Illness Management and Recovery

Implementation and evaluation of a psychosocial program for schizophrenia and schizoaffective disorder

RICKARD FÄRDIG
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Abstract

The aim of the present thesis was to examine the effectiveness of the Illness Management and Recovery (IMR) program for teaching clients with schizophrenia or schizoaffective disorder to better manage their illness and to promote recovery.

A randomized controlled trial compared 21 participants in the IMR program to 20 participants receiving treatment as usual. The IMR program participants demonstrated greater improvement in illness self-management, reduced psychiatric symptoms, improved coping skills, and decreases in suicidal ideation. The findings suggest that the IMR program is effective in improving the ability of individuals with schizophrenia and schizoaffective disorder to better manage their illness.

Possible association between neurocognitive functioning and the acquisition of illness self-management skills was investigated in a total of 53 participants who completed the IMR program. Speed of processing was related to client reported illness self-management skills acquisition, before and after controlling for psychiatric symptoms and medication, but neurocognitive functioning did not predict improvement in clinician ratings of client illness self-management skills. The findings suggest that compromised neurocognitive functioning does not reduce response to training in illness self-management.

The impact of symptom severity on outcome of the IMR program was explored in 52 participants who completed the program. The results suggest that significantly more participants met the severity criterion of remission at post-treatment, and it appears that participants not reaching the severity criterion at post-treatment, also benefited from the IMR program, as indicated by the similar effect sizes of the two subgroups (meeting versus not meeting the severity criterion at post-treatment).

The psychometric properties of the Illness Management and Recovery Scale (IMRS) were evaluated in 107 participants with a diagnosis of schizophrenia or schizoaffective disorder. Both the client and clinician version of the IMRS demonstrated satisfactory reliability, and convergent validity with conceptually related measures of psychiatric symptoms, quality of life, and perception of recovery. The findings support the utility of the IMRS as a measure of illness self-management and recovery in clients with schizophrenia and schizoaffective disorder.

The general findings of this thesis support the IMR program to be effective in improving the ability of the participants to manage their disorder.

Keywords: illness management and recovery, IMR, recovery, schizophrenia, schizoaffective, evidence-based, psychosocial, intervention outcome, neurocognition, remission, IMRS, psychometric properties, reliability, validity

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List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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Abbreviations

ANOVA  Analysis of Variance
BPRS  Brief Psychiatric Rating Scale
CBT  Cognitive Behavioral Therapy
CPT  Continuous Performance Test
DDD  Defined Daily Dose
DSM  Diagnostic and Statistical Manual of Mental Disorders
GAF  Global Assessment of Functioning
ICD  International Classification of Diseases
IMR  Illness Management and Recovery
IMRS  Illness Management and Recovery Scale
LNS  Letter-Number-Sequencing
MANSA  Manchester Short Assessment of Quality of Life
MCSI  Modified Colorado Symptoms Index
PANSS  Positive and Negative Syndrome Scale
PECC  Psychosis Evaluation Tool for Common Use by Caregivers
RCT  Randomized Controlled Trial
RAVLT  Rey Audio Verbal Learning Test
RSWG  Remission in Schizophrenia Working Group
SAMHSA  Substance Abuse and Mental Health Service Administration
SD  Standard Deviation
SPSS  Statistical Package for the Social Sciences
TAU  Treatment As Usual
TMT  Trail Making Test
UKU  Udvalg for Kliniske Undersøgelser Side Effect Rating Scale
WAIS  Wechsler Adult Intelligence Scale
WCQ  Ways of Coping Questionnaire
WCST  Wisconsin Card Sorting Test
1. Introduction

One of the key features of schizophrenia is its debilitating impact on psychosocial functioning (1). Individuals suffering from the illness often experience difficulties in work, social interactions and daily living skills, as well as poor treatment adherence and recurrent relapses (2,3). Although empirically supported interventions have been developed to manage the difficulties associated with schizophrenia, few clients have access to them (4,5). The past decade has witnessed growing efforts to increase the availability of evidence-based psychosocial interventions for individuals with schizophrenia and several programs have been standardized and curriculum-based in order to ease implementation and dissemination (6,7).

In a review of the research, Mueser and colleagues (6) identified five key interventions (psychoeducation, social skills training, behavioral tailoring for medication adherence, relapse prevention planning, and coping skills training for managing symptoms) of what was defined as illness management, professional-based interventions aimed at helping clients collaborate with professionals in the treatment of their mental disorder, reduce their susceptibility to relapses, and cope more effectively with psychiatric symptoms.

The Illness Management and Recovery (IMR) program is aimed at promoting recovery in clients with severe mental illness through the acquisition of illness self-management skills. The program model posits that the proximal outcomes of training in illness self-management (i.e., psychoeducation, social skills training, relapse prevention planning, behavioral tailoring for treatment adherence, and coping skills training for managing stress and symptoms), combined with setting and pursuing personally meaningful goals, will instill hope and help clients make progress towards longer-term recovery outcomes, including a sense of purpose, more rewarding social relationships, and improved role functioning (8,9). Several studies have demonstrated the effectiveness of IMR at improving illness management and reducing psychiatric symptoms (10-13), and one study has shown that IMR can be implemented with high program fidelity by frontline clinicians working in routine treatment settings serving people with severe mental illness (14).

The general aim of the thesis was to examine the effectiveness of the Illness Management and Recovery program for teaching clients with schizophrenia or schizoaffective disorder to better manage their illness and to promote recovery. This was accomplished through an examination of the pro-
gram’s effects on psychosocial functioning and psychopathology, the evaluation of general and specific impact of neurocognition on learning the fundamentals of illness self-management, and the impact of symptom severity on outcome of the IMR program. The utility of the illness management and recovery scale to evaluate illness self-management of clients with schizophrenia and schizoaffective disorder was also investigated.

1.2. Schizophrenia and schizoaffective disorder

According to Van Os and colleagues (15), schizophrenia “may be considered the poor outcome fraction of a truly ‘complex’ multidimensional psychotic syndrome.” Psychosis, negative symptoms, affective dysregulation, and neurocognitive difficulties are correlated in the psychotic syndrome (lifetime prevalence of 2-3%), but can also be found in 10-20% of the non-clinical population (16). Psychotic symptoms (also called positive symptoms) are characterized by loss of contact with reality, false convictions or beliefs (delusions), perceptual experiences not shared or experienced by others (hallucinations), and bizarre or disorganized behaviors. Negative symptoms are relatively stable over time and represent states in which basic emotional and behavioral processes are absent or reduced (blunted affect, anhedonia, apathy). Affective dysregulation refers to symptoms of anxiety, mania, and depression (17). Neurocognitive dysfunction includes difficulties in attention and concentration, speed of information processing, learning and memory, and executive functioning. Neurocognitive dysfunction is pervasive over time and, just like negative symptoms (18), strongly associated with functional impairment (difficulties in work, social relationship, independent and community living) (2,19-22).

A diagnosis of schizophrenia (lifetime prevalence of around 0.5-1.0%) is characterized by psychosis, negative symptoms, neurocognitive impairments, long duration, and few affective symptoms, whereas a presentation of psychotic symptoms, fewer negative symptoms, and high levels of affective symptoms are usually diagnosed as psychotic depression or bipolar disorder (1). Schizoaffective disorder, however, presuppose an affective state concurrent with symptoms of schizophrenia, a period of positive symptoms in the absence of prominent mood symptoms, and the presentation of mood symptoms for a substantial proportion of the illness duration (23,24).

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and the tenth International Classification of Diseases (ICD-10) are currently used to diagnose schizophrenia and schizoaffective disorder. The DSM-IV uses a somewhat narrower definition of schizophrenia with requirements of social and occupational impairment (not included in ICD-10) and a 6-month duration of illness (versus 1-month in ICD-10). The
same is true for schizoaffective disorder where DSM-IV require a temporal difference in occurrence between psychotic and affective symptoms for a period of at least 2 weeks (23,24). There are important differences between the diagnostic criteria of ICD-10 and DSM-IV, possibly resulting in a more favorable outcome of schizoaffective disorder than schizophrenia, according to the ICD-10 criteria (25). The reliability and validity of the schizoaffective disorder have been under considerable debate and some propose that it should be eliminated from the diagnostic nomenclature altogether (26,27).

High heritability estimates indicate a strong genetic influence of psychosis, and the ‘stress-vulnerability’ model of etiology assumes that genetic factors make individuals selectively vulnerable for environmental risks (gene-environment interaction) (28-32). Until recently it has been difficult to provide data supporting this model, but a growing body of meta-analytic work suggest that psychotic outcomes are related to growing up in an urbanized area (30), belonging to a minority group (33,34), cannabis use (35-37), and developmental trauma (38-41). Research findings also suggest earlier onset and worse outcome of schizophrenia in men than in women, which to some extent may be contributed to social risk factors (42-46). A diagnosis of schizophrenia is also highly predictive of almost all other DSM-IV Axis I and Axis II disorders in the same individual and symptoms observed in psychotic disorders (psychosis, neurocognitive dysfunction, and affective dysregulation) are also prevalent in common psychiatric disorders (anxiety disorders and depression), and the differences between the two groups seem to be quantitative in nature rather than qualitative (47-50).

1.2.1. Symptom remission

A broad majority of persons with schizophrenia experience sustained periods of symptomatic relief and functional improvement interrupted with relapse and recurrence (51). These periods of remission imply that the person is “relatively free of disease-related psychopathology” but has not yet recovered and is still vulnerable to relapse (52). The remission criteria proposed by the Remission in Schizophrenia Working Group (RSWG), provide a standardized method of assessing outcome in the long-term treatment of schizophrenia and allow for cross-study comparisons (53). According to numerous studies, remission of symptoms is related to better psychosocial functioning, cognitive functioning, fewer relapses, fewer antipsychotic medication side effects, and better quality of life (54).

The remission criteria consist of a symptom-based criterion (severity of core symptoms) and a time-based criterion (low impact symptom severity over at least 6 months). The core symptoms of schizophrenia represent three dimensions of psychopathology identified by factor analyses (positive symptoms, negative symptoms, and disorganization) (55).
Table 1. Constructs of psychopathology in schizophrenia and cross-scale item correspondence of remission criteria (adapted from De Hert et al., 2007)

<table>
<thead>
<tr>
<th>DSM-IV symptoms</th>
<th>PANSS-items</th>
<th>PECC-items (see 3.4.2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>Delusions (P1)</td>
<td>Delusions (P)</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>Unusual thought content (A9)</td>
<td>Unusual thought content (P)</td>
</tr>
<tr>
<td>Disorganized speech</td>
<td>Hallucinatory behavior (P3)</td>
<td>Hallucinations (P)</td>
</tr>
<tr>
<td>Grossly disorganized or</td>
<td>Conceptual disorganization (P2)</td>
<td>Conceptual disorganization (C)</td>
</tr>
<tr>
<td>catatonic behavior</td>
<td>Mannerism/posturing (A5)</td>
<td></td>
</tr>
<tr>
<td>Negative symptoms</td>
<td>Blunted affect (N1)</td>
<td>Blunted affect (N)</td>
</tr>
<tr>
<td></td>
<td>Social withdrawal (N4)</td>
<td>Passive/apathic social withdrawal (N)</td>
</tr>
<tr>
<td></td>
<td>Lack of spontaneity (N6)</td>
<td></td>
</tr>
</tbody>
</table>

These three dimensions correspond to the symptomatic domains of the DSM-IV and ICD-10 diagnostic criteria for schizophrenia. According to the RSWG, the symptomatic domains of the diagnostic criteria are represented by a number of specified items on validated assessment scales, where the Positive and Negative Syndrome Scale (PANSS) is one of the most widely employed (Table 1) (56,57). Since the PANSS provides ratings that are based on both symptoms and functional impairment, the RSWG considered a simultaneous score of mild or less (≤3) on all core symptoms to be representative of the severity criterion of symptomatic remission.

1.2.2. Neurocognitive dysfunction

Many clients with schizophrenia have impaired neurocognitive functioning in areas such as verbal learning and memory, executive functioning, attention and vigilance, speed of processing, and working memory (2,20). As a group, clients with schizophrenia perform worse than controls on almost every neurocognitive measures (19). The results of several studies implicate that neurocognitive dysfunctioning is a core feature of schizophrenia, that it is present prior to the onset of the illness, and that it tend to be relatively independent of symptomatic state (58). Neurocognitive dysfunction is a better predictor of functional outcome than any other measure of psychopathology (59-61), and may prevent functional recovery and interfere with the clients’ ability to fully benefit from psychosocial interventions (2,22,62). However, some research suggests that enriched psychosocial settings and behavioral interventions may improve neurocognitive functioning (63-67). For an example, one experimental study of a relatively intensive social skills training program for older persons with severe mental illness reported significantly greater improvements in executive functioning, but not other areas of cognitive functioning, for clients who received the intervention (68).
1.3. Illness management

Illness management is defined as professional-based interventions designed to help clients and clinicians collaborate in the treatment of mental illness, reduce susceptibility to relapses, and develop effective coping strategies for the management of symptoms. Illness self-management refers to strategies that individuals with a mental illness use to more effectively manage their own illness (8). In a review of the research, Mueser and colleagues (6) identified five interventions with empirical support for improving outcome in severe mental illness (i.e., major depression, bipolar disorder, psychotic disorders including schizophrenia and schizoaffective disorder, and personality disorders), including psychoeducation, social skills training, relapse prevention planning, behavioral tailoring for treatment adherence, and coping skills training for managing stress and symptoms.

Teaching clients and their families or significant others about specific disorders in order to improve adherence to recommended treatments are especially common in chronic illnesses such as diabetes, heart disease, and cancer. In the field of mental health, psychoeducation has been defined as a systematic, didactic intervention with the aim to inform clients and their relatives about the illness and the available treatment options in order to foster an understanding of the illness and enable informed decision-making (8). Several studies have shown that clients with schizophrenia who receive psychoeducation demonstrate greater knowledge about their illness, are more compliant to treatment, experience fewer relapses and hospitalizations (69-73), and that the benefits of the relatively short intervention are retained over several years (74,75).

Social skills training strategies are based on social learning theory (76) and incorporate techniques such as goal setting, role modeling, behavioral rehearsal, corrective feedback, and homework assignments to promote generalizability of the skills learnt (77). A recent meta-analysis, including 22 studies and 1 521 clients, supports the utility of social skills training for improving functional outcomes such as social adjustment and independent living (78).

Relapse prevention programs teach how to recognize early environmental stressors and early warning signs of an approaching relapse and how to respond in order to prevent further symptom exacerbation (79,80). Decreases in relapse or rehospitalizations have been demonstrated and benefits involving relatives in relapse prevention planning is consistent with research that shows that family intervention is effective in preventing relapses (70).

Strategies for increasing medication adherence usually involve identifying risk factors for nonadherence and then using an intervention based on cognitive-behavioral strategies and motivational interviewing. Cognitive-behavioral strategies have been shown to improve adherence among clients with bipolar disorder and schizophrenia (81,82). Motivational interviewing
in combination with cognitive approaches has been reported to increase medication adherence among clients with psychosis (83,84).

Coping programs aim to increase clients’ ability to deal with symptoms or stress or persistent symptoms (85-87) Cognitive-behavioral based coping skills training identified by Mueser and colleagues (6) produced positive results in reducing symptoms and relapses.

1.4. Recovery

The term recovery may refer both to a process and to an outcome (88-91).

Broad heterogeneity in the outcome of schizophrenia has been documented and several rigorous longitudinal studies suggest that 25-65% of persons diagnosed with serious mental illness will recover from their disorders (92-94). Recovery as an outcome refers to the remission of symptoms and other deficits associated with the disorder over a sustained period of time and to such a degree that they no longer interfere with daily functioning or social and vocational activities (88,95,96). This definition of recovery is based on explicit criteria (e.g. RSWG remission criteria) and identifies a point at which remission has occurred, and thus holds many advantages from clinical and research perspectives since it is reliable, and relatively easy to define and measure (52,97).

A different use of the term recovery has been proposed that presents a more constructive approach for meeting the needs of the remaining 35-75% who do not recover in the first sense and for whom existing care is relatively ineffective (98,99). Being in recovery has to do with pursuing and participating actively in a meaningful life within the limitations imposed by mental illness and not to postpone living until recovery from mental illness has occurred. The conceptualization of recovery as a process thus deemphasizes the absence of psychopathology and instead refers to a unique and personal process rather than an outcome (89,91,100).
1.5. Illness Management and Recovery (IMR)

The Illness Management and Recovery program is based on key illness management skills and strategies, and was designed for clients with severe mental illness, including schizophrenia, schizoaffective disorder, bipolar disorder, and major depression (6,101). The program model posits that the proximal outcomes of training in illness self-management (i.e., psychoeducation, social skills training, relapse prevention planning, behavioral tailoring for treatment adherence, and coping skills training for managing stress and symptoms), combined with setting and pursuing personally meaningful goals, will instill hope and help clients make progress towards longer-term recovery outcomes, including a sense of purpose, more rewarding social relationships, and improved role functioning. The program is provided in an individual or group format over 40 sessions or more during which trained clinicians help clients to develop individualized strategies for managing their psychiatric disorder. In the sessions, clients and clinicians work collaboratively in reviewing the information of the program, including skills and strategies that may be helpful for the clients when pursuing recovery.

Setting and pursuing personally meaningful goals is a critical aspect of the IMR program and provide much of the motivation for learning and using the information and strategies taught in the program. Clinicians help clients identify goals, and evaluate and monitor them over the course of the program. Larger goals are broken down into smaller steps to increase the chances for success.

The content of the IMR program is organized into nine handouts containing practical information. They describe skills and strategies to develop and set personally meaningful recovery goals, make informed decisions about treatment, increase social support, relapse prevention planning, take medication as prescribed, and to cope effectively with symptoms and stress. A corresponding Clinician’s Guideline for each of the nine modules suggests specific ways to help clients learn the information and put it into practice. An overview of the nine modules is presented in Table 2.

Since the completion of this study, two new modules have been developed. One for Drug and Alcohol Use, which provide information on the effects of substance use on mental illness, reasons for using, continued use vs sobriety, and developing a personal sobriety plan, and one for Healthy Life-styles (optional module) (101).
Table 2. *Topic and goals of the Illness Management and Recovery modules (adapted from Mueser et al., 2006)*

<table>
<thead>
<tr>
<th>No.</th>
<th>Topic</th>
<th>Goals</th>
<th>Number of sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Recovery strategies</td>
<td>• Engage clients in group&lt;br&gt;• Increase awareness of recovery&lt;br&gt;• Set personal recovery goals&lt;br&gt;• Develop plan for achieving goals</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Practical facts about psychosis</td>
<td>• Identify symptoms associated with schizophrenia&lt;br&gt;• Dispel myths about schizophrenia&lt;br&gt;• Address stigma&lt;br&gt;• Help clients become aware of people with schizophrenia who lead productive lives</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>The stress-vulnerability model</td>
<td>• Explain that stress and biological vulnerability cause symptoms of schizophrenia&lt;br&gt;• Discuss strategies for reducing stress and biological vulnerability&lt;br&gt;• Inform clients about treatment options</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>Building social support</td>
<td>• Discuss how building social support can facilitate recovery&lt;br&gt;• Teach strategies for increasing support, such as finding places to meet people, conversation skills, and getting closer to people</td>
<td>7</td>
</tr>
<tr>
<td>5.</td>
<td>Using medication effectively</td>
<td>• Teach clients about benefits and side effects of medication&lt;br&gt;• Increase skills for discussing medication with psychiatrist&lt;br&gt;• Help clients weigh pros and cons about taking medication&lt;br&gt;• Teach behavioral tailoring for facilitating medication adherence</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>Reducing relapses</td>
<td>• Teach clients that relapses are predictable and preventable&lt;br&gt;• Develop an individualized relapse prevention plan</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>Coping with stress</td>
<td>• Inform clients that they can reduce stress and improve their ability to cope with it effectively&lt;br&gt;• Identify and practice strategies to prevent and to cope with stress</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>Coping with problems and symptoms</td>
<td>• Teach problem-solving model&lt;br&gt;• Help clients identify common problems and symptoms that cause distress&lt;br&gt;• Practice coping strategies for persistent symptoms</td>
<td>6</td>
</tr>
</tbody>
</table>

(continued on next page)
1. **Recovery strategies** introduces the concept of recovery and encourages the clients to explore their own definitions of recovery. The module helps them to set personally meaningful recovery goals and take steps toward realizing them. During the course of the program the recovery goals are reviewed, evaluated, and updated.

2. **Practical Facts about Psychosis** provides information about schizophrenia, explains how the diagnostic procedure is established, and describes common symptoms. Basic facts about mental illness help the clients to conceptualize their problems and experiences as related to a psychiatric condition for which effective treatments are available.

3. **The Stress-Vulnerability Model and Treatment Strategies** suggests that although psychiatric disorders are biological in nature, they can be affected by stress. The interaction of biological vulnerability and environmental stress can be reduced helping the clients to improve their outcome and functioning. Taking medication as prescribed and not misusing substances can reduce biological vulnerability, whereas improving social support, and learning effective coping strategies can minimize exposure to stress. The Stress-Vulnerability Model establishes the foundation for treatment and provides a message to the clients that effective symptom management is possible.

4. **Building Social Support** introduces strategies for improving social relationships and social interaction. Building upon social skills training, the module helps the clients to evaluate their satisfaction with their social support and increase the closeness in their current personal relationships. Needed social skills are trained by the means of role-play and shaping techniques in session and practiced in the community.

5. **Using Medication Effectively** provides information about how medications can reduce biological vulnerability and helps the clients achieve their goals. The benefits and side effects are explored and discussed. Strategies for incorporating medication into the daily routines of the clients are taught.

6. **Reducing Relapses** involves examining past experiences with relapses in order to prevent future ones. Through identification of triggers and early
warning signs of relapse a specific relapse prevention plan is developed. The clients are encouraged to involve significant others in the discussion.

7. *Coping with Stress* helps the clients to recognize different types of stressors and increase their own awareness of emotional and physical reactions to stress. Different strategies for coping with stress are taught in this module. Effective coping can reduce symptoms distress and improve the clients’ ability to manage their illness.

8. *Coping with Problems and Symptoms* includes teaching a step-by-step problem solving method to manage difficulties, and to increase adaptive coping skills that the clients exhibit or developing new ones. The problem solving method and the coping skills training are practiced both in session and at home.

9. *Getting Your Needs Met in the Mental Health System* provides an overview of the mental health system, community service programs, and benefits that the clients may be entitled to. The clients get help in navigating the system and are also taught strategies for advocating themselves when they encounter problems such as eligibility requirements or application procedures.

1.5.1. Previous studies of the IMR program

The IMR program has been evaluated in different settings for relatively diverse and heterogeneous samples (10-13). The general pattern of the results provide support for the program’s effectiveness in improving illness self-management, knowledge of the disorder, psychopathology, psychosocial functioning, perception of recovery as a process, and subjective quality of life. The results are also in line with the primary theoretical aims of the IMR program - that training illness self-management skills combined with setting and pursuing personally meaningful recovery goals increases the clients’ chances of making progress towards longer-term recovery goals.

Mueser and colleagues (13) conducted an uncontrolled pilot study of the program at three sites, one in Australia and two in the USA. Twenty four participants completed the program and were eligible for post-treatment analyses. Seventeen participants completed the 3-months follow-up assessments. The mean age at baseline was 39.12 years (SD=11.20). Most participants were male (63%), Caucasian (89%), never married (83%), and had a primary diagnosis of schizophrenia or schizoaffective disorder (88%). At post-treatment, the participants demonstrated improved illness management and recovery (IMRS; F[2,16]=10.82, $d=.83$, p<.01), improved perception of recovery (RAS; F[2,41]=4.76, $d=.64$, p=.01), and improved ratings of global functioning (GAF; F[2,18]=10.91, $d=.80$, p<.01). Although not utilizing an experimental design, the general findings of the pilot study support the utility, acceptability, and the effectiveness of the IMR program.
The first randomized controlled trial of the IMR program was conducted at 13 psychiatric community rehabilitation centers in Israel (11). A sample of 210 participants was randomized to IMR (N=119) or a control condition (N=91). The mean age at baseline was 33.92 (SD=11.10) in the IMR group, and 35.45 (SD=11.24) in the control condition. Most participants were male (68% and 62%), single (77% and 76%), and had a primary diagnosis of schizophrenia (80% and 89%). At post-treatment, participants in the IMR group demonstrated improvements in clinician-rated illness management and recovery (IMRS; F[1,146]=7.60, d=.96, p<.01), and in client self-reported illness management and recovery (IMRS; F[1,148]=7.20, d=.41, p<.01). Client self-rated improvements in coping efficacy were also shown (Coping Efficacy Scale; F[1,128]=4.78, d=.42, p<.05). The results showed that the IMR program is effective in increasing the clients’ knowledge of their illness, helping them make progress towards personal goals, and increasing their perceived ability to cope more effectively with their illness.

A second randomized controlled trial was carried out with 104 participants with severe mental illness who were receiving supportive housing services (12). The participants were randomly assigned to either IMR groups (N=54), or a waiting list control condition (N=50). The mean age at baseline was 52.91 years (SD=10.79) in the IMR group, and 55.02 years (SD=9.41) in the control condition. Most participants were male (63% and 64%) and never married (63% and 58%). In the IMR group, 26% had a primary diagnosis of schizophrenia or schizoaffective disorder, and in the control group this figure was 38%. At post-treatment, participants in the IMR group demonstrated improvements in client self-reported illness management and recovery (IMRS; F[1,89]=8.68, d=.36, p=.002), and clinician reported illness management and recovery (IMRS; F[1,93]=12.52, d=.39, p=.001). They also showed improved self-reported quality of life (Quality of Life Scale-Abbreviated; F[1,93]=7.07, d=.52, p=.005), and blinded ratings of psychopathology (BPRS; F[1,97]=3.03, d=-.20, p=.043). The overall pattern of the results provides additional support for the effects of the program on people with severe mental illness.

An uncontrolled study of the IMR program for clients with schizophrenia was carried out in Japan (10). Over two years 25 participants completed the program and were compared to a waitlist control group. The mean age was 33.02 years (SD=8.82). Most participants were women (66%), unmarried (100%), and unemployed (96%), with a mean duration of illness of 10.80 years (SD=7.30). At post-treatment, the participants showed significant improvements in psychopathology (p<.01), functioning (p<.001), self-reported activation in self-management (p<.01), quality of life (p<.01), and self-efficacy in community living (p<.05). The study suggests that the IMR program is effective for people with severe mental illness in Japan.
2. Aims of the thesis

1. The general aim of the thesis was to examine the effectiveness of the Illness Management and Recovery program for teaching clients with schizophrenia or schizoaffective disorder to better manage their illness and to promote recovery.

2. The aim of the first paper was to evaluate the effects of the Illness Management and Recovery program on mental illness and psychosocial functioning of clients with schizophrenia and schizoaffective disorder through a randomized controlled trial.

3. The aim of the second paper was to evaluate the psychometric characteristics of the Illness Management and Recovery scales with regard to internal consistency, test-retest reliability, and convergent validity, in order to investigate its utility as a measure of illness management and recovery.

4. The aim of the third paper was to investigate neurocognitive predictors of outcomes of the Illness Management and Recovery program (i.e. illness self-management skills). Statistical analyses investigated improvements in neurocognitive functioning and the possible moderation of illness self-management skills acquisition by neurocognitive functioning.

5. The aim of the fourth paper was to investigate whether participation in the IMR program was associated with more frequent symptomatic remission, and whether participants meeting the severity criterion of symptomatic remission experience greater improvement in other outcomes of the IMR program compared to participants not meeting the criterion.
3. Methods

3.1. Preparation, setting and procedure

In the fall of 2005 the authors came into contact with the IMR-program when in search for a psychosocial approach that would have potential benefits in meeting the needs of persons with schizophrenia and schizoaffective disorder. Since the program was relatively new and previously not evaluated in a randomized controlled trial, it was decided to investigate its effects prior to implementation into routine mental health practice.

Prior to setting up the study, the curriculum, group manual, and clinician guidelines (approximately 300 pages) was translated into Swedish (Figure 1) (102). Study design and outcome measures were chosen on the basis of relevant research questions (see Aims of the thesis). The studies were conducted at six psychiatric rehabilitation centers serving clients with psychotic disorders, in the County of Uppsala between May 2006 and March 2011. The clinicians assigned to lead the IMR groups at each center were recruited on the basis of expressed interest in the program, and they received five full days of training. The only prerequisite for participation in the training was documented working knowledge of cognitive behavioral therapy (CBT). The clinicians were mental health workers, occupational therapists, social workers, and medical nurses. After completing the training, two clinicians co-facilitated each IMR program group at the psychiatric rehabilitation centers. During the weekly sessions, each lasting approximately one hour, the IMR curriculum was reviewed, between-session homework assignments were chosen, and goals were set and evaluated.

3.2. Materials

The IMR-program materials consist of three parts: a nine module curriculum that the participants and clinicians work through during the sessions, nine clinician guidelines corresponding to each module, and a group manual is setting the standardized structure of each session of each module. All materials were obtained through the SAMHSA tool-kit website (102).
Figure 1. Flowchart of the preparation and evaluation of the IMR-program (Paper I)

3.3. Sample

A total of 107 clients with a DSM-IV diagnosis of schizophrenia or schizoaffective disorder participated in the studies. Most participants were male (N=66; 62%), born in Sweden (N=70; 65%), living alone (N=91; 85%), unemployed (N=57; 53%), had at least 9 years of education (N=65; 65%), and a DSM-IV diagnosis of schizophrenia (N=76; 71%). Inclusion criteria were a DSM-IV diagnosis of schizophrenia or schizoaffective disorder, proficiency in Swedish, and willingness to provide informed consent after receipt of
detailed study information. Medical records were reviewed for current diagnosis at the time of inclusion.

For Paper I, 41 participants who completed baseline assessments were randomly assigned to one of the six IMR groups (N=21) or to a treatment as usual control condition (N=20) (Figure 1). The participants for Paper I was recruited between May 2006 and May 2007.

For Paper II, the participants of Paper I (N=41), the additional participants of Paper IV (N=20), and an additional 46 subjects recruited during 2009 (total N=107), were assessed and reassessed two weeks later.

For Paper III, a total of 53 participants from Paper I and Paper IV who completed the IMR-program, and baseline and post-treatment assessments, were included in the study.

For Paper IV, 32 participants from the IMR group and the treatment as usual control condition of Paper I and an additional 20 participants recruited during 2008-2009 (N=52), were included in the study.

3.4. Outcome measures

For Paper I all outcome measures were administered at baseline, post treatment (9 months post baseline), and at follow-up (21 months post baseline). For Paper IV all outcome measures were administered at baseline and post treatment (9 months post baseline).

3.4.1. The Illness Management and Recovery Scales (IMRS)

The client and clinician versions of the IMRS include 15 items rated on 5-point behaviorally anchored scale (103). The items are: 1-Progress towards goals; 2-Knowledge about mental illness; 3-Involvement of family and friends; 4-Contact with others outside of family; 5-Time spent in structured roles; 6-Symptom distress; 7-Impaired functioning; 8-Relapse prevention planning; 9-Relapse of symptoms; 10-Psychiatric hospitalizations; 11-Coping; 12-Involvement with self-help activities; 13-Using medication effectively; 14-Functioning affected by alcohol use; 15-Functioning affected by drug use. Previous research has shown good internal consistency (with Cronbach’s $\alpha = .72$ for the client version, and Cronbach’s $\alpha = .82$ for the clinician version), and test-retest reliability at 2-weeks ($r=.81$ for both versions). Convergent validity between the IMRS and measures of coping, social support, and drug use has been established (104,105). Also, controlled studies have demonstrated their sensitivity to change over time (11,12). Hasson-Ohayon and colleagues (105) investigated the underlying factor structure of the IMRS for severe mental illness (psychosis, bipolar disorder, major depression, and personality disorders) and found three factors representing coping with mental illness, knowledge about mental illness/goal...
orientation, and using medication. Support for the use of both the single-factor and the three-factor models, was found in a large sample (n=10,659) of people with severe mental illness in San Diego, USA (106).

3.4.2. The Psychosis Evaluation Tool for Common Use by Caregivers (PECC)

The PECC was used to assess psychiatric symptoms. The PECC is a 26-item scale that is used by a trained interviewer to rate the frequency and severity of psychiatric symptoms, including psychosis, negative symptoms, mania, depression and anxiety, cognitive symptoms, insight, and suicidality (107). Previous research has established its interrater reliability and intrascale validity (108). For the purpose of the present study, six interviewers completed two days of PECC training and were considered fully trained when satisfactory agreement on each item was established (interrater reliability r >.80). Total PECC score and subscale scores for psychosis, negative symptoms, mania, depression and anxiety, cognitive symptoms, and insight were used in the statistical analyses. A dichotomized variable was used to evaluate the presence or absence of suicidal ideation the week before the assessment.

3.4.3. Symptom severity

The PECC only evaluates 6 of the 8 core symptoms of schizophrenia that were proposed by the RSWG to constitute the remission severity criterion (Table 1). However, De Hert and colleagues (109) discussed that the PANSS item N6-Lack of spontaneity is part of the PECC item N-Passive/apathic social withdrawal, and that the PANSS item A5-Mannerism/Posturing is only active (i.e. ≥ 4 on a 7-point scale) in a minority of clients with schizophrenia. The severity criterion was evaluated on a dichotomized scale (presence/absence) using the RSWG definition of mild core symptoms (≤3).

3.4.4. The Recovery Assessment Scale (RAS)

The RAS is a 41-item self-report scale assessing perceptions of recovery in mental illness (110). The 41 items are rated on a 5-point Likert scale, ranging from ‘Strongly disagree’ to ‘Strongly agree’. The scale includes five factors composed of 24 items: personal confidence and hope, willingness to ask for help, goal and success orientation, positive reliance on others, and not dominated by symptoms. Both the total scale and its subscales have good internal consistency (between .70 and .93) and test-retest reliability (r=.81-.88) (110-114).
3.4.5. The Ways of Coping Questionnaire (WCQ)

The WCQ is a 66-item scale that assesses eight aspects of the respondents coping style: confrontive coping, distancing, self-control, seeking social support, accepting responsibility, escape-avoidance, “planful” problem solving, and positive reappraisal (115). The eight coping factors have been shown to have good internal reliability and convergent validity for persons with schizophrenia (116).

3.4.6. The Manchester Short Assessment of Quality of Life (MANSA)

The MANSA is a 16-item self-report scale that elicits information about satisfaction in different life domains, including job, financial situation, number and quality of friends, leisure, living situation, personal safety, people that the client lives with, sex life, relationship with family, physical health, and mental health. Four of the items investigate objective quality of life. Satisfaction is rated on a 7-point scale ranging from 1=”could not be worse” to 7=”could not be better”. The objective items are dichotomized with the alternatives “yes” or “no” (117). Research has shown good validity ($r$=0.83; $p<$0.001), internal consistency (Cronbach’s $\alpha = 0.74$) and correlation with the Brief Psychiatric Rating Scale (BPRS) ($r=-0.49; p<0.001$). An evaluation of a Swedish version of the MANSA revealed satisfactory internal consistency (Cronbach’s $\alpha = 0.81$), and convergent validity with measures of social network, empowerment, and psychosocial functioning ($r=0.52-0.73; p<0.05$) (118).

3.4.7. The Udvalg for Kliniske Undersøgelser Side Effects Rating Scale (UKU), self-rating version (SERS-Pat)

The UKU is a 48-item scale assessing the frequency and severity of symptoms of drug side effects (119). The items are clustered into four subgroups, including psychic, neurological, autonomic, and other side effects. Possible scoring range between 0-3 with higher scores denoting greater drug side effects.

3.4.8. The Modified Colorado Symptom Index (MCSI)

The MCSI is a 14-item self-report scale that measures the frequency of symptoms over the previous 30 days (120). The scale has been show reliable and valid for individuals with severe mental illness (121).
3.5. Neurocognitive measures

The participants of Paper I and Paper IV completed a comprehensive computerized battery of neuropsychological tests relevant to functioning including verbal learning and memory, attention and vigilance, speed of processing, executive control, and working memory (2,22). The neuropsychological tests were administered at baseline and at post treatment. Each neurocognitive domain and the corresponding neuropsychological tests are presented in Table 3.

<table>
<thead>
<tr>
<th>Neurocognitive domain</th>
<th>Neuropsychological test</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal learning and memory</td>
<td>Rey Audio Verbal Learning Test-Trials 1-5</td>
<td>(122)</td>
</tr>
<tr>
<td></td>
<td>Rey Audio Verbal Learning Test-Delayed Free Recall</td>
<td></td>
</tr>
<tr>
<td>Attention and vigilance</td>
<td>Continuous Performance Test-Identical Pairs</td>
<td>(123)</td>
</tr>
<tr>
<td>Speed of processing</td>
<td>Trail Making Test-Part A</td>
<td>(127)</td>
</tr>
<tr>
<td>Executive control</td>
<td>Wisconsin Card Sorting Test-Perseveration Errors</td>
<td>(128)</td>
</tr>
<tr>
<td></td>
<td>Trail Making Test-Part B</td>
<td>(127)</td>
</tr>
<tr>
<td>Working memory</td>
<td>Letter-Number Sequencing</td>
<td>(133)</td>
</tr>
</tbody>
</table>

3.5.1. The Rey Audio Verbal Learning Test (RAVLT)

In the Rey Audio Verbal Learning Test, verbal learning and retention is analyzed by a five-trial presentation of a 15-word list and its corresponding delayed free recall (122). The words are read to the subject at the rate of one per second. After each administration, recall is assessed by having the subject repeat the words in any order. Total scores across the five trials assess total recall. After a 20 minutes delay the subject is asked to repeat the words without prior reading of the wordlist.

Impaired verbal learning is a reliable finding in schizophrenia and the literature is reporting performances over trials of approximately 1.5 standard deviations below average (19).

3.5.2. The Continuous Performance Test (CPT)

As a measure of attention and vigilance, the Continuous Performance Test-Identical Pairs (CPT-IP), measures the ability to differentiate target stimuli from distractors (123). A computerized version of the test was used. During testing, the subject’s task is to respond as quickly as possible whenever two identical stimuli are presented in a row. In the 150 trials, stimuli are presented at a constant rate of 1 per second. The stimulus is on screen during 50
milliseconds. The estimate d-prime (difference between hit rates and false alarms) was selected for analysis.

When compared to healthy controls, persons with schizophrenia perform approximately 1 standard deviation below average (124). The attention/vigilance deficit is commonly found in persons with schizophrenia and those who are at risk for the disorder (125). The CPT-IP has been elected as one of the most appropriate tests to evaluate endophenotypes relevant to schizophrenia (124), and has recently been included in the Measurement and Treatment Research to Improve Cognition in Schizophrenia Consensus Cognitive Battery (MCCB) (126).

3.5.3. The Trail Making Test A & B (TMT A & B)

Trail Making Test A measures speed of information processing and requires the participants to connect consecutive targets in a timed trial. Trail Making Test B requires the participants to switch between different targets in a timed trial, and in doing so monitor on-going behavior, which is regarded as an aspect of executive functioning (127). For Test A, the subject is presented a sheet of 25 randomly placed circled numbers and instructed to draw a line connecting them in a correct ascending sequence (1 to 25). For Test B, the subject is presented a sheet of 25 randomly placed circled numbers and letters, and is instructed to alternate between number and letter, numbers in an ascending sequence and letter alphabetically, when connecting the circles (1-A-2-B-3, and so forth).

3.5.4. The Wisconsin Card Sorting Test (WCST)

The Wisconsin Card Sorting Test (WCST) measures the ability to display flexibility when presenting changing schedules of reinforcement (128). The test requires the subject to match a stimulus card to one of four key cards on the basis on number, shape, or color. The present study used 64 trials and perseverative errors were selected for analysis. Scores of perseverative errors (i.e. matching to the wrong category despite correcting feedback) are generally the most sensitive to neurocognitive dysfunction (128,129). In schizophrenia, performance on WCST is markedly impaired on perseverative errors and has been correlated with both psychosocial functioning and work functioning (130-132).

3.5.5. The Letter-Number-Sequencing (LNS)

The Letter-Number-Sequencing subtest of the Wechsler Adult Intelligence Scale-III (WAIS-III) measures working memory and requires the subject to repeat sequences of letters and numbers, placing the numbers in a numerical order and the letters in alphabetical order (133). The number of digits and
letters increase by one until the participant fails three consecutive trials of the same length.

Research investigating working memory performance of persons with schizophrenia reveals impairments with significantly worse performance than healthy controls (134-136).
4. Ethical considerations

The studies followed both international and regional guidelines of informed consent. Consent was voluntary and the participants were informed about their rights to decline participation at any time with no consequences to their present or future care or treatment. The participants were not reimbursed at any time during the studies. The studies were approved by the Regional Ethical Review Board in Uppsala (registration number: 2006:085) and followed the ethical standards of the Helsinki declaration concerning Ethical Principles of Medical Research Involving Human Subjects.

All participants received individualized treatment as usual at the psychiatric rehabilitation centers. After the follow-up assessments at 21 months, participants in the control condition were offered to participate in an open trial of the IMR-program.

Previous research does not indicate any adverse effects of participation in the IMR-program. In addition, the weekly sessions enables the clinicians to respond to any negative changes in the symptoms or functioning of the participants. The assessments enable registration of both adverse and beneficial events.

The results from the studies will contribute to the evidence-base of the IMR-program in the treatment and rehabilitation of schizophrenia and schizoaffective disorder.
5. Summary of the results

5.1. Paper I. *A randomized controlled trial of the illness management and recovery program for persons with schizophrenia*

The aim of the study was to implement and evaluate the effects of the IMR program in an outpatient setting for individuals with schizophrenia and schizoaffective disorder. The study was a randomized controlled trial that compared the IMR program to treatment as usual (TAU). The study was conducted at six psychiatric outpatient rehabilitation services in the county of Uppsala, Sweden. Participants were recruited between May 2006 and May 2007.

5.1.1 Procedure

Participants were recruited from rehabilitation centers serving individuals with psychotic disorders. Inclusion criteria were a *DSM-IV* diagnosis of schizophrenia or schizoaffective disorder, proficiency in Swedish, and willingness to provide informed consent after receipt of detailed study information. A computerized random number generator was used to assign the 41 participants who completed the baseline assessment and gave informed consent to one of the six IMR program groups (N=21) or to treatment as usual (N=20).

All participants received extensive outpatient psychiatric services at the rehabilitation centers, including case management, psychiatric treatments (antipsychotic medication and psychotherapy), and access to recreational and therapeutic activities, such as social, leisure, work, and support activities. Participants in the IMR group received IMR in addition to these services.

Illness management, psychiatric symptoms, quality of life, coping, recovery, and insight were assessed at baseline, post-treatment (nine months), and follow-up (21 months). Hospitalization and suicidality were assessed at baseline and at follow-up. Participants were not reimbursed for completing assessments. Participants’ case managers, who were not blind to treatment assignment, provided ratings on the clinician version of the IMRS, and assessments of psychiatric symptoms were conducted by trained clinicians who were blind to treatment assignment.
At post-treatment (nine months after baseline) all participants completed the assessments. One participant in the IMR group left the program but completed assessments at post-treatment and at follow-up and was included in the final analysis. Thirty-eight participants completed the follow-up assessments at 21 months (19 from the IMR program and 19 from the control group). Two participants (one from each group) did not respond to a request to schedule the follow-up assessment, and one participant in the IMR group had died (see Figure 1, page 22).

5.1.2. Statistics

Baseline between-group differences in background characteristics were evaluated with chi square tests and t tests. The IMR attendance rate was calculated as the group mean of attended sessions. Relative change in outcome variables measuring illness management, psychiatric symptoms, quality of life, coping, recovery, and insight were evaluated at post-treatment and follow-up by using a linear repeated-measures mixed model with baseline data inserted as random covariates. Post hoc analyses of relative change between groups were conducted with independent t tests, with the Bonferroni correction to control for type I errors. Effect size estimates were calculated by using Cohen’s d for group mean scores from baseline to post-treatment and from baseline to follow-up. Hierarchical multiple regression analyses were conducted to investigate whether relative change in coping skills predicted or mediated relative change in psychiatric symptoms at post-treatment and at follow-up. Linear regression was used to investigate whether background characteristics predicted IMR attendance and whether IMR attendance predicted change in PECC total scores. Dichotomous data on hospitalization and suicidality from baseline to follow-up were analyzed with McNemar tests. SPSS release 18.0.1 was used for all statistical analyses.

5.1.3. Results

The IMR program participants demonstrated greater improvement compared with participants in the TAU in illness management as measured on the self-reported (p=0.001) (Figure 2) and clinician reported versions of the IMRS (p<0.001), compared with participants in the treatment as usual control condition. In addition, IMR program participants demonstrated statistically significant greater reduction in total PECC scores (p<0.001) (Figure 3), and scores on the PECC subscales for positive symptoms (p=0.02), negative symptoms (p=0.014), depression and anxiety (p=0.014), and insight (p<0.001). The results for the PECC cognitive symptoms subscale did not remain statistically significant in the post hoc analyses. Also, IMR program participants improved significantly more than participants in the treatment as usual control condition on WCQ coping factors for seeking social support...
(p=0.005), escape-avoidance (p=0.007), and planful problem solving (p=0.018), whereas coping skills associated with the WCQ self-control factor increased for participants in the control condition. Moreover, a statistically significant decrease in suicidal ideation was noted for IMR program participants between baseline and follow-up.

The relative change between baseline and post treatment in the WCQ planful problem-solving factor predicted the decrease in total PECC scores at post treatment.

No differences were observed for either of the groups between assessment points for any other WCQ factor or RAS factor, for the total MNSA scores, for the PECC mania subscale, or for hospitalization.
Figure 2. Mean scores and standard deviations on the Illness Management and Recovery Scale (IMRS) among participants in the Illness Management and Recovery (IMR) program or in treatment as usual (CONTROL) of Paper I, by assessment point.

Figure 3. Mean scores and standard deviations on the Psychosis Evaluation Tool for Common Use by Caregivers (PECC) among participants in the Illness Management and Recovery (IMR) program or in treatment as usual (CONTROL) of Paper I, by assessment point.
5.2. Paper II. *Evaluation of the illness management and recovery scale in schizophrenia and schizoaffective disorder*

The aim of the study was to evaluate the psychometric properties of the IMRS for clients with schizophrenia and schizoaffective disorder, and to conduct an item-by-item investigation to establish their utility in monitoring the clients' progress.

Data from baseline assessments of 41 participants from Paper I and from an additional 66 individuals collected at a later stage were used to evaluate the psychometric properties of the IMRS. The data were collected between May 2006 and May 2007, and during 2009.

5.2.1. Procedure

The participants' case-managers in each of the 6 rehabilitation centers were trained in the use of the IMRS and completed the clinician version of the IMRS. Case-managers were mental health workers, social workers, psychiatric nurses, or occupational therapists. The participants completed the client version of the IMRS. The procedure was repeated after 2 weeks.

Inclusion criteria were a DSM-IV diagnosis of schizophrenia or schizoaffective disorder, proficiency in Swedish and willingness to provide informed consent after receiving detailed study information. No explicit exclusion criteria were employed.

For the present study the scales were translated into Swedish, and independently back translated into English and compared with the original version to identify and correct any discrepancies.

5.2.2. Statistics

Statistical analyses were conducted to examine the internal consistency, test–retest reliability and the convergent validity of the IMRS (137). In the case of missing data in the test–retest examination, no imputations were employed. Pairwise deletion was used and cases with missing data were excluded from the specific analysis.

Internal consistency of the IMRS was examined using Cronbach's $\alpha$. Based on previous studies of the IMRS and the recommendations of Nunnally (138), an $\alpha$–value of $\geq .70$ would be satisfactory.

Test–retest reliability of the IMRS was evaluated using Pearson correlations between Time 1 and Time 2 on total scores and on individual item scores. Based on previous examinations of the IMRS it was expected that the test–retest reliability of total scores would be large ($r>.70$).
Convergent validity was evaluated by assessing Pearson correlations between the two versions of the IMRS, and between the IMRS and conceptually related validation measures, i.e. PECC, MANSA, RAS and MCSI.

In order to investigate convergent validity between the two versions of the IMRS, correlations between the total scores and individual item scores were computed at Time 1 and Time 2. It was expected that moderate (0.40–0.69) correlations would be found between total scores of the two versions. Small (0.00–0.39) to moderate (0.40–0.69) correlations were expected for individual item scores (139).

Correlations were computed between total scores of the IMRS and total scores of the PECC, MCSI, RAS, and MANSA. Correlations between total scores of the IMRS and subscale scores of the PECC were also investigated. Finally, correlations between individual item scores of the IMRS and total scores of the PECC, MCSI, RAS, and MANSA were computed. Based on previous studies (104,105) of the IMRS, small (0.00–0.39) to moderate (0.40–0.69) correlations were expected between the conceptually related validation measures and ratings of the IMRS.

Table 4.
Correlations between the IMRS total scores and conceptually related validation measures with descriptive statistics of the validation measures.

<table>
<thead>
<tr>
<th>Measure</th>
<th>M (SD)</th>
<th>IMRS Client</th>
<th>IMRS Clinician</th>
</tr>
</thead>
<tbody>
<tr>
<td>PECC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50.80 (14.83)</td>
<td>-.51**</td>
<td>-.57*</td>
</tr>
<tr>
<td>Positive symptoms</td>
<td>8.09 (3.73)</td>
<td>-.32*</td>
<td>-.56*</td>
</tr>
<tr>
<td>Negative symptoms</td>
<td>12.39 (4.81)</td>
<td>-.38*</td>
<td>-.19</td>
</tr>
<tr>
<td>Depression-anxiety</td>
<td>12.02 (5.70)</td>
<td>-.40*</td>
<td>-.22</td>
</tr>
<tr>
<td>Mania</td>
<td>7.56 (3.83)</td>
<td>-.25*</td>
<td>-.37*</td>
</tr>
<tr>
<td>Cognitive symptoms</td>
<td>10.73 (3.91)</td>
<td>-.36*</td>
<td>-.21</td>
</tr>
<tr>
<td>Insight</td>
<td>4.49 (1.40)</td>
<td>-.26</td>
<td>-.39*</td>
</tr>
<tr>
<td>Suicidality</td>
<td>1.27 (0.59)</td>
<td>-.35*</td>
<td>-.13</td>
</tr>
<tr>
<td>MCSI</td>
<td>53.11 (12.06)</td>
<td>-.17</td>
<td>-.20</td>
</tr>
<tr>
<td>RAS</td>
<td>144.75 (20.10)</td>
<td>.22*</td>
<td>.16</td>
</tr>
<tr>
<td>MANSA</td>
<td>47.86 (11.16)</td>
<td>.37**</td>
<td>.20</td>
</tr>
</tbody>
</table>

PECC subscale scores of positive symptoms, negative symptoms, depression and anxiety, mania, and cognitive symptoms (range 4-28), insight (range 2-8) and suicidality (range 1-4) with higher scores indicating higher symptom severity. MCSI total scores range between 14 and 70 with higher scores indicating higher symptoms severity. RAS total scores range between 41 and 205 with higher scores indicating more positive perception of recovery. MANSA total score range between 12 and 84 with higher scores indicating higher quality of life. *p<0.05; **p<0.01, two-tailed.
5.2.3. Results

Both versions of the IMRS demonstrated satisfactory internal consistency (the client version of the IMRS had Cronbach’s α = .73-.83, and the clinician version of the IMRS had Cronbach’s α = .70-.71). Large correlations (r=0.84-0.88; p<0.05) of test-retest reliability on total scores for both versions of the scale, and moderate to large correlations (r=0.54-1.0; p<0.05) of test-retest reliability on individual item scores were found. Pearson correlations between total scores of the client and clinician versions of the IMRS demonstrated statistically significant correlations at both the initial test and the retest (r=0.56 and 0.58; p<0.05). Small to large correlations (r=0.34-0.89; p<0.05) for several individual items were also found.

The client version of the IMRS demonstrated convergent correlations with total PECC scores (r=-0.51; p<0.01), and subscale scores for positive symptoms (r=-0.32; p<0.05), negative symptoms (r=-0.32; p<0.05), depression and anxiety (r=-0.40; p<0.05), cognitive symptoms (r=-0.36; p<0.05), and suicidality (r=-0.35; p<0.05). The client version of the IMRS also showed convergent correlations with the RAS (r=0.22; p<0.05), and the MANSA (r=0.37; p<0.01).

The clinician version of the IMRS demonstrated convergent correlations with total PECC scores (r=-0.57; p<0.05), and subscale scores for positive symptoms (r=-0.56; p<0.05), mania (r=-0.37; p<0.05), and insight (r=-0.39; p<0.05).

5.3. Paper III. Neurocognitive functioning and outcome of the Illness Management and Recovery program for clients with schizophrenia and schizoaffective disorder

Although a range of teaching methods are used to facilitate learning and information processing in the IMR program, little is known about the association between client neurocognitive impairment and the proximal outcomes of improved illness self-management in the program. This study evaluated the association between neurocognitive functioning and outcome in Paper I and Paper IV. Neurocognitive functioning was assessed at baseline and post-treatment.

5.3.1. Procedure

Between 2006 and 2009, a total of 53 participants with a DSM-IV diagnosis of schizophrenia or schizoaffective disorder were recruited at 6 psychiatric outpatient rehabilitation centers serving people with psychotic disorder in Uppsala, Sweden. Inclusion criteria other than the specified diagnoses were
proficiency in Swedish and willingness to provide informed consent after receipt of detailed study information. Exclusion criteria were disabling conditions that would interfere with treatment, and absent or incomplete baseline assessments. Between May 2006 and March 2010 the participants completed the IMR program. The mean age at baseline was 41.46 years (SD=7.56). Most participants were male (57%), born in Sweden (70%), living alone (87%), unemployed (66%), had at least 9 years of education (62%), had a primary diagnosis of schizophrenia (87%), and had a mean duration of illness of 14.8 years (SD=8.12).

All participants completed a computerized neurocognitive battery of tests, at baseline and at post-treatment (after completing the IMR program).

5.3.2. Statistics
The statistical analyses were conducted in three stages. First, in order to evaluate changes in, and stability of neurocognitive functioning, paired t-tests for baseline and post-treatment scores of each neurocognitive measure were computed, followed by computing Pearson correlations between the two assessments. Because no improvements in neurocognitive functioning were found, and the two assessments were found to be reliable, means of the baseline and post-treatment scores were computed for each neurocognitive measure for subsequent analyses. Second, the contribution of neurocognitive functioning to improvements in IMRS scores was evaluated by performing linear regression models with post-treatment IMRS scores as the dependent variables, pre-treatment IMRS scores entered in the first block of predictor variables, and then the average neurocognitive scores entered as a second block of predictors. For these analyses, the effect of each neurocognitive variable is a test of whether it predicted post-treatment IMRS scores, controlling for baseline level of those scores. Finally, in order to control for the possible effects of medication and psychiatric symptoms on changes in IMRS scores, similar linear regression analyses were performed, with pre-treatment IMRS scores entered as the first block of predictors, the DDDs and total PECC scores entered as a second block, and then the neurocognitive variables entered as a third block.

5.3.3. Results
No statistically significant changes from baseline to post-treatment were found on any of the neurocognitive measures, indicating there were no changes in cognitive functioning over the course of the IMR program. The Pearson correlations between the two neurocognitive assessments were all significant and in the moderate to high range (r=.40-.89, p<.01), indicating good reliability over time. As there were no changes over time in neurocognitive functioning and test scores were highly correlated over the two as-
sessments, mean scores for each neurocognitive measure were computed for the subsequent analyses.

Speed of processing (TMTA) was the only neurocognitive measure associated with improvements in the client version of the IMRS (std\( \beta = .28, p<.05 \)), explaining 8% of the variance beyond that associated with baseline scores of the IMRS only (\( R^2 = .08; F[2,51]=8.13, p=.001 \)). This relationship remained significant when baseline medication and psychiatric symptoms were included in the model (std\( \beta = .32, p<.05 \)).

None of the neurocognitive measures predicted improvement in clinician ratings of the IMRS, including when baseline medication and psychiatric symptoms were inserted into the statistical model.

5.4. Paper IV. Symptom severity and outcome of the illness management and recovery program for schizophrenia and schizoaffective disorder

It is not known whether participation in the IMR program is associated with more frequent symptomatic remission among participants. Also, it remains largely unknown whether participants meeting the severity criterion of symptomatic remission experience greater improvement in other outcomes (illness self-management, coping, subjective quality of life, perception of recovery, and drug side effects) of the IMR program compared to participants not meeting the criterion.

The aim of the study was to explore the outcome of the IMR program with regard to the severity criterion of symptomatic remission in participants of Paper I and an additional sample of the same population.

5.4.1. Procedure

Between May 2006 and March 2010, a total of 52 participants with a DSM-IV diagnosis of schizophrenia or schizoaffective disorder completed the IMR program. 32 participants from the IMR group and the treatment as usual control condition of Paper I, and an additional 20 participants recruited during 2008–2009 were included in the study. The participants were recruited at 6 psychiatric outpatient rehabilitation centers serving people with psychotic disorder in Uppsala, Sweden. Inclusion criteria other than the specified diagnoses were proficiency in Swedish and willingness to provide informed consent after receipt of detailed study information. Exclusion criteria were disabling conditions that would interfere with treatment, and absent or incomplete baseline assessments. The mean age at baseline was 41.46 years (SD=7.56). Most participants were male (57%), born in Sweden (70%), living alone (87%), were unemployed (66%), had at least 9 years of education
(62%), and had a primary diagnosis of schizophrenia (87%) and with a mean duration of illness of 14.8 years (SD=8.12).

All participants received extensive outpatient psychiatric services at the rehabilitation centers, including case management, psychiatric treatments (antipsychotic medication and psychotherapy), and access to recreational and therapeutic activities, such as social, leisure, work, and support activities. Participants in the IMR group received IMR in addition to these services.

Illness management, psychiatric symptoms, quality of life, coping, recovery, and insight were assessed at baseline and at post-treatment (9 months). Participants were not reimbursed for completing assessments. Participants’ case managers provided ratings on the clinician version of the IMR scale, and trained clinicians conducted assessments of psychiatric symptoms.

5.4.2. Statistics

Differences in the frequency of participants reaching the severity criterion of remission at post-treatment (9 months), and at follow-up (21 months), were investigated in the participants of Paper I using Fisher’s exact test. McNemar tests were also used to examine possible baseline to post-treatment change in the frequency of participants meeting the severity criterion of the schizophrenia core symptoms, in all 52 participants.

Baseline to post-treatment change in total psychiatric symptoms, medication side effects, client and clinician ratings of illness self-management, coping skills, perception on recovery, and subjective quality of life, was analyzed with paired t-tests. For each measure a within-group effect size with pooled standard deviations was calculated.

In order to investigate a possibly different impact of the IMR program on participants meeting or not meeting the severity criterion at post-treatment, and in order to enable direct comparisons, outcomes of the IMR program were categorized into ‘Yes’ and ‘No’ columns. Baseline to post-treatment change, and effect sizes were calculated for these categories.

5.4.3. Results

In Paper I, there were no difference between the groups at baseline (Fisher’s exact test, p=.238). At post-treatment (9 months), significantly more participants were reaching the severity criterion in the IMR group (50%) compared to the control group (11%) (Fisher’s exact test, p=.019). At follow-up (21 months), the difference between the groups was maintained (IMR, 42%, and Control, 5%; Fischer’s exact test, p=.014).

In Paper IV, 9 (17%) of the 52 participants met the severity criterion at baseline. Out of these, 8 participants also met the severity criterion at post-treatment, and in doing so, meeting both the severity and time criteria of symptomatic remission. At post-treatment, the number of participants meet-
ing the severity criterion was increased to 17 (32%). This increase was statistically significant (McNemar test, p<.05).

At post-treatment the results of the total sample demonstrated statistically significantly decreases in psychiatric symptoms (PECC total scores: \(t[1,51]=4.62, d=.72, p<.01\)), improvements in self-reported and clinician reported illness self-management (IMRS client: \(t[1,51]=4.36, d=.65, p<.01\); IMRS clinician: \(t[1,51]=5.02, d=.79, p<.01\)), and better satisfaction with life (MANSA: \(t[1,51]=3.10, d=.39, p<.01\)).

At post-treatment, participants who met the severity criterion showed a decrease in psychiatric symptoms (PECC general scores: \(t[1,51]=3.97, d=.86, p<.01\)), and improvements in self-reported and clinician reported illness self-management (IMRS client: \(t[1,51]=-3.00, d=-.59, p<.01\); IMRS clinician: \(t[1,51]=-2.40, d=-.78, p<.05\)). Participants who did not meet the severity criterion also demonstrated a decrease in psychiatric symptoms (PECC total scores: \(t[1,51]=6.01, d=.82, p<.01\)), and improved illness self-management (IMRS client: \(t[1,51]=-3.22, d=-.64, p<.01\); IMRS clinician: \(t[1,51]=-4.32, d=-.78, p<.01\)). In addition, they reported significantly greater satisfaction with life (MANSA: \(t[1,51]=-2.67, d=-.39, p<.05\)), and improved self-rated problem solving skills (WCQ problem solving: \(t[1,51]=-2.19, d=-.63, p<.05\)), at post-treatment compared to baseline assessments.
6. Discussion

The general findings support the IMR program to be effective in improving the ability of the participants to manage their disorder. The impact of neurocognitive dysfunction on the participants’ ability to learn the fundamentals of illness self-management seems to be limited, and symptom severity did not limit the benefits of the IMR program. Support for the utility of the IMRS to monitor the participants’ progress in the program was also found.

6.1. General strengths and limitations

The IMR program was evaluated in a setting that provides a broad range of psychiatric treatments and support for individuals with schizophrenia, and the findings may generalize well to other settings serving this population. The study design was rigorous and stringent with randomization, blinded ratings, and intention to treat statistical analyses.

The present sample was based on convenience and most participants were men in their forties with a duration of illness of almost fifteen years. It remains unknown whether similar findings apply to clients with a shorter duration of illness or those who are in a more acute phase of the illness. Therefore, the results may only be clinically relevant to a selected sample of this population.

6.1.1. Sample selection and attrition

The attrition rate was surprisingly low in the sample of Paper I and Paper IV. No participants were lost at post-treatment assessments of Paper I, and one participant of Paper IV refused to complete post-treatment assessments. At the 21 months follow-up of Paper I, three participants did not complete the assessments. One participant from each group did not respond to a request to schedule for the assessments, and one participant in the IMR group had died of natural causes.

Studies have reported attrition rates of 25-50% in samples with severe mental illness (140,141). Although the research literature is inconclusive about factors influencing attrition rate, young age and neurocognition have been suggested as client factors contributing to program dropout (142,143).
Age may have contributed to the low attrition rate since most participants were in their forties with a long duration of illness. Longitudinal studies have documented that a significant proportion of clients with schizophrenia make substantial improvement in their illness over time (92). This may be suggested by the low hospitalization rates prior to and after the randomized trial, indicating that the sample of the present investigations was well stabilized. Compromised neurocognition has also been linked to higher attrition (143), but because of the almost non-existent attrition rate in the present sample it was not possible to investigate neurocognitive contribution to dropout.

Client factors such as age, neurocognitive dysfunction, and low hospitalization rates may come short of explaining the few dropouts in the present sample. The recruitment process may have introduced a selection bias working in favor of participation in psychosocial programs. It is possible that the recruitment process and the informed consent procedure excluded clients who were reluctant to participation or who were lacking in motivation, or who experienced more severe symptoms or functional impairments. However, setting and pursuing personally meaningful goals is one program factor of the IMR that is thought to provide much of the motivation for learning and using the information and strategies taught. Progress towards personal recovery goals may also provide motivation for completing the program. Although previous studies of the IMR program have not provided sufficient information on attrition to draw any conclusions, it is possible that the IMR program is successful in improving motivation and adherence to the program. Also, anecdotal information from the present trials revealed that several clinicians were surprised by the high adherence of some of the clients, because the very same clients had never completed a program, let alone a comprehensive curriculum, prior to entering the IMR program.

6.1.2. Fidelity

Fidelity refers to the degree to which a particular evidence-based psychosocial program adhere to a program model, that is, a well-defined procedure to achieve specific goals (144). Since most evidence-based psychosocial programs are complex and may be challenging to implement without preexisting structure and support, fidelity measures are used to assess the adequacy of the implementation (14).

The IMR fidelity scale includes 13 items rated on 5-point Likert scales. The IMR fidelity scale covers ratings of 1-Number of people in a group, 2-Program length, 3-Comprehensiveness of the curriculum, 4-Provision of educational handouts, 5-Involvement of significant others, 6-IMR goal setting, 7-IMR goal follow-up, 8-Motivation-based strategies, 9-Educational techniques, 10-Cognitive-behavioral techniques, 11-Coping skills training, 12-Relapse prevention training, 13-Behavioral tailoring for medication. The
scale also provides information of data source (chart-review, IMR-group leader, client or significant other).

In the present study, the clinician filled out a chart of in-session IMR-teaching principles, goal setting and goal follow-up, and client homework assignments, after each session. ‘Char-reviews’ were then used during supervision in order to assess fidelity and in order to enable corrective feedback to the clinicians. It remains unclear whether this procedure was effective in ensuring that the clinicians adhered to the program guidelines. Since there were no independent raters involved in the present study (because the current study was the first implementation initiative of the IMR program in Sweden, there were no professionals experienced in the program model), these reviews were not quantified according to the fidelity scale. Independent raters using the IMR fidelity scale would have been preferred for objective assessment of fidelity.

6.1.3. Treatment as usual control condition

The randomized controlled trial of Paper I used a treatment as usual control condition (TAU). In theory TAU denotes what would be the expected outcome for a specific group had the evaluated intervention not been implemented (145). In practice, however, TAU comprises an active set of treatments (in contrast to waitlist control conditions or placebo), and its variability (i.e. diversity and quality of treatments included, change over time, and its research and cultural context) may have unforeseeable consequences for the outcomes of effectiveness studies (146,147). According to Burns (148) the problem lies in thinking about TAU as a control condition at all, not just its inadequate characterization. If well characterized, TAU ceases to be treatment-as-usual and turns into a specific treatment to which the evaluated intervention is compared.

Although including extensive outpatient psychiatric services at the rehabilitation centers (including case management, psychiatric treatments (anti-psychotic medication and cognitive-behavioral psychotherapy), and access to recreational and therapeutic activities, such as social, leisure, work, and support activities), it is not possible to tell the quality and frequency of the treatments included in the TAU of Paper I. However, in complying with the preconditions of ethical trials, participants of the IMR group received IMR in addition to the outpatient psychiatric services, which implicate that IMR was compared to participants not receiving IMR rather than being compared to TAU. In effect this design is similar to one of a waitlist control, in which we would expect no change in the preconditions of the groups. This may in turn introduce non-specific effects of factors such as the IMR group meeting approximately one hour each week, which the control group did not.
6.2. Paper I. A randomized controlled trial of the illness management and recovery program for persons with schizophrenia

Paper I describes the first randomized controlled trial of the IMR program delivered exclusively to individuals with schizophrenia and schizoaffective disorder, and the first IMR study conducted in Sweden. The general pattern of the results supports previous research of the program (10-13), and suggests that the IMR program is effective in improving the ability of individuals with schizophrenia and schizoaffective disorder to better manage their illness.

IMR program participants showed significant improvements in illness management as indicated by self-report measures and non-blinded clinician ratings. In addition, assessments by interviewers blind to treatment assignment indicated significant improvements in overall psychiatric symptoms, positive symptoms, negative symptoms, and depression-anxiety as well as improved insight over time among IMR program participants compared with participants in treatment as usual. Participants in the IMR program also had less suicidal ideation at follow-up. This is an important finding because individuals with schizophrenia have a 12-fold higher risk of dying from suicide than persons in the general population (149). Statistically significant improvements favoring the IMR program were found for self-reported and clinician reported IMRS ratings, and self-reported ratings of coping skills in regard to seeking social support, planful problem-solving, and escape and avoidance. Contrary to previous research, no statistically significant differences were found in quality of life and perception of recovery. Insufficient statistical power is one possible explanation.

Improvements that continued beyond the completion of the program was found for coping skills, illness management, and positive symptoms, which may suggest that participation in the program leads to improvements over time and that long-term follow-up is necessary to better understand the full impact of the IMR program.

The study design employed a treatment as usual control condition, and although both groups received extensive outpatient psychiatric services, improvements in the IMR group may have resulted from nonspecific effects. Also, the non-blinded clinician ratings may have introduced bias in favor of the IMR group.

After each session the clinician filled out a chart of what IMR-teaching principles they employed during the session. ‘Char-reviews’ were used during supervision in order to assess fidelity and in order to enable corrective feedback to the clinicians. It remains unclear whether this procedure was effective in ensuring that the clinicians adhered to the program guidelines. Independent raters using the IMR fidelity scale would have been preferred for objective assessment of fidelity.
6.3. Paper II. *Evaluation of the illness management and recovery scale in schizophrenia and schizoaffective disorder*

The results of the second study provide support for the reliability and validity of the IMRS as a measure of illness self-management in schizophrenia and schizoaffective disorder. Both the client and clinician versions of the IMRS demonstrated satisfactory internal consistency and large test-retest reliability on total scores of the scale, and moderate to large test-retest reliability on individual items.

High client ratings of the IMRS total scores were associated with lower overall interview-based ratings of psychiatric symptoms, positive symptoms, negative symptoms, depression and anxiety, and suicidality, as well as higher self-rated perception of recovery and quality of life. High clinician ratings of the IMRS total scores were also associated with less severe overall psychiatric symptoms and positive symptoms. The two versions of the scale seem to capture different aspects of psychiatric symptoms, where the clinician version is associated with symptoms that may be more apparent to others (i.e. positive and negative symptoms, symptoms of mania, and insight) and therefore easier to assess, whereas the client version is associated with symptoms that may be more subjective in nature (depression and anxiety, cognitive symptoms, and suicidality). This discrepancy underscores the importance of using both versions of the scale in order to more fully capture the impact of distressing symptoms and impaired functioning of the disorders.

The internal consistency and convergent validity of the IMRS indicate that it is related to what it theoretically intended to measure.

6.4. Paper III. *Neurocognitive functioning and outcome of the illness management and recovery program for clients with schizophrenia and schizoaffective disorder*

The third study is the first to investigate the associations between neurocognitive functioning and improvements in illness self-management in participants in the IMR program. Speed of processing was the only neurocognitive measure related to outcome on the client version of the IMRS. This association was not reduced when psychiatric symptoms and medication were included in the statistical models. However, none of the neurocognitive measures were associated with outcome on the clinician version of the IMRS.

The results showing that speed of information processing was associated with less improvement in clients’ perception of change on the IMRS are somewhat consistent with previous research that has found speed of processing to be a predictor of psychosocial outcome in schizophrenia (150).
Concurrent prediction of psychosocial functioning from speed of processing has also been demonstrated (63,151).

None of the neurocognitive measures were related to clinician ratings of the IMRS. Clinician rated assessments have previously been associated with more objective measures such as neurocognitive functioning, in contrast to client ratings that tend to be associated with measures of subjective outcome (152). If improvements in both versions of the IMRS had been related to speed of processing, it might have suggested that speed of processing moderated the acquisition of illness self-management skills in the IMR program. However, the finding that speed of processing was related to improvements in only the client version of the IMRS suggests that clients with impaired speed of processing may not fully appreciate their own gains in skills compared to clinician evaluations of their skills. This could underscore the importance of clinicians providing reinforcement and encouragement to clients with impaired information processing, who may be less aware of their improvements in skill over the course of IMR.

What appears to be a practice effect in Wisconsin Card Sorting Test has been demonstrated in one 16-week test-retest trial of WCST, in which persons with schizophrenia were compared to healthy controls (153). In the present study, there were 40 weeks between assessment points and no systematic improvements or deteriorations of the preservation error scores were observed.

6.5. Paper IV. Symptom severity and outcome of the illness management and recovery program for schizophrenia and schizoaffective disorder

The results of the fourth study suggest that significantly more participants met the severity criterion at post-treatment. Improvements in general psychopathology, self-rated and clinician rated illness self-management, and subjective satisfaction with life, were found for the total sample. Although demonstrating significantly higher levels of general psychopathology compared to participants meeting the severity criterion, it appears that participants not meeting the severity criterion at post-treatment also benefited from the IMR program, as indicated by the similar effect sizes of the two groups.

For at least two variables, post-hoc power analysis revealed inadequate sample size for the participants meeting the severity criterion at post-treatment, resulting in an increased probability of failing to reject the null hypothesis for the MANS (44%), and the WCQ escape-avoidance coping factor (36%). The explorative nature of the present study did not allow for a priori power or sample size calculations; however, a substantial number of participants (32%) met the severity criterion at post-treatment, which may provide an estimate for future research.
7. Future research

Based on the results of the present thesis directions for future research may be proposed. First, although several studies have demonstrated benefits of the IMR program to reduce psychopathology, little is known of the effects on relapse and hospitalization. So far, the participants of controlled studies have been well stabilized with low rates of relapse and readmission. Indications of reduced hospitalizations have been suggested (154), but have yet to be demonstrated experimentally. In future evaluations of the IMR program, it would make most sense to focus on people with a recent relapse and hospitalization as recent admissions increase the risk of subsequent ones (155).

Second, adjunctive cognitive remediation therapy may be a promising intervention to facilitate the acquisition of illness self-management skills in the IMR program, especially for participants with neurocognitive dysfunctioning (156). The results of two meta-analyses indicate that adding cognitive remediation to other rehabilitation programs is associated with significantly greater improvements in psychosocial functioning than when cognitive remediation is evaluated as a stand-alone intervention (157,158). Such an application may also provide opportunities to more closely examine the associations between neurocognitive functioning and illness self-management skills acquisition. Future investigations could also examine the effects of more intensive IMR programming on neurocognitive functioning and psychosocial functioning. Finally, during the course of the present program anecdotal information regarding increased job satisfaction was reported among clinician participating as IMR group leaders. Also, several clinicians expressed an increased sense of hope and expectations for the clients’ future when working collaboratively in a recovery-oriented program. Future investigations of the IMR program could examine changes in job satisfaction and attitudes towards clients in clinician participating as IMR group leaders.
8. Conclusions

1. The general findings support the IMR program to be effective in improving the ability of the participants with schizophrenia or schizoaffective disorder to manage their illness.

2. Compared to a treatment as usual control condition, participants in the IMR program demonstrated improvements in psychopathology and psychosocial functioning.

3. The brevity of the scale, and its ability to capture the perspective of both clients and clinicians provide support for the utility of the IMRS to evaluate Illness Management and Recovery of clients with schizophrenia and schizoaffective disorder.

4. Illness self-management skills acquisition may be related to impairments in speed of processing. However, as indicated by the effects of the clinician ratings, this relationship may reflect the clients’ appraisal of their own gains in illness self-management, rather than skills acquisition per se.

5. Significantly more participants meet the severity criterion of symptomatic remission after completing the IMR program. Also, it appears that participants not meeting the severity criterion at post-treatment benefit as much from the IMR program, as those who meet the criterion.
Sammanfattning på svenska

Bakgrund

Illness Management and Recovery (IMR) programmet syftar till att hjälpa personer med svår psykisk sjukdom att identifiera och eftersträva personligt meningsfulla återhämtningsmål och därigenom minska de negativa effekterna av respektive sjukdom. För att öka deltagarens möjligheter att nå sina återhämtningsmål tränas strategier och färdigheter under programmens gång (eng. illness management). De strategier och färdigheter som lärs ut och tränas har forskningsstöd och inkluderar psykoedukation (fakta om psykisk sjukdom och behandlingsstrategier), social färdighetsträning, att använda läkemedel effektivt, återfallsprevention, samt copingstrategier för symtom och stress. IMR har utvecklats för schizofreni, schizoaffectiv sjukdom och bipolär sjukdom samt depression.

IMR är manualbaserat och genomförs individuellt eller i grupp under ca 40 sessioner. Sessionerna leds av utbildade kliniker som är där för att hjälpa deltagaren att utveckla en individuell återhämtningsplan och skräddarsy strategier för att möta den enskildes behov och målsättningar. Under sessionerna samarbetar kliniker och deltagare genom att gå igenom materialet, formulera och följa upp mål samt välja lämpliga hemuppgifter.

Syfte

Syftet med föreliggande avhandlingsarbete var att undersöka IMR programmets effekter av att lära klienter att bättre hantera negativa konsekvenser av schizofreni eller schizoaffectiv sjukdom och att främja återhämtning. Detta åstadkoms genom en utvärdering av IMR programmens inverkan på psykosocial funktion och psykiatriska symtom, en undersökning av specifik och generell påverkan av kognitiva svårigheter vad gäller deltagarnas möjligheter att lära in grundläggande strategier och färdigheter, samt en undersökning av huruvida schizofrenisymtomens svårighetsgrad inverkar på deltagarnas möjligheter att tillgodogöra sig programinnehållet. Vidare undersöktes Illness Management and Recovery Skalans (IMRS) användbarhet för att utvärdera sjukdomshantering och återhämtning hos personer med schizofreni eller schizoaffectiv sjukdom.
Resultat

IMR programmets effekter utvärderades genom en randomiserad kontrollrad studie i vilken 41 programdeltagare jämfördes med deltagare i kontrollgrupp vilka fick enbart sedvanlig psykiatrisk behandling. Deltagarna rekryterades vid sex subspecialiserade psykiatriska öppenvårdsmottagningar och slumpades till att antingen delta i IMR programmet eller kontrollgruppen. IMR programmets deltagare uppvisade förbättringar i sjukdomshantering, minskade psykiatriska symtom, förbättrade coping-färdigheter samt minskade självmordsbeteenden jämfört med kontrollgruppen. Resultaten stöder antagandet att IMR programmet är effektivt vad gäller att förbättra deltagarnas förmåga att hantera negativa effekter av schizofreni och schizoaffektiv sjukdom.

Möjliga associationer mellan kognitiva svårigheter och förmågan att tillämpa sig färdigheter för sjukdomshantering undersöks hos 53 deltagare som genomförde IMR programmet. Resultaten pekar på att kognitiva svårigheter inte inverkar på deltagarnas möjligheter att lära sig färdigheter och strategier enligt IMR modellen. Processhastighet var relaterad till klientrapporterad sjukdomshantering (illness management) men inte till klinikkrapporterad sjukdomshantering. Processhastighet tycks vara relevant för klientens upplevelse av hur väl han eller hon tillägnat sig programmets strategier och färdigheter, snarare än sjukdomshantering per se.

Huruvida schizofrenisymtomens svårighetsgrad inverkar på utfallet av IMR programmet undersöks hos 52 deltagare som genomförde IMR programmet. Remission av schizofrenisymtom inkluderar ett svårighetsgradskriterium (ingen eller mild inverkan av kärnsymtom på deltagarens mående och funktion) samt ett durationskriterium (svårighetsgradskriteriet är uppfyllt under 6 månader eller längre). Resultaten pekar på att signifikant fler deltagare uppfyllde svårighetsgradskriteriet efter genomfört IMR program. Även deltagare som inte uppfyllde svårighetsgradskriteriet hade nytta av IMR programmet något som indikerar av de båda gruppernas (uppfyllde jämfört med uppfyllde inte svårighetsgradskriteriet) likartade effektstorlekar för respektive utfallsmått.

Avhandlingsarbetets resultat stöder antagandet att IMR programmet är effektivt vad gäller att förbättra deltagarnas förmåga att hantera de negativa effekterna av schizofreni och schizoaффektiv sjukdom. Kognitiva svårigheter inverkar i begränsad utsträckning på deltagarnas möjligheter att lära sig sjukdomshantering och schizofrenisyptomens svårighetsgrad tycks ha begränsad inverkan på programutfallet. Resultaten stöder även antagandet att IMRS är ett användbart instrument för att utvärdera sjukdomskontroll och återhämtning för personer med schizofreni eller schizoaффektiv sjukdom, vilket erbjuder en kortfattad och ekonomisk metod att utvärdera effekterna av IMR.
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A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine.