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Mental Health User Narratives

New Perspectives on Illness and Recovery

Bruce MZ Cohen

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This book is dedicated to all those who have experienced mental health problems.

This is just the beginning of the story.

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Preface

Many studies in the field of mental health have focused on service users as passive recipients of psychiatric care. Assumptions have been made that users are unable of understanding their own illness behaviour. Narrative work within medicine and the social sciences, however, calls for a reassessment of the way we research mental health users, arguing that users are active participants and experts on their own state of being. This book details one of the first studies in the United Kingdom to give primacy to user narratives. The book focuses on the listening to and understanding of the voice of users who have suffered from severe mental illness. It differs from other texts in the field by arguing for the avoidance of immediate interpretation. Instead, user 'narratives' (or stories) are taken at face value, building a more rounded picture of the lives of users, and producing new perspectives on mental health and illness. Insights are gained into such areas as spiritualism, self-coping, self-recovery, alternative treatments, positive illness experience and future life paths. Further, comparison of institutional and 'home treatment' user narratives will illustrate the fluidity of illness identity depending on the psychiatric intervention experienced. Far from severe mental illness being a life sentence, it will be shown that with the right philosophy of care, long-term recovery is possible.

The research in this book will demonstrate a need to widen the therapeutic mind to include the mundane and everyday as an additional focus for treatment. This book is the first volume allowing mental health users to speak to the professional community which offers to treat them and as such will be an important resource for professionals, students and policy makers as well as users and carers in the mental health field.

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Finally, heartfelt thanks to all the mental health users who allowed me to listen to their stories.

List of Abbreviations

BHTS	Bradford Home Treatment Service
BMJ	British Medical Journal
CMHRC	Community Mental Health Resource Centre
CPN	Community Psychiatric Nurse
CRT	Crisis Resolution Team
CTO	Community Treatment Order
DLP	Daily Living Programme (Maudsley)
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECT	Electroconvulsive Therapy
EU	European Union
GP	General Practitioner
ICD	International Classification of Diseases
NHS	National Health Service
NUD.IST	Non-Numerical Unstructured Data Indexing Searching and Theory Building
RMO	Responsible Medical Officer
SMI	Severe Mental Illness
UK	United Kingdom
US	United States

Introduction

The World Health Organization (2005a) estimates that 450 million people worldwide currently experience 'mental, neurological or behavioural problems'. In the United States alone, almost 44 million people – approximately one in six of the population – are affected by a mental illness in any given year (United States Department of Health and Human Services 2002). Likewise, the Office for National Statistics (2001: 1) calculates that, at any one time, one in six of the UK population experiences a 'significant' mental health problem. The European Union, meanwhile, suggests that mental ill health affects one in four of their citizens (European Commission Health and Consumer Protection Directorate-General 2005: 3). On the basis of such figures it is accurate to comment that, sooner or later, most of us will experience some form of mental illness: it is an illness of the majority not the minority. Despite mental illness being responsible for approximately 13 per cent of all disease burden in the world and ranking 'first among illnesses that cause disability in the United States, Canada, and Western Europe' (President's New Freedom Commission on Mental Health 2003: 3), most countries continue to give a low priority to mental health care (World Health Organization 2005b). The costs of mental illness to society are enormous: in the United States, the indirect costs (loss of productivity and so on) are estimated to be in the region of $79 billion per annum whilst a further $71 billion per annum is spent on treatment (President's New Freedom Commission on Mental Health 2003: 3).

But what exactly is 'mental illness'? What does it mean to have a mental health problem? Over the past few centuries the nature and form of mental illness in Western society has been widely debated, different theories have been proffered, different treatments developed and, thus, different 'cures' for illness claimed. Mountains of literature have been published on the subject – from moral therapy through the development of new biochemical compounds for treatment to detailing life in psychiatric hospitals. And yet at the beginning of the 21st century, how far can we say we have come in successfully defining and understanding what mental illness actually is? Of course, we have successfully developed groups of experts and practitioners who claim to know what mental illness is and how we can avoid it in our everyday lives. But if you are a mental health practitioner, a service user, a carer or even a researcher you may still be left wondering why the theories of mental health do not match with your own experiences of having or working with someone with mental health problems. This is the central objective of the book: to explore mental illness and what it might consist of. To do this we have to temporarily suspend our own (often professional) beliefs. We need to take at face value what we see and hear from the one source that lies at the heart of the mental health debate but is often ignored – from the service users themselves.

Through reproduction and further analysis of 49 user narratives, this book explores the descent into illness, experiences of institutional psychiatry and home treatment, patterns of recovery and self-coping techniques. The book embeds the reader in the life worlds of those who have suffered mental health problems. There is no finite solution offered, no silver bullet for these problems in living, but the book highlights new approaches to such illnesses and new ways of recovery. The title of this book is as much a political statement as a scientific claim because it challenges the dominant wisdom within psychiatry that users understand very little about their own problems. The 'narrative method' used in this research empowers the user and asks us to think again about the personal nature of illness experience.

Most people diagnosed with a mental health problem will not require specialist psychiatric services (see MIND 2005). In contrast, this book reproduces the narratives of those who have suffered from a 'severe mental illness' (SMI). An SMI is a mental illness that usually requires a period of hospitalization. The President's New Freedom Commission on Mental Health (2003: 2) estimates that between five and seven per cent of all adults in the United States have a severe mental illness (such as schizophrenia or manic depression) in any given year. These SMIs cause the largest economic and social burden on society because they are the most incapacitating of mental illnesses. In the past, those suffering from an SMI required long-term institutional care, yet new medical treatments combined with crisis intervention projects and deinstitutionalization policies have suggested that many can survive without the need for in-patient treatment. In realty, the problem of how to treat this small but highly significant population of users has never been fully resolved. Governmental reviews of mental health policy in Europe and the United States raise similar questions about the uneven base of mental health care, levels of stigmatization, the need for treatment close to home and so on, but provide less tangible solutions (for example, Department of Health 1999, 2007; European Commission Health and Consumer Protection Directorate-General 2005; Jané-Llopis and Anderson 2005; President's New Freedom Commission on Mental Health 2003). In the 21st century, the neo-liberalist concepts of choice, customer care and quality of service are tempered in mental health by the factor of risk – those suffering from SMIs are perceived as being a threat to the public as well as to themselves (Department of Health 1999, 2007; McLaughlin 2006; MIND 2007a). In such cases, mental health policy allows for compulsory medical treatment as well as compulsory hospital admittance. This is sometimes seen as the 'balanced system of care' (Thornicroft and Tansella 2004) in which both hospital and community services are necessary for mental health users. Through comparison of two forms of acute care – hospitalization and home treatment – for those suffering from SMIs this book also assesses the possibility of treating the most severe mental illnesses without the need for institutional treatment.

To summarize then, this book has three main aims: firstly, to investigate periods of mental illness for those defined as acute or severe mental health users with reference to their life stories (or 'narratives'); secondly, to demonstrate the possibility of taking a 'narrative approach' within research methodology and analysis; and, thirdly, to compare the narratives of users who have obtained hospital-only treatment with users who received a new home treatment service. The book is divided into two parts – the first part grounds the reader in the debates on mental illness, narrative theory, crisis intervention projects and narrative methodology; the second part reproduces the user narratives and offers further analysis of these texts. Much of the first half is unapologetically theoretical, for those who wish to move straight to the narratives I would recommend starting at Chapter 5. Additionally, one piece of text from a user narrative is given at the start of each chapter.

An investigation of mental illness experience necessarily involves an investigation of the history and current status of psychiatry. Chapter 1 profiles the rise of psychiatric professionals as the medical experts chiefly responsible for the care of the mentally ill. Whilst producing a dominant medical aetiology with which to understand mental illness, it will be demonstrated that this premise has been constantly critiqued from both inside and outside the profession. A discussion of critical psychiatry will highlight the current views towards psychiatric treatment within the field – psychiatrists often perceive their treatment methods with users as pragmatic and eclectic, yet medical treatment (that is, drugs or ECT) remains omnipresent.

Disillusionment with traditional modes of treatment has led some psychiatrists to take a 'narrative approach' with users. Within psychiatry this approach is seen as a way of changing the balance of power between psychiatrist and user. Chapter 2 introduces the reader to the 'narrative' concept. Critiques of modernity and traditional scientific practice have led to the proliferation of 'narrative approaches' not only within psychiatry, psychology and the therapeutic disciplines but also in the humanities and social sciences. Different definitions and uses which surround this move to narrative are outlined before describing an appropriate theoretical background and definition used in the current research with mental health users.

Crisis intervention projects hold an important place within the development of community-based psychiatric care because they have often attempted to prevent hospitalization for those experiencing an acute crisis. Chapter 3 describes the development of crisis theory and the introduction of crisis intervention projects such as home treatment services. Some time is spent surveying the background, philosophy and development of a home treatment project in Bradford, United Kingdom, which explicitly sought to work with a needs-led approach to psychiatric treatment for those suffering from an SMI. The investigation of this Bradford Home Treatment Service gives the reader a good example of a successful alterative to hospital care that nevertheless suffered changes in its workings due to changing governmental policy. The benefits of this crisis intervention service to local mental health users will be witnessed in the chapters that follow.

A practical account of taking the 'narrative method' in the current research with mental health users is outlined in Chapter 4. Sampling and collection procedures for both hospital and home treatment users are described. Some time is also spent detailing the piloting and introduction of the narrative approach. The problems of the method, particularly regarding the analysis and presentation of the texts, are discussed in detail. Whilst being able to offer some generalizations of user experience, the concern to avoid interpretation of the user narratives results in the different methods of text reproduction outlined in Chapters 5, 6 and 7.

Eight of the user narratives collected – four who experienced home treatment and four who were hospitalized – are reproduced, as close to the original texts as possible, in Chapter 5. It is necessarily the longest chapter in the book, recounting significant life stories of the mental health users. The narratives from those who have experienced hospital treatment tend to concentrate more on illness feelings and psychiatric treatment whilst the home treatment narratives are often broader, illustrating a life that is not always defined by severe mental illness and treatment. Yet the narratives remain fluid and multifaceted, calling for some further analysis of all 49 life stories.

The descent into illness and the periods of psychiatric treatment cited in the user narratives are explored in Chapter 6. Precipitating factors to crisis and referral processes are given, before a detailed analysis of both hospital and home treatment are carried out. Both treatment options are assessed on the basis of user narratives, and improvements are outlined. The narratives highlight the value of the home treatment service and its innovative philosophy, whilst hospitalization also has a number of benefits for some. In both cases, the user narrative is altered by the professional, psychiatric narrative.

The recovery from illness and self-coping strategies are outlined in Chapter 7. A number of significant issues – not often cited in books on mental illness – are highlighted here including the routes out of illness, surviving without psychiatric treatment and user methods of coping with crises. As periods of illness come to be perceived in different ways, so too do ways of self-coping in day-to-day life. It is shown that some service users can alter their illness label downwards, from a severe mental illness to a milder form of mental illness, and in doing so create their own possibilities for recovery. Personal meanings of illness call for personal solutions. Everyday practices – such as work, socializing, sleeping and shopping – are highlighted as significant therapeutic activities for users.

In Chapter 8, the book concludes with a reiteration of the intentions of reproducing the narratives of mental health users. Time is given to explore the workings of the psychiatric paradigm as outlined by the users themselves. Factors of gender, ethnicity and social class in treatment are also summarized. The rest of the chapter offers a discussion of the dominant psychiatric view of mental illness and appropriate treatment in comparison to users' own experiences of illness and recovery. Implications for the future are highlighted in the concluding remarks.

1
Mental Illness and Psychiatry

> ‘Manic depression’ and . . . labeled as a ‘schizophrenic’, ‘paranoid schizophrenic’ at one point in time. But, you know, the classic question is, they ask you, is, ‘do you hear voices?’ you know, ‘when you’re on your own?’ sort of thing . . . and only my own. But I don’t hear voices, I just don’t.
>
> (Bill)

1.1 Summary

This book unashamedly gives primacy to those who have experienced severe or acute periods of mental ill health. The narratives from these users will offer new insights into illness and recovery. Over 30 years ago, Mosher *et al*. (1975: 455–6) asked the rhetorical question, ‘who can tell us better how to get over the illness than its recovered victims?’ It was not the first time – nor the last – that the suggestion was made for the centrality of the voice of the user in understanding mental illness. Yet in 2007, this book is one of the first to comprehensively investigate user narratives without the interception of medical or psychological interpretation. This begs the question as to why it has taken us so long to get to this position. Why has the voice of the service user been marginalized? To answer this question it is necessary to briefly survey the history of madness, the development of the mental health field as a medical project and the rise of psychiatry as the profession chiefly responsible for the care and treatment of the mentally ill. It will be shown that psychiatry is not only a medical project but also a political one. Despite conflicting views on the definition and nature of mental illness within the profession – leading to a variety of treatment options – medical intervention continues unabated, encouraged by the pharmaceutical industry. The result is a continued devaluing and disempowerment of user meanings for illness.

1.2 Histories of madness

1.2.1 The official account

The ‘official account’ of psychiatry’s history, as often profiled in medical text books, is one of slow but steady progress from the unenlightened days of the mistreatment of lunatics in places like Bedlam to the present state of medical expertise (Johnstone 1989). Three key phases are cited in the official account of this progression. Firstly, the shift in the 19th century from primitive views of madness as caused by supernatural agencies to a more sophisticated medical view, with the era of ‘moral treatment’ ending the worse excesses. Secondly, the development of some local outpatients and aftercare facilities in the 1930s, as well as the discovery of new treatments such as insulin coma therapy and electroconvulsive therapy (ECT). Thirdly, the ‘drug revolution’ of the 1950s which enabled discharge and the possibility of users living outside of the psychiatric hospital. Thus, psychiatry becomes accepted as part of the medical establishment and patients avoid the stigma of the old asylums by attending psychiatric units at general hospitals (Johnstone 1989: 172–3).

The history of madness and psychiatry that I will outline challenges this official account, highlighting social, economic and political processes in the identification and treatment of those considered ‘mad’. As Miller (1986: 13) has stated, ‘the history of psychiatry is a history of fundamental transformations of its institutional, theoretical, professional and judicial existence. The critiques mounted against psychiatry, both from inside and outside, are a significant element in this process of modernization and transformation’.

1.2.2 Pre-psychiatric care

‘Prior to the mid-17th century and the advent of the “Classical Age” ’, states Smart (1985: 2), ‘madness or unreason and reason itself were relatively integrated phenomena’. ‘Madness’ could be associated with special, sacred forms of knowledge which gave insights into the human condition. The insane were not stigmatized or removed from the community in which they lived; instead they were an active part of communal life. Kosky (1986), for example, notes that during the 16th century the insane were mainly cared for by relatives. Additionally, medical practitioners were present in most villages and provided an eclectic approach to madness which could involve utilizing diets, laxatives, baths, exercises, purgatives and blood-letting. In cases of suspected depossessions, clerics were called to deal with evil spirits. The medical practitioners themselves were trained by apprenticeship and licensed by the church through bishops. In the cases of the more difficult 'insane', hospitals (such as St Bartholomew's established in 1123 and Bethlem established in 1250) accepted such people on a short- or long-term basis. Taxes were levied on parishes to supplement families caring for insane relatives or for help with hospital fees, and peoples' property was protected by royal prerogatives or Court of Wards (Kosky 1986: 180–1). Kosky acknowledges that 'there are accounts of the insane being imprisoned, held in stocks, whipped and driven from village to village. Nevertheless, the 16th century bore witness to a relatively tolerant and humanistic attitude to the mad and to mental illness' (1986: 181). Likewise, Samson (1995b: 56) notes that although punishment – including the gallows and burning at the stake – existed for the mad it was far from systematic.

In these years before the Enlightenment lunatics were often treated by the family, the clergy, the jailer, the workhouse master and the magistrate rather than by medical men (Scull 1981b). Most importantly though, what was seen as 'teachings of madness' could take a variety of forms and supposed 'cures' during the period. 'Madness' was not attached to the idea of 'moral value' (see also Kroll and Bachrach 1984); that is, there was no separation between the spiritual and the material worlds of the time. People were not conceptualized as *individually conscious* of their own behaviour and thought. Morality was a collective process of the whole society given through religious and monarchical authorities from God. As a result of the explosion of new ideas taking place towards the end of the 16th and into the 17th centuries, however, inevitable upheavals were about to take place in the realm of the spirit (Zweig 1979). Medical practitioners had already made successful moves to separate from the church and establish their independence as professionals with primacy in medical matters. A few London- or university-based doctors of classically derived medicine established the Foundation of London Society of Physicians in 1518 and by the end of the century the group had hounded out even the popular bishop-licensed medical practitioners.

1.2.3 The Enlightenment

Bracken and Thomas (2001) note that 'both supporters and critics of psychiatry agree that the discipline is a product of the European

Enlightenment and that movement's preoccupations with reason and the individual subject'. The Enlightenment brought about far-reaching changes in Western society: the separation of the individual from society, man from God, a move towards secularization and the explosion of ideas initiated by philosophers such as Descartes and Newton, which led to the observable and measurable universe of science. Freeman (1996) locates the philosophical basis of psychiatry in the work of Hobbes (1588–1679) and Locke (1632–1704), both of whom were empiricists and rejected the notion of any *a priori* knowledge existing in the mind; instead peoples' knowledge was derived from experience of the world. Envisaging man as an individual, Hobbes proclaimed, 'the succession of our thoughts is not arbitrary, but governed by laws' (cited in Russell 1984: 533). All men were naturally equal – 'in a state of nature' – but without a social contract to bind people together in communities and to the state (and thus to control their natural state), life would be 'nasty, short, and brutal'. Hobbes's concern was for society to maintain a consensus and some form of control over people's autonomy, whilst Locke's 'philosophical liberalism' argued for the pursuit of happiness as the foundation of all freedom (Russell 1984: 592). What psychiatry took from these ideas were a mixture of liberalism, empiricism and the control of people's 'natural state'.

Kosky believes these new philosophies were also tied to Calvinistic ideas: non-conformity was not only an affront to God; it was also representing subversion of the state. Numbers of the so-called deviant classes (the heretics, criminals, unemployed, sexually deviant, socially rebellious and the insane) had greatly increased due to the long religious wars in Europe and 'concern for organization and order under these conditions focused attention of authorities, secular and religious, on these classes' (Kosky 1986: 181). The stage was set for what Foucault calls 'the great confinement' of these undesirable classes in Western Europe. Foucault has argued in his book *Madness and Civilisation* (1967) that structures of exclusion and division had been dormant since the existence of leprosy in Europe in the Middle Ages and were ready to return with the new period of incarceration in the 17th and 18th centuries; 'when the poor, criminals, and those with "deranged minds" were compelled to occupy the space of exclusion which had been vacated by the leper' (Smart 1985: 3).

Scull (1981b: 113) contends that it was the changes brought about by growing market forces and industrialization that fundamentally changed popular conceptions of human nature: 'economic competition and the factory system are the forcing house for a thoroughgoing