Ethics in Psychiatry
Hanfried Helmchen · Norman Sartorius
Editors

Ethics in Psychiatry

European Contributions

Springer
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## Contents

### Part I  The Context

1 **Societal Framework of Psychiatry** ................................................. 3  
   Hanfried Helmchen and Norman Sartorius

2 **Stigmatisation of People with Mental Illness and of Psychiatric Institutions** ................................................................. 11  
   Nisha Mehta and Graham Thornicroft

3 **Economical Framework of Psychiatric Care** ............................... 33  
   Christina M. van der Feltz-Cornelis

4 **Conflicts of Interest** ................................................................. 55  
   Giovanni A. Fava

5 **Between Legislation and Bioethics: The European Convention on Human Rights and Biomedicine** ........................................ 73  
   Felicity Callard

6 **Ethics Committees for Clinical Research – The West-European Paradigm** ................................................................. 97  
   Elmar Doppelfeld

7 **Clinical Ethics Committees and Ethics Consultation in Psychiatry** ................................................................. 109  
   Jochen Vollmann

### Part II  Principles of Ethics in Psychiatry

8 **Ethical Principles in Psychiatry: The Declarations of Hawaii and Madrid** ................................................................. 129  
   Otto W. Steenfeldt-Foss

9 **Informed Consent in Psychiatric Practice** ..................................... 139  
   Hanfried Helmchen
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Advance Directives: Balancing Patient’s Self-Determination with Professional Paternalism</td>
<td>147</td>
</tr>
<tr>
<td></td>
<td>Hans-Martin Sass and Arnd T. May</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Confidentiality</td>
<td>161</td>
</tr>
<tr>
<td></td>
<td>Roy McClelland</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Justice in Access to and Distribution of Resources in Psychiatry and Mental Health Care</td>
<td>181</td>
</tr>
<tr>
<td></td>
<td>Ruud ter Meulen</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Part III</strong> The Applications of the Ethical Principles in Psychiatric Practice and Research</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Ethics of Diagnosis and Classification in Psychiatry</td>
<td>199</td>
</tr>
<tr>
<td></td>
<td>Juan José López-Ibor, Maria-Inès López-Ibor, and Hanfried Helmchen</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Competence Assessment</td>
<td>209</td>
</tr>
<tr>
<td></td>
<td>Lienhard Maeck and Gabriela Stoppe</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>General Overview of Ethical Issues in Psychiatric Treatment</td>
<td>227</td>
</tr>
<tr>
<td></td>
<td>Hanfried Helmchen</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Prevention and Early Treatment</td>
<td>235</td>
</tr>
<tr>
<td></td>
<td>Joachim Klosterkötter and Frauke Schultze-Lutter</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Ethical Implications of Psychopharmacotherapy</td>
<td>263</td>
</tr>
<tr>
<td></td>
<td>Hanfried Helmchen</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Ethical Problems in Psychotherapy</td>
<td>281</td>
</tr>
<tr>
<td></td>
<td>Ulrich Rüger and Christian Reimer</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Neuromodulation – ECT, rTMS, DBS</td>
<td>299</td>
</tr>
<tr>
<td></td>
<td>Matthias Synofzik and Thomas E. Schlaepfer</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>‘Coercive’ Measures</td>
<td>321</td>
</tr>
<tr>
<td></td>
<td>George Szmukler</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Ethics of Deinstitutionalization</td>
<td>341</td>
</tr>
<tr>
<td></td>
<td>Dirk Claassen and Stefan Priebe</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Ethical Issues in Forensic and Prison Psychiatry</td>
<td>363</td>
</tr>
<tr>
<td></td>
<td>Norbert Konrad and Birgit Völlm</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Treatment of Substance Dependence</td>
<td>381</td>
</tr>
<tr>
<td></td>
<td>Ambros Uchtenhagen</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Dementia and End-of-Life Decisions: Ethical Issues – A Perspective from The Netherlands</td>
<td>401</td>
</tr>
<tr>
<td></td>
<td>Ron L.P. Berghmans</td>
<td></td>
</tr>
</tbody>
</table>
25 Ethics of Research with Decisionally Impaired Patients ........ 421
Giovanni Maio

26 Ethical Concerns in Carrying Out Surveys of Psychiatric Morbidity ................................................. 437
Howard Meltzer and Traolach S. Brugha

27 Genetics – Ethical Implications of Research, Diagnostics and Counseling .................................................. 459
Peter Propping

Part IV Non-medical Uses of Psychiatry

28 Political Abuse of Psychiatry .............................. 487
Norman Sartorius and Hanfried Helmchen

29 Abuse of Psychiatry for Political Purposes in the USSR: A Case-Study and Personal Account of the Efforts to Bring Them to an End .......................... 489
Robert Van Voren

30 (Neuro-)Enhancement ........................................ 509
Bettina Schöne-Seifert and Davinia Talbot

Part V Teaching Ethics in Psychiatry

31 Teaching Ethics in Psychiatry .......................... 533
Deborah Bowman

Part VI Conclusions and Summary

32 Summary and Conclusions .............................. 547
Norman Sartorius and Hanfried Helmchen

Index .......................................................... 551
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Introduction

Hanfried Helmchen and Norman Sartorius

The title of this book – Ethics in Psychiatry – expresses our conviction that there is no such thing as ‘psychiatric ethics’ and that the principles of ethics in general should be used when examining psychiatric research and practice. The subtitle – European contributions – draws attention to the fact that the ethicists, philosophers, lawyers, psychiatrists and historians are all Europeans and that we believe that it is important to make European perspectives of ethical issues better known.

Although Europe – seen from outside – may seem as a culturally homogenous there are many differences between Eastern, Central and Western Europe as well as between the Northern and Southern parts of Europe. Even within countries the cultural differences are often marked – partly because of different history and partly because of migrations that have marked the twentieth century and created sizeable minority groups in several European countries. These differences influence the development and understanding of ethical issues and are reflected in the contributions that compose the volume. We did not ask authors to change their contributions in order to make the chapters follow a particular, impersonal line feeling that the differences between them will illustrate the variety of cultural variations within Europe and indicate the difficulties that might be met by anyone wanting to make the whole continent follow exactly the same lines of ethical consideration. However, this situation can be seen also as a challenge or even a singular chance e.g. to compare prospectively the regionally different legal implementations of the same basic ideas in order to prove which regulations promote best the welfare and well-being of the mentally ill. Furthermore, these differences could give reason to observe, to make aware, and perhaps to control from different perspectives the transformative effects of the biomedical progress on law and ethics.

In addition to cultural influences, personal preferences and ideological convictions may also influence action in the field of psychiatry. Thus, for example, the choice of treatment, the information given to the patient and the evaluation of the results of treatment may be guided by both the theoretical orientation and the clinical

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experience of the therapist underlining the need to examine the risk benefit ratio for each form of treatment in each individual case taking the preferences of the informed patient into account. The same principle of making decisions dependent on the specific individual must also be central in considering the value of recommendations for guidelines and regulations helping to make ethical choices and concerning matters such as the distinction between need and preference, welfare and well-being, therapy of an illness or enhancement of functioning, persuasion or coercion and help while dying or help to die.

The book is divided into 6 parts. The first part addresses the context in which psychiatry is practised and in which research on issues of importance for psychiatry is carried out. It thus examines the stigmatization of mental illness and the consequences of stigmatization, the legislation relevant to the practice of psychiatry and the arrangements – such as the ethical committees – that have been put in place to ensure that the ethical principles are applied in research and in clinical work. The relatively recent areas of considerable interest – the economic aspects of care for people with mental illness and the conflicts of interest that might arise in the practice of psychiatry and in relevant research are also addressed in this section of the book.

The second part of the book examines four areas of the currently central issues of ethics in relation to health care – informed consent, autonomy of the patient, confidentiality and distributive justice – added to the old medical principles of acting for the welfare of the patient (salus aegroti) and avoiding harm (nil nocere). The challenges of their application in psychiatry are considerable and there is little doubt about the fact that this contributes to the negative image that psychiatry has in many societies. The consensus about the application of ethical principles in psychiatry adopted by the World Psychiatric Association (WPA) – the Declarations of Hawaii and of Madrid – is also discussed in this part of the book.

In the third part of the book a series of contributions examine systematically the ethical aspects of psychiatric assessment and treatment. In the selection of topics we gave priority to areas of most controversy and to areas that are usually not included in texts about ethics – for example the ethical implications of procedures in institutions. They are followed by chapters that address the application of ethical principles in research with persons who are unable to decide for themselves as well as to issues arising in epidemiological and genetic research.

The fourth part of the book discusses ethical issues related to the non-medical uses of psychiatry and focuses on two subjects: the abuse of psychiatry for political purposes and the (ab)use of psychiatry for enhancement purposes. The first of these two topics has torn psychiatry apart in the nineteen sixties and seventies and we felt that despite of the fact that the political abuse of psychiatry seems to have declined in frequency it should be included in the book as an example of an ethical problem whose solution depends mainly on political action rather than only on a change of behaviour of psychiatrists. The second topic on the contrary seems to be gaining in importance in the context of globalization and continuing emphasis on the elevation of personal (and societal) aspirations for success in all spheres of life and might thus remind that new types of ethical problems are likely to emerge in the near future.
The fifth part of the book deals with education about ethics in psychiatry this being one of the possible ways to improve the likelihood that psychiatric research and practice will be beyond ethical reproach. The importance of internalizing the ethical principles and making them an integral part of the value system of medical professionals should be of primary concern for all medical schools: sadly until now this has not happened.

Finally, the Part VI summarizes the major points addressed by the various chapters and draws conclusions based on the material presented in the volume.

The complexity of ethical considerations in relation to psychiatry called for a very careful preparation of the text. The editors have corresponded with the authors about their chapters and given them numerous suggestions. In addition each of the chapters was reviewed by two experts whose opinion was provided to the authors with the expectation that they will finalize their chapter taking the views of the editors and the reviewers into account. In some instances this seemed impossible for the authors and we had therefore had to seek alternative authors. In considering these decisions we have kept in mind that Europe is far from a homogenous entity and that there are very few experts who are familiar with the practice and ethical considerations in all of the more than fifty European countries. In some instances therefore we have accepted chapters that describe the situation in a single country in Europe, as a paradigm illustrating issues that arise in relation to a topic such as that of dementia and end-of-life decisions.

As in any multi-authored book there is a certain amount of overlap between the chapters. This was unavoidable in this book and we have not insisted on removing the overlap – not least also because the chapters, as they now stand, treat their topics comprehensively which would not have been possible if all overlap had been removed. In some instances the overlap is apparent but there is little of it: thus, for example, the chapter on de-institutionalization and the chapter on coercive measures both address the delicate issue of balance between patients’ autonomy and their welfare but from different standpoints – once from the point of view of the person responsible for providing service and once from the more abstract, theoretical level.

In some instances the authors wrote vehemently about topics about which they feel passionately and their treatment of the topic is therefore not as comprehensive as might be desired. Thus, for example, the chapter on the political misuse of psychiatry written by an author who has been involved in fighting against it for decades describes the developments in the Soviet Union in fascinating detail and with remarkable insights while neglecting to address the general question of ways of abusing psychiatry for political purposes and its limits towards the systematic neglect of patients’ needs and towards the use of psychiatric methods in interrogations concerning criminal activities. We did not feel that we should complement such descriptions with more systematic reviews and believe that these chapters will be well placed to draw attention and engagement of the reader to specific issues.

The psychiatrists’ task is to recognize the needs of people suffering from mental illness and to help them by controlling the symptoms of mental disorder, by preventing or reducing the disability related to the disorder, by overcoming their lack or loss of adequate social relationships and by finding ways to facilitate their inclusion into
Introduction

society. In doing so the psychiatrists are confronted with moral problems that they need to recognize and resolve. A central issue in this regard is to find, in each individual case, the right balance between patients’ autonomy and the protection against harm related to illness, between the need to empower patients while reducing their disability and between the responsibility of patients themselves and the help that their carers offer. In addition the psychiatrists have to deal with attitudes to mental illness and to psychiatry, with laws and regulations and with their own biases – all of which raises moral questions and ethical issues at the individual and social level.

Fundamental changes of our societies – related, for example, to demographic change, migration, unemployment, social disintegration and conflicts of cultural value systems – as well as the increasing costs of medical care using new techniques and interventions reopen questions about the nature of man and increase the sensitivity for autonomy and dignity of all participants in the treatment process. At the same time, the continuing stigmatization of mental illness and of psychiatry, the gradual acknowledgement of rights of the mentally ill, the changes of the role of the patients (from patient to client) and of therapists (from a father figure to a partner and from an independent professional to a guideline dominated practitioner) modifying the nature of medical care and of the relationship between patients and doctors thus revitalising old and adding new ethical problems. Whether the well established ethical principles and codes are sufficient to solve the new ethical problems – for example the conflicts between the protection and the autonomy of the patient, between individual and common welfare and between the claim of global validity of human rights and culture-bound morals and customs is an open question.

We hope that this book will help in thinking about these issues – in practice, in drafting regulations and guidelines and in the education about ethics in schools of health personnel. We also hope that it will orient research and focus attention on unresolved ethical issues. The achievement of these aims would be the greatest reward for the contributors of this book.
Part I
The Context
Chapter 1
Societal Framework of Psychiatry

Hanfried Helmchen and Norman Sartorius

Contents

1.1 Society and the Individual ........................................ 3
1.2 Society and the Mentally Ill Individual ............................. 5
1.3 Conclusion .......................................................... 8
References ............................................................. 8

Abbreviations

EDEN European Day-Hospital Evaluation
EPSILON European Psychiatric Services: Inputs Linked to Outcome Domains and Needs
ESEMeD European Study of the Epidemiology of Mental Disorders
EUROSTAT European Statistics
IMS International Measuring System
OECD Organisation for Economic Co-operation and Development
GP General Practitioner
WHO World Health Organisation
SES Socio-Economic Status

1.1 Society and the Individual

The ideas expressed in the Bill of Rights (1688), the Constitution of the United States of America (1787) and the French Revolution (1789) gave rise to the concept of the constitutional state in which the rights and obligations of the individual towards society – and vice versa – are regulated by law. However, the balance between the rights and obligations of the individuals and the state varies among the countries that have accepted the idea of being a constitutional state. There are
states – for example the USA – that emphasize the importance of the individual’s freedom and self-reliance which can be harmful for those who are not able to care for themselves such as some of the mentally ill people. On the other side are states with a strong social welfare policy which provide a necessary minimum of social security, sometimes at the expense of individual freedom particularly in societies deformed by totalitarian features as was the former Soviet Union or the German Democratic Republic. Most European countries try to maintain a position between these two extremes, but experience increasing problems in financing such a system because of the demographic change and the progress of scientific medicine entailing higher cost of care, and because people’s understanding of the system’s subsidiary character fades and the population probably because of that no longer accepts the obligations stemming from the maintenance of strong welfare policies.

Dominating ideas in contemporary Western European societies are the principles of individual autonomy, solidarity and justice. The German philosopher Habermas explained:

“The more the structures of the living world differentiate the more it can be seen that the increasing autonomy of the ‘individuated’ single is interwoven with the increasing integration into multifold social dependencies. The more the individuation is going on the more the single subject gets entangled in a closely woven and at the same time more subtle net of reciprocal defencelessness and exposed needs of protection.” Thus morals “show the integrity of individuals to advantage by demanding even respect for the dignity of each; however, they also protect to the same extent the intersubjective relations of reciprocal recognition by which the individuals keep themselves as members of a community. Both complementary aspects correspond with the principles of justice and solidarity” (Habermas 1991).

The principle of distributive justice in health care can only be realized through solidarity among members of a society. The importance of solidarity grows with the decrease of resources or with an increase of the needs of care with a stable amount of resources. The principle of solidarity competes with the concept of increasing the common welfare by the powers of the free market. If these concepts prevail the solidarity will weaken and the support for those who are in need will become less available which will lead to lesser care for the mentally ill and an increased moral problem of (mental) health care. With the diminution of the resources provided by the community (previously characterised by solidarity) the psychiatrists obligation to act for the welfare of the mentally ill individual becomes more difficult because they have to face the conflict between their primary obligation to ensure the welfare of the individual and their social obligation to save the limited resources so that other members of community can use them for their welfare.

The traditional focus of ethics in medicine were on ethical problems which arise in medical treatments of the individual, e.g. a conflict between the welfare and autonomy of the patient, to do no harm, or confidentiality. In contrast the ethics of modern public health considers – according to a recent Report from the Nuffield Council on Bioethics:

“the responsibilities of governments, individuals and others in promoting the health of the population. We conclude that the state has a duty to help everyone lead a healthy life and
reduce inequalities in health. Our ‘stewardship model’\(^1\) sets out guiding principles for making decisions about public health policies\(^2\). Although the report has been attacked by the UK media as a way into a ‘nanny state’\(^3\) it is a thoughtful examination of the question: “whose job is it to ensure that we lead a healthy life?”, or more specifically “how and when the state should act?”\(^4\).

### 1.2 Society and the Mentally Ill Individual

The balanced relationship between the individual and his social environment is at risk in the case of mental illness. Mental illness may impair the capacity of individuals to live their lives in accordance with their intentions, objectives, wishes, needs and expectations. It may reduce their chances of using the social context and of adequately tackling its constraints. The social context will also influence the individuals’ mental health if it exceeds their capacity to cope with the multitude of stresses resulting from insults (e.g. mobbing, stigmatisation), broken relationships, bad company (e.g. drug abusing friends), overwork (e.g. workaholic), social insecurity (unemployment, homelessness), war persecution and many others. Such social events may influence the causes, the development, the manifestation, the course (remission, recurrence, relapse, chronification) or outcome of mental illness. At least as important for the fate of the mentally ill are attitudes prevailing in a society – such as those leading to exclusion, discrimination and stigmatisation of the mentally ill or those that make it impossible to rejoin society. The conviction that mental illness is untreatable – widely held by the populations of European countries (including mentally ill people) and by many health professionals – can lead to the belief that people struck by mental illness no longer have any value for society and that therefore they should be eliminated.

These ideas found their catastrophic expression during second world war’s mercy killings in Germany, in the forced starvation of the mentally ill in mental hospitals in France and other countries, in the forced sterilisation of people with intellectual

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\(^1\) According to this model ‘acceptable public health goals include: (1) reducing the risks of ill health that people are exposed to as a result of other people’s actions or behaviours, for example reducing drunk-driving and passive smoking; (2) reducing causes of ill health relating to environmental conditions, such as drinking water safety and housing standards; (3) protecting and promoting the health of children and other vulnerable people; (4) helping people to overcome addictions and other unhealthy behaviours; (5) ensuring that it is easy for people to lead a healthy life, for example by providing convenient and safe opportunities for exercise; (6) ensuring that people have appropriate access to medical services; (7) reducing unfair health inequalities. At the same time, public health programmes should: (1) not attempt to coerce adults to lead healthy lives; (2) minimise interventions that are introduced without individual consent of those affected, or without procedural justice arrangements (such as democratic decision-making procedures) which provide adequate mandate; (3) seek to minimise interventions that are perceived as unduly intrusive and in conflict with important personal values’ (Nuffield Council on Bioethics 2007).


\(^4\) See footnote 3.
disability and in other legally supported ethical transgressions of European societies in relation to their mentally ill members. The notion the mentally ill are of no value to society however has not vanished: it finds its more subtle expression today in the low priority given to mental health programmes in most parts of the world, in the continuous insistence of providing the cheapest possible care to people with mental illness and in other forms of discrimination and stigmatization of the mentally ill.

A rough indication of relevant attitudes of societies may be found in considerable differences of psychiatric care among European countries (Becker and Kilian 2006, de Girolamo et al. 2006). Differences are related to (i) the provision of mental health services, (ii) to their appropriateness to meet the needs of the mentally ill, (iii) to their use and (iv) to the outcome.

“The number of psychiatrists per 100,000 inhabitants ranged from 3.6 in Spain to 17.5 in Finland, psychiatric beds from 0.4 per 1,000 inhabitants in Italy and Spain to 1.3 in Ireland.” (Carta et al. 2004). “In countries such as Switzerland or the United Kingdom in which gerontopsychiatry is institutionalised to a greater extent in the ‘medical society’ and health politics the service provision for depressed elderly persons seem to be more elaborated and better available” (Bramesfeld 2003). The “levels of unmet need in the population ranging from 3.6% in Northern Ireland (McConnell et al. 2002) to 15% in the Netherlands (Alonso et al. 2007, Bijl and Ravelli 2000)”.

Studies of representative samples in 6 European countries show actually that need of formal healthcare (Alonso et al. 2007) to respond to clinical (e.g. psychopathological symptoms and side-effects, embarrassing or dangerous behaviour etc.) as well as social needs (e.g. such as personal hygiene, getting meals, household is not provided to almost the half of people who need it etc.).

Since these differences are not only due to methodological problems (Alonso et al. 2002, Kiejna et al. 2002, Kilian et al. 2001, Schene et al. 2000), they are likely to be related to other and probably more important differences in cultural attitudes towards the mentally ill and differences of the priority that European countries give to the development of mental health care. Therefore, a major factor of unmet needs of the mentally ill will be due to societal and attitudinal influences (Alonso et al. 2007, Andrews et al. 2001).

European cross-country studies found that in general “the care of the mentally ill is rather limited in Europe”, the use of psychiatric services is fairly low, especially in Italy (de Girolamo et al. 2006): roughly only one quarter of non-institutionalised people with a mental disorder consulted a formal health service, more than a fifth of them received no treatment: “the factors associated with this limited access and their implications deserve further research” (Alonso et al. 2004). There are, e.g. studies which “show that SES [Socio-Economic Status] influences psychiatric services utilization, however the real factors linking SES and mental health services utilization remain unclear” (Amaddeo and Jones 2007). A mental disorder will be recognised by a GP in only about the half of concerned people (Alonso et al. 2007, Linden et al. 1996), although “the disability rate of patients

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5 Which are met in international epidemiological studies of psychiatric services (type, structure, number, access to, use of, efficiency etc) such as a lack of adequate assessment instruments some of which have been developed only recently (EPSILON, ESEMeD, EDEN) and some others, insufficient approaches (e.g. indicated by low response rates) and insufficient mental health reporting systems (up-to-now only global and unspecific data are available gathered by WHO, OECD, EUROSTAT, IMS).
with a well-defined disorder is between 67% and 72.7%” (Linden et al. 1996). Such figures are important because disability may be a determinant of the need of care although “determining the need of care is a complex process” (Alonso et al. 2007, Andersen 1995). They are the more important because the majority of people would contact their GP first (Kovess-Masféty et al. 2007). Ethnic factors seem to play a role (Commander et al. 2003), e.g. South Asian people consulted their GP significantly more frequently than whites, but only one half reported disclosing their problem to a GP (Commander et al. 2004).

The fact that people with mental illness do not receive the care that they need can be related to two groups of factors. The first is that the governments of European countries (and of most other countries of the world!) do not provide adequate resources for the psychiatric care and that they provide less for the services for the mentally ill than for people with other illnesses. The second is that people with mental illness often do not use services that are available. The first of these facts is a clear transgression against the principle of distributive justice and a demonstration of discriminatory tendencies affecting the principle of solidarity. The second fact – the non-use of services when they are available – is also a transgression against distributive justice using two different mechanisms. People do not seek psychiatric care because they are ashamed to do so in a society that stigmatizes mental illness and people who suffer from them; they are also afraid to use the services because they are often not providing competent services, i.e. that competence, attitudes and behaviour of the mental health service personnel will be experienced by mentally ill patients sometimes and somewhere as insufficient (Schulze 2005) – which is at least in part a remote effect of the negative selection of personnel entering psychiatry that is itself a stigmatized discipline. The fact that general practitioners are often not willing or not able to recognize the presence of mental illness in the persons who contact them for help may also play a role in this respect.

Ethical problems are related to attitudes toward and to concepts as well as systems of psychiatric care, in which the treatment of the individual is embedded. Thus, e.g. the process of deinstitutionalisation of mentally ill patients faces the psychiatrist on the individual level with striking a balance between the respect of the patient’s autonomy and his protection. In some countries as in Italy the rash beginning of deinstitutionalisation led to some individual tragedies, because the idea of freeing the patients initially overburdened their families and not everywhere the development of community care was sufficiently supported (de Girolamo et al. 2007, Ernst and Ernst 1992). Or, to give another example, significant differences in rates of detaining people with mental disorders compulsorily in mental hospitals (Commander et al. 2003) suggest differences in attitudes and habits of psychiatrists towards the mentally ill, differences in relating the dignity and autonomy of the mentally ill to the safety of him as well as to those of the community.

In Italy the process of radical deinstitutionalisation of mentally ill patients indicated a change in attitudes and concepts in general (Tansella 1986), but its realisation was hampered by insufficient support from some communities to build up community mental health services.

Furthermore, the process of deinstitutionalisation seems to be counteracted by a special form of re-institutionalisation in Europe, i.e. the recent increase of forensic
beds and supported housing, which outweigh in some countries the reduction of beds for psychiatric care. Together with the increase of the general prison population it was suggested that this development may reflect general attitudes to risk containment in society – and “may be more important than changing morbidity and new methods of mental health care delivery” (Priebe et al. 2005). Moreover, it indicates also the persistence of prejudices, stigmatisation and exclusion.

1.3 Conclusion

The purpose of this chapter was to provide a background to the discussion of the elements of the context in which psychiatric care and research take place. It is clear that attitudes held by populations affect the priority given to mental health care and that the principle of distributive justice is therefore not respected in the instance of mental health care. Consequently at least psychiatric policy should adapt the mental health care services more specifically to the needs of the mentally ill, should target these needs more specifically, should improve the capacity of GPs to recognise mental disorders, should motivate the GP to coordinate the treatment of mentally ill patients with the psychiatrist, and should increase the general awareness of the public towards the needs of the mentally ill and the treatments psychiatry has to offer. One of this necessary actions is the international campaign to fight the stigma of mental disorder and of psychiatry (Sartorius 2006).

The chapters that follow will provide specific evidence about the ways in which the society reacts to mental illness by examining the process of stigmatization of mental illness, the impact of the economic imperatives on mental health care, the reflection of the populations’ views in legislation, the multiple conflicts of interests besetting action in this field and the way in which the psychiatric profession decided to behave in order to reduce the probability that it will contribute to the transgression of ethical principles.

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Chapter 2
Stigmatisation of People with Mental Illness and of Psychiatric Institutions

Nisha Mehta and Graham Thornicroft

Contents

2.1 Introduction ................................. 12
2.2 Defining Terms ................................. 12
  2.2.1 Stigma .................................. 12
  2.2.2 Ignorance: The Problem of Knowledge ............. 14
  2.2.3 Prejudice: The Problem of Negative Attitudes .......... 14
  2.2.4 Discrimination: The Problem of Rejecting and Avoidant Behaviour 15
  2.2.5 Structural Discrimination .......................... 15
2.3 Global Patterns of Stigma .................................. 16
2.4 Stigmatisation and Human Rights in Psychiatric Institutions 19
2.5 Conclusion ................................... 26
References ...................................... 27

Abbreviations
BME Black Minority and Ethnic
CESCR Committee on Economic, Social and Cultural Rights
CPT European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment
CRPD Convention on the Rights of Persons with Disabilities
DISC Discrimination and Stigma Scale
ECHR European Convention on Human Rights and Fundamental Freedoms 1950
ICCPR International Covenant on Civil and Political Rights 1976
ICESCR International Covenant on Economic, Social and Cultural Rights 1976
OHCHR UN High Commissioner for Human Rights
UDHR UN Declaration of Human Rights 1948
2.1 Introduction

The effects of stigmatisation upon people with mental illness are common and profoundly socially excluding, and so constitute unethical barriers to full social participation. This chapter will therefore discuss the ethical dimension of stigma by defining terms, discussing the existing literature on stigma related to mental illness, considering global patterns of stigma, and examining stigma and human rights within psychiatric institutions.

2.2 Defining Terms

2.2.1 Stigma

Stigma (plural stigmata) has been used to refer to an indelible dot left on the skin after stinging with a sharp instrument, sometimes used to identify vagabonds or slaves (Cannan 1895, Gilman 1982, 1985, Thomas Hobbes of Malmesbury 1657). Recently stigma has come to mean ‘any attribute, trait or disorder that marks an individual as being unacceptably different from the ‘normal’ people with whom he or she routinely interacts, and that elicits some form of community sanction’ (Goffman 1963, Hinshaw and Cicchetti 2000, Scambler 1998).

A considerable literature now refers to stigma (Falk 2001, Goffman 1963, Heatherton et al. 2003, Mason 2001, Corrigan 2005a, Wahl 1999, Hayward and Bright 1997, Link et al. 1989, 1997, Link et al. 1999, Pickenhagen and Sartorius 2002, Sartorius and Schulze 2005, Smith 2002). The most complete schema of the component processes of stigmatisation has four key components (Link and Phelan 2001) which are: (i) Labelling, in which personal characteristics, which are signalled or noticed as conveying an important difference. (ii) Stereotyping, which is the linkage of these differences to undesirable characteristics. (iii) Separating, the categorical distinction between the mainstream/normal group and the labelled group as in some respects fundamentally different. (iv) Status loss and discrimination: devaluing, rejecting, and excluding the labelled group. Interestingly, more recently the authors of this model have added a revision to include the emotional reactions of both people who are stigmatised and of the ‘stigmatisers’, which may accompany each of these stages (Jones et al. 1984, Link et al. 2004).

Stigma can also be seen as an overarching term including three elements:

- problems of knowledge (ignorance or misinformation)
- problems of attitudes (prejudice)
Stigma can produce changes in feelings, attitudes and behaviour for both the person affected (lower self-esteem, poorer self-care, and social withdrawal) and for family members (Kadri et al. 2004, Link et al. 1989, Littlewood et al. 2007, Ritsher and Phelan 2004, Thornicroft 2006, Weiss et al. 2001). Consistent findings have emerged from evaluating stigma in Africa (Alem et al. 1999), Asia (Thara et al. 2003), South America (de Toledo Piza and Blay 2004), in Islamic countries of North Africa and the Near East (Al-Krenawi et al. 2004), and in Europe (Sartorius and Schulze 2005). First, there are few countries, societies or cultures in which people with mental illness are considered to have the same value as people who do not have mental illness, as shown for example lower rates of financial investment in mental health services, which has been described as an aspect of structural discrimination. Second, the quality of information that we have is relatively poor, with few comparative studies between countries or over time. Third, there are clear links between popular understandings of mental illness and whether people in mental distress seek help or feel able to disclose their problems (Littlewood 1998). The core experiences of shame (to oneself or to one’s family) and blame (from others) are common, although they vary to some extent between cultures. Where comparisons with other conditions have been made, mental illnesses are usually more stigmatised, and indeed this has been called the ‘ultimate stigma’ (Falk 2001). Finally, the behavioural consequences of stigma (rejection and avoidance) appear to be universal phenomena. Nevertheless, this literature says little about a core issue: how such processes affect the everyday lives of people with mental illness.

Research on stigma and mental illness largely consists of attitude surveys, investigating what people would do in imaginary situations or what they think ‘most people’ would do, for example, when faced with a neighbour or work colleague with mental illness. This work has emphasised what ‘normal’ people say rather than the actual experiences of people with mental illness themselves. It also assumes that such statements (usually on knowledge, attitudes or behavioural intentions) are linked with actual behaviour, rather than assessing such behaviour directly. In short, with some clear exceptions, this research has focussed on hypothetical rather than real situations, shorn of emotions and feelings (Crocker et al. 1998), divorced from context (Corrigan et al. 2004), indirectly rather than directly experienced, and without clear implications for how to intervene to reduce social rejection (Rose 2001). In this context, discrimination is understood in this Chapter to mean: ‘make an unjust distinction in the treatment of different categories of people, especially on the grounds of race, sex, or age’.

Recently a growing body of qualitative evidence which considers how mental health service users subjectively experience, describe and cope with stigma. This has allowed an enhanced understanding of: the scope and dimensions of stigma; the personal consequences of stigma; mental health service users views on anti-stigma campaign priorities; and the impact of stigma on the family, along with the development of related scales to measure stigma (King et al. 2007).

Understanding stigma is important because it can lead to low rates of help seeking, lack of access to care, under-treatment, material poverty, and to social marginalisation (Thornicroft 2007). These effects can be the consequences of
experienced (actual) discrimination (for example being unreasonably rejected in a job application), or they can be the consequences of anticipated discrimination (for example when an individual does not apply for a job because he or she fully expects to fail in any such application) (Rusch et al. 2005). This distinction between experienced and anticipated discrimination is closely related to what has been described as the difference between ‘enacted’ and ‘felt stigma’. ‘Enacted stigma’ refers to events of negative discrimination, while ‘felt stigma’ includes the experience of shame of having a condition, and the fear of encountering ‘enacted stigma’ (Jacoby 1994), and is associated with lower self-esteem.

2.2.2 Ignorance: The Problem of Knowledge

There is an unprecedented volume of information in the public domain, but the level of accurate knowledge about mental illnesses (sometime called ‘mental health literacy’) is meagre (Crisp et al. 2005). In a population survey in England, for example, most people (55%) believe that the statement ‘someone who cannot be held responsible for his or her own actions’ describes a person who is mentally ill (Department of Health). Most (63%) thought that fewer than 10% of the population would experience a mental illness at some time in their lives.

Measures taken to improve public knowledge about depression can be successful, and can reduce the effects of stigmatisation. At the national level, social marketing campaigns have produced positive changes in public attitudes towards people with mental illness, as shown recently in New Zealand and Scotland (Vaughn 2004, Dunion and Gordon 2005). In a campaign in Australia to increase knowledge about depression and its treatment, some states and territories received this intensive, co-ordinated programme, while others did not. In the former, people more often recognised the features of depression, were more likely to support help-seeking for depression, or to accept treatment with counselling and medication (Jorm et al. 2005). Similarly recent evidence comparing trends between Scotland and England in public attitudes towards people with mental illness are consistent with a positive effect of the Scottish ‘See Me’ anti-stigma campaign (Mehta et al. 2009).

A new campaign is now starting in England, entitled ‘Time to Change’ aiming to fundamentally reduce stigma and discrimination (Henderson and Thornicroft 2009).

2.2.3 Prejudice: The Problem of Negative Attitudes

The term prejudice is used to refer to many social groups which experience disadvantage, for example minority ethnic groups, yet it is employed rarely in relation to people with mental illness. The reactions of a host majority to act with prejudice in rejecting a minority group usually involve not just negative thoughts but also emotion such as anxiety, anger, resentment, hostility, distaste, or disgust. In fact prejudice may more strongly predict discrimination than do stereotypes. Interestingly, there is almost nothing published about emotional reactions to people with mental illness apart from that which describes a fear of violence (Graves et al. 2005). An
example of such negative attitudes are the terms used by school students towards people with mental health problems, and in one English study, among 250 such terms used, none were positive and 70% were negative (Rose et al. 2007).

2.2.4 Discrimination: The Problem of Rejecting and Avoidant Behaviour

Attitude and social distance surveys (of unwillingness to have social contact) usually ask either students or members of the general public what they would do in imaginary situations or what they think ‘most people’ who do, for example, when faced with a neighbour or work colleague with mental illness. Although such research is useful, as discussed above it has emphasised what ‘normal’ people say rather than the actual experiences of people with mental illnesses themselves and does not assess behaviour and discrimination directly. In short, most work on stigma has been beside the point.

2.2.5 Structural Discrimination

In 1999 the UK government published the Macpherson (Macpherson 1999) report which described the failings of the London Metropolitan Police in handling the investigation of the racially motivated murder of the black teenager, Stephen Lawrence. The racist gang responsible has not been brought to justice. Now widely regarded as a seminal work in the fight against racial discrimination in the UK, the Macpherson report tied police failings to the issue of institutional racism in the police, defined as follows:

The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people.

As a result of this there emerged a notable determination by central government to take the Macpherson recommendations seriously. As a result, the UK government has imposed targets on police authorities requiring the modernisation and diversification of the police to boost numbers of black, minority ethnic (BME) officers. In addition, the Home Office ‘Strength in Diversity’ agenda is actively pursued within all strands of policing policy development, and the Macpherson recommendations continue to be reproduced in official documents and their implementation monitored in all aspects of policing. The Macpherson ethos has permeated other public institutions, and has been enshrined in legislation, meaning that the identification and elimination of institutional racism as defined by this report is now firmly on the agenda of every UK government department and of every UK public body.

The lessons learned from the successes of this movement may be applied to the concept of ‘structural discrimination’ identified by Corrigan et al. (2004).
authors argue that an understanding of macro-societal determinants of stigma are just as important as the individual experience of the person with mental illness. ‘Structural discrimination’ is defined as:

The policies of private and governmental institutions that intentionally restrict the opportunities of people with mental illness and policies of institutions that yield unintended consequences that hinder the options of people with mental illness (Corrigan et al. 2004).

This definition is similar in many ways to Macpherson’s definition of institutional racism. Corrigan et al. argue for further methodological and conceptual work to understand structural discrimination, and this will be of undoubted benefit. Additionally, we argue that by publicising structural discrimination in bold terms, and by relating macro-level analyses to the plight of individuals (in the way that was achieved in the wake of the Lawrence Inquiry), the stigma agenda may achieve similar prominence. People affected by stigma and mental illness are equal if not greater in number than those affected by institutional racism. We can learn important lessons from the successes of the UK race relations struggle. Coupled with the impact of powerful domestic and European anti-discrimination law and proven governmental goodwill and resources (eg the ‘See Me’ anti-stigma Campaign in Scotland), the European anti-stigma movement has the ingredients to empower governments and institutions to tackle the problem of stigma and mental illness head on.

2.3 Global Patterns of Stigma

Does stigma vary between countries and cultures? The evidence here is stronger, but still frustratingly patchy (Littlewood 2004). Although studies on stigma and mental illness have been carried out in many countries, few have been comparison of two or more places, or have included non-Western nations (Fabrega 1991b).

One study in Africa described attitudes to mentally ill people in rural sites in Ethiopia. Among almost 200 relatives of people with diagnoses of schizophrenia or mood disorders, 75% said that they had experienced stigma due to the presence of mental illness in the family, and a third (37%) wanted to conceal the fact that a relative was ill. Most family members (65%) said that praying was their preferred of treating the condition (Shibre et al. 2001). Among the general population in Ethiopia schizophrenia was judged to be the most severe problem, and talkativeness, aggression and strange behaviour were rated as the most common symptoms of mental illness (Alem et al. 1999).

A survey was conducted in South Africa of over 600 members of the public on their knowledge and attitudes towards people with mental illness (Minde 1976, Stein et al. 1997, Hugo et al. 2003). Different vignettes, portraying depression, schizophrenia, panic disorder or substance misuse were presented to each person. Most thought that these conditions were either related to stress or to a lack of willpower, rather than seeing them as medical disorders (Cheetham and Cheetham 1976). Similar work in Turkey (Ozmen et al. 2004), and in Siberia and Mongolia