Working with People at High Risk of Developing Psychosis

A Treatment Handbook

Edited by

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Jossey-Bass, 989 Market Street, San Francisco, CA 94103-1741, USA

Wiley-VCH Verlag GmbH, Boschstr. 12, D-69469 Weinheim, Germany

John Wiley & Sons Australia Ltd, 42 McDougall Street, Milton, Queensland 4064, Australia

John Wiley & Sons (Asia) Pte Ltd, 2 Clementi Loop #02-01, Jin Xing Distripark, Singapore 129809

John Wiley & Sons Canada Ltd, 22 Worcester Road, Etobicoke, Ontario, Canada M9W 1L1

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Library of Congress Cataloging-in-Publication Data

Working with people at high risk of developing psychosis : a treatment handbook / edited by Jean Addington, Shona M. Francey and Anthony P. Morrison.
p. cm.
Includes bibliographical references and index.
ISBN-13: 978-0-470-01162-1 (cloth : alk. paper)
ISBN-10: 0-470-01162-9 (cloth : alk. paper)
ISBN-13: 978-0-470-01163-8 (pbk : alk. paper)
ISBN-10: 0-470-01163-7 (pbk : alk. paper)
1. Psychoses—Handbooks, manuals, etc. 2. Psychoses—Treatment—Handbooks, manuals, etc.
I. Addington, Jean. II. Francey, Shona M. III. Morrison, Anthony P., 1969–
[DNLM: 1. Psychotic Disorders—diagnosis. 2. Psychotic Disorders—therapy. 3. Risk Factors.
WM 200 W926 2006]
RC512.W67 2006
616.89—dc22 2005018265

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN-13 978-0-470-01162-1 (hbk) 978-0-470-01163-8 (pbk)
ISBN-10 0-470-01162-9 (hbk) 0-470-01163-7 (pbk)

Typeset in 10/12pt Times by TechBooks Electronic Services, New Delhi, India
Printed and bound in Great Britain by Antony Rowe Ltd, Chippenham, Wiltshire, UK
This book is printed on acid-free paper responsibly manufactured from sustainable forestry in which at least two trees are planted for each one used for paper production.

To Oliver, Zoë, Leo, Jack and Don, who are always encouraging, supportive and tolerant.

—JA

To Mark, for all his emotional, practical and intellectual support and for our wonderful Ned and Abbey.

—SF

To Soph, who has taught me that earlier is better, but that some things are worth waiting for.

—APM

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About the Editors

Jean Addington completed her PhD at the University of Calgary, Alberta. She is currently Director of the PRIME Clinic and Director of Psychosocial Treatments in the First Episode Psychosis Program at the Centre for Addiction and Mental Health in Toronto, Canada. She is also an Associate Professor in the Department of Psychiatry, University of Toronto. The Toronto PRIME Clinic is a research-based clinic for individuals who have an 'at risk mental state'. Her clinical and research interests lie in the understanding and management of this 'at risk mental state' and of early psychosis. She has published widely in this area: including psychosocial interventions, cognition, social functioning and substance use in early psychosis and the development of early intervention services. Her current work includes the development of risk assessment models for the conversion to psychosis and cognitive behaviour therapy in the ultra high risk period.

Shona M. Francey is a clinical psychologist with 20 years' experience in public mental health. She began working in the field of early intervention for psychosis when the Early Psychosis Prevention and Intervention Centre (EPPIC) was first established in 1992 in Melbourne, Australia. Within the EPPIC programme she worked as a case manager, COPE therapist and Group Programme leader. COPE is a cognitively oriented psychotherapy that was developed at EPPIC to promote recovery from first episode psychosis. Shona has also been involved in education and training about early psychosis, and the establishment of the PACE Clinic for young people thought to be at risk of developing psychosis. At PACE she has contributed to the development and evaluation of psychological therapy for this at risk group. She completed her PhD examining neurocognitive indicators of risk for psychosis in the PACE population and is currently the Clinical Coordinator of the PACE Clinic.

Anthony P. Morrison is a Reader in Clinical Psychology at the University of Manchester and is also a Consultant Clinical Psychologist in a specialist programme of care for people with early psychosis in Salford and Trafford. He has published a number of articles on trauma and psychosis, cognitive therapy for psychosis and experimental studies of cognitive processes in psychosis, and has been involved in a number of treatment trials for cognitive therapy for early psychosis and the prevention of psychosis. He has also published several books on the topic of psychological approaches to the understanding and treatment of psychosis. Unkind observers have suggested his interest in both trauma and losing touch with reality stem from his support of Manchester City Football Club.

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Foreword

Most people who develop a psychotic disorder, such as schizophrenia, do so gradually with initially rather subtle changes in experience, emotional state and behaviour. These changes are usually distressing and impact insidiously on relationships, cognitive capacities and daily functioning. This frequently unfolds during the critical period of adolescence or young adulthood, at a time when such changes may be difficult to distinguish from normal developmental vicissitudes, but also when they can derail and constrain the pathways to fulfilment of one's potential. Even when the young person, their family, teachers or the family doctor may be aware that 'something is not quite right', the problem is difficult to characterise and diagnose. This undifferentiated clinical state has been termed the 'at risk mental state', a label that underlines the change in mental state and implies that the person is at risk for something more serious. If the person progresses to a fully fledged psychotic episode because the positive symptom dimension has become more severe and sustained, then and only then are we able to use the term 'prodromal' (retrospectively) for this preceding sub-threshold stage.

Even though people in this 'at risk mental state' are below the diagnostic threshold for an Axis 1 psychotic disorder, they are often clinically unwell with distress and functional impairment. They may meet criteria for other syndromes such as depression. Frequently they or their families do seek help. What are we to offer them? Whatever we offer should ideally be not only helpful, but safe. We are on firm ground when we offer needs-based intervention, e.g. treating their depression, improving their relationships, tackling comorbid substance abuse and/or monitoring risk. Less secure is the attempt, based on the fact that between 20 and 50% of these young people will progress to first episode psychosis within a year if something more specific is not offered, to try to prevent progression to psychosis. Recent landmark studies, conducted by the authors of this handbook and their colleagues, have shown that cognitive-behaviour therapy is effective in reducing the risk of early transition and at least delaying the onset of frank psychosis. In contrast to antipsychotic medication, also effective in this regard, cognitively based therapies are appealing in that they are essentially safer and better accepted by most patients, at least as a first line therapy. The authors of the various chapters are international experts and pioneers of the psychological approach in the earliest phases of psychotic illness, and have much accumulated clinical wisdom and ongoing innovative techniques to impart to the reader. This book forms part of the renaissance of the psychological interventions in the psychotic spectrum and focuses on a phase where, at least for some patients, psychological approaches may be not only necessary but sufficient.

Patrick McGorry MD, Professor, University of Melbourne,
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and President, International Early Psychosis
Association (IEPA)

Acknowledgements

Many people have been supportive, encouraging and helpful in the development of this book. I would first like to acknowledge Jane Edwards from EPPIC for 'encouraging' me to put this book together. I would like to thank the research staff of the PRIME Clinic, in particular Amanda McCleery, Maria Haarmans, and Huma Saeedi, for all of their work in editing and proof reading chapters. Last but certainly not least I would like to thank Diane Kirsopp for her tremendous effort and work involved in developing the idea of this book until its final completion.

Jean Addington

CHAPTER 1

Introduction

Shôn Lewis

AT RISK MENTAL STATES IN PSYCHOSIS: AN INTRODUCTION

The idea that a set of subjective experiences exist which, in many cases, herald imminent psychosis has a long history in psychiatry. However, the operational delineation of these features, often coupled with alterations in functioning and a background of demographic risk factors, was only developed to the extent that it was reliably definable and therefore useable in research, by Alison Yung, Patrick McGorry and colleagues in the mid 1990s (Yung et al., 1998). These criteria, which comprise four sub-sets, have given rise to a paradigm of research which promises much in terms of early detection and secondary, or even primary, preventions. The closest previous attempt at a set of reliable criteria was made by the Bonn group in the 1970s (Huber & Gross, 1989).

Terminology in this area continues to be confusing. The term 'prodrome' to describe this collection of subjective features is widely used, although it is technically wrong and possibly misleading to the sufferer. Epidemiologists define a prodrome as a set of symptoms, which in all cases will lead on to the full syndrome. This is not the case with this set of features described by Yung and colleagues (1998). Only a proportion of such cases go on at follow-up to develop psychosis, which means that the epidemiologically correct term is that this set of features is a 'precursor'. This term has not caught on, perhaps because it lacks clinical immediacy. Instead, the terms 'at risk mental state' (ARMS) or 'ultra-high risk mental state' (UHR mental state) have been applied in an attempt to convey the message that nothing is inevitable.

The descriptive epidemiology of ARMS, how common they are, who gets them, how long they last and so on, is still in its infancy. We have little reliable data about the incidence and prevalence of this constellation of symptoms in the general community. Part of the reason for this is that studies which have set out to identify such cases are often in the context of treatment studies or clinical trials where, for ethical reasons as well as reasons of convenient ascertainment, clients are seeking help for these symptoms. Factors which cause an individual to seek help on the basis of these symptoms are not well understood. Community surveys, especially in Europe, have shown that a surprisingly high proportion of apparently healthy individuals, perhaps 5–15%, will report isolated psychosis-like phenomena for which most will not seek help. Presumably, the decision to seek help is partly

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driven by the subjective distress and this will vary from one individual to another. On top of that, individuals will vary in the extent to which they seek help for a given level of distress, which will depend on a range of internal and external trait and state factors, including health beliefs, perceptions that the abnormalities constitute a threat to health and might be amenable to intervention, availability of health care and so on.

These currently unmeasured factors will inevitably mean that sample structure will be very sensitive to social context and thus collected samples will differ from one another in ways which are likely to be important, and influence final transition rates to psychosis, but are essentially unknown. Nonetheless, follow-up studies are in general agreement that the risk of developing an operationally defined Axis 1 psychosis over the next 12 months is massively increased. Rates of transition to psychosis in follow-up studies published so far vary between 10% and 50%. While some commentators see this five-fold variation as a weakness in the field, it is small in comparison to the increased risk this represents over the base population. An age-matched community sample of young adults would show an incidence rate of new cases of no more than five per 10 000 per year. Even a 10% risk of psychosis in the year following detection of an ARMS will therefore represent a 200-fold increased risk. This huge increase in risk, particularly in a population of young people, immediately raises the prospect of intervention to head off the psychosis.

INTERVENTION STUDIES: GENERAL METHODOLOGICAL ISSUES

Two plausible treatment modalities present themselves straight away, by inference from the treatment of psychosis: antipsychotic drug treatment and specifiable psychological treatment, specifically cognitive behaviour therapy. The evidence base for the effectiveness of antipsychotic drug treatments in psychosis is incontrovertible. The evidence base supporting the effectiveness of cognitive behaviour therapy in psychosis is more recent and smaller. However, several systematic reviews and meta-analyses have supported its effectiveness (Cormac, Jones & Campbell, 2002; Pilling et al., 2002), although only as an adjunct to antipsychotic drug treatment: it has not formally been assessed in the absence of drug treatment.

Three randomised controlled trials of interventions have now published interim or final data. The first was the Personal Assessment and Crisis Evaluation (PACE) trial by McGorry and colleagues (2002) in Melbourne, which evaluated the effectiveness of a six-month combined intervention of low dose risperidone, a second generation antipsychotic drug, plus cognitive behaviour therapy in addition to case management, compared to case management alone. This was an open trial. The second trial by McGlashan and colleagues (2003) at Yale was a double-blind randomised placebo controlled trial of low dose olanzapine, another second generation antipsychotic drug, versus placebo, for 12 months. The third trial, the Early Detection and Intervention Evaluation (EDIE) trial by Morrison and colleagues (2004) in Manchester, compared the effectiveness of a six-month (26 sessions) package of cognitive behaviour therapy versus monthly monitoring. The trials had important similarities. Each used the Melbourne criteria for defining cases; had a 12-month follow-up after commencement of treatment; randomised about 60 subjects and had rates of transition to psychosis as the primary outcome. The trials had important differences too, particularly in case-finding strategies. Assessment measures at baseline differed too: the PACE trial

used the Comprehensive Assessment of At Risk Mental States (CAARMS) structured assessment tool (see Chapter 2), the Prevention through Risk Identification Management and Education (PRIME) trial used the Structured Interview for Prodromal States (SIPS: Miller et al., 2003), and the EDIE trial used the Positive and Negative Syndrome Scale (PANSS).

Results showed that each of the interventions had some therapeutic effect in terms of reducing transition rate, although this tailed off after treatment was discontinued. Differences between the results of the trials appeared in other areas. One important finding to emerge was that consent rates from eligible subjects differed between these studies and were lowest for the double-blind drug study and highest for the psychological treatment study. This is in no way surprising given the way that subjects themselves tend to formulate their problems, often not in the framework of a medical model. It does have implications for the generalisability of any findings and for considerations about how useful any treatment might be. Even if a treatment is highly effective, if it is not acceptable to the target population it is of little use. This difference in ascertainment is the most likely reason that the three trials reported differences in final transition rates, regardless of randomised treatment group. Transition rates at one year were highest for the double-blind trial (27%) and lowest for the psychological treatment trial (15%). One explanation for this is that only those people who are most distressed and urgently seeking help will elect to go into a double-blind placebo controlled trial, whereas a higher proportion of the eligible population, including less distressed cases, will consent to an open psychological treatment trial. That this is the case appears to be supported by data from the PACE trial, which usefully followed up subjects who declined to go in to the trial (McGorry et al., 2002). Surprisingly, those subjects did better than the clients overall who consented to the treatment trial. In almost all other clinical trial contexts, refusers do worse than those consenting to go in to the trial: presumably the explanation here is that the non-consenters did not feel sufficiently distressed or in need of urgent treatment that they wished to go in to the trial.

One of the still unanswered issues which is important from the public health viewpoint when trying to judge the potential impact of an effective preventive intervention is not 'How many help-seeking ARMS cases go on to develop psychosis?' but 'What proportion of new cases of psychosis came through the prior route of help-seeking ARMS?' From this, the population attributable fraction can be estimated: what proportion of new cases of psychosis would be prevented by an effective intervention for people with ARMS? These are difficult data to collect accurately since they involve retrospective accounts by people with first episode psychosis.

ETHICAL ISSUES

There are particular ethical dilemmas thrown up by research and the possibility of treatment in this area. The first, and in some ways the most obvious, concerns the giving of treatment to a group of at risk individuals where most of whom (60% or more) will not, even without treatment, develop the disorder. To what extent is it justified to expose all the at risk group to treatment in that case? Not surprisingly, any answers in this area are not black and white but rather a matter of degree. What is the level of risk of transition at which it becomes acceptable to treat the whole group? To give a related real-life example, we know that about 20% of individuals following a first episode of psychosis will not have a subsequent episode, even without treatment. Yet we make the judgement clinically that treating all individuals with

maintenance drug treatment after the first episode is justified, since 80% will benefit. It is not possible currently to predict accurately who will be in the 20% who will not need ongoing treatment, in the same way that it is not currently possible to predict who are the 60% or more of ARMS who will not go on to develop psychosis. The assumption implicit with the relapse prevention example is that 80% is a sufficiently large number to justify intervention across the board. Clearly, a judgement is also being made about the undesirability of the outcome: one can argue that a first episode of psychosis (or a first relapse) is a sufficiently severe outcome to warrant intervention in all cases. Further dimensions are the effectiveness of the intervention (will it reduce transition rates from 30% to 0%, or merely to 20%) and the risk of adverse effects, which is clearly specific to the type of intervention used. For drug treatments the risk of adverse effects may be relatively high and the effects themselves serious. For psychological interventions it is assumed that risk is lower and this may indeed be the case, although there are plausible risks inherent in psychological treatments too, including stigmatisation.

The central ethical dilemma here can be circumvented if the main therapeutic target is defined differently. Currently, the debate circles on the issue of prophylaxis: how many cases of a psychotic disorder can be prevented is weighed against the cost of treating unnecessarily a majority who will not go on to get the disorder in any event. However, other outcomes may be at least as appropriate. Delaying the onset of psychosis or ameliorating its severity once it begins would also be important therapeutic gains from an intervention. The primary outcome of most immediate relevance to people seeking help for ARMS is reducing the severity and functional impact of the symptoms themselves. If the primary therapeutic target is to alleviate these current sub-threshold symptoms rather than explicitly to prevent future psychosis, then all those who receive an experimental treatment may expect benefits. Current models of how symptoms develop in early psychosis are still at an early stage, but it seems inherently likely that reducing current symptoms will lessen the risk of future transition, so as a therapeutic target it makes sense. Severity of baseline sub-clinical symptoms was one of two predictors of outcome, the other being treatment allocation in the EDIE trial. Furthermore, transition to psychosis sounds as if it is an all or nothing phenomenon. In fact, the operational definitions used are rating scales with continuously distributed properties and the definition of transition is based on passing an essentially arbitrary threshold of severity. Again, this makes it less clear that one is best off dealing with a binary or categorical outcome.

WHAT THE FUTURE HOLDS

Research in this emerging area of at risk mental states is only just beginning. On the epidemiological front, more clarity is needed about base rates and the natural history of ARMS. The role of external factors such as street drug use is still unclear. Biological issues have begun to be explored. Potentially important is the issue of progression with preliminary longitudinal evidence suggesting progressive regional structural abnormalities during this early phase can be replicated (Pantelis et al., 2003). The role of normal genetic variants in mediating risk, perhaps via particular cognitive traits and styles, is likely. Connected to this are two interfaces which require more exploration if models for psychological interventions are to be refined. One is the interface between ARMS and full psychosis. The other is the

presumed interface between isolated psychotic symptoms in the general community and the constellation of these symptoms, coupled with distress, which constitute ARMS.

The future role of psychological treatment seems certain to be important. There are good theoretical reasons why psychological interventions might be particularly appropriate at this early, transitional phase and they are certainly more acceptable for this help-seeking client group than drug treatments. However, the relative effectiveness of drug treatments and psychological treatments will at some stage need to be evaluated. It is entirely likely that clinical guidelines emerging from this area will see psychological treatments, particularly cognitive behaviour therapy, as first line treatments, with drug treatments indicated for clients whose symptoms do not respond to psychological intervention.

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