Psychological Recovery

Beyond Mental Illness

Retta Andresen,
Lindsay G. Oades,
Peter Caputi

WILEY-BLACKWELL

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Part II: Elaboration of the Model: From Hopelessness to Flourishing

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Dedication

This book is dedicated to all those people who have experienced mental illness and have generously shared their stories in print or taken part in research in order to further the understanding of mental illness and recovery.

About the Authors

Retta Andresen

Dr Retta Andresen is a Research Fellow at the University of Wollongong, Australia. Her research interests were inspired by personal accounts of the experience of schizophrenia, which led to the development of the stage model of psychological recovery. She is committed to the use of the recovery model in mental health services. To that end, she has developed outcome measures to reflect the consumer recovery experience that have received international attention. Retta is a strong believer in positive psychological approaches in mental health, and worked to develop *Flourish*, a self-development programme of recovery. She is currently working on a project which trains mental health practitioners in the use of a recovery model that focuses on the identification of core values as the basis for a meaningful life.

Lindsay Oades

Dr Lindsay Oades is a Clinical and Health Psychologist and Director of the Australian Institute of Business Wellbeing, Sydney Business School, University of Wollongong, Australia. Lindsay works to combine principles of mental health recovery with positive psychology and positive organizational scholarship in order to develop approaches to recovery oriented services, including measurement of psychological recovery, the development of the Collaborative Recovery Model (CRM) and the *Flourish* self-development programme. During his career Lindsay has worked as a practitioner, manager, researcher, trainer and coach in the service of mental health. Lindsay currently chairs the Serious Mental Disorders Panel at the Illawarra Health and Medical Research Institute, and is on the Board of

Directors of Neami, a major Australian mental health non-government organization.

Peter Caputi

Associate Professor Caputi's expertise is in the area of measurement, with particular interest in outcome measurement. His innovative work on measuring recovery from serious mental illness, in collaboration with Drs Retta Andresen and Lindsay Oades, has received national and international recognition. Peter is an active reviewer for *The Journal of Psychology: Interdisciplinary and Applied, Journal of Constructivist Psychology, Personal Construct Theory and Practice, Personality and Individual Differences, Australian Journal of Psychology, Clinical Schizophrenia & Related Psychoses*. He is also a consulting editor for the *Journal of Constructivist Psychology* and *The Journal of Psychology: Interdisciplinary and Applied*. Since 2000, he has published over 100 peer-reviewed conference papers, journal articles, and book chapters and is currently teaching several statistics based subjects at the University of Wollongong.

Foreword

This book is written in the context of the consumer movement dating back to the 1960s. Alongside that movement, an evolving recovery movement specifically emphasised the empowerment of consumers to get on with their lives and to achieve the goals they choose to pursue and that they value. Some observers of history say that themes and principles of the recovery movement are more than 160 years old but have come to the fore only relatively recently.

My credentials are that I have experienced three mental illnesses since 1984 – paranoid schizophrenia, anxiety attacks and major depression – and have been involved with a modern day mental health service since 1988. I have lived in group homes, being case managed and encouraged to work on my recovery journey since then. My last hospital admission was in 1990. I have developed my role with the mental health service, initially as a Consumer Representative (both unpaid and paid), then as Coordinator of Consumer Initiatives, as a Community Development Officer and now as a Consumer Advocate working in hospital and community settings. I became aware of and exposed to recovery philosophy in the late 1990s.

Consumer workers can be great role models, and I had a good positive group of people around me who encouraged me in the early days after diagnosis. None of them told me I could not recover (unlike the experience of some of my friends). This gave me immense hope. But, like many people, after my diagnosis I reassessed my life and lowered my expectations of and for myself – in a very big way. My identity had taken a huge beating, and only after a long struggle (recovery is hard work) did I rebuild

it. The core of this is a very strong world view based on our place in the universe and caring for our planet and all living things on it (live in harmony with the universe).

My job – I have the best job in the world – is now a big part of my identity and gives me a huge sense of meaning; but it is my interest and active participation in philosophy, science, astronomy, scrabble, my housing community and my local mental health fellowship that give me the greatest meaning. I have accepted that I have a mental illness and am moving on with my life and working on my recovery journey. I give back to my local community by doing a range of voluntary community development activities, and this is one way in which I have taken responsibility for my life. Working on my spiritual development (not to be confused with religious beliefs) by taking an interest in everything around me, and respecting and appreciating it, I try to be the best human being I can be in a rapidly changing technological world.

I first met and worked with Lindsay Oades on the Consumer Evaluation of Mental Health Services Project between 1999 and 2004. I soon learnt that Lindsay has immense understanding of and sensitivity to consumer needs, and his accuracy and meticulous attention to detail make him stand out against other researchers. I have also participated in the Collaborative Recovery Model Training with Lindsay. I met and worked with Retta Andresen on '*Flourish – A Recovery-Based Self Development Program*' in the late 2000s. Retta demonstrated great patience and tolerance for participants and facilitators, and showed significant insight into and understanding of those living with mental illness.

In my profession, as a consumer worker and as a mental health professional, we talk about treating each

other (human being to human being) with respect and dignity as a foundation to working in a modern mental health setting. We expect all mental health professionals to treat their clients with this in mind. In working with the authors I have seen that they show the utmost care and consideration to their work colleagues and the people with whom they interact, and this is reflected in their understanding of recovery philosophy and the human condition.

The book opens with an examination and historical record of recovery from schizophrenia, showing that recovery from any mental illness is not only possible but highly likely. As schizophrenia has been seen as the most disabling and stigmatised mental illness, if recovery from schizophrenia is possible, recovery from other mental illnesses is perhaps even more attainable. The notion that recovery requires ‘returning to a former state’ (or a period in your life) is well examined as a myth and misunderstanding of recovery philosophy, and it is very important to see this highlighted here. The outstanding feature of the book is that the model of psychological recovery is based on thematic analysis of many ‘real’ personal recovery stories; and from these also emerged the major themes: finding and maintaining hope; taking responsibility for life and wellbeing; rebuilding a positive identity, and finding meaning and purpose in life. The stages of recovery - Moratorium, Awareness, Preparation, Rebuilding and Growth – are examined in detail with a separate chapter for each, and this forms the bulk of the text. The ideas therein are supported by many meticulously researched references.

I know the authors believe in life-long learning and have left no stone unturned to adapt, update and find new ways of incorporating new developments, initiatives and insights in philosophy, psychology and spirituality into

their work. Chapter 8 explains how the ideas being developed in positive psychology are relevant to, and complement, recovery philosophy. These ideas can be especially useful in helping someone to get back on track and live the life that they want and value. Psychological recovery is clearly not just absence of symptoms, or about preventing symptoms, but something much bigger, a human growth process, promoting strengths and increasing wellbeing. This is explained clearly and developed in this chapter and I hope interested persons take note, for this is a major step forward in thinking about these issues.

The content of this book will be helpful to students of psychology and mental health, mental health staff, service providers, consumers and carers who want to further understand the recovery process as examined herein, how it relates to their life and how we can all better support persons living with mental health issues. I believe that this text will be a landmark in the development, understanding and uptake of personal psychological recovery in our communities.

On a wealthy planet like Earth, I think we are all entitled to, and deserve, a happy and rewarding life that encourages us to reach our growth potential; a life that we appreciate and respect. This book shows that this is possible, and an increased understanding of recovery philosophy, as demonstrated in the stage model of psychological recovery, may facilitate this for all human beings.

Jon R. Strang
Consumer Advocate
December, 2010

Preface

The moving stories that people with a mental illness have published were the inspiration for this work, and we are deeply indebted to all those people who have shared their experiences with others in order to enhance our understanding. We have written this book to share a model of psychological recovery from mental illness which was derived from many personal accounts. There is a large and growing scholarly literature on recovery, most of which is in broad agreement about the elements of recovery and the many influences on the course of mental illness and its impact on the individual. Our model focuses on the intrapersonal psychological aspects, and does not include external factors such as employment, housing or other social factors. Although these are all extremely important to recovery, they are not the focus of the model. The simplicity of the model brings structure to a very complex field, and has proven to be a useful heuristic in clinical work, education and research. The book elaborates on the model, which was originally published in a journal article (Andresen *et al.*, 2003), and presents our ongoing work, in the hope of furthering understanding of recovery and contributing towards the scientific endeavour of advancing recovery-oriented practice. Although aimed primarily at mental health professionals and students, we hope a wider audience will find the book interesting and informative, particularly people with a mental illness and their loved ones, who may find hope within these pages.

Throughout the book, we have used the term ‘consumer’ – synonymous with ‘service user’ or ‘user’ in the UK – to describe a person who has experienced mental illness. We acknowledge that not all people with a mental illness use mental health services, and are therefore not consumers in this context. We are also

aware of, and deeply respect, the preference for other terminology, including ‘survivor’ and ‘ex-patient’. However, even these terms do not apply to all. Since there is broad consensus on the term ‘consumer’ in the literature, and the book is aimed primarily at professionals, we have adopted this word for simplicity's sake.

In Part I we look at the concept of recovery. Schizophrenia may be considered an exemplar of mental illness, having historically had the worst prognosis. Due to the severity of the illness, there is a large body of literature on the course and outcome of schizophrenia, which provided us with the empirical evidence for recovery. Chapter 1 sets the scene for the book with a historical background of the concept of schizophrenia. It covers how recovery from schizophrenia came to be considered impossible, how this notion was disproved by empirical research, and the reasons for its persistence. The chapter also introduces the consumer recovery movement, and the difference between clinical definitions of recovery and the consumer definition. In Chapter 2 we describe our exploration of what consumers say about recovery, and the psychological processes that they describe. Because this research used earlier consumer accounts, these were less likely to have been influenced by the then burgeoning recovery literature and thus imbued with the language of recovery. This enhances the authenticity of the consumers' voices. These stories led us to a definition of psychological recovery. We also reviewed qualitative studies, and found that a number of researchers had described similar phases of recovery, although they identified varying numbers of phases or stages. From the experiential accounts and qualitative studies, we gleaned the elements of the stage model of

psychological recovery, consisting of four psychological processes that develop across five stages.

Part II elaborates on the model, stage by stage. Chapters 3 to 7 each examine the four processes of recovery within one of the five stages. The discussion is structured around quotes from the consumer stories, and for this we have included some more recent consumer literature. We draw parallels between aspects of recovery and concepts in the broader psychology literature, culminating with the Growth stage, in which we expand on the themes of resilience and wisdom. Chapter 8 addresses some issues and criticisms relating to the model, such as the assertion that recovery is a highly individual and non-linear process, and therefore cannot be ‘modelled’. In order to apply the recovery model to the advancement of research and the enhancement of mental health services, it is necessary to develop measures of recovery, and in Part III we describe our empirical work. Chapter 9 covers our work on developing and testing three approaches to recovery measurement based on the model. These measures have received international attention. The chapter underlines the complexity of this task and the need for more empirical research into the process of recovery and its measurement.

Part IV presents the implications of the model and directions for future research. The recovery literature has clear parallels with that of the positive psychology movement, and these are highlighted in Chapter 10. We explore ways in which the tenets of positive psychology can combine with the recovery literature in developing programmes for promoting recovery. Examples of such programmes, which have been developed with colleagues at the University of Wollongong, are described.

In conclusion, Chapter 11 serves to reflect on our findings, describe some current applications of the model and measures and propose directions for future research. We hope this book will be an inspiration for service providers, researchers, people with a mental illness and their families.

Retta Andresen
Lindsay G. Oades
Peter Caputi
University of Wollongong
November, 2010

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We would also like to thank our families. Retta especially thanks her husband John, children Mandy, Tony, Paul and Kat, Dave and Jess, parents Martin and Janet, and her brothers and sisters for their love, encouragement and support. Lindsay would like to thank his wife Alison and two sons Bodhi and Jai. Peter wishes to thank Elayne, James and Jack for their support and encouragement. We also wish to thank editor Karen Shield for her assistance, publisher Andy Peart and the team at John Wiley & Sons for their work in bringing this book to publication.

Part I

Recovery in Historical Context

Chapter 1

Introduction: Recovery from Schizophrenia

Overview

In this chapter, schizophrenia serves as an exemplar of a most serious form of mental illness, which historically has been difficult to understand, classify or treat. As such, it has been widely researched over many years, generating a large body of empirical research into recovery. Much of the consumer-oriented qualitative research into recovery, however, includes other mental illnesses Therefore, we have utilized the empirical research into schizophrenia to provide ‘hard evidence’ for recovery from mental illness before expanding our work to incorporate the consumer-oriented literature.

Here we put into historical perspective how the idea that there was no hope of recovery from schizophrenia became entrenched within the mental health profession. First we present an historical overview of concepts of schizophrenia, and how these influenced diagnostic systems and prognosis. Next, we present findings from longitudinal and cross-cultural research that show that recovery, in the medical sense – that is, freedom from signs and symptoms of mental illness – occurs more frequently than once believed, and discuss why the rate of recovery went unrecognized for most of the twentieth century.

We then look at how the consumer recovery movement grew from diverse ideological standpoints, and how the consumer movement describes a form of recovery in addition to the traditional medical meaning of the term. Finally we conclude that there is a need for consensus on the consumer definition of recovery, which can be operationalized, in order to meet demands for evidence-based practice with a recovery orientation.

Early Conceptualizations of Schizophrenia

A diagnosis of schizophrenia has traditionally been considered tantamount to a ‘prognosis of doom’ (Deegan, 1997, p.16), which denied all hope of recovery or even of a reasonably satisfying life. Mental health professionals, in particular medical professionals, have a pessimistic outlook regarding the prognosis for schizophrenia (Hugo, 2001; Jorm *et al.*, 1999). The idea that schizophrenia had an inevitable deteriorating course culminating in a life which revolved around stabilization, medication management and survival, has its roots in early descriptions, in which chronicity was considered a criterion for schizophrenia. The earliest description of schizophrenia was that of Emil Kraepelin, who, over many years of clinical observation, asserted that the diseases then known as hebephrenia, catatonia, and paranoia were all characterized by commencement in adolescence followed by a progressively deteriorating course culminating in dementia (1913, cited in Weiner, 1966/1997; Turner, 1999). Kraepelin believed that these diseases all had a common aetiology, course and outcome, and should be identified as forms of a single disorder, *dementia praecox*, the fundamental criterion for which was its outcome, dementia (Turner, 1999; Pull,

2002). Kraepelin considered the illness to be an irreversible disease of the brain, probably caused by autointoxication – toxicity due to metabolic or other bodily processes (Turner, 1999) – and was not open to the idea that any symptoms of the illness could have psychological underpinnings (Weiner, 1966/1997). Although 12% of Kraepelin's patients made a complete, or almost-complete, recovery (Warner, 2004), he felt that those who recovered had been incorrectly diagnosed, as an outcome of dementia was fundamental to the disease (Weiner, 1966/1997; Read, Mosher and Bentall, 2004).

Eugen Bleuler, on the other hand, did not think that dementia was an essential aspect of the disease, and he noted that the illness did not always commence in adolescence (E. Bleuler, 1911/1950). He asserted that the fundamental symptom of schizophrenia was a ‘splitting’ of the various psychic functions – a loosening of associations between ideas and incongruous emotional responses. Bleuler coined the term *schizophrenia*, which comes from the Greek for ‘to split’ (schizin) and ‘mind’ (phren), and advocated the use of this term to replace *dementia praecox* (E. Bleuler, 1911/1950). Bleuler elaborated on Kraepelin's formulation of *dementia praecox* with a number of new concepts. First, he argued that symptoms could range over a continuum from the almost unnoticeable to the most florid; second, he claimed that the label schizophrenia could apply to people who are making reasonable life adjustments in the community, with no psychotic symptoms; and third, he asserted that, although a person may be socially reinstated after an acute episode, residual symptoms were always present (Weiner, 1966/1997). Bleuler also argued that schizophrenia was not one single illness, but rather a group of several diseases with different aetiologies, courses and outcomes (Pull, 2002). He added

two new subgroups: *simple schizophrenia*, which broadened the concept of schizophrenia considerably (to apparently include those who hold menial jobs and bad housewives who are nagging shrews); and *latent schizophrenia*, which parallels later concepts of schizoid and schizotypal personality (Wing, 1999). Bleuler's conceptualization of schizophrenia was much more psychodynamic than was Kraepelin's, and he believed that there was a link between symptoms of schizophrenia and psychological processes (Weiner, 1966/1997). Bleuler posited that the symptoms of schizophrenia may be the result of psychological factors, but was unsure as to the underlying cause of the disease. He concluded that schizophrenia was a group of disorders, some endogenous (and therefore organic), and some reactive (and therefore psychological) (E. Bleuler, 1911/1950; Clare, 1980). The organic form carried a worse prognosis than the reactive form.

In contrast to those of Kraepelin, 60% of Bleuler's patients recovered well enough to work and support themselves outside hospital. There are a number of possible explanations for this difference in outcome. First, Bleuler broadened the definition of schizophrenia to include those with a better prognosis; and second, Kraepelin would have defined recovery as freedom from symptoms, rather than social functioning (Warner, 2004). However, we cannot overlook the effects of Bleuler's more psychodynamic perspective, and his belief that there were psychogenic causes for much of the observed symptomatology (Warner, 2004). This point of view resulted in a more therapeutic approach to treatment, in which great importance was placed on minimizing hospital-based care, on the quality of the person's environment, and on providing opportunities for work (Warner, 2004). Although Bleuler did not agree that

schizophrenia necessarily resulted in dementia, neither did he believe that people ever fully recovered: ‘Personally I have never treated a patient who has proved on close examination to be entirely free from signs of the illness’ (E. Bleuler, 1911/1950, p. 256).

These early formulations of Kraepelin and Bleuler have had long-reaching effects. With no firm evidence of its aetiology, schizophrenia has continued to be conceptualized and classified in terms of its clinical manifestations. Theorists have classified the symptoms of schizophrenia on a number of dimensions, in attempts to improve diagnosis and prognosis. In terms of diagnosing schizophrenia, the formulations of Bleuler (1911/1950) and Schneider (cited in Pull, 2002) have been widely influential. Bleuler differentiated *fundamental* symptoms from *accessory* symptoms. The fundamental symptoms – disturbances in association and affect, ambivalence and autism – were always present in schizophrenia, while the accessory symptoms – including hallucinations and delusions – may or may not be present, and may also be present in other illnesses. The fundamental symptoms were direct manifestations of the disorder, and therefore necessary for a diagnosis of schizophrenia, whereas the accessory symptoms were psychological reactions to the illness, and were not required for a diagnosis (E. Bleuler, 1911/1950; Pull, 2002). In contrast to Bleuler, Schneider (1950, cited in Pull, 2002) held that such symptoms as hallucinations and delusions were pathognomonic of schizophrenia. That is, these symptoms alone were sufficient to give a diagnosis of schizophrenia. Schneider differentiated between abnormal *experiences* and abnormal *expressions* (1950, cited in Pull, 2002). He identified 11 first-rank symptoms, which can be grouped into three categories: passivity experiences, in which thoughts, emotions and actions are felt to be externally

controlled; auditory hallucinations in the third person; and primary delusions, which arise suddenly and without explanation from a normal perception (Clare, 1980). These abnormal experiences he called ‘first-rank’ symptoms, and the presence of any one of these was sufficient for a diagnosis of schizophrenia. ‘Second-rank’ symptoms included disturbances in language, writing and movement, affective symptoms and emotional blunting, all of which could occur in other illnesses (Clare, 1980). A diagnosis of schizophrenia could also be given when only second-rank symptoms were present (Schneider, 1950, cited in Pull, 2002).

Whereas Kraepelin's definition of schizophrenia was based on onset, course and prognosis, Bleuler focused on the dissociative symptoms and Schneider emphasized the importance of the psychotic symptoms such as hallucinations and delusions. All three formulations have been influential to varying degrees in different diagnostic systems until the present day, including the *Diagnostic and Statistical Manual of Mental Disorders* (4th Edition) (DSM-IV; American Psychiatric Association, 1994), the tenth revision of the *International Classification of Diseases and Related Health Problems* (ICD-10; World Health Organization, 1992) and Present State Examination (PSE; Wing, Cooper and Sartorius, 1974).

Diagnostic Systems and Prognostic Pessimism

For the first half of the twentieth century, there was no universal or even widespread definition of schizophrenia. In the United States, the strong psychoanalytic tradition led to a leaning towards Bleuler's broader definition, while in the United Kingdom, Schneider's first-rank