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Are users and survivors of psychiatry only allowed to speak about their personal narratives?

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[–] Abstract and Keywords

In modern psychiatry, professionals claim to speak to patients as equals, to take them seriously as a person. In this article, the author shares his personal experience, in which he—like other former psychiatric inmates—is reduced to the role of a former patient who is expected only to speak about his personal patient narrative. This happens despite the fact that he received international awards in acknowledgement of exceptional scientific and humanitarian contributions about how to minimize risks of withdrawal from psychiatric drugs, build alternatives beyond psychiatry and develop possibilities for self-help for individuals experiencing madness and strategies toward implementing humane and ethical treatment. Can psychiatry solve its intrinsic ethical problems when professionals do not leave behind their roles as “experts” (and users and survivors of psychiatry their roles as “patients”) and their associations continue to refuse even discussion about psychiatric human rights violations?

Keywords: psychiatry, psychiatrists, psychiatric patients, ethics, discrimination, stereotype, monologue of experts, psychiatric violence

One of the many discriminations brought upon my life by being labelled in 1977 with the psychiatric diagnoses of “schizophrenia,” “psychosis,” “hebephrenia,” etc., could have been the lifelong sentence—not only by psychiatrists—of being reduced to someone who has been a “psychiatric patient” and who is expected to report about my experiences as patient. That happens to many people. “Stay who you are!” has been one of the many customary urgings in therapy. “Do not pass this point; no step further!” is another version of this command.

How was it to be a patient?

I return in abbreviated version to the beginning in 1977, the rupture in my life: I was displaced into psychiatry after an exceptional mental state, and received involuntary treatment and huge dosages of neuroleptics; as a consequence neuroleptic-induced parkinsonism, tardive dyskinesia (rabbit syndrome), obesity, and suicidal ideation, then continued treatment on an outpatient basis, more experiences of being injected, discontinuing medication on my own account and recovery (except for permanent liver problems). In *Coming off Psychiatric Drugs* (Lehmann 2004), I described this episode in detail. How I mastered a second exceptional mental state I recounted in *What Helps Me if I Go Mad?* (Lehmann and Stastny 2007). How I came to terms with this episode, I addressed in the interview recorded in the book *The Lunatics Offensive* by Tina Stoeckle (“Interview” 2005).

Before others and I founded an anti-psychiatry self-help group in 1980, I had attended an education course for adults run by two psychiatric nurses on the topic of “Care of the mentally ill,” based on the philosophy of local community mental health care—my first and last participation at such an event. The reprimand of having my own program and ideas on this topic and that I was a disturbance still rings in my mind. I had dared to voice own experiences. What followed was years and years of trying to help myself, and the publication of my first book, *The Chemical Gag: Why Psychiatrists Administer Neuroleptics* (Lehmann 1986). Through this, I became relatively

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well-known, invitations to presentations followed, also from abroad. I was not anymore only the former psychiatric patient, but a more or less appreciated speaker at various types of meetings. In my own support group, my occasional absence was not always well-received. The fact that my book sold well and I made some money from them, that I had a small car and a steady girlfriend, were critically watched: I was doing too well; a psychiatric admission should be pondered to again bring back to mind what it means to be a psychiatric patient.

“Those really afflicted should ideally stay poor, speechless and living on the edge. Words should get stuck in the throat, and if voiced, should be like eruptions, unplanned and emotional”

writes Kerstin Kempker, about the general stereotype of the (ex-) user and survivor of psychiatry; and at the same time, she addresses the distorted discrimination, also used by psychiatrists:

They like to talk about the “afflicted elite” if their arguments against their criticizers are weak and they try to expound that it does not suit “their patients” to be successful and to come to money or influence. Why do they protest? They do have a good life! Then it could not have been that bad, could it?

Kempker 1998a, p. 131.

The insistence on the stereotype of the (ex-) user and survivor of psychiatry was one of the reasons I withdrew from my self-help group and started a new and mixed organization. Thanks to many years of dedicated work, a lot of support and a donation, we were able to open the Runaway House in 1996, a house for people who were seeking shelter from psychiatric violence. Through contact with the media, who reported about this innovative project, I learned about another type of discrimination, also described by Kerstin Kempker:

To the outside world, that is towards the media and in public meetings, we co-workers don't show ourselves as afflicted or not, the reason being that those afflicted are usually only asked about their personal history whereas the others are automatically seen as professionals. To forestall this discrimination that one is either afflicted or otherwise trained, the non-afflicted have to live with the possibility of being seen as (ex-) users and survivors of psychiatry, whilst those cannot any more withdraw to and argue with only their personal history

Kempker, 1998b, p. 20.

When I am myself busy as author, writing or speaking about experienced-based scientific insights and understandings, for example, withdrawal from psychiatric drugs, my background is difficult to hide. This again proved fateful when a report about the awarding of an honorary doctorate in Greece appeared in the daily newspaper of the town in which I had grown up. In this report by Eva Herschmann (2010), nothing was mentioned about my publications of the last 30 years; this reduction into the role of only a patient was critically commented upon by Jonas Dallmann as:

... article, in which the emphasis according to me is placed too much on the far back-dated history of Peter Lehmann as patient (already thirty years ago!) and through that losing sight of the reasons why the University of Thessaloniki awarded him an honorary doctorate (...), and thus the impression is created that the honorary doctorate is a recognition for a personal experience of being a patient. That is not what it is about! It is understandable that the author wanted to tell a “story” and therefore focused on the biographical background. It is however misleading if by doing that important scientific achievements are ignored and Lehmann is forced into the role of a victim, a role he has left behind him since several decades.

Dallmann 2010

Positive experiences

I now want to describe, following three of my own experiences, what can be achieved if both sides vacate the pre-existing roles of either patient or expert.

When I returned to the university in 1978 after recovering from the effects of neuroleptics and with a one-year delay to finish my graduate exam in social pedagogy, I was able to, as part of a learning objective, impart my

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knowledge about the damaging effects of neuroleptics. The offer to write a dissertation shortly thereafter (Lehmann 2010a) led to education of psychiatric personnel about the topic “Coming off Psychiatric Drugs.”

From the collaboration with the psychiatrist Peter Stastny, who translated my article about psychiatric mass murder during the Nazi era (Lehmann 1994), followed the mutual publication of the book *Alternatives Beyond Psychiatry* (Stastny and Lehmann 2007) about alternatives worldwide, current possibilities of self-help for individuals experiencing madness, and strategies toward implementing humane treatment.

Diverse presentations at congresses led to me receiving an invitation to join the organizational committee of the congress “Coercive treatment in psychiatry: a comprehensive review” of the World Psychiatric Association (WPA) 2007 in Dresden and to negotiate, as representative of Mind Freedom International and the European Network of (ex-) Users and Survivors of Psychiatry, a new kind of involvement of (ex-) users and survivors of psychiatry at a psychiatry congress: two keynote lectures, the conducting of two symposia including the management of costs, the distribution of information about participating organizations of (ex-) users and survivors of psychiatry, participation at the press conference, free information stands and reduced congress fees for (ex-) users and survivors of psychiatry (Lehmann 2006).

At this congress, Juan Mezzich, in his role as WPA president, announced the dialogue with representatives of organizations of (ex-) users and survivors of psychiatry (Lehmann 2010b, p. 215), but his successor on the executive committee did not follow these words up with action. Maybe there was a realization that the representatives of organizations of (ex-) users and survivors of psychiatry were interested in breaking up the traditional division of roles, especially to discuss psychiatric violations of human rights, meaningful involvement of (ex-) users and survivors and alternatives beyond psychiatry—but not to practice a form of discussion such as the “dialogue” developed by social psychiatrists and their friends in Germany: a discussion held between “experts,” “mentally ill patients,” and their “relatives.” Thilo von Trotha criticized this as a “cheap cover up for a well-known traditional monologue” (von Trotha 1995). In such a dialogue, the range of power, influence, and material resources over which psychiatry wields influence in the institutional, scientific and social spheres, is simply denied:

Whilst (ex-) users and survivors of psychiatry within the framework of the *dialogue* talk about themselves and their personal experiences, psychiatrists and relatives talk about others and their respective reactions to experiences of madness and the behaviour triggered by this. Whilst (ex-) users and survivors of psychiatry and relatives are dependent on their individual and common ways of interpretations, psychiatrists have at their disposal a complex, structured and specialized language, which allows them to hide themselves as persons. As a consequence the *dialogue* is in danger of being just a variation of the classic psychiatric case study: a person has experienced something but the other already knows what he has “really” experienced. (...) Even if (ex-) users and survivors of psychiatry feel being taken more serious than in the ward and psychiatrists think of themselves as more advanced, more open and understanding than their conventional acting colleagues, these attempts are still only subtly camouflaged new editions of the well-known traditional psychiatric attitude of making the mad other into a medical object and thing

von Trotha 2001, p. 206.

Nearly the same assessment was given by Darby Penney, who participated in a project which brought together nine (ex-) users and survivors of psychiatry with seven psychiatrists for a series of structured dialogues about the concept of recovery. After those meetings, organized in the 1990s by the New York State Office of Mental Health, she mentioned the psychiatrists’ efforts to continue to define reality for the others and to shut down threatening topics:

While we spoke from the heart about experiences that had defined our lives and our sense of ourselves, they were still able to listen from their “doctor” roles. They learned some new ideas, rejected others that made them uneasy, and went away with their professional roles intact. We, on the other hand, felt emotionally spent, slightly patronized, and decidedly unfulfilled by the experience.

Penney 2000, p. 42

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What to do?

Many (ex-) users and survivors of psychiatry are undoubtedly proud if psychiatrists ask them—for the first time—to talk about what they have experienced. In modern psychiatry, where the administration of drugs and electroshocks (ECT) are standard practice, to listen is rather an exception. The exchange between (ex-) users and survivors of psychiatry about their experiences with madness and psychiatry serves the working through of conflict and can also be the starting point in discussions with those working in the psychiatric field. Wilma Boevink, former Professor for Recovery at the Hanze University Groningen:

To me, talking about and working on recovery with others is a political matter. (...) Only learning from each other's knowledge, gained from our own experiences over so many years, will enable us to make stories in which we can recognize ourselves. Stories from which we can say: "that is how it is, this is who I am, that is of help to me." Our stories are not only of value to us. They also offer the possibility for professionals to learn to speak a new language. A language that both users and professionals understand.

Boevink 2002

Such a discussion, however, demands parties who are able to leave behind their roles as "patients" or "experts": (ex-) users and survivors of psychiatry, who then look beyond the narrow confines of their own experiences; on the other hand, participants who show interest in these insights coming from own experience and realize—as for example, the psychiatrist Pat Bracken from Ireland:

... that when it comes to issues to do with values, meaning and relationships, it is users / survivors themselves who are the most knowledgeable and informed. When it comes to the recovery agenda, they are real experts.

Bracken 2007, p. 402

That the abilities of (ex-) users and survivors of psychiatry as professionally active people (in theory and practice, as scientists and service providers) can be valued has been proven by Kostas Bairaktaris, Fibos Zafiridis, and Maria Dikaiou of the University of Thessaloniki in their approval of my publications and activities since 1979, in which they—by all means generalizable—emphasize the necessity to end the traditional monologue of the experts:

Neither should the discourse of people with psychiatric experience be captivated in the analysis of the experts, thus reproducing the traditional scientific monologue and, consequently, the dominance over the subjects. (...) His publications on practices of violence, on psychiatric drug abuse and on the quest for alternatives to psychiatric practices are tools of support, involvement and self-help of the interested ones themselves. They also constitute important stimuli for us experts, as well, not only if we want to stand critically against our own theories but also if we want to search for a different approach and practice, a different, that is to say, "meeting" with the people with psychiatric experience.

Bairaktaris et al. 2010, pp. 48/51

In view of massive violations of human rights in the psychosocial sphere—such as fatalities due to treatment without informed consent and the withholding of appropriate psychosocial support to solve mental problems that are largely of a social nature (Lehmann, 2014)—one has to take seriously and talk about the concerns of many actively engaged (ex-) users and survivors of psychiatry (such as Karl Bach Jensen, Dorothea Buck, Judi Chamberlin, Leonard R. Frank, Maths Jespersen, Hannelore Klafki, Tina Stoeckle, Jan Wallcraft, Don Weitz). Also, members of the psychiatric profession will need to relinquish their laissez-faire attitude towards violations of human rights, name the wrongdoers by name, and remove them from honorary positions in their associations, compensate the injured and take measures to safeguard human rights within the psychiatric domain.

The ethical problem depicted here in dealing with reports of experiences in psychiatry is but one aspect of the central ethical problem of psychiatry, as expressed by David Oaks, former director of MindFreedom International:

... the stunning silence of psychiatric professional organizations failing to address these human rights issues, or to even agree to dialogue about them, threatens to doom the credibility and future of the entire psychiatric profession itself.

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Oaks 2011, p. 197

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Peter Lehmann

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