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Responding to the Catastrophic Reduction of Psychiatric Patients' Life Expectancy

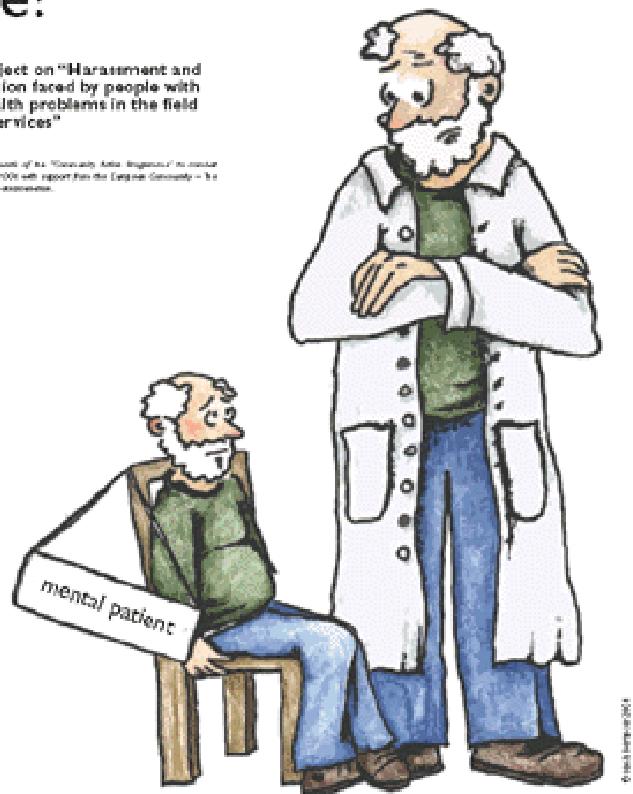
Lecture to the National Association for Rights Protection
and Advocacy (USA)

Conference "Rights Under Siege: Fighting Back"
Phoenix, Arizona
August 27, 2016

No discrimination and harassment here!

Action project on "Harassment and discrimination faced by people with mental health problems in the field of health services"

Report of the discussion of the "Community Action Programme to combat discrimination 2001-2006 with regard to the European Community - The European Union against discrimination".



The information contained in this document is not necessarily in line with the position and/or of the European Commission.

Action project against
"Harassment and discrimination
faced by people with mental
health problems in the field
of health services"

Organised in the framework of the
European Union's "Community Action
Programme" to combat discrimination
2001-2006

- ➡ Representation of users and survivors of psychiatry in congresses, networking and international exchange of organisations representing (ex-) users and survivors of psychiatry

Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development

“Significant strides have been made in increasing life expectancy and reducing some of the common killers associated with child and maternal mortality.

However many more efforts are needed to fully eradicate a wide range of diseases and address many different persistent and emerging health issues.”

United Nations (2016). *Sustainable Development Goals. Goal 3: Ensure healthy lives and promote well-being for all at all ages*
www.un.org/sustainabledevelopment/health/

Reduced Life Expectancy

“25 Years. Average number of years prematurely that people with serious mental illness die.”

FEMHC – The Foundation for Excellence in Mental Health Care (2014). *Just the Facts*. Wilsonville, OR. www.mentalhealthexcellence.org/

“Research has shown that the life expectancy for people living with a serious mental health condition is, on average, 25 years shorter than the general population. Heart disease, diabetes, respiratory diseases, and infectious diseases (such as HIV/ AIDS) are the most common causes of death among this population.”

Janssen Pharmaceuticals, Inc. (2012). The importance of total wellness. *Choices in Recovery—Support and Information for Schizophrenia, Schizoaffective, and Bipolar Disorder*, 9(2), 12

Reduced Life Expectancy

“It has been known for several years that persons with serious mental illness die younger than the general population. However, recent evidence reveals that the rate of serious morbidity (illness) and mortality (death) in this population has accelerated. In fact, persons with serious mental illness (SMI) are now dying 25 years earlier than the general population.”

Parks J. (October 2006). Foreword. In: J. Parks, D. Svendsen, P. Singer, & M.E. Foti (Eds.), *Morbidity and mortality in people with serious mental illness* (p. 4). Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD), Medical Directors Council

www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf

Reduced Life Expectancy

“However, with time and experience the second generation antipsychotic medications have become more highly associated with weight gain, diabetes, dislipidemia (*fat metabolism disorder*), insulin resistance and the metabolic syndrome and the superiority of clinical response (except for clozapine) has been questioned. Other psychotropic medications that are associated with weight gain may also be of concern” (p. 6).

Parks J., Svendsen D., Singer P., & Foti M.E. (Eds.) (October 2006). *Morbidity and mortality in people with serious mental illness*. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD), Medical Directors Council

www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf

Reduced Life Expectancy

Adverse Effects and Withdrawal Problems at Psychiatric Drugs:

Metabolic syndrome, cardiovascular diseases (especially in elderly people, children and adolescents),
Takotsubo cardiomyopathy (especially at additional restraint),
thrombosis, embolisms, stroke, diabetes, overweight, renal failure, neuroleptic malignant syndrome, malignant hyperthermia, agranulocytosis, asphyxia, tardive dyskinesia, hormone changes combined with sexual disorders and neoplasm in the mammary glands, malformations in newborn, paradoxical or intrinsic suicidal drug effects, states of cramping at withdrawal, etc.

Reduced Life Expectancy

Adverse Effects and Withdrawal Problems at Psychiatric Drugs:

“At a dosage of 13.3 mg/ kg of chlorpromazine, abrupt withdrawal led to a sudden death within 14 days, probably due to irreversibly blocked metabolic processes that stopped functioning (similar observations in human beings have been published in which death followed a brief stage of cramping)” (p. 487).

Sommer, H. & Quandt, J. (1970). Langzeitbehandlung mit Chlorpromazin im Tierexperiment. *Fortschritte der Neurologie-Psychiatrie und ihrer Grenzgebiete*, 38, 466-491

Reduced Life Expectancy

“In the neonates of mothers who took antipsychotics (including haloperidol) during the third trimester of pregnancy, there is risk of extrapyramidal symptoms and / or withdrawal symptoms. These symptoms in newborns may include agitation, abnormally increased or decreased muscle tone, tremors, sleepiness, difficulty breathing or feeding problems. These complications may vary in their severity. In some cases, the symptoms were self-limiting, in other cases, the newborns required monitoring in the intensive care unit or a longer hospitalisation.”

Janssen-Cilag AG (Switzerland) (2016, March 16). Haldol. Product information. In: *Arzneimittel-Kompendium Online*. Basel: Documed AG
<https://compendium.ch/mpro/mnr/3404/html/de?start=1#7450>

Dealing with Reduced Expectancy of Life

“Consensus recommendations included regular monitoring of body mass index, plasma glucose level, lipid profiles, and signs of prolactin elevation or sexual dysfunction. Information from monitoring should guide the selection of antipsychotic agents. Specific recommendations were made for cardiac monitoring of patients who receive medications associated with QT interval prolongation including thioridazine, mesoridazine, and ziprasidone, and for monitoring for signs of myocarditis in patients treated with clozapine. ...

Dealing with Reduced Expectancy of Life

Patients who receive both first- and second-generation antipsychotic medications should be examined for extrapyramidal symptoms and tardive dyskinesia. Patients with schizophrenia should receive regular visual examinations. (...)

Some of the recommendations in this report may be difficult to implement in certain mental health settings. For example, clinics of private offices may not have the capacity to monitor plasma glucose levels or provide ECGs and may not have ready access to weight-management programs" (pp. 334 / 1346).

Marder S.R., Essock, S.M., Miller A.L., Buchanan R.W., Casey D.E., Davis J.M., et al. (2004). Physical health monitoring of patients with schizophrenia. *American Journal of Psychiatry*, 161, 1334-1349

Dealing with Reduced Expectancy of Life

“1/4 mg haloperidol, a dose that would not produce a plasma level which could be measured with currently available methods, can result in a significant prolactin secretion; a maximum prolactin secretion is, however, reached with 1 1/2 mg haloperidol. Thus it becomes evident that haloperidol is biologically effective even in this dose range” (p. 113).

Langer G. (1983). Contribution to the discussion. In: H. Hippius & H.E. Klein (Eds.), *Therapie mit Neuroleptika* (pp. 113-114). Erlangen: Perimed

Dealing with Reduced Expectancy of Life

“To put it bluntly, when treating a patient with an acute condition, it is as if the doctor were always conducting an uncontrolled individual experiment.”

Seeler W. (1983). Contribution to the discussion. In: H. Hippius & H.E. Klein (Eds.), *Therapie mit Neuroleptika* (p. 140). Erlangen: Perimed

“We have also learned that, at therapeutically flawless and even low doses, harmful concomitant effects and potentially lethal outcomes can occur—due to still largely unknown individual dispositions or other complicating factors that we hardly survey” (p. 201).

Kranz H. (1964). Schlusswort. In: H. Kranz & K. Heinrich (Eds.), *Begleitwirkungen und Misserfolge der psychiatrischen Pharmakotherapie* (pp. 201-202). Stuttgart: Thieme

Dealing with Reduced Expectancy of Life

About modern *atypical* neuroleptics

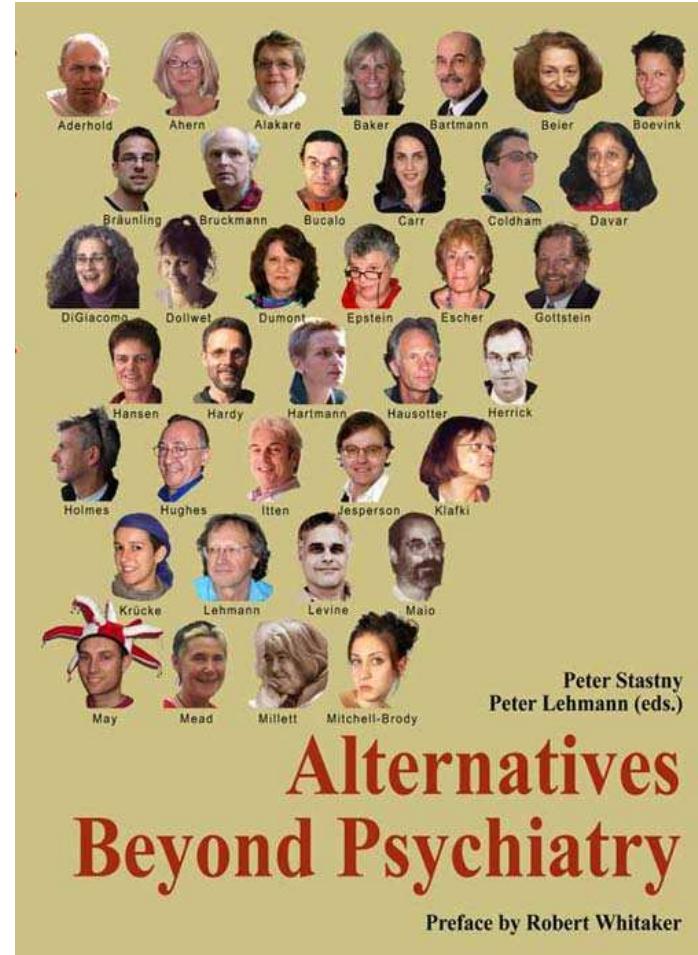
“It is not a case of fewer side-effects, but of different ones which can be just as debilitating even if the patient isn't immediately aware of them. Therefore, patients can be more easily motivated to take these drugs because they no longer suffer instantly and as much from the excruciating dyskinésias / extrapyramidal side effects” (p. 30).

Ebner G. (2003). Aktuelles aus der Psychopharmakologie. Das Wichtigste vom ECNP-Kongress in Barcelona 05.-09.10.2002. *Psychiatrie*, (1), 29-32

Measures to Reduce Psychiatric Patients' Mortality

Humanistic alternatives like

- Soteria
- Intervoice
- Unusual Belief Groups
- Runaway-house (Berlin)
- Trauma informed peer run crisis alternatives
- Crisis Hostel (Ithaca)
- Windhorse
- Hotel Magnus Stenbock
- Open Dialogue
- Personal Ombudsman
- Icarus Project



Measures to Reduce Psychiatric Patients' Mortality

“Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users of psychiatry.

Development of primary care and specialized mental health services focusing on quality of care and the development of new non-stigmatizing and self-help approaches. (...)

Development of mental health legislation based on human rights, emphasising freedom of choice, and the importance of appropriate confidentiality” (p. 9).

World Health Organization / European Commission (1999). *Balancing mental health promotion and mental health care: A joint World Health Organization / European Commission meeting*. Brussels: World Health Organization 1999
www.peter-lehmann-publishing.com/articles/others/consensus.htm

Measures to Reduce Psychiatric Patients' Mortality

“The integrated intervention for depression would extensively cover medical and metabolic history. Further it would address the autonomic nervous system responses through a range of body techniques such as relaxation, biofeedback, guided imagery, mindfulness training, breathing rhythms, trance, meditations, tai chi or yoga” (p. 88).

Davar B. (2007). Depression and the use of natural healing methods. In: P. Stastny & P. Lehmann (Eds.), *Alternatives beyond psychiatry* (pp. 83-90). Berlin / Eugene, OR / Shrewsbury: Peter Lehmann Publishing (ebook 2014)

Measures to Reduce Psychiatric Patients' Mortality

Saint Camille Association, West African Republic of Benin:

Social support, including personal hygiene, food, clean clothes, work rehabilitation (learn to farm, sew, raise small animals, bake, weave, make mats or do hair to be productive upon return to their villages and be social reintegrated).

Education about mental illness as a treatable medical condition.

Evaluation from a psychiatric nurse and start on a course of psychiatric drugs “if warranted.” Optimize the use of neuroleptics.

Treatment not Chains (undated). *Modern psychiatric treatment in a caring environment.* www.treatmentnotchains.org/projects/

Pharmacists Without Borders (undated). *Pharmacists Without Borders Canada in collaboration with the St-Camille Association will be conducting a development mission from 2016-2018 in Benin.* <http://psfcanada.org/mission-disp.asp?i=2>.

Measures to Reduce Psychiatric Patients' Mortality

MindFreedom Ghana:

“Support and assist people with severe mental distress to receive the treatment they want or get protected from a treatment they do not agree with (...).

Support and assist in rehabilitative schemes for the people in recovery from severe mental distress and psychiatric treatment” (p. 338).

Taylor D. (2007). MindFreedom Ghana: Fighting for basic human conditions of psychiatric patients. In: P. Stastny & P. Lehmann (Eds.), *Alternatives beyond psychiatry* (pp. 336-342). Berlin / Eugene, OR / Shrewsbury: Peter Lehmann Publishing (ebook 2014)

Additional information: MindFreedom Ghana (undated). *About us*
www.idealyst.org/view/nonprofit/g24cjKCGb4w4/

Measures to Reduce Psychiatric Patients' Mortality

Seher Urban Community Mental Health and Inclusion Program.
Pune, India:

A. Non-formal Care

Information meetings with subsequent talks with families of people with severe emotional distress or with the people directly.

First if all: Listen. Then emotional support, try to understand out psychic and social needs. Basic counselling, body therapies, addressing hunger and starvation, nutritional information, establishing neighbour and foster care support, setting up material and social support systems, teaching relaxation techniques.

Helping to identify problems, enabling decision making, proceeding step by step, supporting hope and co-operation with systems planning livelihoods.

Measures to Reduce Psychiatric Patients' Mortality

Seher Urban Community Mental Health and Inclusion Program.
Pune, India:

B. Formal Care

Structured therapeutic measures including talk therapies, arts based therapies and referral to therapeutic support groups.

If physical health problems, refer to health institutions.

Cooperation with a psychiatrist, when people cannot exist in their current life-condition without taking psychiatric drugs.

Non-formal care: <http://youtu.be/22bIQzYFoMg>

Peer support and support counselling: <http://youtu.be/U73aE3fhe6I>

Asha case study using arts based therapy: <http://youtu.be/xLxsXL1ZMVs>

Formal care: <http://youtu.be/uDTRjfgMHLE>

Measures to Reduce Psychiatric Patients' Mortality

La Cura and Associazione Penelope. Sicily, Italy

“Gives to these people a place to live, a place to eat, to be heard, but also a place where they can wash themselves, can obtain clothing, find a job and a place to live, or where they can lay back and go on a journey within themselves. (...) The headquarter for this net is La Cura, an emergency social service open 365 days a year, 24 hours a day. (...) The center is ‘de-psychiatrized,’ which means that mental health workers are not allowed in the center and the guests are free to choose whether they want to be under pharmacological treatment or not” (p. 222).

Bucalo G. (2007). A Sicilian way to antipsychiatry: La Cura. In: P. Stastny & P. Lehmann (Eds.), *Alternatives beyond psychiatry* (pp. 217-223). Berlin / Eugene, OR / Shrewsbury: Peter Lehmann Publishing (ebook 2014)

Measures to Reduce Psychiatric Patients' Mortality

- Education about risks of psychiatric drugs, their damages, and alternatives
- Support in withdrawal

“It is his role yet to prescribe drugs. This physicians do learn. How to withdraw drugs, they do not learn.”

Finzen A. (2015). Wie man Medikamente absetzen, lernen Ärzte nicht. *Soziale Psychiatrie*, 39, (2), 16

Which withdrawal symptoms may occur especially during the transition from mini doses to zero?

Which naturopathic methods are useful to relieve withdrawal symptoms to stabilize in particularly the vulnerable period immediately after withdrawal?

Measures to Reduce Psychiatric Patients' Mortality

What are the options for detoxifying and “emergency pharmacies” use?

How to withdraw combinations?

How can dosages be reduced beyond given product units?

How can pellets be protected from breaking down in the stomach, if they require an intestinal absorption?

How can doses be reduced by time stretching?

Which environment, lifestyle, diet and physical activity support a successful withdrawal?

How to cope with sleeping problems caused by the withdrawal?

Which support options, but also which risks, can be expected in the self-help sector?

Measures to Reduce Psychiatric Patients' Mortality

- ➡ Advance directives based on equality before the law
 - Including personal experiences and values
 - Listing personal and family burdens with physical diseases
 - Description of concrete situations with severe emotional distress and suggesting self-determined ways to overcome them

Lehmann P (2013, September 7). Forced psychiatric treatment (and protection against it) in Germany in 2013. Contribution to: Mad in America – Science, Psychiatry and Community. www.madinamerica.com/2013/09/forced-psychiatric-treatment-protection-germany-2013/

Measures to Reduce Psychiatric Patients' Mortality

Pursuing reckless psychiatric treatment

“Conduct whereby the actor does not desire harmful consequence but ... foresees the possibility and consciously takes the risk [...or alternatively as] a state of mind in which a person does not care about the consequences of his or her actions” (p. 1053).

Garner B. (Ed.) (2005). *Black's law dictionary*. 8th edition. Boston: West Publishing Co.

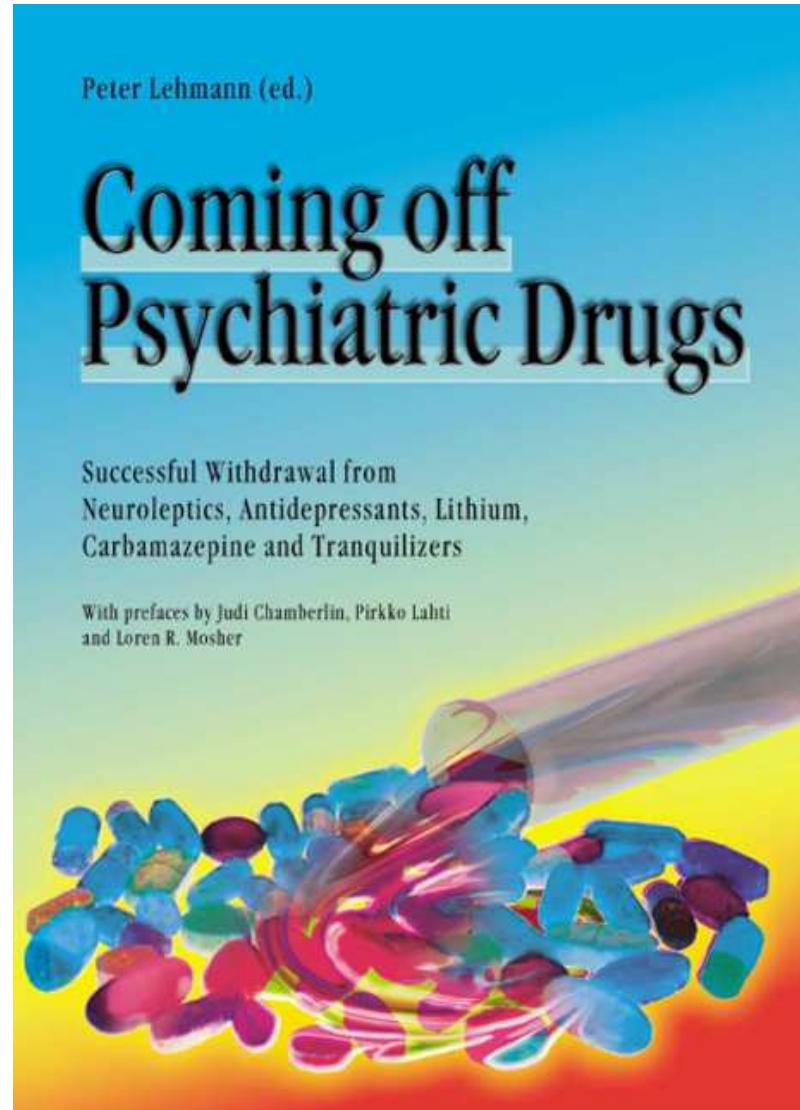
Synthetics and Profit Orientation

“Assuming that our world is becoming ever more artificial and ‘man-made,’ and the demands by our modern performance-oriented society on our mental stability are constantly on the rise, wouldn’t it make sense to investigate every possible chemical influence on mental functions with respect to its potential social usefulness?” (p. 17)

Helmchen H. & Müller-Oerlinghausen B. (1978). Klinische Prüfung neuer Psychopharmaka. In H. Helmchen & B. Müller-Oerlinghausen (Eds.), *Psychiatrische Therapie-Forschung – Ethische und juristische Probleme* (pp. 7-26). Berlin / Heidelberg / New York: Springer

.... Or Ecology and Humanistic Orientation

“In this field ex-users/ survivors can play an important role as staff-members and consultants, having the knowledge about what helped us to recover. Such services linked with a positive subcultural identity and dignity can be provided by the public or with public financial support by the user/ survivor movement it self giving people the space to meet and create their own lives. (...)



.... Or Ecology and Humanistic Orientation

Until the final abolition of these drugs, a lot of people need help and support to withdraw from the drugs. Alternative systems and decentralized services to meet the needs of people experiencing mental health problems would minimize and in the long run make the use of synthetic and toxic psychiatric drugs needless" (p. 308).

Bach Jensen K. (2004). Detoxification—in the large and in the small: Towards a culture of respect. In: P. Lehmann (Ed.), *Coming off psychiatric drugs: Successful withdrawal from neuroleptics, antidepressants, lithium, carbamazepine and tranquilizers* (pp. 303-309). Berlin / Eugene, OR / Shrewsbury: Peter Lehmann Publishing (ebook 2013)

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