secondary effects, any treatment should initially take place for two to four weeks without neuroleptics, even in psychiatric acute wards. This time is rarely given to those people with little tendency to regression with neuroleptics because team competence, ward size and inadequate staffing stand in the way. Taking into consideration the latest findings of pharmacological research, I shall now describe a recommended procedure for any use of neuroleptics.

Low neuroleptic dosage in acute treatment

For acute treatment with neuroleptics, the D2 receptors should only be blocked in a dose range, a therapeutic window, in which only 50-70% of these receptors are blocked, as dopamine is a vital neurotransmitter. It plays an active role in complex functions such as emotion, motivation, attention, curiosity, reward or reactions to unpleasant stimuli. Therefore, the blockade should not be stronger than absolutely necessary.

In order to remain within this “therapeutic window,” individual dosages can vary up to tenfold because of specific sensitivities and responsiveness of the brain, but in most cases they are significantly lower than the dosages used in psychiatry to date. For first-time patients, they are usually between 1-2 mg of haloperidol¹ or correspondingly low dosages of other neuroleptics. These equivalents are called haloperidol equivalents, so that dosages can be converted to other neuroleptics in each case. Higher dosages are usually not more effective and have significantly more adverse effects. For first-time recipients, these equivalent starting dosages of newer neuroleptics according to an international consensus commission (in which representatives of organisations of users and survivors of psychiatry were not involved) are: amisulpride² 100 mg; aripiprazole³ 10mg; olanzapine⁴

1 Note by the editors: Marketed as Agidol, Avant, Benzydol P, Brain-Rest, Cizonil, Cizoren, Haldol, Hal-kid, Haloperidol, Haloxem, Haloxen, Manace, Motivan, Serenace.

2 Note by the editors: Marketed as Aktiprol, Amgrace, Amipride, Amisulpride, Amisure, Amisyt, Ampicon, Solian, Sulprix.

3 Note by the editors: Marketed as Abilify, Abyraz, Apiz, Arena, Aridus, Arifril, Arilan, Aripiprazole, Aristada, Arizofy, Arizole, Arpoya, Elxeda, Mactril, Real One, Tevaripiprazole, Zykalor.

4 Note by the editors: Marketed as Dopin Tab, Hiolanz, Jolyon-MD, Joyzol, Jubrex, Lanazyp, Lanopin, Olancer, Olancor, Olankline, Olanzaccord, Olanzapin, Olanzapine, Olanzavita, Olanzine, Olazax, Onzapin, Ozapram, Prexolan, Rolyprexa, Tevatiapine, Tolanz, Xepat, Zalasta, Zolanz, Zozapin, Zypadhera, Zypine, Zyprexa.

5 mg; risperidone⁵ 2 mg; quetiapine⁶ 100 mg; ziprasidone⁷ 40 mg (Gardner et al., 2010). Compared with usual practice, they are therefore extremely low. This is important in order to minimise adverse effects and subsequent dose increases that may be useful. Because the possible reduction of symptoms under this dosage can take four weeks for first-time recipients under a chosen dose, and eight weeks or longer for people who have been through multiple episodes, or have not completed a course of medication, it is advisable to wait four or eight weeks before increasing the dose. In everyday clinical practice, however, the dose is usually increased too quickly, continued and not reversed when the desired effect is not achieved. Since many adverse effects are dose-dependent, this has serious consequences for treated people.

In people who have been treated before, the doses increase, partly because the dopamine receptors multiply and therefore only a higher dose blocks them to the same extent. However, if the initial doses are low, the receptor proliferation is less pronounced, so that a sensible increase in dose would also be lower (more on this later).

From randomised double-blind dose-finding studies, Stefan Leucht of the Psychiatric University Hospital Munich and colleagues (2014) and John Davis and Nancy Chen (2004) of the Psychiatric University Hospital Chicago determined minimally effective doses and dose upper limits of clinical effectiveness in people after multiple episodes. However, guidelines are usually much higher than those of the study evaluations and in everyday clinical practice they are often higher still.

It makes sense to try to get by with the minimum effective dose if one does not attempt discontinuation. Adjustment should be made cautiously. Exceeding the upper limit determined by studies should not be accepted by psychiatric patients and their supporters without a comprehensible justification. Often the health risks increase further without improving effectiveness on unwanted experiences. On the contrary, exceeding the dosages often makes problems worse. Guideline recommendations obviously do not help to determine doses, because the doses specified are often determined by a compromise amongst experts, many of whom have conflicts of interest because they receive fees from the pharmaceutical industry. That the pharmaceutical industry itself has no interest in low doses needs no further explanation - higher doses are more profitable.

5 Note by the editors: Marketed as Auperdal, Donresp, Eperon, Gen-Peridone, Helposper, Nodiril, Perdamel, Perida, Perizal, Phallus, Rescor, Respecor, Respizim, Ridal, Ridkline, Risina, Risnia, Rispacor, Rispador, Rispefar, Risperdal, Risperidex, Risperidon, Risperidone, Risperlet, Risperon, Rispeva, Rispevon, Rispide, Rispolux, Risponse, Risponz, Rixadone, Rutra, Schizorol, Zoxadon.

6 Note by the editors: Marketed as Adequet, Alvoquel, Atrolak, Biquelle, Brancico, Conquet, Dopaquel, Geroquel, Ketipinor, Kizofrin, Mintreleq, Noletil, Notiabolfen, Pequit, Placidin, Psyquet, Psyquit, Quentiax, Quesery, Quetapel, Quetapil, Quetex, Quetiapin, Quetiapina, Quetiapine, Quetoser, Qusel, Serez, Seropia, Seroquel, Setinin, Sizonorm, Socalm, Sondate, Syquet, Tevaquel, Truvalin, Zaluron, Zimbiquet.

7 Note by the editors: Marketed as Azona, Geodon, Zaprone, Zeldox, Ziprasidone, Zipsydon, Zipwell.

However, the industry continues to influence prescribers, who mostly have no time or access to read the relevant studies. Many doctors make use of free training sponsored by pharmaceutical companies in order to collect their continuing education points; the law describes continuing education as free from economic interest.

Neuroleptic low-dose and adverse effects

Some adverse effects would be almost completely avoidable because they only occur beyond the upper limit of the required D2 blockade of 50-70%:

- Movement disorders and restlessness from a D2 blockade above 78%
- Cognitive impairments (attention, memory, problem-solving behaviour, self-regulation and goal-directed behaviour, which play a central role in a person's independent living) from 70%
- Dysphoria from 70%
- Increased depressive and so called negative symptoms (impoverishment of speech, reduced intensity of feelings, lack of energy, drive, endurance and impetus, loss of interest, indifference, inability to feel pleasure, social withdrawal and tendency to isolate) from 70% upwards
- Prolactin increase with sexual disorders, milk flow or absence of menstruation from 72%.

This applies to conventional neuroleptics and those classified as second or third generation. If these adverse effects occur, in most cases an overdose is to be assumed, called "overshooting," and a dose reduction would be appropriate. Other significant adverse effects, which are associated with an increased risk of mortality, can occur with individual neuroleptics, sometimes to quite different degrees, have no dose threshold, but usually increase with higher doses: lipometabolic and sexual disorders, obesity, diabetes, coronary and cerebrovascular diseases, myocardial infarction and sudden cardiac death.

Since it is not possible to predict the lowest effective dose for an individual, if a solution other than the administration of neuroleptics is not currently possible for the patient, the dose should be determined by starting with the lowest dose that is expected to have a positive effect; provided that the patient is physically fit, informed about all risks and agrees to the treatment. If possible, the dose should then be increased after four weeks, or even eight weeks after previous treatments (Levine et al., 2010; Case et al., 2011). Natural remedies or, if necessary, benzodiazepines with a long half-life can temporarily help to reduce anxiety and improve sleep during this time. To increase within a few days is nonsensical because of the four- or eight-week duration for the (almost) complete and achievable desired effect. An increase often causes an avoidable overdose with additional health risks. In the longer term, symptom remissions remain incomplete more and more often mostly due to receptor changes caused by neuroleptic medication; the outcome can

be further, excessive dose increases.

Under no circumstances should the dose be increased if symptom relief is already sufficient. If a dose increase seems reasonable, it should occur in small steps. If extrapyramidal movement disorders occur (trembling, lack of movement, muscle stiffness, for example, with narrowed handwriting), an existing overdose is probable. Here, the dose should be lowered. If an increased dose does not lead to a further reduction or suppression of the symptoms, it should be lowered again, even if there are still residual symptoms. This can usually be decided after two, or at the latest, three months. If this does not happen, there is an increased risk of developing or intensifying a so-called supersensitivity syndrome (see, Whitaker, this issue).

Blood and plasma levels are not suitable for finding the right dose as individual differences in the responsiveness of dopamine receptors to neuroleptics are common. The blood level can only be used to check whether a potentially effective dose or a possible overdose is present, or to control the intake in the first place.

A change of substance is possible if it is clear that a neuroleptic is not working as desired (which can usually be assessed after four weeks for initial treatment, and after eight weeks for follow-up treatment) or if adverse effects occur. This can, however, have the disadvantage that the desired effect is lessened afterwards.

According to the studies, the new neuroleptic should potentially be more effective or have fewer adverse effects; the question will arise for the practitioners why they have not administered it before. In addition, it must be asked whether published studies correspond to reality. Newer neuroleptics are generally assessed too optimistically at the beginning - until the true extent of damage becomes apparent. It also depends very much on whether and how many industry-independent studies have been conducted. Unlike the means of the available studies, different neuroleptics can have very different effects on individual people. And since the effects of psychoactive substances are determined based on the assessment of emotional states and the behaviour of the test subjects and are therefore subjective and easily influenced processes, it goes without saying that the results of studies on the effective effect must always be viewed with some scepticism.

Sustained D2 blockade should also be viewed with scepticism. The D2 blockade required for so-called relapse prophylaxis is lower than 60% of a dopamine receptor blockade in the long term. Therefore, the dose can usually be lowered during the course of treatment for relapse prevention.

In principle, treatment should be with only one neuroleptic (monotherapy); prescribing or taking several neuroleptics at the same time over a longer period of time is almost never sensible. The patient must notice an improvement, and additional undesirable effects must not cause additional harm.

Some experts and expert groups recommend prescribing neuroleptics at the lowest possible dose and – this too should go without saying - after careful consideration of risks

and benefits (Ho et al., 2011). This makes sense because of a possible supersensitisation of dopamine receptors and a possible increase of mortality of psychiatric patients. Adverse neuroleptic effects such as diabetes, obesity, cerebrovascular and coronary artery disease, supersensitivity, tardive dyskinesia (chronic involuntary movements or twitching, often of the tongue and in the face and trunk, occurring during the course of treatment, on discontinuation or afterwards), increased prolactin levels and decreased grey matter in the brain are serious and in part significant factors in the pronounced and increasing early mortality. Likewise, treatment approaches should be implemented that make it easier to minimise doses of neuroleptics or make selective use possible - only for a portion of patients and only for a limited time - such as the 'Open Dialogue' or Soteria facilities (Seikkula et al 2011; Bola & Mosher 2003).

Forcibly enforced administration of neuroleptics often triggers traumatisation in patients and is deplored by them as a violation of their human dignity and their human right to physical integrity. Humanistically oriented psychiatric institutions largely refrain from violence and coercion (Zinkler, 2016, 2017). And even from the viewpoint of mainstream psychiatry, it has not been proven that the forcible injection of "medication" decreases so called psychotic symptoms and improves further recovery. In several studies with experimental control groups, delaying the use of neuroleptics by four weeks in the context of psychosocial support did not lead to worse outcomes after two years (Johnstone et al., 1999; Lehtinen et al., 2000; Bola & Mosher, 2003; Bola et al., 2009). Therefore, intensive psychosocial support rather than early administration of neuroleptics is considered crucial by reform psychiatrists (De Haan et al., 2003).

Efficacy of neuroleptics

Overall, the desired effect of neuroleptics is only "minimal," a conclusion from the evaluation of data from 21,774 patients treated for longer periods of time in a large review study published in the *British Journal of Psychiatry*. 82% of the study participants had been treated with newer neuroleptics. Clozapine⁸, amisulpride and olanzapine had better-than-average outcomes. Most of the others had no detectable specific effect of attenuating psychotic phenomena at all (Lepping et al., 2011). A further evaluation of higher-quality studies with a so-called placebo control group of 7,327 patients also determined a "medium effect size," which sounds reassuring at first. However, this was again almost insignificant in terms of a reduction of psychotic phenomena. Thus, on average, six patients have to be treated to achieve a symptom reduction of between 20 and 30% in one patient. This level of symptom reduction is well below a threshold that has been defined as clinically significant. (By setting the target in studies so low that it is still below a clinically significant threshold,

8 Note by the editor: Marketed as Cloment, Clonia, Clopin, Clopine, Closin, Clozalux, Clozapin, Clozapine, Clozarem, Clozaril, Clozatab, Denzapine, FazaClo, Leponex, Leudex, Merbaril, Versacloz, Zaponex.

one can increase the effect sizes. This misleading approach is also used in antidepressant studies). And the difference between the neuroleptic-treated and the placebo control group decreases more and more during the course of treatment (Leucht et al., 2009). A further limitation is that the overall proportion of premature treatment discontinuations in the studies was almost 50% and the placebo control group always comprises patients who are withdrawn from neuroleptics within a few days at the beginning of the studies and who can thus develop withdrawal phenomena and relapses more quickly. However, the word “placebo” suggests that these are people who reflect the “natural course” of “schizophrenia.” How can this overall low effect of neuroleptics be explained?

Neuroleptic-caused supersensitivity

When people experiencing what are described as psychotic phenomena or with a diagnosis of schizophrenia are treated with neuroleptics for the first time, 30% show a significant reduction in symptoms of 60-75%. In 70% of these first-time patients, this is already less than 30% (Levine et al., 2010). In the subsequent treatments, this effect becomes fewer. After more than 15 years of long-term neuroleptic treatment, for example, the symptoms continue to increase. In most cases, this occurs gradually, but in 6% of cases there is a symptom increase of 20% in one year under neuroleptics, and in 9% even of 60%, according to the later evaluation of a very large industry-independent study (CATIE) in the USA by the National Institute of Mental Health (Levine et al., 2012).

Today, the development of supersensitivity due to neuroleptics is considered to be the primary cause of this decreasing effectiveness (see, also, Whitaker, this issue). Blocking the dopamine receptors leads to an increase (“up-regulation”) of these dopamine receptors. In animal experiments, the average increase is 34% after several months, and the percentage increases to 70-100% after several years (Silvestri et al., 2000; Ginovart et al., 2009). Furthermore, in animal experiments, a supersensitisation of these dopamine receptors develops, with a tripling of the dopamine receptors and a state of increased sensitivity to dopamine (“D2High state”) (Seemann et al., 2005, 2006; Samaha et al., 2008).

In humans, this supersensitisation of dopamine receptors cannot yet be studied. It is not certain whether these brain changes - increased and supersensitised dopamine receptors - necessarily occur in everyone treated. How long these changes last after discontinuation is also uncertain. Based on animal experiments, it is assumed to be over one year in humans (Murray et al., 2016). Other researchers also consider several years as a possible period, and sometimes they consider them as irreversible (Chouinard et al., 2008).

To diagnose a supersensitivity psychosis, at least two of the following characteristic criteria must be met (Chouinard et al., 1990; Fallon et al., 2012):

- Development of tolerance to neuroleptics, i.e., higher and higher doses are

required (at least 20% more in the last five years).

- With very high tolerance development, psychotic symptoms occur (“breakthrough psychoses”) despite continuous treatment with the same dose.
- Return of psychotic symptoms at the end of the depot interval.
- Shortening of the interval between psychotic episodes with continuous neuroleptic intake.
- Recurrence of psychotic symptoms a few days to about six weeks (three months for depot) after dose reduction or discontinuation of neuroleptics.
- Psychotic symptoms after dose reduction are different or stronger than before.
- Psychotic symptoms occur after large reductions of over 10%, but not after slow reductions (less than 10%).
- Rapid remission of psychotic symptoms after dose increase. (Remission in actual new psychoses takes several weeks or longer.)
- Abnormal involuntary movement disorders of the face, lips, jaw, tongue, arms, wrists, hands, fingers, legs, knees, toes, neck, shoulders, hips.
- Increased stress sensitivity, i.e., even minor psychosocial stress causes psychotic reactions to worsen or relapse.
- Prolactin levels more than twice as high above the gender-specific, age-dependent norm.

This list shows the potential consequences of supersensitivity. In addition, there are often increased so-called positive symptoms such as delusions and hallucinations in later psychotic episodes compared to the first. These consequences rarely occur in all cases and not in every patient. The incidence of supersensitivity psychosis ranges from 22 to 43%, depending on whether tardive dyskinesia is included. The higher the dosages, the more and more frequently tardive dyskinesias occur. Ways to limit supersensitivity in its development are (Remington & Kapur, 2010; Uchida et al., 2011):

1. Low dosage from the beginning.
2. With mental stability, delayed intake initially every second day and after success over three months only every third day. Exceptions are: quetiapine, clozapine.
3. Delayed depot administration: With risperidone depot, an extension from two to four weeks has been shown to be sufficiently effective; with fluphenazine⁹ depot, an extension from two to six weeks.
4. Additional administration of antiepileptic drugs: gabapentin for less pronounced symptoms, valproic acid or lamotrigine for more pronounced symptoms (Chouinard & Chouinard, 2008). Under this medication, the dose should then

⁹ Note by the editors: Marketed as Anatensol, Depregdina, Fludecan, Fluphenazine, F-Tensil, Modecate, Phenodec, Prolinate.

be reduced to the minimum effective dose, despite persistent positive symptoms such as delusions and hallucinations.

Delaying the intake by one to two days presumably has advantages over low dosing because the receptor can always slow the pathological changes during a prolonged intake interval. Usually, however, in everyday psychiatric practice, the reaction to the decreasing effectiveness of neuroleptics is excessive higher dosing and the prescription of several neuroleptics at the same time ("polypharmacy") and even additional electroshocks. This exacerbates the problem and leads to more undesirable effects.

Polypharmacy

The effectiveness of polypharmacy has not been proven by studies of sufficient quality (Correll et al., 2017) and its possible consequences are not harmless (Lochmann van Bennekom et al., 2013):

- more extrapyramidal disorders
- more weight gain and diabetes
- increased rate of sudden cardiac deaths
- worsened cognitive functions
- more sexual dysfunction
- increased delusions and hallucinations
- increased death rate. Some studies with divergent results evaluate treatment courses of patients in middle age and do not record deaths after the age of 53 or 65.

Even the American Psychiatric Association therefore campaigned in 2013 to curb polypharmacy:

"Don't routinely prescribe two or more antipsychotic medications concurrently. Research shows that use of two or more antipsychotic medications occurs in 4 to 35% of outpatients and 30 to 50% of inpatients. However, evidence for the efficacy and safety of using multiple antipsychotic medications is limited, and risk for drug interactions, noncompliance and medication errors is increased. Generally, the use of two or more antipsychotic medications concurrently should be avoided except in cases of three failed trials of monotherapy, which included one failed trial of clozapine where possible, or where a second antipsychotic medication is added with a plan to cross-taper to monotherapy."(APA, 2013)

Because Approximately 50% of the patients are treated with neuroleptic polypharmacy with large regional differences against the scientific evidence and even the recommendations of the professional societies, one must probably assume the direct or

indirect influence of the pharmaceutical industry among others.

If polypharmacy is nevertheless started, the following should be considered. Unfortunately, the effectiveness of a combination often only becomes clear after several weeks, but at the latest after three months. If there is no improvement, the polypharmacy should be gradually reversed. If there is a clear improvement, which is seldom possible, additional harmful effects (for example, weight gain, ECG and lipid metabolism disturbances, deteriorated cognitive abilities) should prevent a continuation. If possible, the patient should make this decision after careful consultation with persons they trust.

According to (limited) studies, polypharmacy can be reversed in most patients. For example, when taking three to four neuroleptics, a reduction of almost 60% of the dose and often more than one neuroleptic was possible in 88% of those patients over a period of only three months. Over a longer time, further reductions would probably have been possible, according to the study leaders. In 50% of those patients, residual psychotic symptoms and mental and social abilities improved. Only 12% of those patients deteriorated, but this could be reversed by returning to higher doses and without inpatient treatment (Suzuki et al., 2003). When taking only two neuroleptics, reduction studies were successful in about 70% of the treated patients. The study duration was even shorter here, one and three months. Weight was reduced by an average of 2.3 kg after six months. Mental and social abilities improved and symptoms remained unchanged (Essock et al., 2011; Hori et al., 2013). One should not proceed too quickly.

Since the different neuroleptics block other receptors besides dopamine receptors and affect the body in other ways, there are other undesirable physical effects. The following are associated with particular risks, especially premature mortality.

Life-shortening effects: Obesity, metabolic syndrome and diabetes, cardiovascular disease and sudden cardiac death

Weight gain

In 2011, a review of all available studies determined the following extent of weight gain in first-episode patients after one year of treatment with different neuroleptics in this decreasing rank order: olanzapine + 11-17 kg; amisulpride + 10 kg; clozapine + 10 kg; quetiapine + 10 kg; risperidone + 8-9 kg; haloperidol + 4-11 kg; chlorpromazine¹⁰ + 6 kg; ziprasidone + 5 kg; perphenazine¹¹ + 1 kg (Foley et al, 2011).

Metabolic syndrome

10 Note by the editor: Marketed as Chlorpromazine, Clonactil, Clozine, Largactil, Largo, Matcine, Megatil, Plegomazin, Prazin, Serectil, Zinectil.

11 Note by the editor: Marketed as Perphenazine.

40-50% of people on long-term neuroleptic medication suffer from metabolic syndrome (Correll et al., 2006). It is characterised by obesity and dyslipidemia with a decrease in HDL fats and an increase in triglyceride fats, with hypertension, insulin resistance, elevated fasting blood glucose or diabetes mellitus. For metabolic syndrome to be diagnosed, three of these criteria must be met. The longer the treatment lasts, the more the incidence of metabolic syndrome increases. Therefore, it is important to check these values regularly (more at the end of this article). Metabolic syndrome is most common with clozapine, olanzapine, quetiapine and risperidone (in descending order), as well as with polypharmacy.

Other causative factors are smoking, unhealthy diet and inactivity. Even half an hour of “walking” per day significantly reduces the risk of coronary artery disease and diabetes (de Hert et al., 2011).

Since the likelihood of reducing weight gain in the long term by switching between different neuroleptics is low, one should react to an increase in weight early on. If one has already gained a few kilos in a few weeks on a new neuroleptic, one should not continue to wait, as the gain usually continues for a year or more, but look for an alternative. Obesity as an adverse effect is also dose dependent. This is shown by significantly lower weight gains at low but still “effective” doses.

Type 2 diabetes

In people diagnosed with “schizophrenia,” the diabetes rate is on average four to five times higher than in the normal population. One must consider the age at which diabetes occurs. The incidence rate increases with age. Among people aged 55 to 65, the incidence rate is now 25% (de Hert et al., 2006). It is argued that it is more the so-called mental illness than the neuroleptics that is responsible, or the latter are simply not mentioned. A simple look at the different diabetes rates for individual neuroleptics speaks volumes. For example, according to a recent review (Vancampfort et al., 2016), the rate of diabetes among individual neuroleptics is, in ascending order: amisulpride: 3.9%; aripiprazole: 6.7%. Conventional neuroleptics: 10.6%; olanzapine: 10.6%; risperidone: 13.2%; clozapine: 15.5%; quetiapine: 16%. If neuroleptics were never taken, the rate is only 2.9%. In addition, there are further research results that are important for practice:

- Diabetes develops in 60% of cases in the first six months of administration (Koller et al., 2001, 2002, 2003). Therefore, control examinations must be carried out before the intake and then again after six and twelve weeks.
- The risk of diabetes increases dose-dependently and through polypharmacy (Citrome et al., 2004; Correll et al., 2007). Therefore, fasting blood glucose must be closely monitored when combination treatment is started. Even better, polypharmacy should be avoided altogether.
- A combination of neuroleptics with antidepressants from the serotonin reuptake inhibitor group or with Lithium also increases the rate of diabetes. So here, too,

the blood sugar must be controlled from the beginning.

- In about 25% of cases, diabetes without obesity develops because of a direct effect of the neuroleptics on the insulin metabolism. Therefore, even with normal weight, fasting blood glucose must be checked regularly.
- Elevated fasting blood glucose is found in 30% of patients on atypical neuroleptics who are not known to have diabetes; even this is associated with an increased risk of cardiovascular disease (Gerstein et al., 1999; Coutinho et al., 1999). Early conversion to a more tolerable neuroleptic is also useful here.
- The determination of haemoglobin A1c, the iron-containing red blood pigment needed for oxygen transport in the body, together with fasting blood sugar, is the most suitable screening test.

The risk of sudden cardiac death is increased up to fivefold in people diagnosed with schizophrenia (Ruschena et al., 1998). High doses of neuroleptics additionally double the risk compared to low doses (Ray et al., 2009). Severe cardiovascular diseases, which can also be caused or aggravated by neuroleptics, further increase the risk. The simultaneous intake of several substances with their incalculable interactional effect amplifies and increases the risks requiring additional ECG checks.

ECG checks are generally required at the intervals recommended by guidelines, and more frequently with increased risk. A QT prolongation of over 500 msec is considered a threshold value that requires a change in the prescription. (QT time refers to the time in the electrocardiogram from the onset of Q [depolarisation] to the end of T wave [repolarisation]). These effects are significant, especially for life expectancy:

- Metabolic syndrome doubles the risk of developing cardiovascular disease within ten years.
- A metabolic syndrome with diabetes results in a 7.7-fold increased risk of cardiovascular disease (Correll et al., 2006).
- The overall mortality rate for cardiovascular disease increases 3.6-fold.
- The years of life lost in obesity with a body mass index (BMI) of 30 to 35 are on average two to four years; with a BMI of 40 to 45 it is eight to ten years (Prospective Studies Collaboration et al., 2009).
- The years of life lost with diabetes amount to two or more years. With neuroleptic drug-induced diabetes, the age of onset is usually much lower. Thus, it can be assumed that the number of years of life lost in diabetes due to neuroleptics is usually much higher.
- If neuroleptics are taken over a period of 30 years, a rate of 4.5% of neuroleptic-related sudden deaths can be calculated. This is a very conservative calculation, because one only assumes a doubling of the risk under neuroleptics. The actual risk is probably higher.

- The years of life lost due to smoking average ten years. The extent of smoking also increases with the dosages of neuroleptics.

Neuroleptics in particular, in combination with the effects of precarious living conditions of psychiatric patients, contribute to the increased rate of early mortality (Weinmann et al., 2009). A foreword in the Lancet summarises the problem in the following way:

“The combination of antipsychotic side-effects with poor diet, physical inactivity, high rates of smoking, and other factors associated with psychotic illness, together with socioeconomic deprivation, has a devastating effect on cardiometabolic health. It is no surprise, therefore, that people with severe mental illness have lives 16-25 years shorter than does the general population, and that coronary heart disease, not suicide, is the major cause of death.” (Lancet, 2011)

Control examinations

Anyone who prescribes potentially harmful medicines must ensure the exclusion or control of these harms and inform the patient of this. If this is not done, it is a treatment malpractice. It is scandalous that it turned out that in all studies on the so-called monitoring of potential harm from neuroleptics, the necessary control examinations by the treating physicians were carried out inadequately and rarely led to changes in the treatments, whether in adults or children (Mitchell et al., 2012).

The German treatment guidelines are currently being revised. Even the examinations recommended in the old guidelines are only carried out in a minority of patients. Further, important control examinations can be derived from the known adverse effects: intraocular pressure at the beginning, after a few weeks and every six months; movement disorders after a few weeks and every six months; with a sense of pointlessness, suicidality must be checked throughout.

Since neuroleptics have a multitude of undesirable effects and can produce and aggravate diseases, extend mental problems and contribute to the increased mortality of psychiatric patients, it is vital that certain parameters are monitored by doctors in order to identify - even at comparatively low doses - possible early damage and appropriate countermeasures taken. For women, the risks seem to be even higher than for men. This corresponds to the gender-specific differences in the effects of neuroleptics on the heart and metabolism.

If people are concerned that their own suspicions will be dismissed lightly by GPs or specialists, possibly because they are unfamiliar with the extent of the risks of neuroleptics, discount adverse effects as symptom shifting, or consider these patients to be hypochondriacs, they should write down their complaints before seeing a doctor,

take relatives, friends or other supporters with them to their next visit, give the doctor the document with the complaints for the medical record, and strongly request an examination. In particular, medics should prevent these consequences of psychotropic drug administration: metabolic syndrome (obesity, dyslipidemia, hypertension, insulin resistance, elevated blood sugar, diabetes mellitus) and cardiovascular disease and sudden cardiac death.

Conclusion for prescription practice

Neuroleptics do not have a causal effect on so-called psychosis, i.e., they cannot cure. Besides the somatic and hormonal side effects, the neurotoxic effects are becoming increasingly obvious. Therefore, the often suggested everyday logic of “more helps more” does not apply. Instead “less is more.”

Since in most cases the harmfulness of neuroleptics in particular is dose dependent, many scientists increasingly recommend using only the lowest possible dose for symptom control. A complete remission of symptoms is apparently not achievable in many cases and less so in the course of treatment. The longer neuroleptics are used, the more severe the undesirable neurotoxic effects usually become, making it more difficult for symptoms to subside. With few exceptions, the simultaneous use of several psychotropic drugs (polypharmacy) should be avoided and, if possible, reversed.

Supervised slow reduction and discontinuation attempts are sensible and necessary in order to find the minimal neuroleptic dose - necessary from both a medical point of view and as desired by patients - to improve quality of life, ability to work and everyday activity if the neuroleptics cannot be completely discontinued. In treatment without neuroleptics accompanied by the already mentioned psychosocial forms of treatment the long-term outcome is better.

The optimum would be to address problems via self-help or to make them manageable. If the problems cannot be solved in this way, they become too severe and for people seen as psychotic who want to use neuroleptics, acute treatment without neuroleptics for three to four weeks would actually be better, especially for so-called first- and second-time sufferers in suitable therapeutic contexts (for example, Soteria). In my view, the following core interventions should have priority:

- Systemic, team-based early intervention in the living environment of the clients, which therapeutically involves families and social networks from the beginning and in no case takes place against the will of the patient.
- Relationship continuity through multi-year support by these teams, for as long as it appears necessary and is desired.
- Integration of experts-with-experience into these teams.
- If necessary, a small psychosis-supporting trauma-sensitive milieu. Here too, so-called lay people as well as experts by experience are a particularly effective team

component.

- Individual psychotherapy - if the client experiences it as meaningful and the psychotherapist approaches the client unbiasedly and client and therapist are a suitable match. The methodological approach can vary and is secondary. If necessary, the integration of trauma-specific aspects and methods should be possible. Good cooperation between the psychotherapist and the outpatient team is also important.
- Non-verbal psychotherapeutic methods such as art, music or dance therapy.
- “Supported employment teams,” i.e., separate support or support integrated into the outpatient team for the earliest possible integration into training or for taking up or maintaining a job in the primary labour market. It would also be important to provide support in taking up or maintaining an apprenticeship or a course of study, in finding housing, childcare, debt repayment and all the other social and economic problems that often enough lead to the demoralisation of the patients.

In my opinion, are all other interventions secondary. The rate of non-use of neuroleptics as well as their dosage level are a criterion for the quality of the treatment.

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The Observatory for Mental Health Rights: Cooperative support in withdrawal

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ABSTRACT: This paper discusses the work of the Observatory for Human Rights in the Mental Health Field, a two-decade old Greek initiative helping people withdraw from psychiatric drugs.

KEY WORDS: Crisis Intervention, Collective, Iatrogenesis, Demedicalisation

The Observatory for Human Rights in the Mental Health Field is a collective founded in Greece in 2002 as an initiative against psychiatric violence. After this, the first cases of allegations against psychiatric institutes that addressed complaints of violation of individual's human rights were brought to our attention. It soon became clear that these allegations did not lead to change, as they seemed to stand against a powerful and well established medical system; in many cases they were further abused by the media. Our response to this was to offer strategic alternatives which would allow people in crisis to bypass mainstream clinical/hospital psychiatry.

In 2006, the Observatory received its current name and started a five-year campaign to raise awareness of human rights in psychiatry within Thessaloniki, and to introduce "alternatives", i.e., appropriate support for people in emotional crises, initially suggested by the international mental health movement. By 2012, the Observatory had established a network of collaborations with several international groups, movements and initiatives that held a critical stance towards mainstream psychiatry. Large events in the city of Thessaloniki and the wider region had already started having an impact on the dominant view of mental health issues.

The members of the Observatory are people with psychiatric experiences, psychologists, psychotherapists, family members and members of the community. Decisions are taken only when they are unanimously agreed during non-hierarchical assemblies. The Observatory's only income comes from donations of trainees on the training course on "Non psychiatric Crisis Intervention". All the money is used for the purposes of supporting people in crisis in an alternative, non-violent and non-psychiatric ways. Most of the trainers are Observatory members (psychologists and ex-users and survivors of psychiatry). None of the trainers receives any payment for delivering the training.

In 2010, the Observatory became a formal Association. From 2012, the first Greek groups of self-help for people with psychiatric experiences and their families - independent of any psychiatric leadership or support - were created in Thessaloniki. In 2009, Peter Lehmann started training our members on how to support people to reduce and/or stop taking psychiatric drugs.

In 2016, the first support guide was compiled. This guide drew from the Observatory members' long experience with individual cases of reduction of and withdrawal from psychiatric drugs. A subgroup named "Network of Practical Assistance to People Wanting to Reduce or Stop Psychiatric Drugs" was formed, with 8 members at the time, trained by members of the Observatory experienced in psychopharmacological issues and the Observatory's withdrawal model.

The Observatory developed a special model of supporting people in reducing and stopping psychiatric drugs. This requires significant life changes beyond medication reduction as it has been found that an isolated effort of withdrawal from psychiatric drugs doesn't necessarily bring a good enough life. On the contrary, it usually leads to new psychiatric admissions and further violence against patients. This model is based on the following principles:

1. The Observatory's role is not to encourage individuals to stop taking psychiatric drugs; it is rather to respond to such a request when it comes from the patient as an already-taken decision. The Network aims at helping people to withdraw in a safe way for themselves preventing any possible new violent involuntary hospitalization. This includes an invitation for changes in several aspects of the individual's life.
2. The process of support begins with providing the individual and family with information on psychiatric drugs and suggesting appropriate ways to deal with their emotional problems.
3. When a request comes, a 'reference group' of three Network members is appointed: one person is responsible for communicating with and supporting the family with the person with psychiatric experience (only if they allow it), and two people accompany them in taking the following steps:
 - Creating a vision for a future without psychiatric drugs, and also in establishing and leading a human network for support both during and after the withdrawal

- process;
- Finding the most appropriate life practices (such as healthy diet, exercise, interests, education, psychotherapy, socialising, and work) based on the person's uniqueness and history;
- Engaging with reflections, conversations and thinking about the process initiated by the reduction/withdrawal; and
- Writing an advance directive in case of any future psychiatric crisis.

These three members of the reference group are accessible 24 hours the day, so that they can accompany the person through a crisis. They try to avoid the use of psychiatric drugs as much as possible and they always act in the person's best interests and according to the person's preferences. This consistency of support has been proven invaluable in ensuring a good outcome, as it allows the establishment of trustful solidarity between all the people involved.

The person with the psychiatric experience is encouraged to join self-help groups of the Observatory, where experiences regarded as psychotic, depressive or manic and current everyday challenges are shared and discussed. These groups stand in contrast to psychiatric psychoeducation where the above experiences would be "explained" or "taught" by professionals as chemical imbalances in the brain which require synthetic drugs to create an artificial new balance. Other groups based on shared interests, such as cinema, theatre, self-education and philosophy, may be selected by the individual, with a focus on resources and quality of life.

The three members of the reference group are supported and supervised regularly in meetings with the whole "Network of Practical Assistance to People Wanting to Reduce or Stop Psychiatric Drugs" group of the Observatory. These meetings are focused on the reference group's own needs and they are called at a reference group's request.

The relevant doctors' collaboration is desirable but not necessary for the process to begin. The pace of reducing the psychiatric drugs usually follows a pattern of '10% every four weeks' but it can vary depending on the specific dosage, the type of drug and the person's physical reaction to the reduction. It is very important that all possibilities have been discussed with the psychiatric patients in advance, including the possibility of a new crisis or a return to a higher dosage in the case of a severe physical reaction to reduction.

A person's overall health is taken into consideration throughout all the aforementioned steps of the reduction process. Physical wellbeing is considered as precious as mental wellbeing and the Observatory is based on a holistic approach which promotes both. The whole process is guided and controlled by the individual with the psychiatric experience. The reference group members make suggestions following the person's preferences. At any time they wish, the person can end the collaboration with the Observatory and the reference group.

People who do not wish to follow this model of reduction/withdrawal are only given the information and no further collaboration takes place. Based on our 10-year experience, we have agreed that the Observatory does not take any responsibility to support the withdrawal from psychiatric drugs if it is not accompanied by the person's willingness to changes in other aspects of life. The whole model is practiced on a free-of-charge basis and the Network has no external sources of funding. The Observatory members who want to join this Network have to undergo an internal training course on the specific model and other matters around withdrawal.

Throughout the years, we are grateful to have received continuous support from Peter Lehmann, Peter Bullimore, Marius Romme & Sandra Escher and 'Hearing Voices Network England' who deliver information and training on the Maastricht Interview on voices and paranoid ideas. We profit from the books co-edited by Peter Lehmann with detailed accounts of how to come off psychiatric drugs without ending up once again in the doctor's office as well as information on alternatives beyond psychiatry, current possibilities for self-help for individuals experiencing madness or depression, and strategies toward implementing humane treatment. Aside from this, the most important part of our work is the humanistic engagement by our members and finally by the people themselves who withdraw from their psychiatric drugs. About 3-4 people per year in the last four years were freed successfully from their psychiatric drugs, with short crises of 2-3 weeks without those drugs or without crises at all. All of them have stayed for a long time or until now in contact to the Observatory and the self-help group, by which they were supported during the whole process. This is a good beginning. We continuously correct and supplement the model, as we see that it works in a global way and supports the former psychiatric patients in all areas of their lives.

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Attitudes of researchers concerning discontinuation of psychopharmacological treatment

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ABSTRACT: Via a Web-based survey of researchers this paper provides an overview of the scientific community's attitude regarding the need for psychiatric drugs to be available in doses that allow safe and effective discontinuation processes. The authors suggest that technologies must be developed that allow prescribers and users to have access to psychiatric drugs in doses that guarantee their discontinuation with a minimum of withdrawal symptoms.

KEY WORDS: Deprescribing, Pharmacology, Withdrawal, Drug Dependence

Although many of the problems that are classified as psychiatric disorders can be treated in non-medical ways, the hegemonic mode of treatment is psychopharmacological. Medical practitioners learn to prescribe, but not to deprescribe. Discontinuing psychopharmacological medication is usually accompanied by unpleasant physical and psychological experiences, or even death. The received wisdom is that such experiences

are symptoms of the primary disease, although a body of scientific evidence now suggests that they are actually symptoms of withdrawal from the prescribed drug. Official protocols provide very little guidance on withdrawal symptoms. The lack of availability of psychiatric drugs in doses that allow the safe and effective discontinuation of their use is one of the major challenges facing health.

According to current standards, psychopharmacological treatment is one of the problems that causes most embarrassment, controversies, and disputes in the field of psychiatric care. Prescribers are taught how to prescribe, but they have trouble when it comes to deprescribing.

Psychiatric drugs are considered to be a first-line treatment (Gallego et al., 2011; Schennach et al., 2012; Wolfe et al., 2008; Yatham et al., 2018). The assumption is that psychotropic drugs can help correct an abnormality in the brain that is supposedly responsible for producing the symptoms of a particular mental disorder (Janicak et al., 1993; Pies, 2005). The underlying theory is that abnormalities of different neurotransmitters are the cause of different psychiatric disorders. Likewise, hyperactivity of the dopamine system has been presented as the cause of schizophrenia (Brisch et al., 2014; Meltzer & Stahl, 1976; Rossum, 1966), the positive symptoms of schizophrenia or acute psychosis (Kapur, 2003). Also, the monoamine theory suggests that depression is caused by a deficiency of monoamine neurotransmitters, known as serotonin and norepinephrine (Schildkraut, 1965). Without refuting the idea that psychiatric drugs work by correcting supposed chemical imbalances, there are scientists who suggest that the effects of psychiatric drugs result not exactly from the correction of abnormalities involving neurotransmitters, but from adaptations in the brain, producing therapeutic responses by altering the functional activity of neuronal circuits (Hyman & Nestler, 1996).

Psychiatric drugs are among the most prescribed and consumed classes of medications today. In recent times, there has been a dramatic increase in the number of psychiatric drugs being prescribed, which include antidepressants, antipsychotics, anxiolytics, antiepileptics, and sedatives (FRANK et al., 2005). In the United Kingdom, according to the NHS, the total number of prescriptions increased by about 50% in ten years, from 138 million in 2007 to 208 million in 2017 (Iacobucci, 2019b). In the USA, prescriptions saw a 22% increase from 2001 to 2010, and it is estimated that one in five Americans uses at least one psychiatric drug (Smith, 2012). Psychiatric drug use is a phenomenon that has acquired epidemic proportions (Whitaker, 2017).

The role of deprescribing is attracting increasing attention in public health policy discussions (Farrell & Mangin, 2019). We understand deprescription as the “reduction or cessation of potentially inappropriate medications in situations where there are potential risks that exceed the benefits, taking into account the patient’s medical and functional status and preferences” (Scott, 2015). Several factors indicate the urgency of deprescription, from polypharmacy to harmful impacts on the health of older people (Scott et al., 2015;

Woodward, 2003). Nevertheless, there are numerous significant barriers to making a psychiatric drug withdrawal process safe, effective, and with as little suffering as possible.

Recognition of the importance of withdrawal for the health of the user

There is inadequate evidence on how long psychiatric medications should be used and how to discontinue their use. Problems associated with withdrawal were already reported 60 years ago (Hollister et al., 1961; Selikoff IJ et al., 1953). For decades, patients have complained of physical and mental issues associated with withdrawal of psychiatric drugs. However, this issue has largely been ignored in the scientific literature (Groot & Van Os, 2020; The Withdrawal Project¹; Surviving Antidepressants²; Benzo Buddies, 2020; Recovery Road, 2020; Hall, 2012; Groot, 2010).

Doctors, and in particular psychiatrists, faithful to official protocols, are often fearful of adjusting or reducing their prescriptions of psychiatric drugs, especially when the patient has achieved medical stability with some difficulty (Steinman & Landefeld, 2018). Under the general obligation to “do” something in the face of a person’s suffering, in line with academic training that leads them not to value anything that may be “secular” knowledge, physicians tend to carry on prescribing the same medication or additional medications; even when clinical experience shows that the continued use of a drug has more negative than positive effects, contrary to the tenet of *primo est non nocere* in the Hippocratic Oath.

Recently, psychiatric drug withdrawal gained the attention of the scientific community. In 2019, the Royal College of Psychiatrists, in the UK, admitted for the first time that the symptoms of withdrawal from psychiatric drugs could be much more severe and lasting than had hitherto been admitted; and also, that there lacks an evidence base on how to proceed with withdrawal safely and effectively (Royal College of Psychiatrists, 2019). The UK National Institute for Health and Care Excellence (NICE), in a statement about a future revision of the protocols for antidepressants, reached similar conclusions (Iacobucci, 2019a), as did the American Food and Drug Administration and the Centers for Disease Control (Dowell et al., 2019) in reference to opioid withdrawal. Recently, the journal *Brain Communications* (Lerner & Klein, 2019) published an extensive in-depth literature review focusing on the problems of “dependence,” “abstinence,” and “rebound,” phenomena that are characteristic when discontinuation occurs.

What is available on the psychopharmacological market today does not favor a safe and effective discontinuation process:

1 Website available at: <https://withdrawal.theinnercompass.org>

2 Surviving Antidepressants is a site for peer support, documentation, and education of withdrawal symptoms and withdrawal syndrome caused by psychiatric drugs, specifically antidepressants, with more than 6000 reports of patients experiences, <https://www.survivingantidepressants.org/>

- Medicines are not available in intermediate doses, often presented in the form of tablets or capsules in standard doses, making it almost impossible to tailor a tapering process according to individual users' needs;
- Existing clinical guidelines implicitly assume that there are universal parameters, although a schedule that works well for one patient can be disastrous for another;
- The reduction rates recommended by official protocols are generally vague and usually very fast, and when problems arise they are often attributed to the patient's condition rather than the speed of the drug discontinuation;
- Reduction plans are generally not individualized to reflect the varied responses of patients, failing to take account of their choices and experiences;
- Doctors with some patients who successfully withdraw from psychiatric medications may mistakenly expect all patients to be able to do so in the same way.

It seems that one of the greatest difficulties when withdrawing medications is the lack of availability of psychiatric drugs in smaller doses, which are required to facilitate the reduction and/or interruption of drug use. This research therefore aimed to obtain an overview of how the scientific community today considers the viability of the alternatives.

The study

A list of respondents to the web survey was generated from the e-mail addresses of authors of scientific publications on the subject of this study indexed in the Clarivate Analytics Web of Science Core Collection (WoS) database. For this, the following search strategy was used:

ti = ("mental disorder *" or "mental health disorder *" or "neurotic disorder *" or "psychotic disorder *" or "psychiatr * disorder *" or "depressi * disorder *" or "emotional depressi *" or "depressi * neuros * " or "endogenous depressi * " or "depressive syndrome * " or "neurotic depressi * " or "melancholia * " or "unipolar depressi *" or "bipolar disorder *" or "schizophreni *" or "anxiety disorder *" or "social anxiety * " or "social phobia * " or "anxiety neuros * " or "neurotic anxiet * ") Refined by: Research Areas: (Psychiatry OR Neurosciences Neurology OR Pharmacology Pharmacy). Timespan: 2013-2018. Indexes: SCI-EXPANDED, SSCI.

This strategy combined terms from Medical Subject Headings (ncbi.nlm.nih.gov/mesh) and free text words related to psychiatric illnesses. The search was performed in the WoS advanced search mode using the Title (ti) classification, which restricts the search to article titles, and the Science Citation Index Expanded (SCI-Expanded) and Social Sciences Citation Index (SSCI) indexes, to identify researchers in the field of the natural and social sciences. The time interval was restricted to 2013-2018 to identify respondents who published recent research in the area.

The search was carried out in September 2018 and yielded 34,444 records of scientific publications (all types of documents). These were imported into the VantagePoint 10.0 data/text mining software, where, using the Super Profile script, it was possible to retrieve 15,701 distinct emails. This list of respondents was then exported to the online survey platform SurveyMonkey (surveymonkey.com), where the questionnaire was built and conducted. After uploading, the number of respondents was reduced to 14,981 after removing bounced email addresses and opted out contacts.

The questionnaire was structured in two parts. The first qualified the respondents according to their level of knowledge on the topic (good, some knowledge, or no knowledge). Those respondents who reported having no knowledge on the topic were excluded from the study and did not answer the other questions. In the second part, respondents with good or some knowledge were asked to respond to nine statements related to the withdrawal of psychiatric drugs. The statements related to the drug withdrawal process, and the answer options were restricted to “likely,” “unlikely,” and “unknown.”

The web-based survey was conducted in October 2018. Invitation and reminder emails were sent to all the respondents. In the messages, they were informed about the purpose of the study, the anonymity of the data collected, and the non-identification of the participants in any report. The questionnaire was available for eight consecutive days. During that period, up to three reminder emails were sent to non-responders.

Results

Of the 14,981 invitations sent, 384 valid responses were obtained. (Forty-six questionnaires from researchers who declared they had no knowledge and 16 questionnaires in which the researchers answered only the question about their level of knowledge were excluded.) Of these, 318 (83%) consisted of fully answered questionnaires, which is equivalent to a representative sample with a 95% confidence level and a 5% margin of error. Of the 384 researchers who answered the questionnaire, 211 (55%) claimed to have good knowledge and 173 (45%) some knowledge about psychiatric drug withdrawal.

A large majority of the respondents, both those who had good knowledge (90%) and those who had some knowledge (91%), considered the withdrawal of psychiatric drugs an important question for the well-being of patients (see Table 1).

The occurrence of symptoms related to withdrawal from psychiatric medication is common knowledge in the scientific community (Albert et al., 2019; Baldessarini & Tondo, 2019; Cohen & Recalt, 2019; Declercq et al., 2009; Fava et al., 2018; Maund et al., 2019), and this was reflected in the respondents' answers (see Table 2).

The controversy over the effectiveness of psychopharmacological treatment was also echoed by the respondents. Interestingly, there is a growing literature showing the harmful effects of using psychotropic drugs in the short term, and especially in the medium and long term (Gopalakrishnan et al., 2020; Hengartner, 2020; Jakobsen et al.,

Table 1: Psychiatric drug withdrawal is an important issue for the well-being of the patients

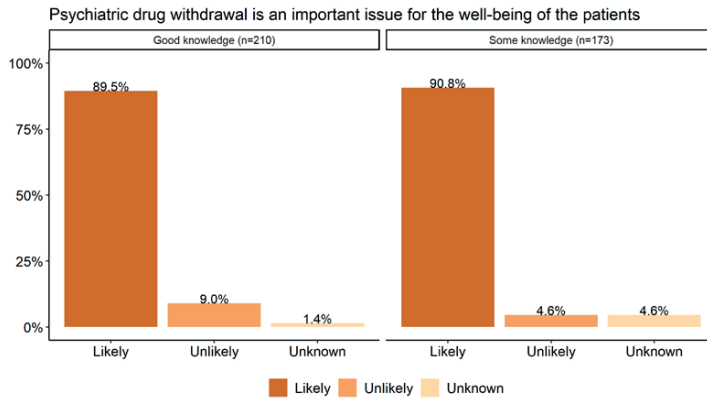


Table 2: Withdrawal symptoms occur when a person stops taking psychiatric drugs

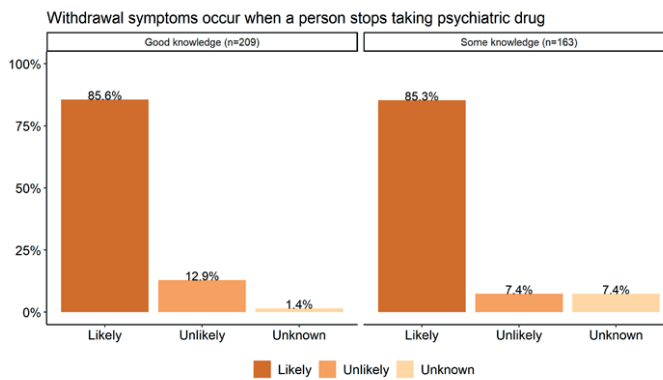


Table 3: Mental health treatment without psychiatric drugs improves patients' health

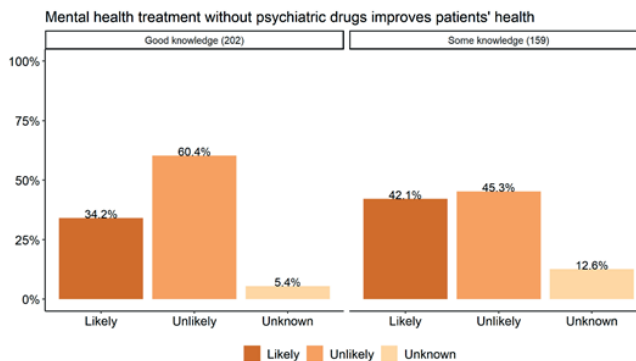


Table 4: *Withdrawal symptoms of psychiatric drugs are worse in patients who have used the drug for a long time*

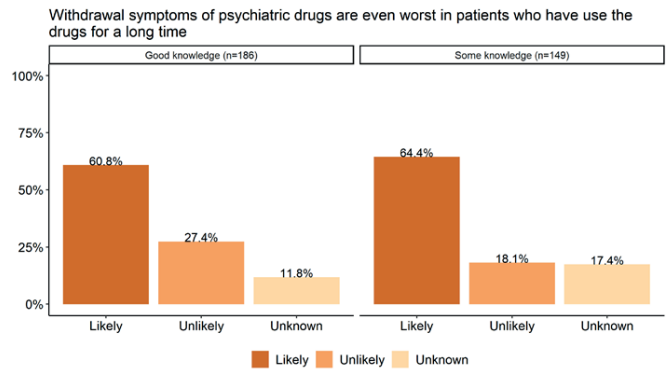
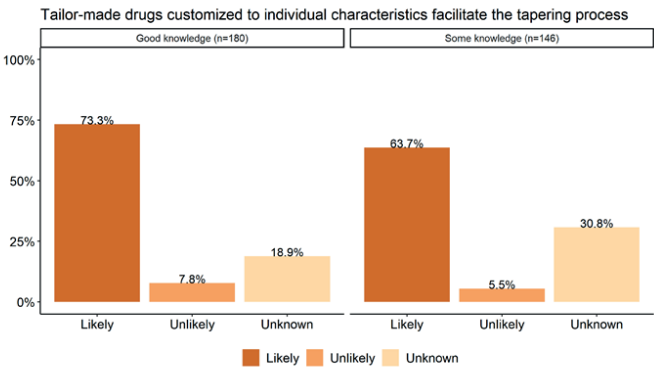


Table 5: *Tailor made drugs customised to individual characteristics facilitate the tapering process*



2019; Kaufmann et al., 2017; Kaufmann et al., 2017; Read & Sacia, 2020; Valtonen & Karrasch, 2020; Gotzsche, 2020). See Table 3.

The scientific literature and users' life experience indicate that the longer an individual uses a psychiatric drug, the more likely they are to suffer more severe withdrawal symptoms (M. Harrow et al., 2012; M. Harrow & Jobe, 2013; Martin Harrow & Jobe, 2007; Moncrieff, 2006). Most respondents agreed with this position (see Table 4).

There is a growing body of evidence that suggests the importance of prescription drugs being made available according to the individual characteristics of patients, both for the effectiveness of treatment and for the discontinuation of the use of the prescribed drug. Knowing the respondents' opinions on this was certainly the most important point of this research. The vast majority of respondents agreed with the statement presented, reiterating

the need to provide personalized discontinuation of psychiatric drugs, respecting each individual's characteristics and needs and thus allowing a greater chance of success for the procedure (see Table 5).

Some conclusions

As expected, a high percentage of the respondents felt they did not have much knowledge (45.05%) on the withdrawal process for psychiatric drugs. Although patients have been complaining for decades about sometimes unbearable physical and mental symptoms, even leading to suicide, the scientific literature on psychiatric drug withdrawal is still incipient.

It was only in 1997, with the introduction of "antidepressant discontinuation syndrome," that the difficulty of discontinuing the use of psychotropic drugs was officially admitted (Schatzberg et al., 2006). Even so, the scientific literature still demonstrates great difficulty in recognizing that such symptoms are actually "symptoms of dependence" (Kirk et al., 2013).

Most respondents agreed with the importance of withdrawal from psychiatric drugs for the well-being of patients. This suggests there is growing recognition that the psychiatric drug withdrawal process is accompanied by physical and mental symptoms that demand adequate assistance.

The hegemonic thesis of psychiatric thinking, whereby psychiatric drugs correct supposed chemical imbalances in the brain that underlie diagnosed psychiatric disorders, is far from being consensual, with strong evidence suggesting its lack of scientific validity (Moncrieff, 2009; Valenstein, 1998; Gotzsche, 2016; Kirsch, 2010; Breggin, 1993; Royal College of Psychiatrists, 2019). Therefore, it is not surprising that the vast majority of the respondents were willing to admit that the benefits of psychiatric drugs might outweigh their innumerable harms, particularly when their use is long-term. It is known that the longer the use of psychiatric drugs, the greater the likelihood of users presenting withdrawal symptoms. The scientific literature is strongly guided by the double-blind randomized methodology, which is designed to indicate whether a drug being tested improves the results of the condition to be treated more than the "control" treatment. Most research is done under "artificially" created conditions, usually focusing on short-term effects. However, as the body of evidence that psychiatric drugs create chemical dependency in their users grows, it becomes increasingly imperative for technologies to be developed that make psychotropic drugs available in doses that can be tailored according to the characteristics and preferences of their users.

Finally, the core issue of this investigation was to find out what the scientific community thinks about having "personalized medicine" available to clinicians (prescribers) and patients that meet the individual needs of users in order to facilitate the withdrawal process. This was the point where there was the greatest agreement: the vast majority agreed that there should be, which is consistent with the latest scientific literature. In

2019, it was admitted for the first time in the UK that psychiatric drug withdrawal symptoms may be more severe and lasting than had previously been assumed (Horowitz & Taylor, 2019). The argument that users must be provided with means to obtain compatible dosages to enable their safe and effective tapering is starting to be advocated more strongly in the scientific literature (P. Groot, 2020; P. C. Groot & van Os, 2018).

To conclude: the outcomes of this study demonstrate that in a context of mass prescription and use of drugs for the treatment of psychiatric disorders, there is a marked lack of scientific evidence on dependence, withdrawal symptoms, and especially safe and effective withdrawal technologies. The results of our study suggest the importance of developing technologies to assure the availability of psychiatric medications in adequate doses to enable the tailored discontinuation of psychiatric drug treatment.

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Discontinuing psychotropic drugs? And if so, how?

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ABSTRACT: Anyone who wants to stop taking psychotropic drugs is well advised to think through this decision carefully, to take possible withdrawal problems into account and to proceed gradually, especially after a longer period of taking the drugs.

KEY WORDS: Deprescribing, Demedicalising, Antipsychotic, Humanising

No one can predict how a psychotropic drug discontinuation process will go in detail. Mainstream psychiatrists are only interested in problematic discontinuation attempts, not in those that succeed, especially when people stop taking psychotropic drugs on their own. The number of those who discontinue without problems is unknown; they do not appear in any statistics. Attempts to stop can also fail, for example, because psychological problems are still too severe, because additional problems have arisen due to drug-caused changes in receptors, the cronification of the original problems included. Often, withdrawal problems increase exponentially around the zero line, i.e., they grow faster and faster the closer the dose is to zero, so it can be more bearable sometimes to maintain a low dose than to do without psychotropic drugs altogether.

The latter is especially true for antidepressants and low-potency and atypical neuroleptics such as clozapine¹, because the complete withdrawal can often be associated with immense difficulties, or with too much fear of not being able to go through the discontinuation process. A dogmatic approach that psychotropic drugs must always be discontinued is as harmful as the psychiatric tenet that psychotropic drugs must be taken for the long term.

For some time, some psychiatrists have been trying to identify which factors indicate that discontinuation processes are favourable. Among the factors they have found so far are the ability to self-manage crises, the existence of other life goals beyond discontinuation, the use of effective psychotherapy, stable parents, a supportive family and others, a low-stress social environment, the absence of stressful life events, the recognition of clear triggers of past episodes, a period of six months without noticeable mental symptoms, two years without relapse, and a supportive doctor (Aderhold, 2016).

Patients on psychotropic drugs who are willing to come off them will not be deterred from discontinuing by the absence of these conditions. It is difficult to find doctors and psychotherapists who are unbiased, supportive and competent in discontinuation counselling, and to develop self-management skills or new life goals under a damping effect of psychotropic drugs. Or if the environment itself is a stressful life event and has contributed to the psychotropic drugs' prescription. Or if noticeable psychological symptoms are precisely the effects of psychotropic drugs. A one- or two-year wait would then perhaps be the time when physical dependence develops, a supersensitivity psychosis, a chronification of depression or other physical damage.

Favourable factors for successful discontinuation are supportive and competent doctors and their regular consultation. However, a doctor is usually assigned a different role, according to the German psychiatrist Asmus Finzen:

"After all, his job is to prescribe medication. Doctors learn that. How to stop medication is not what they learn" (2015).

And yet people discontinue their psychotropic drugs. They do this with the support of a doctor or against medical advice. People decide on their own, with or without a doctor, to take a certain path, act as carefully and prudently as possible, and orient the next step based on the respective current situation.

In order to improve the chances that the withdrawal process will end successfully, the following aspects should be considered:

1 Marketed as Cloment, Clonia, Clopin, Clopine, Closin, Clozalux, Clozapin, Clozapine, Clozarem, Clozaril, Clozatab, Denzapine, FazaClo, Leponex, Leudex, Merbaril, Versacloz, Zaponex.

Don't be impatient

This is also the first general advice from responsible doctors and from ex-patients. Those who have been taking psychotropic drugs for a long time should stop gradually and start with a smaller reduction trial to see how he or she copes. What is “long-term” is related to the individual physical process of getting used to the psychotropic drugs. Patent recipes and general statements are not possible here.

The 10% formula developed by the US-American doctor David Richman in 1984 and often mentioned, according to which the starting dose is used as the basis for discontinuation and then progresses gradually in ten steps, is merely a calculation example, not a general guideline. If withdrawal symptoms occur after a dose reduction, one remains at the same dose until they subside or disappear, and only then proceeds to the next step. Alternatively, one can return to the previous step (with the higher dose) where he or she did better and stay there until he or she moves on again to the next lower step (NAPA, 1984, pp. 54-56).

While tablets can be divided precisely with pill cutters, capsules pose a problem. They contain not only the pharmacological active ingredient but also flavourings and preservatives. Since dividing them does not guarantee that the actual active ingredient is evenly contained in the powdered parts, it may be advisable to switch to taking them in a tablet or drop form before gradual withdrawal.

Extreme care is needed in the transition from the final mini-dose to zero. Repeatedly in the past, patients have spoken out in the self-help field, whose nervous system, which was particularly sensitive during this time, played a trick on them just when they thought they had already reached their goal. The stronger and longer the receptors were blocked, over-sensitised, or were changed in other ways by the psychotropic drugs, the stronger and longer rebound, hyper- and supersensitivity symptoms can naturally occur.

Those who fear such symptoms or have already experienced them and have a competent doctor at their side should suggest that the doctors write prescriptions for individual dose preparations at the pharmacy if sufficiently small doses via capsules, tablets or drops are not possible. In Germany, for example, the statutory health insurance can reimburse the costs of such prescriptions. The amount of active ingredient is freely selectable, write psychiatrists Jann E. Schlimme and Uwe Gonther. Usually doctors can work in the milligram range to one decimal place (2018).

Further advice

Besides the standard advice to proceed slowly and gradually after a longer period of ingestion, there are other sensible pieces of advice:

- Become informed about risks, adverse effects and half-lives of psychotropic drugs and about alternate ways to cope with emotional distress. Consider withdrawal symptoms that can last for weeks or occur with a delay, and residual symptoms

that can take several months or even years. Be around people who understand psychotropic drug withdrawal. Possibly see doctors who have understanding, empathy and tact. Be cautious of doctors who pretend to be understanding and try to talk you out of the wish to come off psychiatric drugs when you have the slightest problem, and who recommend other psychiatric drugs as alternatives that are said better tolerated. If you have confidence in your doctor, inform him or her and ask whether he or she is familiar with discontinuation counselling and supports withdrawal.

- Plan ahead. Consider changing your doctor if you anticipate that he/she may refuse or be unable to help support your withdrawal, if support is necessary. Before withdrawing, be sure you are informed about risks of losing your apartment, welfare or other benefits if any of these are dependent upon your willingness to take psychiatric drugs. Look for the right season for change.
- Seek confidant and support. Inform close, well-meaning people of the plan. Establish regular contact with a person you trust or with one or more professional, trustworthy and easily accessible people who is ready for a supportive contact once or twice a week. Initiate discussion rounds (“therapy convention,” “network discussions”) with important therapeutic and private reference persons to consider and agree on the course of action and check the individual situation including fears, risks and possibilities for their realistic content. This applies in particular to fears of acting against medical advice, fears of the reactions of relatives and fears of recurring emotional problems or a new hospitalisation.
- Get advice. Talk with others who have experienced withdrawal. Join a self-help group where each member is respected as an individual. Beware of “self-help groups” whose members have undergone psychoeducation and who believe that relapse is 100% certain if you do not follow the doctor’s instructions. Don’t let yourself be talked into a panacea and don’t let yourself be pressured. Don’t do anything simply to please or impress someone else.
- Have herbal therapies on hand to ease withdrawal. Take organ-strengthening, detoxifying and withdrawal-relieving preparations. Chlorophyll-rich and sulphur-containing foods support detoxification. These include all edible green plants, wild plants, herbs, vegetables, green sprouts, juice from wheat grass (or grass from other cereals), as well as sea vegetables (brown, red and green algae) and micro-algae (spirulina, chlorella). Naturopathic remedies and omega-3 fatty acids can also be helpful, as well as folic acid, vitamin C and E for three to four months at a time.
- Get legal direction. For the imminent case of renewed contact with the compulsory psychiatric system, contact a confidant in advance, draw up an emergency plan and protect yourself with a psychosocial advance directive against unwanted

administrations of psychotropic drugs and electroshocks. Don't forget: Refusal to take clozapine (or other neuroleptics) is an indication for electroshocks. You should ask yourself ahead of time: What do I need if I become anxious, depressive, suicidal, manic, or crazy? What will help me in that situation? What should I refuse? What will I accept? What am I risking? Who are the people who will support me?

- Create a quiet environment. Keep away from burdening relatives or relatives who cannot be burdened during withdrawal. Avoid stress and aggressive places. Don't answer the phone if telephoning is associated with stress. Do not allow intrusive "helpers" into your home. Go somewhere peaceful, for example, to the seaside or the countryside.
- Get enough exercise. Go walking, hiking, jogging, dancing, swimming, cycling, practice gymnastics, aerobics. When it is too hot outside, go to the gym.
- Take care to get good nutrition. Eat well—regularly, but not excessively. Make sure you get plenty of fibre, whole wheat foods, salad, fresh vegetables, fresh fruits, and lots of liquids, eventually diet. Possibly avoid drinks that make you nervous, such as coffee or black tea, alcohol, fast foods sugar (sweets, ice cream, soft drinks), stimulants and drugs such as marijuana or ecstasy. If you are used to coffee or black tea and stop drinking them when you stop taking neuroleptics, consider that they will no longer interact with them and that Parkinson's symptoms caused by neuroleptics may temporarily increase in intensity despite their reduced dose.
- Do something good for yourself, live with awareness. Listen to relaxing music, read pleasant literature. Stay in touch with friends. Keep a diary, paint, modell, make music, write, plant, sewe, cleane, build, craft, engage with an animal... If there are supportive professional workers, it can be beneficial to write a successive protocol about the withdrawal process. Reaffirm yourself with effective positive words and images that make you feel strong and able to carry through with withdrawal.
- And be sure to get enough sleep. Helpful are Kneipp cures, physical exercise, quiet sleeping room with suitable sleeping temperature, relaxation exercises, autogenic training and autosuggestion. Avoid and remove environmental toxins, use proven home remedies such as a glass of warm milk with honey, do not eat late at night, do not consume caffeinated drinks and do not consume excessive amounts of protein in the evening. Access herbal substances (valerian, hops, Californian poppy, passion flower, lavender, lemon balm, etc.), Bach emergency drops, aromatherapy (as essential oils to be inhaled), the hormone melatonin, food supplements, sleep diaries, stimulus control (linking the stimulus "bed" to the reaction "sleep") and sleep restriction (consciously limiting the duration of sleep and increasing sleep pressure). In emergencies, benzodiazepines and benzodiazepine-like substances can also be used. However, because of their addictive potential, these should only

be taken temporarily, for a maximum of about four to six weeks—the shorter the better—and if you have been able to sleep for two or three days, it is better to take a break from these drugs. Because of possible withdrawal problems (Lehmann, 2018, pp. 348-374) as well as to avoid a so-called hangover, one should also limit oneself to preparations with a medium half-life (approx. 8 hours)². During the time she worked at the Weglaufhaus Berlin, Kerstin Kempker described how sleep problems can be dealt with institutionally through physical abreaction and attention, as long as there is the good will not to adapt the rhythm of life of people with emotional problems to standard working hours by pharmacological means:

“The punching bag in the basement is used, even more than the wide fields that stretch from the end of the street to the next village. If you can’t sleep at night, you stay up and talk with us or those staying here or with yourself, take a bath, listen to music, read, cook something for yourself. The staff and/or the occupants love to take long evening walks” (2004, pp. 270-271)³.

Self-responsibility and Support

Reducing or discontinuing psychotropic drugs also means taking responsibility for oneself and not continuing to be satisfied with chemically modified sensory impressions. One declares oneself responsible for one’s own person and psyche (Zehentbauer, 2004). This includes that individuals themselves have to understand what happened to them, what they experienced and why they reacted with depression or psychosis and not otherwise. Where does the problem lie, how did it develop, what triggered the worsening of the problem which led to the need for help or to conspicuous behavior? It is vital to consciously address this issue in self-reflection, in a self-help group or in therapy. What happened? Who was involved? Had it to do with school, work, parents, relationship, sexuality? Has it to do with jealousy, dependency, addiction? Was it about excessive demands, for example, the feeling, the fear, or even the certainty of not performing satisfactorily, of not meeting the demands and expectations of parents, partners, teachers, professors or even the expectations placed on oneself? Was it about the fear of not passing an exam, not earning enough, not being sexually satisfied, not living up to the prevailing ideal of beauty? Was it about growing up,

2 For information about half-time of benzodiazepines see, for example, <http://www.vhpharmsci.com/vhformulary/tools/benzodiazepines-comparison.htm>, https://en.wikipedia.org/wiki/List_of_benzodiazepines#Pharmacokinetic_properties_of_various_benzodiazepines, <https://www.sciencedirect.com/topics/medicine-and-dentistry/benzodiazepine>, https://www.emcdda.europa.eu/publications/drug-profiles/benzodiazepines_en

3 For more advice on reducing withdrawal symptoms and risks, and in particular on alleviating withdrawal-related sleep problems, see Peter Lehmann’s summarising and concluding chapters “Closing remarks by the editor” (Lehmann, 2004, pp. 309-319) and “And Now, How to Proceed? A resume” (Lehmann, 2020).

breaking away from the parental home and entering working life? Was it about loneliness, the impossibility of approaching other people or developing relationships with other people and maintaining these relationships? These are questions that can torment all people, and if they increase and remain unresolved for a long time, they can trigger depressive or psychotic states again after coming off psychotropic drugs when their damping effect is gone.

These questions are also about taking a critical look at oneself and what one has contributed to psychiatrisation (Boevink, 2004). For Marc Rufer, an in-depth examination of the psychiatric diagnosis is indispensable:

“Psychotherapy that does not confront this issue misses the point. Psychiatric diagnoses are arbitrary social constructs, using them means medicalising psychosocial problems and serves as a justification for the administration of psychotropic drugs and electroshock.

Anyone who is convinced that he or she suffers from a biologically determined disorder will never finally get away from the idea that it must be corrected with psychotropic drugs. However great the need is for a life free of psychotropic drugs, however much the person suffers from the effects: There will always be an ambivalence, a great uncertainty in this situation. After all, the patients were clearly told that the regular intake of psychotropic drugs was indispensable. In most cases, the desire to stop taking the drugs is associated with fear of the consequences of discontinuation. And fear is a terrible companion. It is very possible that it—as a self-fulfilling prophecy triggered purely psychologically—is responsible for the feared ‘relapse’ actually occurring.

The meaningful but difficult to achieve goal should be a person who has finally detached him- or herself from the identity of the psychiatrically diagnosed person and who is convinced that he or she can live without psychotropic drugs—a person who can independently and freely determine his or her life and future.

One way for patients to achieve this goal is to leave their environment; but this requires a lot of strength. The support of people who are positive about discontinuing would be helpful in this.

If the people remain in their previous sphere of life, this also means a challenge for their relatives: Their small and at the same time large contribution to successful discontinuation would comprise them also giving up the psychiatric way of looking at things. They would have to let go of the conviction that the person in front of them is mentally ill and urgently dependent on taking the psychiatric drugs. They would have to seriously show that they accept, respect and appreciate them unconditionally—without at the same time blackmailing them, which unfortunately happens all too often: ‘You can live with us, we stand by you—but this only on the condition that you take your medication every day’”(2017).

The appearance of a ‘mental illness’ should be understood as a signal of departure

and shows the need for change, according to Maths Jespersen:

“Madness is no illness to be cured. My madness arose as a means of forcing me into a new life”
(2004, p. 76).

In the meantime, there are isolated cases of competent advice on risk-reducing measures when discontinuing, especially on questions that cannot be answered with general advice, for example, the problem of discontinuing psychopharmaceutical combinations, which is completely negated by mainstream psychiatry. In the context of the expert conference “Competent help when discontinuing antidepressants and neuroleptics” 2017 at the Charité Berlin, Jann E. Schlimme (2017), a psychiatrist, for the first time, set out to develop steps towards a set of rules for discontinuing psychopharmaceutical combinations, also considering their interactions, from the tendencies of individual experiences.

Where to get advice you can find on the Internet at www.absetzen.info⁴. Information you can find in particular in the book *Coming off psychiatric drugs: Successful withdrawal from neuroleptics, antidepressants, mood stabilizers, Ritalin and tranquilizers* (Lehmann, 2004, 2020). In this book, former psychiatric patients from many countries who are now free or at least relatively free of psychiatric drugs write about their experiences with discontinuation and withdrawal. Additionally, relatives, doctors, psychotherapists and other professionals explain how they help with discontinuation. In the meantime, the first associations of professional psychosocial workers also offer useful information on risk reduction when discontinuing psychotropic drugs, for example, the German Society for Social Psychiatry (DGSP, 2014) or the British Council for Evidence-based Psychiatry⁵.

In order to make the discontinuation successful in the medium and long term, it is generally necessary to refuse to adapt to situations that are perceived as unpleasant. This can include leaving a stressful environment as well as ending an unhappy partnership—which is certainly not as easy as it sounds. Of course, there are also unpleasant situations that you have to learn to cope with, such as crowded subways, bad news or inconsiderate car drivers or cyclists.

One reduces the danger of being prescribed psychiatric drugs again so quickly if one learns to take one’s own feelings seriously, to follow one’s own intuition, to deal with the meaning of depression and psychosis, to recognise one’s own active contribution to psychiatrisation and to look self-critical in the mirror, to assess one’s own vulnerability, to recognise warning signs of emerging crisis situations and to react accordingly.

Warnings

4 See also <http://bit.do/absetzen>

5 See <http://cepuk.org>

As in all areas of life, we advise caution when blanket support or panaceas are offered. Occasionally you may encounter charlatans, dogmatists and would-be therapists. Basically, one should be careful with professionals as well as in the self-help sector. You should steer clear of therapists, family and self-help groups who have undergone psychoeducation and learned from information material sponsored by the pharmaceutical industry that psychological problems express metabolic disorders and that relapses occur as a matter of course when psychotropic drugs are discontinued.

Doctors who do not inform about receptor changes, formation of treatment resistance, tolerance building and discontinuation and withdrawal problems with psychotropic drugs are serious risk factors for failed discontinuation attempts. They also bear a significant responsibility for unwanted continued administration of psychotropic drugs, or even electroshock. An example of a relatively responsible practice of psychosocial workers in dealing with psychotropic drugs is the educational brochure that German psychiatrists at the Rhein-Mosel-Fachklinik Andernach, the Rheinhessen-Fachklinik and the Pfalzkrinikum Klingenmünster already present to their patients when they want to administer neuroleptics to them. They provide information not only about risks, harms, discontinuation problems (but yet not about dependency risks), alternatives and independent sources of information. And they offer help with discontinuing psychotropic drugs right from the start: "If you decide to take this path, we would be happy to support you to the best of our ability" (see the article "Antipsychotics Information Brochure" by the Network Self-help on Mental Health in Rhineland-Palatinate in this book).

It would be nice if this point of view would become accepted in practice and set a precedent.

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Using the Wellness Recovery Action Plan to withdraw from psychiatric medications

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ABSTRACT: This article describes the ways in which the author withdrew from psychiatric drugs and the subsequent development of a self-help tool for withdrawal – the Wellness Recovery Action Plan (WRAP)

KEY WORDS: Psychiatric Drugs, Self-Advocacy, Support, Lived Experience

My personal experience of getting off psychiatric drugs was in the late '80s. Medications were taking away my life. They made me sluggish, fat, unmotivated, unhappy and unhealthy. I had dry mouth. My vision was blurry. My existence was minimal. I ended up, in my 40s, living in a public housing complex for the elderly that included a few younger people with disabilities. I was diagnosed bipolar. I was on Social Security disability benefit and I was on Social Security records as permanently disabled. I was marginalized and discriminated against.

How did I begin to travel the road of using psychiatric medications? I was experiencing deep, deep depressions that were debilitating and unsafe. I went to a psychiatrist and told him my story, including the story of my mother, who spent eight years when I was growing up in a large state “mental institution”. He said, “Ah, your mother was manic depressive. You are manic depressive. You need to take these pills, and perhaps these.” Over time he prescribed more and more pills. And hospitalizations. And more pills. There was never a suggestion that I might have Post Traumatic Stress Disorder from some horrific incidents and times in my life. There were no ideas for simple, safe, non-invasive options that might help me to feel better and move on with my life. I felt like my life was being taken away. I asked a doctor what people like me did on a day to

day basis to manage their moods. He told me he would have the information for me at the next appointment. By the next time we met, he thought that I would have forgotten about my request. But I hadn't. He told me that there was information on medications and hospital programs and even electroshock administration, but no information on how people might manage their lives, and, of course, nothing at all about recovery. I decided to change that. Using primitive but effective research methods - it was the 1980s, before the widespread use of computers - I did a qualitative study of 125 people who were living with a psychiatric diagnosis. I asked them open-ended questions about how they managed their lives. And I asked my mother. I received mountains of information. That was the beginning of my career of learning how people like me cope and how they get well and stay well. I found out from this cohort of people with lived experience that there were lots of things I could do to help myself feel better. I used their feedback for my own recovery, and then began sharing it as widely as I could. I used it to write the first of many books on this topic. I started using the word recovery in my writings about my findings. I was lambasted for that. I was told, in no uncertain times, that I was giving people false hope! (I ignored these critics.)

With my adult son's encouragement (he was the only one), I decided that I would take my chances, defy the doctor's orders and gradually reduce the drugs. My goal was getting off the medications completely. I had no support from anyone, no health care providers, no counsellors, just one son who thought the medications were doing a lot more harm than good.

I was successful, but that was a fluke. I was very, very fortunate. Gradually, over time I got off the medications and got my life back. I developed a successful career, bought a home, and eventually got into a relationship that has nurtured and sustained me for over 25 years, something I could never have done if I had not stopped taking the psychiatric medications. The system needs to change to one where, when a person asks for help, they are encouraged to use simple, safe, non-invasive Wellness Tools, rather than medications.

If, unfortunately, you are already on psychiatric medications and they are stealing your vitality and your life, how do you get off these medications and reclaim your life?

Don't do it the way I did. Don't do it without a Wellness Recovery Action Plan® (WRAP®) and a team of supporters that assist and support you in developing and using your WRAP. When I reduced and then stopped taking psychiatric medications, there was no WRAP yet. Just lots of tools and techniques that I could use to help myself stay better and feel safe, tools that I learned from the people in my studies. The way I did it was risky. I was lucky. It could have been a disaster.

If I had to get off psychiatric drugs now, I would prepare by developing an intensive Wellness Recovery Action Plan (I do have one now that I use to make sure that I never again get into a situation where a doctor might prescribe psychiatric drugs). Then I would use it every day, so that I use it very well and can easily use it in emergency situations, like

when I am having symptoms caused by withdrawing from the medications, or there is a return of the feelings that preceded taking the medications.

A Wellness Recovery Action Plan includes 1. a list of Wellness Tools, 2. a description of what you would like to be like; 3. a Daily Maintenance Plan, which is a list of Wellness Tools you need to use every day to stay as well as possible, 4. a list of your Triggers (now sometimes called stressors) and a list of Wellness Tools that you can use to help yourself feel better if one of these situations occurs; 5. a list of Early Warning Signs, signs that you may not be doing so well, along with a list of Wellness Tools you will use when you notice those signs; 6. a list of signs that things are “breaking down” or getting much worse and a very structured plan of Wellness Tools you will use if you experience signs that things are breaking down; 7. a Crisis Plan that describes signs that others should step in and help you, and gives them instructions on how to assist and support you if you can no longer take care of yourself. In the Crisis Plan you also name those people you want to take over for you, and those you don’t want involved. 8. The last part of WRAP is a Post Crisis Plan that you develop as you are recovering from a crisis and that you can use to guide you through that time when you are recovering from the crisis.

Although I was part of developing WRAP, I have found that it is the only recovery and wellness plan that I have reviewed that I thought would help me get well and stay well over time, and would work for many different circumstances, including getting off psychiatric medications. WRAP was developed by a group of people in a recovery workshop that I was leading, people who felt they needed a structure around the strategies they were using to get well and stay well. WRAP was not developed by mental health professionals who claim to have no lived experience.

WRAP has worked for me in keeping me stable and well for the long term. I have heard from many others that it has worked for them, helping them achieve goals they had come to believe were impossible. My books describing WRAP have sold millions of copies and are the basis for multitudes of recovery trainings. WRAP groups are held every day, in all kinds of settings, around the world. It is evidence-based. WRAP incorporated many of the ideas that I learned in my early research. People have used WRAP to get off psychiatric drugs. That is what I would do if I had it to do now. That is what I would urge anyone to do that is contemplating getting off psychiatric medications. I have learned what I am sharing from people who have “lived experience”, including my own personal experience, who have figured out how to get their lives back after years as a “psychiatric patient”.

If you are working on getting off psychiatric medications, start by getting yourself a WRAP book or a WRAP resource as a guide (see mentalhealthrecovery.com). If it seems right to you, go to a WRAP group or watch a WRAP video.

Before I describe the parts of WRAP in detail, you need to understand the Key Concepts of WRAP, concepts to live by as you move forward:

1. There is lots of hope. Lots of people get through what you are going through,

recover and move on and you will too. It is up to you to do it. No one will do it for you. To go through the process that you may be contemplating, you need to fully believe that there is hope, and that you will successfully get through this. It is hard. You can do it. I did.

2. You need to be in charge of every aspect of your life, including your withdrawal from psychiatric drugs. This is your life. If other people insist you do things a certain way, let them know that is not acceptable. You can get good information from others, but final decisions are your choice and no one else's. This is your life.
3. Educate yourself. Learn all you can about the medications you are taking and the protocols for reducing and getting off your medications so you can make good decisions for yourself as you go through this process. The internet is a vast store of information that can facilitate this process.
4. Advocate for yourself. Ask for what you want and what you know you need, and keep asking for it until you get it. Refuse what you don't want or what you know is not right for you.
5. Develop a strong cohort of supporters who are willing to walk this difficult journey with you, who will listen to you, stay with you in hard times, go with you to appointments with health care providers if you want them to, and respect you, your priorities and your decisions. Many people don't have this kind of a support system. Build it over time by going to support groups, joining special interest groups and participating in community events. You may have family members who will support you through this process. Your choice of supporters is up to you. Don't let anyone try to convince you of who your supporters should be or who should make your decisions for you.

It would be easier if someone could develop a WRAP for everyone and we would just follow it and we would be fine. This is not possible. We are all different people. How we respond to psychiatric drugs and how our body responds as we reduce them differs from person to person. Each person needs their own idiosyncratic WRAP - developed by them, for them - and open to revision as needed, whether frequently or not so often.

The Wellness Recovery Action Plan as described here is a plan that works for lots of people who experience mental health challenges, so that is why we describe it that way in resources, groups and trainings. However, you can adjust it in any way that works best for you, or makes the most sense to you. That does not mean that you are not using it right. It means that you are using it in the way that works best for you.

Working on your WRAP

You can do this by going to a WRAP group, or on your own using one or several of the WRAP resource books (www.mentalhealthrecovery.com) or by following the simple

description I am including here. It helps to work on it with a friend or friends, especially if they have similar issues and are working on their WRAP at the same time.

What is in your WRAP is up to you. Don't let anyone else tell you what should or should not be in it. You don't have to share it with anyone else unless you want to.

Wellness toolbox

Begin by developing a list of Wellness Tools - things you can do to stay well, things that help you feel better when you do not feel well and things that will enrich your life. My list contains over 200 Wellness Tools. Even now, if I am having a hard time, there is a Wellness Tool, and usually several, that will help me feel better and get me through rough times. They can be simple or more complex. They are specific to you. Although you might get ideas for your list of Wellness Tools from mine, many of them may not be helpful to you. Include only Wellness Tools you know would work for you. You are the only expert on yourself. Some of my Wellness Tools are the same ones that most people put on their list, like eating breakfast, taking a shower, listening to music, going for a walk, petting my dog, doing a relaxation exercise or watching a funny video. Some that are more specific to me would be going on long hikes, playing the piano, working on a quilt, calling my grandson, working in my flower garden, sketching, looking at the view, doing a Tapping exercise and (would you believe it) vacuuming. I add new tools to my list of Wellness Tools all the time as I become aware of what helps me feel better. It helps to include things that have worked well in the past.

One of the key Wellness Tools for me is support. From my early studies, I learned how important support is to wellness and to getting through hard times. In my first study, I learned from the participants that everyone should have at least five mutual supporters who will listen without critiquing and only give advice when asked - people for whom you provide the same kind of support. (I believe that, to be most effective, support has to go both ways.) When I went off psychiatric drugs, I knew little about support. I did it on my own. That was not good. Over the years, I have learned more and more about support from people with lived experience. Support has kept me going when times have been hard.

The time and effort you put into developing your list of Wellness Tools is time well spent. You can find ideas for Wellness Tools in my book, WRAP for Life. You can get lots of ideas for Wellness Tools from others with similar issues if you join a WRAP group. Keep adding tools to your Wellness Toolbox as you become aware of them. The tool box is not static. It changes and grows. Things that used to be helpful may not be helpful any more. You will become aware of more and more Wellness Tools over time. Most nights, before I go to sleep, I think about all the Wellness Tools I have used that day.

What you are like when you are well

One more thing to do before beginning to work on the action plans part of your WRAP; write a simple description of yourself when you feel great, the way you would like to feel much of the time. It can be a simple list of words, or more extensive. Some people like to include their favorite picture of themselves. Then you can refer back to it when it is hard to remember feeling well.

Daily maintenance plan

The Daily Maintenance Plan is a short list of Wellness Tools to use every day to stay as well as possible. It can include things you want to avoid. Keep it doable. Some suggestions would be: eating 3 meals a day, exercising for at least ½ hour, showering, spending at least ½ hour doing something you love to do, and talking with a supporter. You can include things you want to avoid like sugar, alcohol, street drugs and certain people. Revise these lists as you need to, and as you learn things that help and things that don't help. You can also include a list of things you might need to do today - a list to review every day to assure yourself that you are staying on track; things like contacting a counsellor, health care provider or an advocate, getting groceries, cleaning and doing laundry. These are things you don't need to do every day, but if you do need to do them and forget, it can be upsetting. And it's hard to deal with one more thing when you are reducing your medications, already a very stressful time.

Triggers or stressors

These are the unexpected, stressful things that happen to everyone, that are upsetting, that can cause us to feel worse, and can change the way we respond to medications and our withdrawal from medications. They can be small, with minor impact, or they can be huge, changing the way we think and feel and perhaps changing our life, and changing the way we respond to our efforts to withdraw from medication. Examples of Triggers or Stressors might be a storm, an argument, the anniversary of a traumatic event, a minor or major loss, an unexpected bill or a disappointment.

The challenge is to come up with Wellness Tools, that can be easily used when Triggers or Stressors occur, that relieve their impact on our stability and our reactions to drug withdrawal.

Review your list of Wellness Tools to develop a plan you think would help relieve the effects of these Triggers or Stressors. This list needs to include a variety of options so that there is always one to use, whatever the circumstances. It might include a meditation practice, increased contact with supporters, time off from responsibilities, playing or listening to music, creative activities and intense exercise. I include several tools that I can use in situations where I have limited resources, like on the bus or in a crowd, things like deep breathing or repeating a positive affirmation in my mind.

Early warning signs

These are not as easy to identify, but responding to them quickly can make all the difference in whether things get much worse. For instance, you might notice a particular tick in your face, an unusual ache or pain, numbness, a mild headache, fatigue, difficulty with balance, lack of feeling, depression, negativity, or increased nervousness. Identifying them can be difficult as they are minor or mild. The list can be increased over time as you notice more and more of these signs. Next, referring to your list of Wellness Tools, make a list of things that will help relieve the Early Warning Signs. The list might include: contact a health care provider, take a nap, use an ice pack on a particular area, get more exercise, slow down your medication reduction or do a relaxation exercise. Use those that will work best, depending on the circumstance. This becomes easier, even habitual, over time. While the Stressors or Triggers list needs to include lots of different options for different circumstances, for Early Warning Signs, many people feel that since they are in a mode where it is hard to figure out what to do next, this plan needs to be more structured, reminding yourself of specific things you must do.

When things are breaking down

The original developers of WRAP, a group of people who were having struggles to stay well, wanted to call it “When Things are Going to Hell in a Handbasket”. But they decided that might not be acceptable, so it became “When Things Are Breaking Down”, a time when things are much worse and you are afraid you might get into a crisis where others need to make decisions for you or take over your care. I have heard numerous reports that once people start using WRAP intensively, they no longer have crises. They are more considered about how they feel and take action to avert a crisis. It is challenging but many people are doing this successfully.

It is even more challenging when you are reducing psychiatric drugs. You don’t know what you will experience when you go off medications and you may have a hard time figuring out what to do about disturbing things when they occur. It may be hard to get needed assistance and support. You may have to revise your plan often so that it is effective and include lots of options. Your signs that “Things are Breaking Down” may include things like trembling, numbness, confusion, memory issues, lightheadedness, mood swings, dizziness, nausea and blurred vision. Then you have to figure out which of your Wellness Tools might work in these situations, and make a plan to use them if they occur. This is not going to be an easy task. Getting input from other people who have gone off psychiatric medications, perhaps in a WRAP support group, and having the guidance of supportive health care providers, is really helpful. We could say this support is “essential” but we know that it may not be available. You may really have to figure things out for yourself as you go along. For instance, you may find that a warm compress stops the trembling or helps the numbness, that more (or less) exercise relieves your mood swings, that limiting

certain types of activities helps, and that dietary changes make you feel better, or worse. This part of your plan may change often.

Crisis plan

These first sections of the plan, Wellness Tools, What You Are Like When You Are Well, Daily Maintenance Plan, Triggers or Stressors, Early Warning Signs and When Things Are Breaking Down, are all developed and used by the person who, in this case, is withdrawing from psychiatric medications. The next section, the Crisis Plan, is, like the rest of WRAP, developed by the person who is withdrawing from psychiatric medications. It differs from previous parts of the plan, however, because it gives instructions to supporters that tell them what to do for you if you get into a situation where the signs you list tell your supporters that they need to take over responsibility for your care. This means that your supporters must be people who know and support what you are doing and are willing to act on your behalf if it becomes necessary.

The first thing you write in your Crisis Plan is a list of signs that would indicate to your supporters that they need to take over for you. This is not easy. It may take time to think about these indicators and, as you proceed through this journey of withdrawing from psychiatric medications, you may discover other signs that you had not anticipated. You might ask others who have withdrawn from psychiatric medications what to expect, and what you might include on this critical list. It might include things like being unconscious, unable to move, unable to move parts of your body, severe tremors that keep you from being able to move or speak, aggression, not recognizing family members, and threatening suicide.

Next, name the people you want to take over for you if they observe these signs, people who have the needed knowledge, and that you trust to follow your direction as described in your WRAP. They can be family members, friends or health care providers. Perhaps, it is someone you met in a WRAP group. Depending on your circumstance, you may also want to list people you do not want to take over for you; people like family members who refuse to follow your direction or who don't approve of your withdrawal from psychiatric medications.

Include a complete list of the medications you are taking and the protocol you are following to withdraw from each medication. As with the rest of the plan, but importantly with this section, keep it up to date with any change in plans of how you are proceeding. You may also list any supplements that you are taking and, if that is what you want, ask supporters to make sure you can continue to take those supplements when you are in a crisis, or if that is what is recommended by a naturopathic physician. Add a list of your health care providers, what they do for you and when they should be contacted.

You may want to include your feelings about various therapies that you may have had in the past or that are used to treat people who experience what are often referred to

as “psychiatric symptoms” - like electroshock administration. These things could be done to you unless you include a strongly worded statement that these treatments are not to be used. When you complete this plan, you may want to have it signed by a person to whom you have given medical power of attorney. If you feel strongly about it, you may want to have the attorney also sign this section of the plan.

Next, make a list of any therapies that have been helpful to you and that might be helpful if you were in a crisis - things like massage, cranial sacral therapy or chiropractic - and under what circumstances arrangements for these therapies should be made.

Follow that with a list of hospitals or care facilities where 1. you would want to be taken if needed and why, and 2. a list of those places where you would never want to be taken and why.

Next make a detailed plan of what a “hospital day” at home or in the community would be for you. This is challenging. Include information on: 1. where you would want to be, 2. who you would want to be with, 3. who you would want to avoid, 4. what kind of food you would like, 5. what activities should be available (videos, reading materials, computer, art supplies, exercise equipment, etc.), 6. the time you usually get up and go to bed, and 7. any other details of daily living that are important to you.

Next make a list of things that others can do that would help. You will get ideas about this as you move through your withdrawal from medications. Refer to your list of WellnessTools. You might want to ask supporters to bring you or prepare certain foods for you, to play games with you, to go for a walk with you or take you for a ride. You might ask them to just sit with you in silence for a time, to listen to you without interruption, to hold you or to listen to you. Include a list of people who should be contacted and, perhaps, a list of people that you don’t want to know anything about what you are doing.

Then make a list of things you would not want people to do for you when you are having a hard time. This list might include things like: forcing you to do anything, ordering you around, lying to you, yelling at you, praying over you, talking to you constantly, trying to convince you of something, cooking you certain foods that you don’t like, leaving you alone.

Complete your Crisis Plan by making a list of indicators that your supporters can easily observe that will let them know you are doing well and no longer need them to care for you or take action in your behalf. These indicators might include:

- Getting up at the usual hour and going to bed at the usual hour
- Getting dressed
- Minimal expression of pain
- No unusual or jerky movements
- Clear speech
- Clear thinking

The requirements for Crisis Plans vary from state to state and when followed, help assure that your Crisis Plan will be followed. You can build these parameters into your plan. In any case, it may help with the implementation of your plan if it is signed by a person to whom you have given Power of Attorney.

Post crisis plan

As you are recovering from this Crisis, you will have learned some important things about how to manage yourself and your life when you are working to get off psychiatric medications. These things will help you avoid another crisis. The Post Crisis Plan was developed after the rest of WRAP, as people who were using WRAP figured out that another section of the plan was needed. During a crisis, and as people recover from a crisis, they may discover different pathways that are needed to move forward more effectively and to prevent crises in the future. Although the parts of WRAP you developed prior to the crisis will help you in developing this part of the plan, it is meant to be developed as you are recovering from the crisis.

The first part of the Post Crisis Plan is a list of indicators that will let you, and others if you share this list with them, know that you are no longer in a crisis. You may not be recovered when you write this. And you don't have to feel perfect or be perfect to consider yourself out of the crisis.

In the next section of your Post Crisis Plan, you describe what you would feel like if you were feeling well. You did that as you were beginning to develop your WRAP, but over time, and especially as you are recovering from a crisis, the descriptions you include in that section may have changed. You may want to replace the section at the beginning of your WRAP with this new one you develop as you work your way through and out of a crisis.

Through the challenge of withdrawing from psychiatric medications, and of going through a crisis where you may have felt terrible, did things you wish you hadn't done, experienced loss and may have been at extreme risk, your perceptions of yourself, who you are, who you want to be and what you want your life to be like, may have changed. I found this to be a worthwhile exercise to do when I was hospitalized. Knowing what you want the outcome to be, what you want to be like and what you want your life to be like, will provide the guidance you need to continue to move forward.

Next, describe the things that happened or that you did that you feel may have precipitated the crisis; things like reducing a medication too quickly, not keeping hydrated, alcohol use, disagreements with family members, a big disappointment, having the flu or an injury. Then write what you learned from recognizing the things that caused the crisis.

Next, write the changes you want to make in your life as a result of what you have learned, and how you will make those changes, including the people you may need to help you do that.

Then, the most important thing to do in my view, is to carefully review your WRAP. What are the changes you want to make in your WRAP to keep from having a crisis in the future? Perhaps you learned some new Wellness Tools. Your daily maintenance list may need to be changed. Perhaps there are things you need to do every day that aren't on your list, and there may be some you want to take off your list. You may have discovered some new Triggers, and some Wellness Tools that work effectively to relieve them. You may have noticed some Early Warning Signs, and you may want to make changes in how you would respond to them. For me, the most important part of my WRAP to reconsider and revise is the section "When Things Are Breaking Down". If I got into a crisis, that plan didn't work. It is good recovery work to do, to figure out what didn't work and what you hope will work in the future, changes you hope will keep you from having a crisis in the future.

Include a section at the end of the Post Crisis Plan that reminds you of things that will ease your transition back to everyday life after the crisis. Such as: things you can ask someone else to do for you, things that can wait, people to support you and what you want them to do for you, things you need to do or might need to do for yourself every day. People, places and things to avoid, and people to thank, and things you want to take care of to avoid more difficult things that might happen as a result of the crisis.

WRAP is a living, fluid life plan. It has become my constant companion as I make my way through life. As my leg twists inward this morning, a remnant of my years of using psychiatric medications, I realize this is an Early Warning Sign for me. Perhaps it was triggered by a long hike I took a couple of days ago. I didn't realize I had been triggered so I got to the Early Warning Signs part of my plan. That tells me I need to do specific exercises that I have learned that help keep the leg from twisting - take a warm bath each day, wear high tops and a knee support, and avoid activities that aggravate the leg. If the twist continues and worsens, my plan tells me to contact my neurologist and arrange for a Botox shot.

This paper can get you started on WRAP. Go to WRAPandRecoveryBooks.com (Advocates for Human Potential), for a variety of books, resources and an app that will guide you through WRAP. Call (978) 261-1400. For information on WRAP training, or to find a WRAP group, go to copelandcenter.com or call (802) 254-5335 if you live in the USA. You can find support groups for people who are withdrawing from psychiatric medications on line.

The journey to withdraw from psychiatric medications can be a perilous one, as can the challenge of managing possible mental and physical health issues that may arise as you decrease your medications. My own answer to that has been vigilance and action - and using WRAP as my guide. It has worked for me. I am convinced it will work for others, too.

Do antipsychotics reduce the risk of relapse?

Robert Whitaker

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ABSTRACT: This article explores drug-induced dopamine supersensitivity as an explanatory discourse for the finding that relapse and subsequent re-psychiatrization is higher for those withdrawn from psychiatric drugs than for those who stay on the medication.

KEY WORDS: dopamine, schizophrenia, supersensitivity, meta-analysis

There are hundreds of studies, dating back to the 1960s, that are cited as providing evidence that antipsychotics reduce the risk of relapse in patients diagnosed with schizophrenia and other psychotic disorders. The findings appear quite robust: those withdrawn from antipsychotic medication relapse at higher rates than those who are maintained on the drugs. Yet, there is another line of research, also stretching back to the 1960s, that leads to the opposite conclusion. This research tells of how antipsychotics induce a “dopamine supersensitivity” that makes patients more biologically vulnerable to psychosis, and thus, over the long-term, increase the risk that patients will become chronically ill.

Although it may appear that these two lines of research are at odds, they can be reconciled. Drug-induced dopamine supersensitivity provides an explanation for why those withdrawn from antipsychotic medication relapse at a higher rate than those maintained on the drug. The high relapse rate in the withdrawn group can be understood as a drug-withdrawal hazard, as opposed to a return of the “disease.”

Chlorpromazine, which is remembered today as the first “antipsychotic,” was introduced into asylum medicine in the mid 1950s. Once short-term use of this drug and other similar “phenothiazines” became commonplace, an obvious question arose: how long should schizophrenia patients stay on the medication? To answer that question, researchers conducted randomized studies in which patients would be maintained on the drug or withdrawn from it.

In a 2012 meta-analysis of this research, Leucht identified 65 drug-withdrawal studies that had been conducted from 1959 to 2011. Most of the studies were with chronic patients; more than half were in hospitalized patients, and in 54 of the studies, the drug was abruptly withdrawn. In the 11 other studies, the medication was either tapered over at least a 3-week period, or depot treatment was allowed to lapse (Leucht et al., 2012).

At the end of three months, the relapse rate was 12 percent for the drug-maintained group versus 37% for the drug-withdrawn group. At the end of one year, the relapse rate was 27% for the drug-maintained group versus 65% for the drug-withdrawn patients. *“The results clearly demonstrate the superiority of antipsychotic drugs compared to placebo in preventing relapse,”* Leucht and colleagues concluded.

There is, however, an obvious design flaw with this research. The “placebo” group is really a “drug withdrawal” group, and it is well known that withdrawal from an antipsychotic exposes patients to many hazards, including severe psychotic symptoms (Correll, 2008; Larsen-Barr et al., 2018). As such, the relapse studies do not provide evidence that antipsychotics help people remain stable and reduce psychotic symptoms over the long-term compared with the “natural course” of the disorder.

The relevant scientific question remains: How do antipsychotics affect the “natural” long-term course of schizophrenia and other psychotic disorders? Do they help ameliorate symptoms and improve functioning over the long-term?

Stay well rates in the pre-antipsychotic era

The relapse studies tell of two-thirds of the drug-withdrawn group “relapsing” within one year, with that finding presented as the natural risk of relapse in schizophrenia patients. However, studies of first-episode patients conducted from 1945 to 1955 tell of a much higher stay-well rate.

- At Warren State Hospital in Pennsylvania, 62% of first-episode psychotic patients admitted from 1946 to 1950 were discharged within 12 months. At the end of three years, 73% of the initial cohort was living in the community. (Cole, 1959)
- At Delaware State Hospital, 85% of 216 schizophrenia patients admitted between 1948 and 1950 were discharged within five years. Seventy percent of the initial cohort were living in the community six years or more after initial hospitalization. (Cole, 1959)
- At Hillside Hospital in Queens, more than half of the 87 schizophrenia patients discharged in 1950 never relapsed during the next four years. (Lehrman, 1961)
- In Norway, a study of 6,315 psychotic patients hospitalized from 1948 to 1952 found that 63% had been discharged and never readmitted as of December 31, 1953. (Odegard, 1964)

These studies reveal that in the decade prior to the arrival of chlorpromazine,

a majority of people described as “first-episode psychotics” would be discharged within 12 months, and that two-thirds or more would be living in the community in follow-up studies of one to five years.

The revolving door syndrome appears

If antipsychotics reduce the risk of relapse compared to “placebo,” then re-hospitalization rates for discharged patients should have declined after the introduction of antipsychotics. There are studies from four countries that investigated this question:

- A British study of 100 schizophrenia patients found that those treated in 1956/57, had, if anything, a “higher rate of readmission” in the three years following discharge than those treated in 1952/53, prior to the introduction of the phenothiazines (Pritchard, 1967).
- A Norwegian study of hospitalized patients in 1948-1952 and in 1955-59 determined that while there may have been a slight improvement in discharge rates after chlorpromazine arrived in asylum medicine, the total number of readmissions “increased 41.6%,” which the researchers described as “characteristic of the drug period,” (Odegard, 1964).
- In a study of 221 first-episode schizophrenia patients admitted into Scottish hospitals from 1949 to 1957, with patients followed for three years, there was no difference in the percentage that suffered a single “attack” (about 70% of all patients in both the pre-drug and post-drug eras), but among all discharged patients, there was an “increased relapse frequency” in males following the introduction of chlorpromazine (McWalter et al., 2006).
- A study of the five-year outcomes of psychotic patients treated at Boston Psychopathic Hospital in 1947 found that 45% didn’t relapse during the next five years, and that 76% were successfully living in the community at the end of that period. In contrast, only 31% of patients treated in 1967 remained relapse free over the next five years, and as a group they were much more “socially dependent” - on welfare and needing other support- than the 1947 cohort (Bockoven and Solomon, 1975).

These four studies all suggest that relapse rates rose after the introduction of antipsychotics. Clinical reports in the 1960s hinted at the same finding. Discharged patients were returning to hospitals with such frequency that staff dubbed it the “revolving door syndrome.”

Researchers also noticed that “relapse is greater in severity during drug administration than when no drugs are given”, (Gardos and Cole, 1976). At the same time, if patients relapsed after quitting the medications, their psychotic symptoms tended to “persist and intensify,” and at least for a time, they suffered from a host of new symptoms

as well: nausea, vomiting, diarrhea, agitation, insomnia, headaches and weird motor tics (Gardos, Cole and Tarsy, 1978). Initial exposure to a neuroleptic appeared to be setting up patients for a future of severe psychotic episodes, regardless of whether they stayed on their medications.

Clinical studies deepen the worry

In the early 1960s, the National Institute of Mental Health (NIMH) conducted a nine-hospital study that is remembered today as establishing the short-term efficacy of antipsychotics (chlorpromazine and two other phenothiazines). In a trial of 344 newly admitted patients, those randomized to one of three drugs had a greater reduction of symptoms than those randomized to placebo during the first six weeks.

However, many in the placebo group had recovered, and when the researchers studied one-year outcomes for the 344 patients in the trial, they were startled to discover that “patients who received placebo treatment were less likely to be re-hospitalized than those who received any of the three active phenothiazines,” (Schooler et al., 1967). This was the first evidence from a clinical trial that these new drugs, while perhaps effective over the short term in ameliorating psychotic symptoms, might make people more vulnerable to conduct seen as psychosis over the long term.

With worries about the long-term effects of antipsychotics rising, the NIMH funded three studies in the 1970s to re-examine whether schizophrenia patients - and particularly those experiencing a first episode of schizophrenia - could be successfully treated without use of these medications. The first study, led by William Carpenter, was conducted at the NIMH’s clinical research facility in Bethesda, Maryland. Those treated without antipsychotics were discharged sooner than the drug-treated patients, and only 35% of the non-medicated group relapsed within a year after discharge, compared to 45% of the medicated group, (Carpenter, McGlashan and Strauss, 1977).

In the second study, at Agnews State Hospital in California, 80 young males newly diagnosed with schizophrenia were randomized into drug and non-drug cohorts. After an initial hospital stay, patients were discharged into the community and followed for three years. At the end of that period, the best outcomes were seen in the patients who were randomized to placebo and stayed off the drugs during the follow-up period. The patients that had the worst outcomes, by far, were those who were randomized to drug treatment and remained medication compliant during the follow-up (Rappaport et al., 1978).

The third experiment, known as the Soteria Project, was led by the head of schizophrenia studies at the NIMH, Loren Mosher. Newly diagnosed psychotic patients were treated in a home-like environment, without the initial use of antipsychotics, and their outcomes were compared to a matched cohort of hospitalized patients. At the end of six weeks, psychotic symptoms had abated to the same degree in both groups. At the end of two years, the Soteria patients had “lower psychopathology scores, fewer [hospital]

readmissions, and better global adjustment,” (Matthews et al., 1979). Forty-two percent of the Soteria patients had never been exposed to antipsychotics at the end of this period, 39% had used them on a temporary basis, and 19% had used them throughout the two-year follow-up, (Bola and Mosher, 2003).

All three studies, while different in design, told of better overall outcomes for the experimental groups. Relapse rates at the end of one to three years were lower for those not put on antipsychotic medications at the start of the study. These results stood in contrast to findings from the relapse studies, which led Carpenter to raise a haunting question:

“There is no question that, once patients are placed on medication, they are less vulnerable to relapse if maintained on neuroleptics. But what if these patients had never been treated with drugs to begin with... We raise the possibility that antipsychotic medication may make some schizophrenic patients more vulnerable to future relapse that would be the case in the natural course of the illness,” (Carpenter, McGlashan and Strauss, 1977).

And if that were so, it would mean that antipsychotics were worsening the very symptoms they were supposed to treat.

Drug-induced Dopamine supersensitivity

Two Canadian researchers, Guy Chouinard and Barry Jones, soon provided an answer to Carpenter’s question. Antipsychotics block dopamine receptors in the brain, and in particular, a subtype known as the D2 receptor, (Seeman et al., 1976). In a compensatory response to this blockade, dopaminergic neurons in the brain increase the density of their D2 receptors, (Burt, Creese and Snyder, 1977; Hietala et al., 1994). The brain is now “supersensitive” to dopamine and this “leads to both dyskinetic symptoms and psychotic symptoms,” Chouinard and Jones concluded. “An implication is that the tendency toward psychotic relapse in a patient who has developed such a supersensitivity is determined by more than just the normal course of the illness,” (Chouinard, Jones and Annable, 1978; Chouinard and Jones, 1980).

Their work provided a biological explanation for why patients relapsed so frequently when they were abruptly withdrawn from their antipsychotic medication. By blocking dopamine receptors, an antipsychotic acted as a brake on dopamine activity. However, it also induced an increase in dopamine receptors, which served to accelerate dopaminergic activity. When the drug was withdrawn, the brake would be absent, but the accelerator would still be present, and the dopaminergic pathways would fire in hyperactive, dysregulated ways.

Yet, as Chouinard and Jones wrote, even if patients stayed on their antipsychotic, this drug-induced dopamine supersensitivity could lead to permanent motor disabilities

and chronic psychotic symptoms. In 1982, they reported that 30% of 216 schizophrenia outpatients they studied showed signs of tardive psychosis (Chouinard and Jones, 1982). When this sets in, they concluded, “the illness appears worse” than ever before. “New schizophrenic symptoms of greater severity will appear,” (Chouinard, 1991).

Forty years of confirming evidence

This picture of neuroleptics, as agents that could increase a patient’s biological vulnerability to psychotics, emerged within the first 25 years of use of these drugs. In the 40 years since then, there is a mix of research that supports the conclusion that long-term antipsychotic use increases the chronicity of psychotic disorders and leads to worse overall outcomes.

WHO Cross-cultural Studies

In the 1970s and early 1980s, the World Health Organization (WHO) conducted two studies comparing schizophrenia outcomes in three “developing” countries - India, Nigeria, and Colombia - to outcomes in the United States and five other “developed countries.” The first was a five-year study; the second was a two-year study in mostly first episode patients. Each time, the patients in the developing countries had a “considerably better course and outcome.”

After the first study, the WHO researchers hypothesized that perhaps the better outcomes in the developing countries were due to better compliance with antipsychotics. However, in the second study, they discovered the opposite was true. Only 16% of patients in the developing countries were regularly maintained on the drugs, versus 61% of the patients in the rich countries (Jablensky et al., 1992).

Later, in 1997, WHO researchers interviewed the participants in the first two studies once again and found that the “outcome differential” held up for “general clinical state, symptomatology, disability, and social functioning.” In the developing countries, 53% of the schizophrenia patients were simply “never psychotic” anymore, and 73 percent were employed (Hopper and Wanderling, 2000).

MRI Studies

The invention of magnetic resonance technology provided researchers with a tool to measure brain volumes in people diagnosed with schizophrenia, with the thought that this would help identify abnormalities that might characterize the “disease.” However, this same technology could also provide insight into the impact of antipsychotics on brain volumes, and in a series of studies, researchers reported that antipsychotics caused basal ganglion structures and the thalamus to swell, and the frontal lobes to shrink, with these changes “dose related” (Chakos et al., 1994; Gur, Maany, et al., 1998; Madsen et al., 1998). In 1998, Gur reported that the swelling of the basal ganglia and thalamus was “associated with greater severity of both negative and positive symptoms,” (Gur, Cowell, et al., 1998).

A few years later, Andreasen and colleagues reported that schizophrenia patients suffered from a “progressive reduction in frontal lobe white matter volume,” which was associated with a worsening of negative symptoms and functional impairment. Initially, they attributed this brain shrinkage to the disease, (Ho et al., 2003). They subsequently reported that long-term use of antipsychotics was “associated with smaller brain tissue volumes” and that the more drug a patient had taken, the greater the association “with smaller grey matter volumes,” (Ho et al., 2011).

The MRI studies provide a clear picture of an iatrogenic process. Antipsychotics cause a change in brain volumes, and as this occurs, the patient becomes more psychotic, more emotionally disengaged, and more functionally impaired.

Modelling Psychosis

In the 1980s and 1990s, investigators developed a number of methods to “model psychosis.” They studied brain changes induced by various drugs - amphetamines, angel dust, etc. - that can trigger delusions and hallucinations in humans. They developed methods to induce psychotic-like behaviors, as evident in their locomotion, in rats and other animals.

In 2005, Seeman reported that all of these psychotic triggers share a final common pathway: they all cause a marked increase in D2 receptors that have a “high” affinity for dopamine, meaning that they bind quite readily with the neurotransmitter. Antipsychotics, including the second-generation drugs, double the density of “high affinity” D2 receptors (Seeman, 2011). Seeman estimated that once schizophrenia patients are medicated for longer periods of time, 70% develop this dopamine supersensitivity, which “leads to treatment failure over time,” (Samaha et al., 2007).

Longitudinal studies

The best U.S. study of long-term outcomes of patients diagnosed as psychotic was conducted by Martin Harrow and Thomas Jobe. Beginning in the mid 1970s, they enrolled 200 patients into their study, (Median age 22.9 years; two-thirds were either first-episode patients or had only one prior hospitalization). The patients were treated with antipsychotics in the hospital, and after discharge, Harrow and Jobe periodically assessed how they were doing (at 2 years, 4.5 years, 7.5 years and so forth). After 15 years, they still had 145 of the 200 in their study; 64 were diagnosed with schizophrenia and 81 with other psychotic disorders.

At the two-year mark, the schizophrenia patients who had stopped taking antipsychotic medications were doing slightly better than those who were medication compliant. Over the next 30 months, the off-med group began to significantly improve, such that by the end of 4.5 years, 39% were in recovery and more than 60% were working. In contrast, outcomes for the medicated group worsened during this period, and at the 4.5-year mark, only 6 percent were in recovery and few were working.

That stark difference in outcomes remained for the next ten years. At the 15-year follow-up, 40% of those off anti-psychotics were in recovery, more than half were working, and only 28% experienced psychotic symptoms. In contrast, only 5% of those taking anti-psychotics were in recovery, and 64% were actively symptomatic (Harrow and Jobe, 2007). There was a similar divergence in outcomes for those with other psychotic disorders. Those off meds were doing much better at all follow-up assessments. Even more surprising, those diagnosed with schizophrenia who got off antipsychotic medication fared better over the long-term than those diagnosed with milder psychotic disorders at baseline who stayed on the drugs.

In their 20-year report, Harrow and Jobe charted psychotic symptoms over time according to antipsychotic use. They found that 72% of the patients who were “always on antipsychotics” were persistently psychotic, (e.g. Psychotic at four or more of the follow-up assessments); 46% of those “sometimes” on antipsychotics fell into this category, and only 7% of those who never used antipsychotics did, (Harrow, Jobe and Faull, 2014).

With such startling results in mind, Harrow and Jobe pointed to dopamine supersensitivity as a possible explanation for the poor long-term outcomes for the medicated patients. “How unique among medical treatments is it that the apparent efficacy of antipsychotics could diminish over time or become ineffective or harmful?” they wrote. “There are many examples for other medications of similar long-term effects, with this often occurring as the body readjusts, biologically, to the medications.” (Harrow and Jobe, 2013)

Conclusion

As can be seen in this historical review, there is a 65-year record of scientific findings that tell of how antipsychotics increase the chronicity of psychotic symptoms and impair functioning over the long-term. The relapse studies, rather than providing evidence that antipsychotics lower the risk of relapse, tell of drug-withdrawal hazards that come with use of these drugs.

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The prospect of recovering compensation for psychiatric drug withdrawal harm through litigation because of missing or misleading information

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ABSTRACT: This article explores the prospects of people who were not told about the risk of withdrawal effects of psychiatric drugs obtaining compensation for the harm through litigation. The analysis is based on United States law and some of the principles may be relevant in other countries and some also may not.

KEY WORDS: Legal, Damages, Iatrogenesis, Drug Companies

To make a case for compensation (“damages”), for failure to inform about the risks of psychiatric drug withdrawal the following questions have to be answered in the affirmative:

1. Was there a duty to inform?
2. Who might have such a duty?
3. Was the duty breached (violated)?
4. Did the breach cause harm?

There are also practical issues, such as can one obtain a good lawyer to pursue the case, and the impediments created by the powerful doctor lobby through what is called Tort¹ Reform.

1 “Tort” is the legal term for a claim against another person for harm that person caused.

Duty to inform

Prescribers

It is fairly universally accepted that prescribers, such as psychiatrists and other medical doctors have an obligation to obtain “informed consent” before treatment is administered. A prominent legal case articulating this is *Cobbs v. Grant*:

[A] person of adult years and in sound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment [and] ... the patient’s consent to treatment, to be effective, must be an informed consent².

More on “in sound mind,” later. With respect to what informed consent means, different US states have different standards. In some states, what a prescriber is obligated to inform a patient is determined by whether it is the custom of physicians practicing in the community to make the particular disclosure to the patient (“Standard of Care”). In other states the question is what the patient would have decided if they had been provided with the information (“Subjective Standard”). In others, the question is what would a “reasonable” or “prudent” patient have decided (“Objective Standard”).³

Each of these approaches has its supporters and detractors, although the Standard of Care standard has generally fallen out of favor as exemplified by *Cobbs*, one of the first to reject it:

[T]he patient’s right of self-decision is the measure of the physician’s duty to reveal. That right can be effectively exercised only if the patient possesses adequate information to enable an intelligent choice. The scope of the physician’s communications to the patient, then, must be measured by the patient’s need, and that need is whatever information is material to the decision.⁴

The Objective standard, has recently been articulated by the Iowa Supreme Court in the following way and in some states the standard has been adopted by statute:⁵

Generally, to succeed on a claim of informed consent, the plaintiff must establish four elements:

1. The existence of a material risk [or information] unknown to the patient;

2 502 P.2d 1 (Cal. 1972).

3 See *Hondroulis v. Schuhmacher*, 553 So.2d 398, n11 (La 1988).

4 502 P.2d at 11.

5 See, e.g., Revised Code of Washington, RCWA 7.70.050.

2. A failure to disclose that risk [or information] on the part of the physician;
3. Disclosure of the risk [or information] would have led a reasonable patient in plaintiff's position to reject the medical procedure or choose a different course of treatment;
4. Injury.⁶

There are exceptions to the duty to disclose such as an emergency situation where an unconscious accident victim needs immediate care. This exception would not apply to warning about the withdrawal effects of psychiatric drugs. One that could be seized as a defence against establishing a violation of the duty to warn about the withdrawal effects of psychiatric drugs, however, is if the patient is "so ill or emotionally distraught on disclosure as to foreclose a rational decision, or complicate or hinder the treatment, or perhaps even pose psychological damage to the patient."⁷ This is the type of exception psychiatrists regularly abuse.

The primary objection to the Subjective Standard is the difficulty of determining what the patient would have decided, especially because once the harm has occurred the patient will tend to believe they would not have consented if they had been told about the risk.⁸

The main objection to the Objective Standard isn't what a reasonable patient would have decided, but what that specific patient would have decided.⁹ This criticism is clearly correct. The Objective Standard has been adopted because of the difficulty in determining after the fact what a person would have decided when the undisclosed risk has actually occurred. However, logically, if a reasonable person would have rejected the drug if provided the information this means no reasonable person would ever choose the treatment if adequately informed. This in turn means the drug should never be offered, at least for the particular use for which it was prescribed. In the case of more than very short term use of benzodiazepines (benzos), or any use of Selective Serotonin Reuptake Inhibitors (SSRIs) I think this is true. For the SSRIs this is based not only on the withdrawal effects, but also on their other adverse effects, such as permanent sexual dysfunction and their propensity to lead people to become manic, commit suicide, or commit violence, including homicide.

The lawsuits against prescribers for failure to obtain informed consent are sometimes considered malpractice claim, other times battery and other times simply a claim that the patient had not been provided informed consent.

⁶ *Andersen v. Khanna*, 913 N.W.2d 526 (Iowa 2018).

⁷ *Canterbury v. Spence*, 464 F.2d 772, 789 (DC. Cir. 1972).

⁸ *Cobbs*, 502 P.2d at 11.

⁹ *Arena v. Gingrich*, 748 P.2d 547, 549 (Or 1988).

My experience and understanding is prescribers rarely warn about any negative effects of psychiatric drugs, let alone withdrawal effects.¹⁰ In states that have adopted the Objective or Subjective standard, they have breached the duty to warn, where the withdrawal effects would have caused a “reasonable patient,” or that particular patient, respectively, to reject the drug. In states where the duty to warn is based on the Standard of Care, even though the normal practice is not to warn I doubt many expert witnesses would testify the practice is not to warn. Cases against prescribers for failure to warn about the withdrawal effects of psychiatric drugs are legally sound, depending, of course, on the facts in each case.

Drug companies

Because drug companies are, to my mind, evil and have a lot of money, people want to sue them. The big impediment to successfully suing the drug companies is “The Learned Intermediary Doctrine” in which the drug companies are only obligated to inform the prescribers and normally have no liability to the patient if the prescriber has failed to warn. The prescriber is supposed to be knowledgeable about the drugs, including withdrawal effects, and use their expertise to make recommendations and provide all information material to a decision on whether to accept the drug or not. In other words, the prescriber is supposedly a “Learned Intermediary.”

The Learned Intermediary Doctrine was applied, in *Presto v. Sandoz Pharmaceuticals Corp.*, where the patient committed suicide after quitting Clozaril¹¹, holding “Ordinarily, in the case of prescription drugs, a warning as to possible danger in its use to the prescribing physician is sufficient.”¹² In that case, the following warning to the prescriber in the package insert was found sufficient:

[P]atients [should] be removed from the drug by gradually reducing the dosage over a one-or two-week period and stated, “[s]hould a patient’s medical condition require abrupt discontinuation..., the patient should be carefully observed for the recurrence of psychotic symptoms.”

The big cases against drug companies for failure to warn, such as the massive litigation over Zyprexa causing diabetes and other metabolic problems, are based upon the drug companies hiding damning information from the prescribers. In the Zyprexa

10 However, far too frequently the prescriber will fail to warn the patient, but the medical chart will erroneously state the patient was informed.

11 Note by the editors: Neuroleptic; active ingredient clozapine; marketed in countries with English as first or second language as Cloment, Clonia, Clopin, Clopine, Closin, Clozalux, Clozapin, Clozapine, Clozarem, Clozaril, Clozatab, Denzapine, FazaClo, Leponex, Leudex, Merbaril, Versacloz, Zaponex.

12 487 S.E.2d 70, 73 (Ga. 1997).

case, Eli Lilly actively hid and denied that Zyprexa caused diabetes and other metabolic problems. In such circumstances, the Learned Intermediary Doctrine is inapplicable because the drug company had violated its duty to inform the prescribers. In the case of Zyprexa, this author was instrumental in making public the information about Zyprexa causing diabetes and other metabolic problems and Lilly was forced to add a warning about it on the approved FDA label.¹³ While this was good in terms of informing the prescribers and the public, it cut off Lilly's liability to patients going forward for failure to inform about diabetes and other metabolic problems.

The drug "labels" that inform prescribers about psychiatric drugs tend to warn about withdrawal symptoms. For example, the Food and Drug Administration (FDA) label for Prozac (fluoxetine¹⁴) includes the following:

During marketing of PROZAC, SNRIs, and SSRIs, there have been spontaneous reports of adverse reactions occurring upon discontinuation of these drugs, particularly when abrupt, including the following: dysphoric mood, irritability, agitation, dizziness, sensory disturbances (e.g., paresthesias such as electric shock sensations), anxiety, confusion, headache, lethargy, emotional lability, insomnia, and hypomania. While these reactions are generally self-limiting, there have been reports of serious discontinuation symptoms. Patients should be monitored for these symptoms when discontinuing treatment with PROZAC.

It is perhaps noteworthy that this warning covers the whole category of SNRI (Serotonin-Norepinephrine Reuptake Inhibitor) and SSRI (Selective Serotonin Reuptake Inhibitor) drugs. In other words, the prescribers have been warned by the drug manufacturer about the withdrawal effects for these whole classes of so-called anti-depressants.

Similarly, the FDA label for Ativan (lorazepam¹⁵), one of the benzodiazepines includes the following about its withdrawal effects:

Physical and psychological dependence

The use of benzodiazepines, including lorazepam, may lead to physical and psychological dependence...

In general, benzodiazepines should be prescribed for short periods only (e.g., 2 to 4 weeks).

Extension of the treatment period should not take place without reevaluation of the need for

13 See The Zyprexa Papers, by Jim Gottstein, Jim Gottstein, Anchorage, Alaska 2020.

14 Note by the editors: Antidepressant; marketed as Adef, Afeksin, Affex, Barazac, Cozac, Dawnex, Deprexin, Flonital, Fludac, Fluohexal, Fluox, Fluoxetine, Fluoxone, Flutinol, Fluxil, Fluzac, Gerozac, Lorien, Lovan, Magrilan, Movox, Nuzak, Olena, Oxactin, Plazeron, PMS-Fluox, Proctin, Prohexal, Prolax, Prozac, Prozamel, Prozep, Ranflocs, Rezak, Salipax, Sarafem, Trizac, Zactin.

15 Note by the editors: Marketed as Almazine, Ativan, Larosh, Larpose, Lorans, Lorazepam, Lorivan, Temelor, Trapex, Tranqipam, Verlapam.

continued therapy. Continuous long-term use of product is not recommended. Withdrawal symptoms (e.g., rebound insomnia) can appear following cessation of recommended doses after as little as one week of therapy. Abrupt discontinuation of product should be avoided and a gradual dosage-tapering schedule followed after extended therapy.

Abrupt termination of treatment may be accompanied by withdrawal symptoms. Symptoms reported following discontinuation of benzodiazepines include headache, anxiety, tension, depression, insomnia, restlessness, confusion, irritability, sweating, rebound phenomena, dysphoria, dizziness, derealization, depersonalization, hyperacusis, numbness/tingling of extremities, hypersensitivity to light, noise, and physical contact/perceptual changes, involuntary movements, nausea, vomiting, diarrhea, loss of appetite, hallucinations/delirium, convulsions/seizures, tremor, abdominal cramps, myalgia, agitation, palpitations, tachycardia, panic attacks, vertigo, hyperreflexia, short-term memory loss, and hyperthermia. Convulsions/seizures may be more common in patients with pre-existing seizure disorders or who are taking other drugs that lower the convulsive threshold such as antidepressants.

It does not appear there is much in the way of withdrawal warnings for the neuroleptics, misbranded as “antipsychotics.” For example, the Seroquel (quetiapine¹⁶) FDA approved label only includes:

Acute withdrawal symptoms, such as insomnia, nausea, and vomiting have been described after abrupt cessation of atypical antipsychotic drugs, including SEROQUEL. ... The incidence of the individual adverse events (i.e., insomnia, nausea, headache, diarrhea, vomiting, dizziness and irritability) did not exceed 5.3% in any treatment group and usually resolved after 1 week post-discontinuation. Gradual withdrawal is advised.

Another difficulty arises if the drug at issue is generic. The generic drug maker is not allowed to change anything on the FDA approved label and therefore cannot be held liable for failure to inform. The original manufacture may not be liable because the patient did not take their drug. There was a case where the widow of a 57-year old lawyer who jumped in front of a train after six days on paroxetine¹⁷, the generic version of Paxil, sued GlaxoSmithKline (GSK), the original manufacturer, on the grounds it should have changed the label to reflect increased suicide risk, but lost because the FDA had refused to allow

16 Note by the editors: Marketed as Adequet, Alvoquel, Atrolak, Biquelle, Brancico, Conquet, Dopaquel, Geroquel, Ketipinor, Kizofrin, Mintreleq, Noletil, Notiabolfen, Pequit, Placidin, Psyquet, Psyquit, Quentiax, Quesery, Quetapel, Quetapil, Quetex, Quetiapin, Quetiapina, Quetiapine, Quetoser, Qusel, Serez, Seropia, Seroquel, Setinin, Sizonorm, Socalm, Sondate, Syquet, Tevaquel, Truvalin, Zaluron, Zimbiquet.

17 Note by the editors: Antidepressant; marketed as Arketis, Aropax, Brisdelle, Deparoc, Lenio, Loxamine, Onbixin, Oxedep, Paradise, Parax, Pari, Paronex, Parox, Paroxetine, Paxetin, Paxil, Paxtine, Pexeva, Sedarin, Seroxat, Serrapress, Texine, XET.

GSK to add the warning to the label¹⁸.

If the drug companies are withholding information on withdrawal effects that would be material to a decision on whether to take the drug or not from the FDA as well as prescribers then that would form a basis for a breach of a duty to warn. Otherwise, the drug companies are not viable targets for such lawsuits.

Compensation (Damages)

There are three types of damages; (1) economic damages, such as medical expenses and lost wages, (2) non-economic damages, such as pain and suffering or loss of enjoyment, and (3) punitive damages where the act was particularly unconscionable, such as where a surgeon intentionally left a sponge in a patient so they could charge for an additional surgery.

Proving economic damages, such as medical expenses and past lost wages, is pretty straightforward; receipts or checks and pay stubs. In contrast, proving non-economic damages, especially for pain and suffering and loss of enjoyment is more difficult. The courts have tended to hold the loss of future earnings needs to be proven with reasonable certainty and cannot be speculative. Where someone has been diagnosed with serious mental illness this can be a difficult standard because there is often the assumption the person is not employable. However, for the benzodiazepines and SSRIs most of the harmed people have not been diagnosed with serious mental illness - at least not before being prescribed psychiatric drugs. Overall, a psychiatric diagnosis is a hindrance to proving loss of future earnings. Normally, one would want an expert witness to testify about loss of future earnings and in some states it would be required.

Many states have enacted limits on how much one can receive for non-economic damages as so-called "Tort Reform" in response to grossly exaggerated claims by doctors' groups that juries are out of control and awards are often excessive. These limitations, or "caps" as they are known, tend to be in the \$250,000 to \$500,000 range.

The United States Supreme Court has held there has to be some proportionality to punitive damages awards to satisfy the requirement of Due Process of Law.¹⁹

Other issues

Contingent Fees

Most medical malpractice cases are taken by lawyers on a "contingent fee" basis which means the lawyer only gets paid out of the recovery, if any. The percentage seems to be 40% these days, up from the standard one third when I first became a lawyer. The lawyer will also front the expenses, such as expert witness fees, which can be considerable. There

18 *Dolin v. GlaxoSmithKline LLC*, 901 F.3d 803 (7th Cir. 2018).

19 *BMW of North America, Inc. v. Gore*, 517 U.S. 559 (US 1996).

is a real benefit to this arrangement for the plaintiff, but the lawyers evaluate cases very carefully before agreeing to take them on. They try to determine the probability of success and the amount of any likely recovery to arrive at an expected value. Then, they look at how much work and other investment it is likely to take and if this calculation is not favorable they won't take it.

It is possible to pay a lawyer an hourly rate to take such cases, but I don't really recommend it because if the lawyers don't think it will be worth their investment, it is unlikely it will be worth yours.

Litigation is very unpleasant

Another thing to consider is that litigation is an extremely unpleasant process. The other side is entitled to "Discovery" which means requiring one to submit to out of court testimony, known as a deposition, and provide all documents that might be even remotely relevant or lead to relevant information. One's psychiatric history and other history will be examined very closely. It's like a rape victim being interrogated about their sex life and wasn't it their fault because of the clothes they were wearing.

Class actions

People tend to tell me they want to file a class action. I am not a fan in general. The individual class members tend to get relatively little while the lawyers make a huge amount of money. The defendant's liability to class members is cut off whether or not the class member participates in the recovery, usually a settlement. There are also certain requirements for class actions that will normally not be met for a claim of lack of informed consent regarding psychiatric drug withdrawal effects. In order to aggregate claims into a class action, the class members' claims have to be similar enough to be handled en masse. This is called "commonality." Class actions would tend to only be filed against the drug companies because they have "deep pockets" (lots of money to be obtained), but as is explored above, they are not likely to be liable unless actively hiding withdrawal effects from the prescribers.

Pre-suit requirements

As part of so-called Tort Reform, legislatures in many states have also enacted pre-lawsuit requirements such as having a doctor's letter opining that it is a legitimate malpractice case. However, at least one state court has ruled this medical malpractice rule does not apply to informed consent cases because "a claim of lack of informed consent is not a medical negligence claim."²⁰

20 *Shortell v. Cavanagh*, 15 A.3d1042, 1043 (Conn. 2011).

Whodunit

Another possible difficulty arises when there are multiple prescribers involved. Which prescriber caused the problem by not warning about the withdrawal effects when multiple prescribers failed to provide such a warning?

Sound mind

As mentioned above the right to informed consent only applies to people of “sound mind.”²¹ It is beyond the scope of this article to go into this issue in any depth, but a few words are in order. First, it seems likely that most informed consent claims over not being warned about the withdrawal effects of psychiatric drugs are likely to concern benzodiazepines and SSRIs, where many if not most of the people prescribed these would not have been diagnosed with a serious mental illness involving psychosis. Benzodiazepines and especially the SSRIs cause many people to become manic, a psychotic condition, but that shouldn’t apply to the initial prescription.

On the other hand, people who have been diagnosed with a serious mental illness involving psychosis would probably be faced with this as an issue. But informed consent has to be given by someone. If not it is a battery. Legally, a person has to be of “sound mind” for a prescriber to accept the person’s agreement to take the prescription. If, instead, a guardian has been appointed, the guardian would have a claim for lack of informed consent on behalf of their ward. A problem with this is the guardian is often in league with the prescriber.

Another scenario is where a judge orders someone to take psychiatric drugs because the patient is not of “sound mind,” i.e., not competent to decide whether to take the psych drug or not. In that situation, the prescriber makes their case to the judge and the lawyer appointed to represent the patient is charged with rebutting it. Unfortunately, the appointed lawyer normally doesn’t do much on behalf of their supposed client. The doctor is still supposed to provide sufficient information to provide informed consent, but who has the right to sue? I would say the patient still has the right to sue the prescriber for not providing material information to the judge. It is an added hurdle to a successful lawsuit, though.

Conclusions

Prescribers rarely provide any, let alone adequate, information on the withdrawal effects of psychiatric drugs, the most problematic ones of which are the benzodiazepines and SSRIs. This is a clear violation of the prescriber’s duty to provide all information that is material to a decision to take the drug and gives rise to a legal claim against the prescriber. Vindicating such claims in court is difficult.

21 *Canterbury, supra.*, 464 F.2d at 780; *Cobbs, supra.*, 502 P.2d at 9.

And finally atypically careful

Susanne Cortez

Susanne Cortez (pseudonym), was born in 1963 in Germany. She is a primary and secondary school teacher, married, with two children.

ABSTRACT: This article describes repeated attempts to withdraw from various psychiatric drugs and a final, successful withdrawal from quetiapine prolonged-release.

KEY WORDS: Quetiapine, Burnout, Hallucinations, Lived Experience

In 2005, I was 42 years old and started a job at a school in another state in Germany. From the beginning and without my knowledge, an older colleague who wanted the job bullied me. It went from revealing alleged mistakes, libeling me to the charwomen to inciting the colleague's class against me, who then began to behave abominably. After three months, my nerves were raw and I couldn't sleep anymore. One night I had a crying fit, I cried and cried and just couldn't stop any more.

This led me to the family doctor, who wrote me off, saying I had "burnout." When I still could not work after three weeks, she referred me to a day clinic, where I was supposed to get help. This day clinic used a lot of psychiatric drugs, I soon noticed. At first, they gave me antidepressants, which they discontinued when I became slightly manic. Discharged – not with the ability to work, but with the diagnosis "schizoaffective psychosis" – they finally gave me 800 mg of amisulpride¹ (neuroleptic).

From the beginning, medication was part of the problem, not the solution. I became lethargic, fat, developed disordered thoughts, and was severely slowed down; in other words, all the things that one imagines suffered by "learning disabled" people. Nevertheless, I endured the problems for two years. Then I stopped the antidepressants much too quickly, as nobody had informed me about possible withdrawal problems.

1 Note by the editors: Marketed as Aktiprol, Amgrace, Amipride, Amisulpride, Amisure, Amisyt, Ampicon, Solian, Sulprix.

This withdrawal was terrible. Hours of anxiety and panic attacks. Derealisation experiences (disturbed perception of the environment). Visual hallucinations. Nausea and ongoing vomiting. Weight loss of 30 kg within two months. I endured this condition for almost four months. Then they placed me in a psychiatric ward and persuaded me to take a new neuroleptic.

Later, I tried to withdraw a few more times. Probably too fast, but, in any case, I suffered from psychotic symptoms every time I tried. For example, I thought the world consisted of theatre sets, or I heard voices. Then they administered new psychiatric drugs. One of them, the neuroleptic risperidone, caused severe anxiety.

They gave me a lot of different low-potency neuroleptics for the anxieties, but nothing helped. It only got better when I insisted on exchanging risperidone for paliperidone².

With time, however, my mental state got worse and worse. I became so depressed that, for a while, I did not want to live anymore. Soon I was a revolving door patient in a closed ward, and because of strong fears and compulsions I could not even go out the door alone. Among others, I took the neuroleptics haloperidol, quetiapine, olanzapine, risperidone, paliperidone, aripiprazole³, as well as promethazine, chlorprothixene, melperone⁴, pipamperone⁵ and the benzodiazepine-tranquilizer lorazepam, often at the same time and in high doses.

Apart from schizoaffective psychosis, my diagnoses were: psychotic depression, bipolar disorder, dissociative identity disorder, and in 2012, after the last psychosis, they diagnosed me as schizophrenic! I was suicidal and desperate.

The last psychiatric drug I took after haloperidol had caused akathisia was quetiapine prolonged-release (Seroquel prolonged-release) in a dose of 800 mg.

In search of a way out

Something urged me not to give up. Once, I had a life: family, college, an interesting job, an

2 Note by the editors: Marketed as Aspire-Xr, Invega, Palido, Trevicta, Xeplion.

3 Note by the editors: Marketed as Abilify, Abyraz, Apiz, Arena, Aridus, Arifril, Arilan, Aripiprazole, Aristada, Arizofy, Arizole, Arpoya, Elxeda, Mactril, Real One, Tevaripiprazole, Zyklor.

4 Note by the editors: Apparently not currently marketed in Australia, the Bahamas, Barbados, Bermuda, Cameroon, Canada, Ethiopia, Fiji, Ghana, Great Britain, Guyana, India, Ireland, Jamaica, Kenya, Kiribati, Malaysia, Malta, New Zealand, Nigeria, Pakistan, Papua New Guinea, the Philippines, Rwanda, Singapore, Solomon Islands, South Africa, Sri Lanka, Sudan, Tonga, Trinidad & Tobago, the USA, Vanuatu, and Zimbabwe.

5 Note by the editors: Apparently not currently marketed in Australia, the Bahamas, Barbados, Bermuda, Cameroon, Canada, Ethiopia, Fiji, Ghana, Great Britain, Guyana, India, Ireland, Jamaica, Kenya, Kiribati, Malaysia, Malta, New Zealand, Nigeria, Pakistan, Papua New Guinea, the Philippines, Rwanda, Singapore, Solomon Islands, South Africa, Sri Lanka, Sudan, Tonga, Trinidad & Tobago, the USA, Vanuatu, and Zimbabwe.

extended stay abroad. Now, all I had were psychiatric drugs. I couldn't accept the fact that it was all over. Although I had already had several attempts at withdrawal that had failed, failure also means gaining experience. For example, I knew my withdrawal symptoms. I wouldn't accept comments like "This is a new illness emerging!"

In 2012, I started psychotherapy to find out why I react to stress and fear with mental crises. Childhood and adolescence, being able to separate oneself from others, learning to say no, and the right to take breaks were my themes.

I searched for a new psychiatrist outside the day clinic. He was against complete withdrawal, but was in favour of reducing the dose, and he agreed immediately to reduce the 800 mg to 400 mg. (By visiting several doctors—family doctor, neurologist, psychiatrist—I had built up a stock of all possible tablet doses: 400 mg, 300 mg, 200 mg, [tablets of 100 mg are not available with Seroquel prolong,] 50 mg). I started with 800 mg.

- Week 1-5: 600 mg (Went well)
- Week 6-11: 400 mg (Here my psychiatrist wanted me to stop. But I wanted to continue. I felt better gradually and did not sleep longer for 16-20 hours a day)
- Week 12-17: 300 mg
- Week 18-24: 200 mg (Now I was feeling a little anxious)

I went back up to 250 mg and waited six weeks until I was okay again.

- Week 30-35: 200 mg
- Week 36-41: 150 mg
- Week 42-52: 100 mg

One year had passed, and I was still tapering!

- Week 53-60: 50 mg (Actually I was fine. I thought about keeping it at that dose.)

Now I faced the problem that the smallest dose unit of quetiapine prolong available on the market was 50 mg. Tablets of 25 mg each are only available in a non-prolonged release form, i.e., as a preparation that does not delay the release of the active ingredient, as the prolonged-release forms do and to which my body had become accustomed, but immediately releases the active ingredient completely. Nevertheless, I wanted to try these non-prolonged release tablets. But how did I get 25 mg tablets?

At the next appointment, I told my psychiatrist I was having trouble falling asleep and asked if he could prescribe me Seroquel without non-prolonged release. He did so willingly. Normally I am honest and believe that as an adult you should be able to negotiate with your doctor. However, I had experienced too often that, as a psychiatric patient, my cognitive abilities were doubted, so at that moment I did not trust my psychiatrist.

The 25 mg tablets without prolonged release had the advantage that I could divide them with a specially purchased pill cutter. So I started to divide:

- Week 61-64: 12.5 mg – 0-25 mg (The next step could only be taken when I feel stable and secure. If strange fear feelings appeared, I know: at first, NOT further discontinuation, because that was a sure sign that my brain was just struggling with withdrawal symptoms)
- Week 65-68: 12.5 mg – 0 – 12.5 mg
- Week 69-72: 8.3 mg (divided by three!) – 0 – 12.5 mg
- Week 73-76: 8.3 mg – 0 – 8.3 mg
- Week 77-80: 4.15 mg – 0 – 8.3 mg

My rule was, the closer to zero, the smaller the steps had to be. Between 800 mg and 400 mg Seroquel, I did not feel any difference. Between 25 mg and 12 mg, I felt the withdrawal symptoms massively.

- Week 81-84: 12.5 mg (Still using the pill cutter)
- Week 85-88: Still 12.5 mg (I dare not take the next step)

From the 91st week on, I quartered again with the pill cutter. So 6.25 milligrams of Seroquel a night. Slowly I came to an almost homeopathic dose.

What worried me most was the “jump to zero,” the point where earlier attempts had failed. Normally it was like this: After the total withdrawal, I felt great. Once, someone spoke of a “weaning honeymoon.” Two to three weeks later, the withdrawal symptoms began. It takes time for the deposits accumulated in the body to dissolve, and the withdrawal symptoms naturally occur with a time lag.

Physically, the withdrawal was initially characterized by a significant weight loss, 30 kg, especially at the beginning of discontinuation. However, I still weigh 20 kg more than before I started taking neuroleptics, although I do not eat more than I did then.

What I very much welcomed: I slept much less. Instead of 16-20 hours, suddenly only eight to ten hours. I had much more time in the day. And my thinking ability improved enormously. I hadn't been able to read a single page in a book or watch a film for a long time, because I immediately forgot what I had read or seen before. My short-term memory was gone.

I could not remember people either. When I took tests, my cognitive abilities were at their lowest levels. That had been a big blow for me, because I could always rely on my mind. When I reached 100 mg of Seroquel, my cognitive performance improved abruptly, and from then on it went up continuously

My emotions overran me. I had been apathetic for many years, nothing had touched me inside. At about 200 mg of Seroquel, the feelings came back—but I became a cry-baby and experienced first-hand what other people had told me. I could no longer watch the daily news because of all the crying. I found the resulting thin skin so exhausting that I almost took neuroleptics again.

Thank God I had a competent and friendly psychotherapist who helped me deal with my inner feelings. She helped me practice drawing boundaries, to say no, to take breaks; in short, all the things you can't do well when you are suddenly extremely sensitive and open (and which, by the way, I couldn't do before).

Towards the end, the pill-cutting was a pretty crumbly business... But it was worth it for me; I could really come off completely. In the 94th week, I'm done. In 2005, nine years ago, I received my first neuroleptic. In 2014, I am at zero. It took me almost 20 months to come off.

The time after that until today, 2019

It took another two months before I confessed to my psychotherapist I had withdrawn. Although I had found her very affectionate, I had not dared to inform her about my withdrawal. Now she kindly spoke to my psychiatrist, and thank God he reacted neither miffed nor offended, but professionally: *"Promise me you will come to me if you notice any change?"*

When I reflect on my present situation, I can say I have changed. I have become more compassionate, friendlier, more patient. I am often sad, because I was not able to notice parts of my children's development – I had been asleep almost the whole time.

What remains is that I do not know exactly what to do with my life. I have a crack in it. I suffer from a certain aimlessness and I have an idea of things that others cannot imagine, that I cannot talk to them about. When we speak about jobs on holiday trips, etc., I can't talk with them. There are so many things I don't do that adults my age normally do.

Physically, too, the long use of neuroleptics has damaged me. I have developed migraines and polyneuropathy, i.e., sensitivity disorders with numbness, tingling and burning sensations in my legs. Both are neurological disorders. Perhaps these are persistent withdrawal symptoms, so I should not give up hope that they will eventually fade away.

At the moment, everything has settled down. I am happy that I can sympathize again, that I can think, that I can be happy, and also that I can be sad.

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The English article, translated by Peter Lehmann, was originally published in the ebook *"Coming off psychiatric drugs: Successful withdrawal from neuroleptics, antidepressants, mood stabilizers, Ritalin and tranquilizers"*, edited by Peter Lehmann, Berlin / Shrewsbury: Peter Lehmann Publishing 2020.

Book Review

Deprescribing in Psychiatry

Swapnil Gupta, John Cahill and Rebecca Miller

Oxford University Press, 2019, £32.99

ISBN: 978-0-19-065481-8

In their preface, the authors - three Assistant Professors from the Department of Psychiatry, Yale University School of Medicine - describe their approach to deprescribing psychiatric drugs. They want to offer a pragmatic starting point to stimulate and open a conversation between patient, prescriber, clinical team, friends and family. With this approach, they ignore the starting points for such a conversation published in the last quarter of a century about reducing and coming off psychiatric drugs. The authors see deprescribing as a process of shared decision-making - in other words, they overlook the fact that the main person who should decide about reducing and coming off psychiatric drugs is the patient whose human right of bodily integrity, under which the intake of psychiatric drugs falls, is indivisible. The UN convention on human rights supports this position. Further on, the authors accept the common biopsychosocial approach of drug treatment as a rational entity, which means they accept the mainstream-understanding of emotional distress in humans as a basic biological problem. The primary target of the authors is "overmedicalization",

not unwanted medicalization. It is not to show how to support patients who want help with full withdrawal of psychiatric drugs, but to ensure minimum-effective dosing of psychiatric drugs combined with therapeutic measures. I note these restrictions to protect the readers critical of psychiatry from disappointment.

To understand and appreciate the position of the authors and their approach, it is important to know their background. They reach their conclusions from geriatric practice, where it is known that, over the years, elderly people are prescribed and administered masses of drugs without considering which substances are better to discontinue after surviving problems and crises. One author, Swapnil Gupta, was educated in India - a country where psychiatric drug combinations are administered unrestrainedly, for example absurd combinations such as Dep 37 or Depof 37, which contain the neuroleptic trifluoperazine, the antidepressant imipramine, the benzodiazepine-tranquilizer chlordiazepoxide and the antiparkinsonian trihexyphenidyl. India is no exception; mainstream psychiatrists worldwide are administering massive combinations of psychiatric substances. In this respect - despite the criticism mentioned above - *Deprescribing in Psychiatry* is of great importance to mainstream psychiatrists worldwide. Here,

representatives of mainstream psychiatry argue that their colleagues should reduce prescriptions, they name anxieties of patients that oppose a reduction, they name withdrawal and discontinuation symptoms that make a reduction difficult, they name wellness supports that may be suggested by the prescriber but are essentially put in place by the patient to support a deprescribing process that improves the chances of success for the reduction.

In the practical part “The Intervention of Deprescribing” the authors recommend alternative strategies which might prevent or best manage an eventual increase in distress. They refer to the Wellness Recovery Action Plan (WRAP) (see, this issue) with the person’s own identified toolbox of self-management and nonpharmaceutical self-care strategies. They also recommend advance directives (although strangely, as an example, they mention psychiatric drugs and even electroshock as preferences in crises, but not their denial of human rights and prevention of additional burdens). Exercise, family support, various forms of psychotherapy, treatment of insomnia, peer support and online resources are other potential aspects of wellness strategies. Also, acceptance and commitment therapy is mentioned in this frame, but without considering the important risk factors for bodily dependence from psychiatric drugs when accepted by the patient for a longer period and for chronic diseases due to the drugs’ effects.

The section “The Process of Deprescribing” mainly deals with a seven-

step structured intervention for optimizing the collaborative reduction of psychiatric drugs. Step 1 is Assess the Timing and Context, step 2 Medication Reconciliation, step 3 Exploration of the Patient’s Experience, Attitudes, and Meaning About Medication, step 4 Frame Setting for the Deprescribing Intervention, step 5 Decision Which Medication to Deprescribe, step 6 Development of the Specific Deprescribing Plan, and step 7 Implementation, Monitoring and Adjustment of the Plan. In their last chapters, the authors consider special aspects in relation to antidepressants, neuroleptics, mood stabilizers, benzodiazepine-tranquilizers and Z-drugs, and psychostimulants. Using examples, the authors show procedures when patients want to reduce or discontinue psychiatric drugs: switching to other psychiatric drugs, psychoeducation (convincing patients that a relapse is imminent when they stop taking psychiatric drugs), discussion of the desire to stop, further discussion to reach a decision that both doctor and patient can agree on. Being under the influence of personality-altering and attenuating substances while having to convince their doctors is certainly not an optimal starting point for meeting a person’s wishes for a reduction in psychiatric drugs. However, this is the sad reality, unless the patients take the initiative and go ahead on their own.

Despite or rather because of the disastrous prescription practice in mainstream psychiatry and even more so because of its reserved, moderate style of argumentation, and with the above concerns, I can recommend the book as a

step in the right direction for psychiatrists.
Especially for prescribers of psychiatric
drugs.

Peter Lehmann

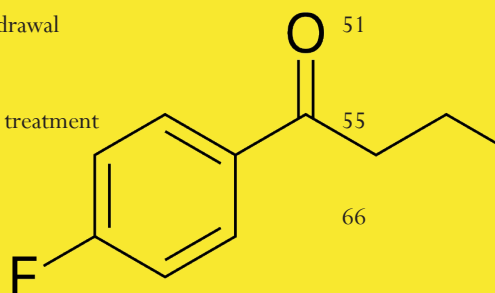
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Special Edition: Withdrawal from Prescribed Drugs

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Cover image: The skeletal formula of *haloperidol decanoate* (trade names Haldol decanoate, Halomonth, Neoperidole), often used in people known to be non-compliant with oral medication.