

Two contradictory sides of recovery and psychosocial rehabilitation.

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“Doctors learn how to administer drugs. They do not learn to how to withdraw drugs. In a time when long- term medication has become the rule for many diseases (blood pressure, high cholesterol, diabetes), not only in psychiatry, this is a deficit, and maintenance treatment is often questionable. It is essential to understand that – from good or less good reasons – many drug consumers have had enough and quit further drug-taking” (Finzen, 2014).

The psychiatrist Asmus Finzen writes this in the abstract of his contribution to the symposium *Coming off psychiatric drugs: Why, when and how*, which will be held in November 2014 in Bremen (Germany) as a pre-event to the annual conference of the German Society for Social Psychiatry,

together with the author of this paper. Both presenters mention the reasons why many are fed up with psychiatric drugs:

“The medical risks of psychiatric drugs (deficit syndrome, metabolic syndrome, tardive dyskinesia, increased cell death and increased mortality rates, especially if combinations are administered) increase steadily over the course of taking the drugs. Receptor changes, withdrawal-, rebound- and supersensitivity-symptoms to all kind of psychiatric drugs, and the customary cascades of combinations, require significant caution in withdrawal. To look nonchalantly the other way is usual, but is not a solution” (Finzen & Lehmann, 2014).

A decade before Finzen, Pirkko Lahti, 2001-2003 President of the World Federation for Mental Health, has already asked:

“Do we not leave our patients alone with their sorrows and problems, when they – for whatever reasons – decide by themselves to come off their psychotropic drugs? Where can they find support, understanding and good examples, if they turn away from us disappointed (or we from them)?” (Lahti, 2004, p. 14).

Finzen now criticizes his colleagues, who abandon their patients when they ask for support in withdrawal:

“Treating doctors too often react to this stubbornly. Some threaten to break off the doctor-patient relationship. But this is not in accordance with the ethical principles of their profession. When a patient wants to reduce or withdraw from drugs that he or she has taken long-term, the treating doctor has to support them kindly, even if they have a different opinion. It is the patient who decides. It is also the patient who carries the risks of taking the drugs. The doctor can support the person by conducting a phased withdrawal and by helping to minimize unnecessary risks” (Finzen, 2014).

No question, some individuals have the experience that they cannot exist in their current life situation without psychiatric drugs. But what if their conditions or opinions change and they decide to quit?

For mainstream psychiatrists, dealing with withdrawal problems and with recovery from drugs is not something they address. Similarly, many patients and ex-patients who took up the cause of recovery and psychosocial rehabilitation also avoid this issue. Why?

Two Sides of Recovery

Recovery is a relatively new concept used by those critical of psychiatry as well as by mainstream psychiatry itself, and turns against the therapeutic pessimism of past decades. “Recovery” can mean, among others things, rediscovery, healing, improvement, salvation, or the regaining of independence. A positive connotation of hope is common to all uses of this term, but it has many different implications, especially in combination with the administration or use of psychiatric drugs. For some, recovery means recovering from a mental illness, a reduction of symptoms, or a cure. Others use it to signify an abatement of unwanted effects of psychiatric drugs after their discontinuation, or the regaining of freedom after leaving the mental health system, or “being rescued from the swamp of psychiatry” (see Stastny & Lehmann, 2007a, p. 41).

In 1937, Abraham Low of the Psychiatric Institute of the University of Illinois Medical School in Chicago, founded the non-profit organisation Recovery, Inc., for people with various psychiatric problems, “a cornucopia of self-help methods and techniques that parallel those used in cognitive therapy” (“The Legacy”, 2005, p. 1). The aim of the program was to learn to cope with distressing

trivialities of everyday life and – with the learned techniques and in conjunction with professional help – to gain expertise in coping with bigger challenges of life. The concept of Recovery, Inc., should be understood as an addition to professional care, not as its replacement: “The issue of medications is never discussed – that’s the physician’s domain” (ibid.).

After many decades of being ignored in the field of mainstream psychiatry, the term recovery was revived at the beginning of the 1990s. Until then, people with serious psychiatric diagnoses like schizophrenia were considered inherently as chronically vulnerable and, in principle, incurable. They could only hope for suppression or alleviation of symptoms. However, activists of the self-help movement, who were able to live an independent and healthy life after withdrawal of psychiatric drugs or after recovery from the brain-damaging effects of electro- or insulin-shock, challenged the concept of incurability. Lectures by users and survivors of psychiatry (also called [ex-] patients, consumers, clients) at conferences and universities, as well as user/survivor-produced books, magazines, publishing houses and websites could not be ignored any longer.

Recovery from the Illness.

In their understanding of recovery, many psychiatric workers have been influenced by William Anthony, director of the Center for Psychiatric Rehabilitation at Boston University, who is “considered the father of the Recovery Movement” (FEMHC, 2012, p. 6). Anthony himself was influenced by Judi Chamberlin, a founder and key leader of the American self-help movement, who had worked at his center. Anthony summarized the descriptions of recovery in the US literature. There:

“Recovery is described as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993, p. 13).

The World Association for Psychosocial Rehabilitation (WAPR) shares this view; they note

“... that research has revealed that recovery in severe mental illnesses, considered as a creative and many faceted path people take in their everyday lives in order to overcome the problems and obstacles associated with the illnesses, and achieve an active, fulfilling and meaningful life, is real and possible...” (“Valladolid Statement”, 2010, p. 9).

Psychiatrist Michaela Amering and Margit Schmolke also put “mental illness,” from which people should recover, into the center of their understanding of recovery. In their book *Recovery: The end of incurability* they consider

“Recovery as development from the limitations of a patient role up to a self-defined and meaningful life (...) for people who have to overcome serious psychiatric illnesses” (Amering & Schmolke, 2012, p. 17).

In articles about recovery, Anthony, Amering & Schmolke, and many other authors like to invoke Patricia Deegan, a US user of psychiatry, who considers the acceptance of disablement as basis of recovery:

“Recovery often involves a transformation of the self wherein one both accepts one’s limitation and discovers a new world of possibility. This is the paradox of recovery, i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. (...) People with psychiatric disabilities are waiting just like that sea rose waited. We are waiting for our environments to change so that the person within us can emerge and grow. (...) It is our job to form a community of hope which surrounds people with psychiatric disabilities” (Deegan, 1996).

Apart from the fact that of course all humans – and not only those with psychiatric diagnoses – are well-advised to know the own limitations (which should not exclude attempts of “transgression” and risk-taking), this raises questions about the recovery process from users and survivors of psychiatry:

- who do not accept the limitations and ascriptions of disability and weakness any more, which are set by outside agencies or temporarily integrated into the self-perception;

whose madness primarily consists of a troublesome and uncomfortable way of living and perceiving life or in a temporarily extraordinary state of mind with boundary-expanding potentials and who therefore have been made into psychiatric patients;

- who have been damaged by psychiatric drugs and/or electroshocks and who want to protect themselves from further electroshocks or find their way back to health and well-being by coming off psychiatric drugs; or
- who are searching for non-medical ways to cope with mental problems or to recover from them.

Recovery from Psychiatric Treatment

Peter Watkins, a psychiatric nurse in Australia who identified with the movement critical of psychiatry (Laing, Foucault, Breggin, Thomas, Romme, Mosher, Bracken etc.), published a holistic concept of recovery. After four decades of professional experience, he recognized the advantage of abstaining from predetermined approaches and trusting in the capability of humans to assign their problems a meaning and to make decisions which make their life more bearable. He based his elaboration of these ideas on anthologies with stories of recovery and on long-term studies, which use a strict set of criteria for the definition of recovery: continuing wellness in spite of – and often also because of – the rebelling mind, no “relapses” within two years, and not taking neuroleptics (Watkins, 2009, p. 17).

With his concept of recovery, Watkins is in line with the British National Institute for Mental Health, which defined the rebuilding of control over one’s own life as the most important criterion for recovery:

“Recovery is not just about what services do to or for people. Rather, recovery is what people experience themselves as they become empowered to manage their lives in a manner that allows them to achieve a fulfilling, meaningful life and a contributing positive sense of belonging in their communities” (NIMHE, 2005, p. 2 – original emphasis).

User- and Survivor-oriented Concepts of Recovery

Users and survivors of psychiatry who accept psychiatric drugs- and those who refuse them-complain, as a general rule, about the fact that the right to make one's own decisions is taken away from them in states of crises. So for all of them, it is important to have alternatives beyond psychiatry, as well as humane treatment within the current system; to have tools to determine possible processes of crises and recovery by themselves (Stastny & Lehmann, 2007b). Advance directives (Ziegler, 2007) belong in this category, as do recovery plans (Copeland, 2010) and recovery plans including advance directives (Perkins & Rinaldi, 2007). Mike Slade of the Institute of Psychiatry at King's College London makes a similar point in his book *Personal Recovery and Mental Illness*; his recovery concept involves a shift away from traditional psychiatric ideology, such as attempts to manage risk and avoiding relapse with psychotropics, towards new priorities: supporting people in working towards their self-defined goals and taking responsibility for their own life:

"Supporting personal recovery requires a change in values. The new values involve services being driven by the priorities and aspirations of the individual, rather than giving primacy to clinical preoccupations and imperatives. This will involve mental health professionals listening to and acting on what the individuals themselves say" (Slade, 2009, p. 3 – original emphasis).

Psychiatric Drugs in the Focus of the Recovery Discussion

In contrast to most psychiatric workers, many users and survivors of psychiatry challenge psychiatric drugs when they discuss recovery or quality of life. Of course, other issues are important, too, like self-stigmatisation, discrimination, withholding appropriate support, dependence on the mental health system on major pharmaceutical companies, and reducing the human being to a psychiatric diagnosis or a function of genes. But one fact is often overlooked: that recovery under the influence of psychiatric drugs is rather unlikely.

The experiences of the Berlin Runaway-house, a house for people seeking shelter from degrading psychiatric forced treatment, as reported by Kerstin Kempker in *Coming off Psychiatric Drugs*, show what people can do "without." Community, support, experienced staff (if possible with their own experience of withdrawal) and responsible doctors

can help to support ambivalent users and survivors of psychiatry in need of support.

"There's a lot of tea-drinking, various herbal teas, and sometimes coffee. 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. (...) Because most people living here for more than two weeks are not taking psychiatric drugs (60%) and/or withdraw completely or gradually while here (40%), there is a lot of experience that gets shared concerning how one can 'do without,' and all that one can do again 'without' the drugs" (Kempker, 2004, pp. 270-271).

Problems beyond Psychiatric Drugs

Even if psychiatric drugs – with their risks or unpleasant effects for mind and body – are a burden for psychiatric patients, simply stopping them, whether slowly or abruptly, often is not a sufficient way to cope with one's mental problems. Going mad is a signal showing the necessity of a change, says Maths Jespersen, a regional secretary of the Swedish National Organization of Users and Survivors of Psychiatry:

"Madness is no illness to be cured. My madness came to call up a new life for me" (Jespersen, 2004, p. 76).

Indeed, those who learn to take feelings seriously, to follow their own intuition and to take notice of and react to warning signals of a developing crisis, are more likely to escape the danger of having psychiatric drugs prescribed a second time. When users and survivors of psychiatry understand the connection between violence or abuse and their difficulties, when they understand mad and troubling symptoms and react in alternative ways to crises, it is easier for them to break emotional attachment to life problems and deal with them. The quest for understanding that begins at the end of an acute phase of madness or depression takes on preventative qualities, as Regina Bellion, a German survivor of psychiatry, explains:

"Whoever gets to the bottom of his or her psychotic experiences afterwards obviously

does not run into the next psychotic phase all too soon” (Bellion, 2004, p. 284).

Some co-authors of *Coming off Psychiatric Drugs: Successful withdrawal from neuroleptics, antidepressants, lithium, carbamazepine and tranquilizers* (Lehmann, 2004), who gave accounts of how they came off psychiatric drugs without once again ending up in the doctor’s office, regard it as a fundamental condition to notice their own (co-) responsibility for their lives, their problem-burdened past and their responsibility for their future. In the same anthology, professional helpers note their humane presence and their availability in the critical moments of coming off as a prerequisite for effective support. But the users and survivors of psychiatry have to do their share in overcoming the problems that can appear when coming off, too.

The problems which led to administration of psychiatric drugs may return when people stop taking them for different reasons, so it is important to understand the reasons for one’s mental problems. Experiences within the self-help movement of users and survivors of psychiatry show that the belief that it was the “evil others” (neighbours, husband, wife, parents, family doctor, psychiatrist, police, psychosocial services etc.) or the “mental illness” (metabolic disturbance, genetic disposition, etc.) that led to the administration of the psychiatric drugs in the first place can prevent or make it more difficult for people to take full responsibility for their own lives, since the habit of looking for someone or something to blame is hard to break. Mental crises – like physical crises – offer a chance for change; in fact, they demand it. This calls for dealing with one’s own history, whether in dialog with oneself, in a self-help group, with friends, relatives, or therapists, as long as they are free of the baggage of psychiatric beliefs and power play.

Psychiatric Drugs or Recovery?

All people, but especially people who decide to try to recover with psychiatric drugs, should know that the life expectancy of psychiatric patients is reduced by – on average – two to three decades (Ösby et al., 2000; Colton & Manderscheid, 2006; Manderscheid, 2006; 2009; Aderhold, 2007; Weinmann et al., 2009; Chang et al., 2011; Lehmann, 2012; Janssen Pharmaceuticals, 2012) and that for three decades, the mortality rate has continued to grow (Saha et al., 2007, p. 1126). “Average number of years prematurely that people

with serious mental illness die,” warns the Foundation for Excellence in Mental Health Care, a charity based in Oregon, USA, on their homepage (FEMHC, 2014). “People with serious mental illness” is another term for people receiving psychiatric drugs – substances with a considerable amount of adverse effects.

While you can discuss endlessly the role of psychiatric drugs in the early deaths of psychiatric patients, if psychiatric workers, nurses included, are seriously interested in recovery processes, they should inform their patients and their relatives about the possible unwanted effects especially of neuroleptics, the most risky group of psychiatric drugs. In general, these are administered without informed consent, especially without information about unwanted effects which could be identified as early warning symptoms for developing chronic and lethal diseases (i.e., neuroleptic malignant syndrome, diabetes, metabolic syndrome, myocardial infarction, apoplectic stroke, agranulocytosis, asphyxia, tardive dyskinesia, etc.). Without being able to identify these warning symptoms, patients, their relatives, friends and supporters cannot react appropriately if these effects arise, when rapid response would be life-saving (Lehmann, 2013).

Users of psychiatry and psychiatric workers should seek information and think carefully about the risks and possibilities of coming off psychiatric drugs, especially when the drugs have been administered long-term. And if the decision is to withdraw from drugs, they should come off slowly, step-by-step, when required (Lehmann, 2004). Too-rapid withdrawal of neuroleptics can cause chronic damage. If, at withdrawal, psychotic symptoms appear, this could point to developing (organic-based) supersensitivity psychoses, which might get chronic by further administration of neuroleptics and make each recovery process impossible, so it would be important to use non-neuroleptic methods to alleviate withdrawal symptoms.

Of course, antidepressants can also trigger chronic problems. One of them is the danger of dependence. In the early 1970s, doctors expressed the suspicion that antidepressants lead to depression becoming chronic (Irlé, 1974, pp. 124-125). Meanwhile, the study of a team led by Paul Andrews (2011) in the Department of Psychology, Neuroscience & Behaviour at the McMaster University in Hamilton, Ontario (Canada), showed that synthetic antidepressants interfere with the

brain's natural self-regulation of serotonin and other neurotransmitters, and the brain can overcorrect once medication is suspended. Therefore, new depression would be triggered (see "Patients", 2011).

Neuroleptics and antidepressants should be a focus of the recovery discussion, not only because of their risks, but because they can also inhibit self-healing tendencies. It is important that all stakeholders become aware of the tremendous lack of resources in the health field when people decide to withdraw from psychiatric drugs. This lack of resources results in preventing recovery and can lead to patients becoming chronically physically ill and psychiatrically disabled. Chronic illness and disability hinder people with mental health problems to reach the status they deserve as citizens with full rights. Chronic illness and disability prevent rehabilitation, too.

Addressing Contradictions

WAPR calls on policymakers, professionals, users, caregivers, and other stakeholders, as well as NGOs, to continue efforts to

"Design and implement community based recovery oriented mental health and rehabilitation services, based on the principles of quality, accessibility, equity, users and carers' participation, shared decisions, choice and self-determination, maximum use of natural supports and settings, and professional relationship built on trust and support..." ("Valladolid Statement", 2010, p. 9).

If the disturbing effects of psychiatric drugs, which might prevent recovery, are ignored, the concept of recovery as a unilateral concept cannot be taken seriously; it would become an empty notion. Existing contradictions, which need to be part of the recovery discussion, lie throughout the entire psychiatric field: obvious as well as hidden damages caused by psychiatric drugs, particularly neuroleptics, and brain damage caused by electroshock, as well as other factors, which obstruct recovery and rehabilitation processes. Concepts of recovery which try to exclude these factors should be regarded as typical psychiatric labelling fraud. In a fair discussion, at least the different approaches of recovery – taking psychiatric drugs or recovery by coming off psychiatric drugs – should be described openly. People could then make their own informed decisions about how to proceed.

Holding a fair discussion could be a step to establish the diagnosis "dependence on neuroleptics" and "dependence on antidepressants," which would enable doctors who really want to support their patients in withdrawal to get their costs reimbursed by insurance companies. Also, doctors could learn better how to support patients in withdrawal from psychiatric drugs. The experience-based wisdom of ex-patients who withdrew successfully on their own and could now be good teachers in education, workshops and conferences, should not be underestimated.

Note: Thanks to Darby Penney and Peter Stastny for support in translation matters. Copyright by Peter Lehmann 2014, all rights reserved. Sources see www.peter-lehmann.de/document/wapr