

Hedmark University College

Faculty of Health and Sports

BRAGE

Hedmark University College's Open Research Archive

http://brage.bibsys.no/hhe/

This is the author's version of the article published in

International Journal of Law and Psychiatry

The article has been peer-reviewed, but does not include the publisher's layout, page numbers and proof-corrections

Citation for the published paper:

Kogstad, R.E. (2009). Protecting mental health clients' dignity — The importance of legal control. *International Journal of Law and Psychiatry*. 32(6), 383-391

DOI: 10.1016/j.ijlp.2009.09.008

Protecting mental health clients' dignity — The importance of legal control

Ragnfrid Eline Kogstad, Hedmark University College, Norway

1. Introduction

In this article, clients' narratives are analyzed in order to explore the nature of negative experiences that infringe on their rights which unfortunately are imposed on groups of users of mental health services. The gap between public values and clients' experiences, as demonstrated in the narratives, has been noted by the Council of Europe (1994), as well as by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment ([CPT, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, 1997] and [CPT, 2006]), which monitors the protection of human rights in Europe. In their reports, the committee has focused attention on indications of the misuse of medication and on the degree of interest in establishing therapeutic relationships with patients. They have further criticized the often underdeveloped and even completely absent components of effective psychosocial rehabilitative treatment (CPT, 1997, 8th General Report). In their report to Norway, the committee has, for instance, criticized the use of handcuffs when clients are brought to hospitals, a practice without ethical or judicial justification (CPT, 2006). The values underlying the ECHR, adopted as Norwegian law in 1999 (Ot.prp 3, 1998–1999), as well as the Norwegian Mental Health Act (1999) and several "soft laws"¹ are that all human beings have an inherent dignity that should be protected. This refers to the Universal Declaration of Human Rights (UN, 1948) which states in Article 1: "All human beings are born free and equal in dignity and rights."

In recent years, different theoretical contributions have focused on the gap between public values and human rights aims on the one hand and clients' experiences on the other ([Monahan et al., 1995], [Harding, 2000], [Höyer, 2000], [Gostin, 2001a], [Gostin, 2001b], [Prior, 2001] and [Bindman et al., 2003]). According to these authors, the gap cannot be accepted simply on the grounds that the client has been given a diagnosis saying he/she has a serious mental illness. Users of mental health services as well as other people have the right to express their needs, influence their treatment and be regarded as equal participants in society. This is also manifested in the Norwegian national guidelines ([Health Directorate of Norway, 2006a] and [Health Directorate of Norway, 2006b], report IS-1315). When such guidelines, along with the establishment by law of the ECHR, still do not provide a sufficient safeguard against infringements, other factors which may influence attitude and treatment of mental health clients must also be considered, as suggested in the following points:

• Definitions of otherness

In several health service settings, a culture has developed which dictates that mental health clients may be treated differently from somatic clients, and ethical principles may be applied

differently. For example, there is a belief that in some situations clients will not profit from dialogue and personal communication (Norvoll, 2007). Evidence also suggests that in using biogenetic causal explanations, people are concerned to a larger degree about mental health clients' otherness (Walker & Read, 2002).

• Reductionist explanations

The way contextual factors such as economy and social situation influence mental illness is often overlooked. Causes outside the individual may then be localized inside the person. This way of attributing cause and effect means that solutions to problems may be sought at the wrong level ([Gostin, 2001a] and [Gostin, 2001b]) and that the stigmatization of individuals increases.

• Broad professional credentials

Concepts about "least restrictive treatment", "necessary" coercion and "true mental disorders" (Norwegian Mental Health Act) allow for subjective, professional judgments. In the same way, the ECHR allows for exemptions when a person is mentally ill (Art. 5). Further recommendations state that a patient can be treated without informed consent when medical experts determine that this is "urgently necessary" in order to prevent immediate or imminent harm to the patient or to others and the person does not have the "capacity to consent" ([MI-principles: Principles for the protection of persons with mental illness and the improvement of mental health care, 1991] and [Council of Europe, 2004]). In Norway, there are wide geographical variations in assessments regarding coercive treatment (Björngaard & Hatling, 2005). These variations indicate that cultures are created across different professional groups and that professional orientation, for instance, medical or contextual approaches (Wampold, 2001) rather than professional training determines assessments.

Based on the factors mentioned above, the objectification of mental health clients can be seen as a core element, resulting in their vulnerable situation. Professionals traditionally take action on *behalf of* these clients, while their subjective needs and opinions are overlooked, a practice which is reinforced by laws and recommendations focusing on a client's need to possess "legal capacity" and "self-insight" in order to have a voice in the decision-making processes concerning treatment.

Clients themselves are the best informants when it comes to investigating whether such a system meets their needs, and reviewing whether a professional's opinions and categories make sense. For this reason, clients were invited to write about their positive and negative experiences with the health care service system.

2. Aim

The aim of this study is to reach a deeper understanding of the nature of infringements and other negative episodes experienced by mental health service users in a variety of circumstances and settings, in addition to proposing actions that can more closely align existing practices with current human rights guidelines in these various circumstances and settings.

3. Method

An underlying assumption in this study is that rationality can be sought through language and that truth — or contextual understanding — is constituted through dialogue (Kvale, 1996). We all contribute to the social construction of reality through narratives and language in general ([Mattingly and Garro, 2000] and [Drevdal, 2002]). Considered from this perspective, users' accounts cannot be deemed as less valid just because they are written by mental health clients. Nevertheless, this group must fight to tell their story and have it heard, accepted and authorized (Kirmayer, 2000). When we ask who is entitled to tell a story, we question the underlying power structure rather than which stories tell the "truth."

Asking for clients' stories means that their experiences, expressed in their own words, are seen as a highly valuable source for understanding how mental health services work and how these services can be improved. This approach also underscores that an equal dialogue with clients is essential for creating effective service systems. Due to stereotyped concepts about the users of mental health services, we have seen a lack of responsiveness to clients' own ideas, needs and explanations. When individual needs and stories about threats to dignity are not listened to or taken seriously, there is a risk that clients' human rights will be violated. By listening to clients' stories, one can better understand the burden of experiences that infringe on their rights and assess the degree to which clients' dignity is protected in a system strongly influenced by the idea that people with mental illnesses may lack the capacity to give consent to treatment and thereby "rightfully" be treated without their informed consent ([MI-principles: Principles for the protection of persons with mental illness and the improvement of mental health care, 1991] and [Council of Europe, 2004]).

Excerpts from the stories unfold and communicate by virtue of their own words (Spiggle, 1994). Nuances in the material are communicated through quotations from several stories. The quotations also provide hints about how categories have emerged. It is essential in these types of studies that the reader reaches a better understanding of what it is really like for someone to experience what the study describes (Polkinghorne, 1988).

3.1. Respondents

The data in this study is selected from a larger study carried out in cooperation with the national user organization in Norway, Mental Health Norway (MHN). MHN was chosen because it is the largest user organization in Norway. The organization has a good relationship with the government, as well as a well-developed administrative system which was able to facilitate the collection of data. During the period of data collection, there were approximately 5000 members throughout the entire country. About 4000 of them were chosen randomly,² and invited to take part in the study with a response rate of nearly 20%. Out of these, 492³ (151 men, 341 women, aged 19–90 years) also answered one or both of the open questions at the end of the questionnaire.⁴ These respondents have experiences from all parts of the mental health care system — traditional psychiatric institutions, outpatient clinics, day centers and individual therapy. Sixty-seven percent received a disability pension, 13% had a job and 20% combined a disability pension with a job or studies.

The material in this article consists of stories written in response to the question: If you have had a strong negative experience, would you like to describe such an event?

Although several informants said it was too difficult to write about negative and humiliating experiences, 335 wrote about such episodes. Statistical representation related to user organization or mental health clients in general cannot be claimed, but distribution by gender, age, disability pension, education, job and the fact that the informants have experience from all parts of the health care system, suggests that the experiences and chosen categories are applicable across many user categories.

The narratives vary in length from one line to several pages. The longer stories often give indepth information concerning background, causes, experiences, feelings and concrete elements in the recovery process or the traumatic experience, but quite brief reports also sometimes contain important information such as: "Strong, painful effects of Trilafon."

Out of the 335 negative stories, 267 were seen as being informative enough to be included in the analysis. The material is still rich and, most importantly, it is written by people who have first-hand knowledge of the experiences they describe.

3.2. Analysis

The data material was analyzed by means of a qualitative content analysis (Graneheim & Lundman, 2004). The stories were read several times in order to discover themes hidden in the texts and obtain a sense of the stories as a whole. Explicit content in the texts is presented in the form of categories which may also be seen as expressions of latent content. The presentation of meaning units in categories is based on the researcher's judgment. Procedures are described and based on this background, and the reader is invited to evaluate the extent to which the findings are credible and relevant.

Different categorization structures were evaluated before it became evident that the stories could be grouped into three main categories: Experienced miscommunication, Rejection, and Humiliation/Punishment (Table 1). The categories may be seen as representing various degrees of encroachment on dignity, but most importantly, they shed light on different kinds of lost opportunities, for clients as well as for staff. This will be described in detail in the next paragraph, in which subcategories are also illustrated.

Table 1.

Distribution of negative experiences, based on the most prominent experience described by each informant (total number of the different negative events in parentheses).

| Miscommunication | Rejection | Humiliation/punishment |
|--------------------------------|----------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| 58 persons (128 events) | 104 persons (188 events) | 105 persons (159 events) |
| Lack of understanding 38 (58) | No treatment in institution, except with medicines 26 (36) | Accused, reproached and made a fool of, use of police, threats and arrogance 31 (64) |
| Not taken seriously 20 (66) | No access to treatment or institution/no follow-up after discharge 26 (61) | Negative experiences with medication 25 (33) |
| | Neg. experiences with state welfare institutions 20 (37) | Commitment 18 (22) |
| | Social dilemmas and religious needs rejected 12 (12) | Forced medication 12 (16) |
| | Confidence lost because of deception 11 (30) | Punishment 10 (10) |
| | Childhood traumas and war experiences rejected 5 (10) | Forced removal of medicines 4 (7) |
| | Children/family not cared about when person committed 4 (4) | Incorrect diagnosis 3 (8) |
| | | Forced sterilization 2 (2) |

Several stories contain a number of different elements or meaning units: for example, childhood traumas rejected, forced medication and incorrect diagnosis, all woven together. To provide an overview of the material, the negative events are counted in two different ways.

First, each person is represented using only the most prominent feature in the narrative. This is done in order to present an overview for the distribution of negative experiences in relation to the total number of participants. Next, all negative events were counted, and the frequency of each experience is indicated in parentheses in the table.

In narrative terminology, the plots considered in the analysis are about negative events and the clients' explicit or implicit reactions. Even the brief quotation: "Strong, painful effects of Trilafon" contains the three central, narrative elements (Hydén, 1997): first event (to be given Trilafon), second event (strong painful experience) and a causal link (effects of).

This categorization process can be illustrated using the following example "story." Once in the 1990s, I was sent to the hospital. I am sorry to say that nothing happened towards my recovery. I just had the feeling of being stored away. After two weeks, I was nearly chased home. It was quite hard to be denied medicines, which I was almost addicted to. In total, it was a negative experience. This was, as a main experience, generalized to "no treatment in institution" and categorized under "rejection." Next, the experiences "no access to treatment or institution/no treatment after discharge" and "forced removal of medicines" were registered and included in the numbers in parentheses. The table also provides some indications of experienced seriousness. For example, all informants who said they have experienced punishment seem to define this experience as the most dramatic one. Still, as this is qualitative material, such interpretations should not be pushed too far.

3.3. Ethical issues

This project is registered at the Norwegian Social Science Database (NSD) which has been granted authority from the Data Inspectorate of Norway to conduct investigations in which sensitive, personal information is involved. The collecting of the data was organized in such a way that the researcher was unable to identify the informants. Letters were sent to the members of the user organization MHN directly from MHN's secretariat after the project had been discussed in MHN's executive committee. In practice, this means that the user organization had ownership of the investigation and asked its own members to participate.

Answers were returned anonymously to the researcher. Since the questionnaires were sent by mail and the right to not participate was emphasized, the respondents' informed consent was ensured, and the right to privacy and integrity were maintained. There were no cases in which informants told of any discomfort in terms of being asked to fill in the questionnaire or write about positive or negative experiences, although some informants stated that they were unwilling to write about bad experiences. One reason given for this was that the retelling of the story would open up old wounds. By contrast, several informants also expressed that it was a relief to be encouraged to write about their stories.

4. Results

Table 1 illustrates the variation in experiences. Several nuances are illustrated in the subcategories, and even more nuances are illustrated in the excerpts from stories which follow after the table. The categories of miscommunication, rejection and humiliation/punishment can be seen as exemplifying different degrees of negative experiences. Related to the ECHR, this would be the case, but when it comes to consequences for the individual in question, a lack of understanding may, hypothetically, be as bad as a negative experience with medication. Instead, the categories should be seen as different dimensions of negative and

infringing experiences. Category 1 is in regard to situations in which the client and therapist are unable to establish a personal rapport. In Category 2, we find situations in which the opportunity to bring help and relief is wasted, even if the client has submitted him/herself to the health care system. Category 3 includes situations in which bad experiences and traumas are imposed on the client by the service system itself.

The different categories are described and illustrated below by excerpts from clients' narratives.

4.1. Miscommunication

This category holds the subcategories "lack of understanding" and "not taken seriously." Both experiences are described in the following stories:

Lack of understanding

My therapist got a new job and I was transferred to another person. When I saw her, I did not feel safe. She wanted to start from the beginning. I was not prepared for this, and thought she knew what the records said. Had she asked me about details in the records, it would have been a help, but she didn't and I wasn't able to start all over again. Then she became disappointed and sent me to another division. Man, aged 36

After 10 years of depression, sick leaves and medicines, I experienced something that caused me to write a lot of poems and prose for three months. I did not sleep much and my doctor sent me to a psychiatrist. After two visits to this "god", he said from behind his huge rosewood desk: I think you have a manic-depressive illness, which means periodic madness! I was given medicines, read about it in the encyclopedia and talked to my doctor. I learned that psychological counseling was not recommended. But I was sure that I had to work through the experiences in my life and insisted on a referral to a psychologist, which I got 10 years later. Without the psychologist, I would never have worked through the traumatic experience with the psychiatrist. Today I am happy, still married, and have two children plus a wonderful little granddaughter. Quite soon, I will finish library school. Woman, aged 51.

Not taken seriously

It is always a problem when I see a doctor. All my suffering is ascribed to nerves. Woman, aged 68.

The first story is about a therapist who did not understand that it is difficult to start telling one's story over and over again as if nothing has been told before. The last story describes a well-known phenomenon: that somatic complaints are not taken seriously when the doctor knows that the client is also a mental health client. In the second story, the woman describes how she was given a diagnosis with the implicit message that her words were not important — the cure would be medicines, even after a period in which she had a deep need to express herself. The informants were not able to establish any therapeutic relation with their therapists and had to seek help elsewhere. All three stories are marked by a disregard of the clients' own words and views, and there is a gap between the therapists' devaluation of their dialogue and the reflections and explanations found in the clients' stories. The situations were experienced as humiliating, even if no direct infringement can be documented in explicit legal terms. The events described are marked however by an objectification and to some degree stigmatization

of the clients. This objectification can, as we will see, have even more serious consequences. In the examples mentioned, no alliance was established.

4.2. Rejection

Subcategories here are "no treatment in institution apart from medicinal treatment"; "no access to treatment or institution/no follow-up after discharge"; "negative experiences at state welfare institutions"; "social dilemma and religious needs rejected"; "confidence lost because of deception"; "childhood traumas and war experiences rejected" and "children/family not cared about when person is committed." Examples of the different categories are given below:

No treatment in institution apart from medicinal treatment

I was forcibly sent to the hospital because I said I felt like committing suicide. I was heavily medicated and had only one talk with the doctor during my entire stay. I felt I was left totally on my own together with other patients who screamed and smashed furniture. I shared a room with people who scared me. It was a painful experience. Woman, aged 45.

No access to treatment or institution/no follow-up after discharge

I attempted suicide in the early 1980s. I was taken to the hospital by ambulance, my stomach was pumped and then I was sent home by taxi, dirty and wearing only my pants. I worried a lot about meeting my mother and my employer. I had no one to talk to after this incident. Man, aged 57.

Negative experiences at state welfare institutions

My financial situation was difficult. I felt I was entitled to economic support, but was met with suspiciousness. I felt like they regarded me as being irrational, and that they suspected that I would "take advantage" of the system. The social security office was my last hope; I would not have gone there if I had had other solutions. Woman, aged 32.

Social dilemma and religious needs rejected

My GP would not accommodate my wishes when I asked for sick leave. The result was that I lost my job and just wanted to commit suicide. Woman, aged 55.

Confidence lost because of deception

I got the clear feeling that the psychiatric ward did what they could to help me when I was an in-patient. But when problems that had been brewing underneath came to the surface and childhood traumas emerged, I was once again alone with no help available. Man, aged 50.

Childhood traumas and war experiences rejected

Once when I was in my thirties, I was in the hospital. The anxiety came back and I asked if I could talk to a psychiatrist. I thought that at last I would be able to open up and talk about the incest I had experienced as a child. His answer was: It was such a long time ago and should just be forgotten. Woman, aged 53.

Children/family not cared about when person is committed

I was committed and had to leave my children, aged 2–19 years. No help was offered. I was neither listened to nor taken seriously, and did not get any help from the community health services. I was just given medicines with painful side effects. Woman, aged 60.

The stories describe various types of rejection. Again, the clients are not listened to and met according to their expressed needs. The users' perspective seems not to have been considered by the professionals in these stories. It is possible that the staff had their professional reasons for the way they acted and that those reasons included not listening to clients' wishes and stories. However, in the situations described above, the opportunity to offer adequate help was lost. In cultures in which clients' voices are disregarded, much essential information is lost.

4.3. Humiliation and punishment

Examples in this category concern situations in which clients experienced threats, arrogance and other humiliating reactions, in addition to negative experiences with medication, commitment, forced medication, punishment, forced removal of medicines, wrong diagnoses and forced sterilization. Each subcategory is illustrated with a patient's story.

Threats, arrogance and other humiliating reactions

I was filled with anxiety the whole night when I was put in a room on my own with a night duty employee who didn't talk to me, but threatened to give me an injection if I didn't calm down. Woman, aged 44.

Negative experiences with medication

I was not believed when I told them I had an adverse reaction to that special medicine. I had convulsions for a long period before I was given the proper antidote. Woman, aged 45.

Commitment

After less than half an hour, this strange doctor concluded that I should be sent to the hospital. I objected and said: "It will not help." But a person in my situation suddenly has no right to express herself. The doctor said: "Then it is a compulsory admission!" I objected and objected, but my voice did not count any longer. My husband signed the paper (after the doctor threatened that if he didn't, the police would do so). I don't think I have ever felt so deceived before. I was angry, sad and empty (...), and overwhelmed by the feeling of being totally turned down. I had lost everything. It felt like mental rape. This happened four to five years ago, though I can still feel it all today. The emotions have become embedded inside me and will always remain with me. Woman, aged 38.

Forced medication

I was medicated by depot injection, but the way they did it was wrong. I didn't want the medicine. Four-five people were in the room. One gave the injection, while the others held me. I resisted. I was afraid. After this, they all left. I was alone. Later, I didn't want contact with the staff at all. I hid under the bedspread. Medication was the only physical contact I experienced during the stay. I think I needed the medicines. That was not the problem. After

having been medicated several times, one person sat down at the bedside. This was a help of course, but all my bad feelings were still there. Woman, age 32.

Punishment

I was confined and did not want to get out of bed. I was punished with no more cigarettes. They took away all I had and locked me into a room for three days. That weekend it was my birthday. Man, aged 37.

Forced removal of medicines

Several times they have given or taken away medicines without telling me what was going on. Man, aged 37.

Wrong diagnosis

I was given a wrong diagnosis. I wasn't believed when I told about my problem and was "stored away" in a nursing home in the countryside. The doctor told me that I would never recover and that this would be my home forever. But I met one person who understood that something was wrong. She was unskilled at that time, but she listened to me, encouraged and supported me, and helped me get away from that place. Today I have been taken off the sick list; I no longer take any medicines, live in my own house, work as a volunteer and study at the university. Woman, age 64.

Forced sterilization

It is difficult to talk about what I have experienced. When my third child was born my husband was a psychiatric patient and sterilization was forced on me. The child died after five weeks. I didn't get help, but I became ill because of the bereavement and was sent to the hospital. The hospital contributed to furthering my mental problems. I have struggled a lot with this, and feel that the system does not believe in me. Woman, age 67.

Even if these stories represent only a small part of the narratives pertaining to humiliating experiences that infringe on clients' rights, the documentation is dramatic. The informants talk about situations in which the service system contributes further harm and trauma to the clients. Many stories are marked by an instrumental attitude to the service users and describe actions that can hardly be understood if they are not motivated by outdated views and the stigmatization of mental health clients, expressing that their voices, feelings and opinions are of minor importance. Some of the episodes happened years ago, while others are quite new. But even if some experiences may belong to the past, the "victims" still fight with the aftermath of stigmatizing attitudes. Lawyers have underlined that encroachment in a person's private life demand treatment and recovery programs of the highest quality (Syse & Nilstun, 1997). As long as this quality does not exist, then the right to intervene dramatically into people's lives must be questioned. Commitment and forced medication are often described by clients as being an extreme and often disabling experience. When we read clients' stories, we also get the impression that such actions are directed towards the stereotype of a mentally ill person and not at one who tells a detailed, thoughtful and emotional story. Several studies carried out in recent years show that there is little difference between the attitudes of the general public and psychiatrists towards people with mental health problems (Lauber, 2006). The studies even indicate that psychiatrists have more of a negative stereotypical view than

the general public or other mental health professionals (Nordt et al., 2006). The lack of responsiveness to clients' voices emerges as a major problem, causing reason for concern regarding the protection of human rights for mental health clients.

5. Discussion — how to create safeguards against infringements

Respecting clients' integrity and dignity is seen as an ethical obligation, but also as the means to recovery ([Spaniol et al., 2002], [Davidson et al., 2005] and [Borg, 2007]). Social psychology has established that decision control creates greater well-being and affects mental as well as physical health (Monahan et al., 1995). Perceiving oneself as being coerced is generally alienating and may result in learned helplessness ([Seligman, 1975] and [Brem and Brem, 1981]).

Monahan et al. further refer to studies in which clients admitted after their stay in the hospital, that in some cases compulsory treatment was necessary, but according to the authors, this does not prove that compulsory treatment led to improvements. In general, studies have shown that coercion has a negative impact on interpersonal relationships and therapeutic outcomes. In fact, related to suicide risk, coercive programs marked by control and strict rules have increased the risk of suicide (Siegel & Tuckel, 1987).

Still, when clients reported that commitment and compulsory treatment were helpful, this must be acknowledged. But there are solutions to the problem of some people wanting to be rescued from themselves other than a legal system which offers unlimited authority to exercise compulsory treatment as soon as a medical expert determines that the treatment is urgently needed. Such professional authorizations have been the reason behind serious infringements and failures when it comes to the establishment of therapeutic relationships. Perhaps even more significant is the fact that this has opened up the possibility for a culture in which clients may be objectified and not listened to, and where experiences, which according to public standards are seen as infringements, are not viewed in the same way when it comes to mental health clients (Costa, 2000).

In regard to people who for a specific period want to give the mental health service system the authorization to take care of and treat them without their informed consent, it in some instances is arranged by a kind of "voluntary compulsion" or "advanced directive" ([Atkinson et al., 2004] and [Varekamp, 2004]), which is much less of a degrading arrangement than compulsion without any preceding cooperation. Furthermore, the principle of necessity will still exist to ensure that the authorities can take action whenever a person's health or life is at risk.

Attempts at reducing professional authority are usually met with arguments about a client's lack of self-insight, and one is often asked to come up with some alternatives. Those questions are briefly elaborated below.

5.1. Beliefs regarding lack of self-insight and legal capacity

When ideas about people arise from stereotypical views instead of knowledge about a given individual, perceptions and actions will lack accuracy. "Lacking self-insight" is a defect easily attributed to mental health clients, thus causing stigmatization. The rationale and criteria behind this "label" are often not questioned. Grisso & Appelbaum (1995) have developed a set of instruments meant to assess abilities — related to legal standards — for competence to

consent to treatment (The MacArthur Treatment Competence Study III). At the outset Grisso and Appelbaum compared patients recently hospitalized for schizophrenia, major depression and ischemic heart disease with three healthy groups, matched with the hospitalized patients for age, gender, race and socio-economic status. Significant impairments in decisional ability were found for only a minority of the people in all groups. One main conclusion from Grisso & Appelbaum's study is that "the justification for a blanket denial of the right to consent to or refuse treatment for persons hospitalized because of mental illness cannot be based on the assumption that they uniformly lack decision-making capacity" (p. 171).

To deprive someone of the capacity to take part in decisions on an equal basis has important ethical implications. In the context of mental health service systems, equal dialogue is considered to be an ethical requirement ([Wifstad, 1997] and [Johnsen et al., 2000]). Alternative approaches to the medical, instrumental approach take this requirement as an element in their point of departure.

5.2. Humanistic-oriented approaches as alternatives

There is a considerable body of knowledge that supports a more user-based, humanistic and contextually-oriented approach ([Mosher and Burti, 1996], [Alanen et al., 2000], [Wampold, 2001] and [Steinkopf, 2004]) to knowledge that demonstrates how disorders, which from a medical perspective seem to qualify for medication and compulsory treatment, may be met with quite different recommendations from professionals in other traditions. Crucial factors are the ability to establish a safe relationship and use the client's own theories about ways to recover as the basis for therapy. The method in this tradition is dialogue, and the therapy is conceived of as a reflective process ([Duncan et al., 1997] and [Seikkula, 2000]). This approach has an affinity to Freire's concept about using dialogue as a "place" where human beings can meet and set each other free (Freire, 1999) and to Habermas' theories about equal dialogues, which arise when no one exercises control over another person (Habermas, 1997). Levinas (2003) has made an important contribution to the understanding of the ethical relationship in his writings about the Other whose strangeness, which cannot be controlled, must be acknowledged before a relationship is established. With total understanding there would be no need for an open dialogue, but by the emotional experience — or "disturbance" - of the Other's strangeness, we are led into an ethical relationship which means to be led into responsibility and compassion ([Levinas, 2003], [Bjerkeset, 2002] and [Buber, 1992]). By contrast, when the face of the Other is concealed from us, not only will our compassion be weakened, but violence is also a possibility (Leer-Salvesen, 2002). From a clinical point of view, Mahoney (1995) has underlined how involvement, compassion and emotional presence can provide a most potent contribution to the client in his/her process of recovery.

In a humanistic tradition, contextual factors play an important role. Everyone lives in a social context that influences the experience of disability. People with mental illness may suffer more from the social consequences of their illness than from the actual symptoms (Harding, 2000). They are often doubly excluded from society, first by being members of disadvantaged groups and second by being marked as deviants ([Gostin, 2001a], [Gostin, 2001b] and [Prior, 2001]). To be helpful, services must relate to the complexity in a client's life situation as described by the client him/herself. Several studies have documented that recovering from mental illness is primarily about the satisfaction of universal human, social and economic needs ([Spaniol et al., 2002], [Topor, 2004], [Davidson et al., 2005] and [Borg, 2007]).

5.3. Steps towards a more humanistic practice

There seems to be a growing consciousness related to the negative side effects of a legal system which permits the extensive use of coercion. As early as 1994, the European Council expressed concerns about the huge number of complaints from mental health clients related to poor treatment, over-medication and the devaluing of patients' needs. The council recommended actions such as the establishment of a patients' advocacy service in order to address practices that cause harm to clients. Norwegian statistics have documented that most clients committed to a hospital or exposed to compulsory treatment are not violent or dangerous (Björngaard and Hatling, 2005), but rather that they disagree with the treatment. Further, there are indications that coercive treatment can cause chronic trauma and illness (Nicholson, 1999), and that not only the actual use, but also the *potential* use of coercion may distort the therapeutic alliance (Höyer, 2000). Often, the reaching of an agreement over treatment is just a question of time, and it is seen as a paradox that professionals are allowed to execute quite serious encroachments in clients' lives, while at the same time not being obliged to use the time necessary to create voluntary treatment programs (Christoffersen, 2001).

In the Norwegian Plan of Action against Coercion ([Health Directorate of Norway, 2006a] and [Health Directorate of Norway, 2006b], IS-1370), the government recommends more reliable criteria in the assessment of clients' legal capacity, the registration of clients' experiences with compulsive treatment, education related to ethical dilemmas in this field and more research on the use of compulsive treatment. These suggestions for improvement illustrate a concern in terms of the human rights situation in the field of mental health care. But even if the need for more humanistic practices is acknowledged, the proper means have not necessarily been found.

5.4. Recommendations for the application of human rights in mental health care⁵

The ECHR (1950) and various soft laws underline the need to protect mental health clients' dignity and autonomy, but to also allow for exemptions from the ECHR and the Universal Declaration of Human Rights, based on medical experts' judgment.⁶

Guidelines about which exemptions can be made from the ECHR are general and invite debate over professional authorizations and the balance between risk to the individual patient and risk to the public. For example, the fact that an increasing number of patients are treated in the community has raised questions related to the use of compulsion outside institutions, and when a community order should eventually end. The White Papers, UK (2000) "Reforming the Mental Health Act", Parts 1 and 2, suggests permissive criteria for compulsory treatment. Szmukler (2001) has expressed concerns that this will result in "the net being cast widely", both because the White Paper states that risk concerns will always take precedence and because the definition of mental disorder is very broad.⁷ Leung (2002) admitted that it is doubtful if the European Court will ever rule the new UK Mental Health Act as being compatible with the ECHR, but also referred to cases in which exemptions similar to what is implied in the UK White Paper have been accepted.⁸ Lieung's conclusion is that safety to the public can hardly be attended to without compromising the human rights of individuals. Until the new UK Mental Health Act is tried in the European Court, this difficult balancing act is shifted to individual psychiatrists and health professionals.

However, the power of authorization given to professionals is questioned. As revealed by research, there exists considerable variation in judgments made by different professionals (Kullgren, Jacobson, Lynöe, Kohn, & Levav, 1996), and the premise that compulsory treatment can secure advancement is being criticized as outmoded ([Harding, 2000], [Prior, 2001] and [Bindman et al., 2003]) There are indications of a change in climate. We will possibly witness a process in which human rights systems are gradually brought in harmony with current knowledge about effective recovery factors and basic ethical values relevant to all human beings.

The UN Convention on the Rights of Persons with Disabilities (2006), which took effect legally in 2008,⁹ is an important step towards the abolition of forced institutionalization and treatment on the basis of disability. Its purpose is to "protect and ensure the full and equal enjoyment of all human rights and fundamental freedom by all persons with disabilities, and to promote respect for their inherent dignity" (Art. 1). The convention further states that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments" and that "persons with disabilities enjoy equal capacity on an equal basis with others in all aspects of life" (Art. 12). If they require support in order to exercise their legal capacity, this shall be provided. Regarding health care, this shall be of the same quality for persons with disabilities as it is for others, "including on the basis of free and informed consent" (Art. 25). The convention signals that there will be changes in a more humanistic direction that will need further ratification and law enforcement in order to benefit the users of mental health services. The European Court of Human Rights may take the lead in this process and affirm that serious infringements are not redefined as necessary treatment.

5.5. ECHR and the European Court of Human Rights

Human rights systems consist of several conventions, charters and declarations in addition to the Universal Declaration of Human Rights. These systems include sources of law that legitimize the international scrutiny of mental health policies and practices within sovereign countries ([Gostin, 2001a] and [Gostin, 2001b]). According to Jean-Paul Costa, the president of the European Court since 2006, the ECHR may be an excellent instrument for the promotion of human rights and liberty in Europe (Costa, 2000). Similar to Gostin, he has also criticized the European Human Rights authorities for being deferential to medical judgment and having very strict definitions of infringement when it comes to the mentally ill in relation to other groups. The European Court has not yet found that conditions in mental hospitals are so inhumane and degrading as to constitute a breach of the convention ([Gostin, 2001a], [Gostin, 2001b] and [Syse, 2006]).¹⁰ It seems that the time is now ripe for the European Court to take a more independent attitude towards medical judgment in the mental health care system (Prior, 2001). In other sectors, the deference of the European Court to medical judgment has been diminished.¹¹ Even if similar cases are not yet found in relation to mental health institutions, statements from President Costa signal changes to come. Knowledge about therapeutic approaches and treatment systems that work without coercion will support positive development. With reference to Article 8 of the ECHR, coercive treatment is not legitimized if less encroaching alternatives exist. This refers to the Proportionality Principle or the Principle of Last Restriction which states that there must be "pressing social needs" and the restrictions must be "proportionate to the aim pursued" (Palm & Ericsson, 2005, pp. 58-59). The Council of Europe's recommendations (2004) also recognize the Principle of Last Restriction as being fundamental in order to protect persons with mental illnesses.

6. Conclusion

The analysis of clients' narratives in this article verifies the existence of a gap between human rights' aims and clients' experiences in several settings. There is a lack of safeguards against infringement. Infringement has substantial consequences in both the short and long term, and it becomes embedded in people's minds and influences the quality of their lives. Hundreds of reflective, detailed and consistent stories told by clients about situations in which they were not listened to or granted credibility provide documented evidence of a mental health service system marked by a lack of responsiveness towards people who are more than able to express themselves.

This lack of responsiveness is well-known from several studies conducted by user organizations and researchers ([Beresford and Wilson, 2002], [Hölling, 2004] and [Norvoll, 2007]) as well as the Council of Europe (1994). In several declarations and recommendations, the need to protect mental health clients' dignity and to avoid degrading treatment is underlined. Still, practices exist in which clients' self-insight is devaluated. As long as professionals, in their capacity to authorize and define the necessary treatment, have the power to set aside clients' human rights by ordering forced medication and using isolation in addition to other forms of compulsion, then such practices are likely to continue.

The lack of evidence of therapeutic effects obtained by compulsive treatment, and the growing awareness regarding the harmful consequences of such treatment ([Ross and Read, 2004], [Whitaker, 2002] and [Whitaker, 2004]) together with up-to-date knowledge about recovery factors and humanistic approaches, indicates that the right to treat clients without their informed consent has lost its legitimacy. This understanding is mirrored in the UN Convention on the Rights of Persons with Disabilities, which states that mental health clients can no longer be discriminated in such a way as to be deprived of their legal capacity. To protect mental health clients' dignity and ensure that their experiences and stories are acknowledged in the mental health services and in society in general, the interpretation of the recommendations and judgments of the ECHR should be brought together in harmony with this new convention.

Acknowledgments

I am grateful to Hege Orefellen, Gro Hillestad Thune, Jan Kaare Hummelvoll, Georg Höyer and Tor-Johan Ekeland for comments on earlier drafts of this article.

Notes

¹ Soft laws are resolutions and recommendations accepted by various international organizations which do not pertain to international law, but are still emphasized. Such soft laws are the UN's principles for the protection of persons with mental illness and the improvement of mental health care (MI-principles, 1991), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), the WPA's Madrid Declaration on Ethical Standards for Psychiatric Practice (1996), the European Council's recommendation 1235 on Psychiatry and Human Rights (1994), the European Council's (2004), and the WHO's Mental Health Declaration for Europe (2005).

² The intention was to include every second member of the 5000 members and send a

reminder to the same sample, but when it came to the second round, the organization could no longer identify every second member from the first round. Therefore, in the second round, questionnaires were sent to the first 3000 members in the new member list. Using a rough estimate, 4000 members received the questionnaire and approximately 1500 of them received it twice.

 3 The number cannot be given more exactly because it is suspected that 5–10 persons answered the questionnaire twice. Altogether, 223 persons wrote both a positive and negative story, 157 persons wrote only a positive story and 112 persons only a negative story; 492 persons responded with stories, for a total of 715 stories.

⁴ The open questions were: 1) Would you like to tell a story from a special meeting with a helper or a health service system that was a positive turning point in your life? 2) If you have had a strong negative experience, would you like to describe such an event?

⁵ There are references to the MI principles as well as to WHO's Mental Health Declaration for Europe and other soft laws in footnote 1.

⁶ The European Council's recommendation on the protection of human rights and dignity for persons with mental illnesses (2004) no longer accepts commitment for treatment or health reasons alone, but provides confusing advice by compiling the criteria based on dangerousness and need of treatment. By contrast, the Universal Declaration of Human Rights does not make exemptions for special groups.

⁷ Mental disorder is defined as "any disability of mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning." The criteria for "care and treatment order" are an unwilling patient and the presence of a mental disorder "of such a nature or degree as to warrant specialist care and treatment" which is "necessary in the best interests of the patient and/or because without care and treatment there is a significant risk of serious harm to other people."

⁸ One such case is the W v. Sweden (1988) in which psychiatric medication outside institutions — as a condition of discharge from a hospital — was ruled as not so severe that it could be characterized as deprivation of liberty.

⁹ In Norway it was signed in July 2008, but is not yet ratified.

¹⁰ From 2005 to 2007, there have been cases in which commitment and prolonged detention in the hospital "after compulsory treatment order was lifted" (Kucheruk v. Ukraine) were ruled as violations, although this has not happened in any case when the complaint was about poor treatment in mental health institutions. In the case of Philip v. Romania (2006), the alleged poor treatment during detention in a psychiatric hospital was not ruled as a violation.

¹¹ The ECHR has found a breach in the prohibition on inhuman and degrading treatment in the context of mentally ill patients in prison facilities (see for instance, Keenan v. United Kingdom and Price v. United Kingdom — ECHR cases, 2001).

References

Alanen, Y. O., Lehtinen, V., Lehtinen, K., Aaltonen, J., & Rakkolainen, V. (2000). The Finnish integrated model for early treatment of schizophrenia and related psychosis. In B. V. Martindale, A. Bateman, M Crowe, & F. Margison (Eds.), Psychosis: Psychological approaches and their effectiveness (pp. 235–265). London: Gaskell. Atkinson, J.M.,Garner, H. C.,&Gilmour, W. H. (2004). Models of advance directives inmental health care: Stakeholder views. Social Psychiatric Epidemiology, 39(8), 673–680. Beresford, P., & Wilson, A. (2002). Genes spell danger: Mental health service users/ survivors, bioethics and control. Disability & Society, 17(5), 541–553.

Bindman, J., Maingay, S., & Szmukler, G. (2003). The Human Rights Act and mental health legislation. British Journal of Psychiatry, 182, 91–94.

Bjerkeset, O. A. (2002). Et spørsmål om alvor. Foredrag Levinas-seminar, Stalheim, Voss. Björngaard, J. H., & Hatling, T. (2005). Tvungent psykisk helsevern med døgnopphold i perioden 2001–2003. Oslo: SINTEF Helse.

Borg, M. (2007) The nature of recovery as lived in everyday life: Perspectives of individuals recovering from severe mental health problems; doctoral thesis; Trondheim, NTNU.

Brem, S., & Brem, J. (1981). Psychological reactance: A theory of freedom and control. New York: Academic Press.

Buber, M. (1992). Jeg og du. Oslo: Cappelen.

Christoffersen, R. M. (2001). Tvang og rettssikkerhet i psykiatrien. Sykepleien, nr. 3. Convention on the Rights of Persons with Disabilities (CRPD) (2006). Adopted by the UN General Assembly on Dec. 13th.

Costa, J. -P. (2000). Traitements psychiatriques et respect de la vie privèe et familiale (psykiatrisk behandling og respekten for privatliv og familieliv). http://hrls.echr.coe. int/uhtbin/cgisirsi.exe/SoA8bW3HN3/COURTLIB/259220020/9 (27.03.2007)

Council of Europe's Report on Psychiatry and Human Rights (1994). Parliamentary Assembly.

Council of Europe. Recommendation no. 10 (2004) of the Committee of Ministers to member states concerning the protection of the human rights and dignity of persons with mental disorders and its explanatory memorandum.

CPT, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1997). 8th General report on the CPT's activities covering the period 1 January to 31 December 1997.

CPT (2006). Report to the Norwegian government after its visit to Norway from 3 to 10 October 2005. Recovery from severe mental illnesses: Research evidence and implications for practice.

Davidson, L, Harding, C., & Spaniol, L (Eds.). (2005). Center for Psychiatric Rehabilitation: 2005: Boston University.

Drevdal, D. J. (2002). Home and border: The contradictions of community. Advances in Nursing Science, 24(3), 8–20.

Duncan, B. L., Hubble, M. A., & Miller, S. D. (1997). Psychotherapy with impossible cases. Efficient treatment on therapy veterans. New York: Norton.

ECHR (European Convention on Human Rights) (1950). Council of Europe.

Freire, P. (1999). De undertryktes pedagogikk. 2. utg. Oslo: Ad Notam Gyldendal.

Gostin, L. (2001). Beyond moral claims: A human rights approach in mental health.

Cambridge Quarterly of Healthcare Ethics, Vol. 10. (pp. 264–274): Cambridge University Press.

Gostin, L. (2001). Public health, ethics, and human rights: A tribute to late Jonathan Mann. Journal of Law, Medicine & Ethics, 29(2), 121–130.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research, procedures and measures to achieve trustworthiness. Nurse Education Today, 24, 105–112.

Grisso, T., & Appelbaum, P. S. (1995). The MacArthur Competence Study. III: Abilities of patients to consent to psychiatric and medical treatments. Law and Human Behavior, 19(2), 149–174.

Habermas, J. (1997). Teorien om den kommunikative handelen. Aalborg Universitetsforlag.

Harding, T. W. (2000). Human rights law in the field of mental health: A critical review. Acta Psychiatrica Scandinavica, 101, 24–30.

Health Directorate of Norway (2006). Brukermedvirkning, IS-1315.

Health Directorate of Norway (2006). Tiltaksplan for redusert og kvalitetssikret bruk av tvang. SHdir IS-1370.

Hydén, L. C (1997). De otaliga berättelserna. In L. C Hydén & M. Hydén (Eds.), Att studera berättelser Stockholm: Liber AB.

Hölling, I. (2004). About the impossibility of a single (ex-) user and survivor of psychiatry position. Acta Psychiatrica Scandinavica, 104(Suppl 410), 102–106. Höyer, G. (2000). On the justification for civil commitment. Acta Psychiatrica Scandinavia, 101, 65–71.

Johnsen, A., Sundet, R. & Torsteinsson, V.W. (red.), (2000). Samspill og selvopplevelse: Nye veier i relasjonsorienterte terapier. Oslo: Tano Aschehoug.

Kirmayer, L. J. (2000). Broken narratives: Clinical encounters and the poetics of illness. In C. Mattingly & L. C Garro (Eds.), Narrative and the cultural construction of illness and healing. University of California Press.

Kullgren, G., Jacobson, L., Lynöe, N., Kohn, R., & Levav, I. (1996). Practices and attitudes among Swedish psychiatrists regarding the ethics of compulsory treatment. Acta Psychiatrica Scandinavia, 93, 389–396.

Kvale, S. (1996). InterViews. An introduction to qualitative research inquiry. London: Sage Thousand Oaks.

Lauber, C. (2006). Do mental health professionals stigmatise their patients? Acta Psychiatrica Scandinavica, 113(Suppl 429), 51–59.

Leer-Salvesen, P. (2002). Profesjonsetiske perspektiver. In I. B. Nyhlen & A. M. Støkken (Eds.), De profesjonelle Oslo: Universitetsforlaget.

Leung, W. -C. (2002). Human Rights Act 1998 and mental health legislation: Implications for the management of mentally ill patients. Postgraduate Medical Journal, 78, 178–181.

Levinas, E. (2003). Humanism of the other. Urbana, III. University of Illinois Press. Mahoney, M. J. (1995). The psychological demands of being a constructive psychotherapist. In R. E. Neimeyer & M. J. Mahoney (Eds.), Constructivism in psychotherapy Washington DC: APA.

Mattingly, C., & Garro, L. C. (2000). Narrative and the cultural construction of illness & healing. London: University of California Press.

MI-principles: Principles for the protection of persons with mental illness and the improvement of mental health care (1991) UN-resolution 46/119.

Monahan, J., Hoge, S. K., Lidz, C., Roth, L. H., Bennett, N., Gardner, W., & Mulvey, E. (1995). Coercion and commitment: Understanding involuntary mental hospital admission. International Journal of Law and Psychiatry, 18(3), 249–263.

Mosher, L., & Burti, L. (1996). Samfundspsykiatri. København: Hans Reitzels forlag. Nicholson, R. (1999). The effects of coerced psychiatric hospitalization and treatment. In J. P. Morrissey & J. Monahan (Eds.), Coercion in mental health services —

International perspectivesResearch in community and mental health, Vol. 10. (pp.) Stamford: Connecticut: JAI press Inc.

Nordt, C., Rossler, W., & Lauber, C. (2006). Attitudes of mental health professionals toward people with schizophrenia and major depression. Schizophrenia Bulletin, 32 (4), 709–714.

Norvoll, R. (2007). Det lukkede rom. Bruk av skjerming som behandling og kontroll i psykiatriske akuttavdelinger. Dr. polit avhandling. Det samfunnsvitenskapelige fakultet. Universitetet i Oslo.

Norwegian Mental Health Act, Ot. Prp 11, 1998–99 (1999) Om lov om etablering og

gjennomføring av psykisk helsevern.

Ot.prp 3, 1998–99: Om lov om styrking av menneskerettighetenes stilling i norsk rett (menneskerettighetsloven).

Palm, E, & Ericsson, M (2005). Att klaga til Europadomstolen. Stockholm: Jure.

Polkinghorne, D. E (1988). Narrative knowing and the human sciences. State University of New York.

Prior, P. (2001). Protective Europe: Does it exist for people with mental disorders? Journal of European Social Policy, 11(1), 25–38.

Ross, G., & Read, J. (2004). Antipsychotic medication: Myths and facts. In J. Read, L. R. Mosher, & R. Bentall (Eds.), Models of madness — Psychological, social and biological approaches to schizophrenia USA and Canada: Routledge.

Seikkula, J. (2000). Åpne samtaler. Oslo: Tano Aschehoug.

Seligman, M. (1975). Helplessness. San Francisco: Freeman.

Siegel, K, & Tuckel, P (1987). Suicide and civil commitment. Journal of Health Politics, Policy and Law, 12, 343–360.

Spaniol, L., Wewiorski, N., Gagne, C., & Anthony, W. A. (2002). The process of recovery from schizophrenia. International Review of Psychiatry, 14, 327–336.

Spiggle, S. (1994). Analysis and interpretation of qualitative data in consumer research. Journal of Consumer Research, 21.

Steinkopf, H. (2004). Nye modeller for intervensjon ved alvorlige psykiske lidelser hos ungdom. Tidsskrift for Norsk Psykologforening, 41, 535–543.

Syse, A., & Nilstun, T. (1997). Ulike regler — lik lovforståelse? Om tvangsregulering og verdikonflikter i nordisk psykiatri. Tidsskrift for Rettsvitenskap, 5, 837–918.

Syse, A. (2006). Det menneskerettslige vernet mot frihetsberøvelse og tvang I behandlingsøyemed innenfor psykiatrien. Nordisk tidsskrift for menneskerettigheter, 24(4), 318–342.

Szmukler, G. (2001). A new mental health (and public protection) act — Risk wins in the balance between providing care and controlling risk. British Medical Journal, 322(7277). Topor, A. (2004). Vad hjälper? Vägar till återhämtning från svåra psykiska problem. Stockholm: Natur och Kultur.

Universal Declaration of Human Rights, adopted by the United Nations General Assembly 11th December 1948, Paris.

Varekamp, I. (2004). Ulysses directives in The Netherlands: Opinions of psychiatrists and clients. Health Policy, 70(3), 291–301.

Walker, I., & Read, J. (2002). The differential effectiveness of psychosocial and biogenetic causal explanations in reducing negative attitudes toward "mental illness". Psychiatry, 65(4), 313–326.

Wampold, B. E. (2001). The great psychotherapy debate. Models, methods and findings. Mahwa, N.J: Lawrence Erlbaum Associates.

Whitaker, R. (2002). Mad in America, bad science, bad medicine and the enduring mistreatment of the mentally ill. NY: Basic Books.

Whitaker, R. (2004). The case against antipsychotic drugs: A 50-year record of doing more harm than good. Medical Hypotheses, 62, 5-13.

White Papers, UK. (2000). Reforming the Mental Health Act. Part 1. The new legal framework, part 2 high risk patients. London: Stationery Office.

Wifstad, Å. (1997). Vilkår for begrepsdannelser og praksis i psykiatri. Oslo: Tano Aschehoug. W v. Sweden (1988) DR, 59.