E-HEALTH AND SEVERE MENTAL ILLNESS: A PAINSTAKING PROCESS

e-health added to the Illness Management and Recovery Program

Titus Beentjes

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For reasons of consistency within this thesis some terms and language issues have been standardised throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

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Verraadt
ons aller angst
zich niet
in wie het leven
weerloos liet?
De glasglans
stemt de
blazer mild.
De kaarsvlam
vormt de
hand tot schild.
De krokus wijst
beton zijn grens.
Hoe kostbaar is
een kwetsbaar
mens.

Okke Jager

Is not
our own anxiety
revealed
in life's frailty?
The glass-gloss
brings solace to
the blower.
The candle flame
turns the hand
into a shield.
The crocus shows
concrete its limits.
How precious then
a vulnerable
human being.

(Free translation)

Chapter 1.

General Introduction

Severe Mental Illness

In the Netherlands approximately 160.000 individuals, 1,5% of the adult population, fit the criteria of a severe (or serious) mental illness SMI (1). Having an SMI is not defined by a specific mental illness, but by its duration and disabilities. According to the Dutch definition, persons with SMI have a mental illness, which lasts longer than at least a couple of years, which causes—and is due to—serious impairments in social and/or occupational functioning, and necessitates coordinated multi-disciplinary care (1). Persons with a SMI have gone (or are going) through devastating unfathomable experiences. They lose grip on the their life and enter a totally foreign world of mental illness, unable to make sense of what is happening to them, in fear of a relapse, often isolated, and without hope for the future. As an extra circumstance, people with SMI have to deal with stigma and consequently experience prejudice and discrimination (2), often resulting in self-stigma and the phenomenon of 'why-try': thus being dissuaded from pursuing life-goals (3).

Recovery

In the Netherlands, as well as in other parts of the world, the care for and treatment of people with SMI are mostly provided in ambulant treatment facilities, such as flexible assertive community teams, outpatient clinics, and supported housing. This differs totally from the time of the seventies of the previous century. At that time, people with SMI depend on institutions far away from city centres. In the 1960's and 1970's a tendency started to reduce the number of beds within these institutions (4). This tendency is still proceeding (5). Because of this trend of de-hospitalisation a growing number of persons with SMI could no longer rely on the constant presence and support of professionals, which led to the increase of community support systems, supported housing and ambulant treatment facilities (4). In the 1980's the practice of rehabilitation came up which laid the foundation for the concept of recovery. In 1993, William Anthony defines recovery as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (4).

Recovery is about living or learning to live with disruptive conditions, disabilities, and vulnerabilities (6). The treatment focus shifted from the illness and severity of symptoms towards living a meaningful life, in favour of human dignity and having the right to make your own mistakes. The CHIME-framework identified five key recovery processes as Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment (CHIME) (7). The concept of empowerment in recovery implies discovering one's strength and ability to wrestle out of the hopelessness and giving life a new turn, with all the challenges, making your own choices and mistakes, and act accordingly with the support that is needed. This is all based on one's life story full of experiential knowledge. People know themselves what is best for them and what kind of support is needed (6). Recovery can enhance outcomes of feeling healthy, changing one's identity from 'patient' into 'citizenship', and having a valuable social role in society (8).

To measure the level of recovery, various outcome measures have been developed over the years. One of them is the Mental Health Recovery Measure (MHRM) (9), which refers to the concepts of self-empowerment, learning and new-potentials, and spirituality. However, it is stated that recovery must not be seen as an outcome, but as a personal process (4,6). In order to support this process, the recovery-oriented professional is present, listens actively, uses his expert knowledge modestly, reacts personally with a transparent attitude, recognizes and makes use of the strength of the person with SMI and their social network, and aims for decrease of suffering and increase of autonomy (10). In the Netherlands the recovery movement was introduced in the early 1990's by the Foundation for Rehabilitation '92 (11).

Illness self-management

Not only in mental health, also in general health this tendency of de-hospitalisation is taking place. In the Netherland, between 1972 and 2007, the number of general hospital beds decreased considerably (12). Hospitals are no longer a place to recover fully from an illness or a treatment such as surgery (12). As a result of better treatments in general health care, the life expectancy grew (13). Because of a longer life expectancy, illnesses became chronic and the challenge to manage the illness and its consequences increased. In reaction to this, the term self-management was introduced in the 1990's, as one of the four major components in Wagner's et al. Chronic Care Model, which puts the patient in a central position in the healthcare process (14).

Trappenburg et al. looks at the concept of self-management from three perspectives (15). In the first perspective self-management is viewed as a paradigm shift from a paternalistic model to a participatory model. Shared decision-making takes a new role in the process of putting personal needs more central instead of what professionals think that they need to provide. In the second, self-management is perceived as an ability. The definition of health changes from "not being ill" into health as an ability to adapt and to self-manage (16). Barlow defines self-management as a dynamic and continuous process of self-regulation that refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (13). From the third angle, self-management is an intervention or treatment in which professionals teach persons how and when to make use of the self-management abilities. To these three perspectives, a fourth can be added: self-management as an outcome and an instrument to measure the effectiveness of a self-management intervention. Such a measure is the Patient Activation Measure referring to the individual's knowledge, skills, and confidence for managing one's health and health care (17).

Debra de Silva describes the concept of self-management support, which means providing information and encouragement to help individuals in maintaining greater control through understanding their condition, and thus becoming able to monitor and act appropriately (18). The need for self-management support is present when an individual feels the need for support related to the necessity of performing a self-management task (19,20). Van Houtum et al. discovered that the extent of self-management support needs is significantly related to whether individuals perceive the chronic illness as episodic and/or progressively deteriorating (20). Since SMIs are episodic and often deteriorating (4,21–24), we assume that the extent of the self-management support needs of persons with an SMI is considerable. The nature of self-management support needs of persons with SMI is not yet investigated.

The Illness Management and Recovery program

There is a relation between recovery and self-management. Slade describes that promoting self-management can provide a vital resource for supporting recovery (25). The two concepts of self-management and recovery come together in the complementary intervention Illness Management and Recovery program (IMR) for people with SMI. Various mental health recovery program models and procedures have been developed over the last decades. Mostly they focus on choosing, getting or keeping a specific valued role (26). A number of interventions, like the IMR, combine the recovery values of person orientation, partnership, self-determination, and hope with the concept of self-management focussing on the reduction of symptoms and the effects of the illness itself (26). In the early 2000's Kim Mueser and Susan Gringerich developed the IMR, grounded on the evidence based treatment strategies of psycho-education, cognitive behavioural approach, relapse prevention, social skills and coping skills training (27). Theoretically, the IMR is based on the stress-vulnerability model of Zubin and Spring (28,29) and on Prohaska's et al. Trans Theoretical Model (30) on stages of processing motivation for change and maintaining changed behaviour. The IMR is a standardized 11 workbooks curriculum-based approach (see table 1) and designed to provide information and skills necessary for managing an SMI effectively and for working towards achieving personal recovery goals (31). The IMR program carries a strong emphasis on helping persons set and pur-

Table 1. The IMR Workbooks

1.	Recovery Strategies
2.	Practical Facts about Mental Illnesses
3.	The Stress-Vulnerability Model
4.	Building Social Support
5.	Using Medication Effectively
6.	Drugs and Alcohol Use
7.	Reducing Relapses
8.	Coping with Stress
9.	Coping with Persistent Symptoms
10.	Getting Your Needs Met in the Mental Health System
11.	Healthy Lifestyles

sue personal goals and helping them to put strategies into action in their everyday lives. In order to measure the effect of the IMR, Mueser et al. developed the Illness Management and Recovery Scales (32).

In 2009, in the region of Rotterdam/Leiden the second version of the IMR was translated into Dutch and introduced in the Netherlands. The Dutch IMR-network organized by Saxion, University of Applied Science, in which institutions that provide the IMR are assembled, was installed aiming for spreading and developing the IMR in the Netherlands. In the Netherlands the IMR is valued as a 'well substantiated' intervention in the long term mental health care (33). The effectiveness of IMR in the Netherlands is yet missing, but results will come out soon (34).

The IMR has proven effectiveness in three RCT's in different countries (35–37). After reviewing the IMR literature, McGuire et al. concluded that the effects of IMR on consumer-reported recovery and symptom reduction are promising but require further exploration (38). This exploration can contribute to the discussion of the medical orientation of the IMR, which is regarded too dominant. Not yet known is what outcome measure is capable of identifying the most relevant and meaningful change in the health status of persons with SMI who participate in the IMR program. The concept of Minimal Important Difference (MID) can be used in this exploration. Guyatt et al. (39) defined the MID as the smallest difference in pre-post scores in the domain of interest that patients perceive as important, either beneficial or harmful, and that would lead the patient and clinician to consider a change in the treatment. For instance, knowing that an intervention enhances a desired outcome may motivate a person to participate in the intervention.

Electronic mental health

The aforementioned de-hospitalisation tendencies were not only driven on by the improvements in medical treatments, the growing demands on healthcare, and the ethical discourse of human dignity and rehabilitation. Another moderator of the changes in healthcare, not to be underestimated, is the increasing costs of healthcare in general and the urge to find solutions to keep healthcare affordable and accessible for everyone. One solution to this issue is the growing possibilities of the information technology (IT) as a vehicle for providing or supporting care and treatment at the time and place of personal preference (40). Electronic Mental Health (e-health) is defined as making use of modern information and communication technologies to support or improve health and healthcare (40). Dutch policy makers and mental health organisations proclaimed the development of e-health to be the cornerstone of their policy (41,42). Current e-health applications are most frequently aimed at adults with depression or anxiety disorders. Some interventions have demonstrated effectiveness in early trials, in which the e-health interventions were controlled by waiting list or care as usual conditions (43). But, e-health interventions have high attrition rates (44). The addition of face-to-face contact to e-health is supposed to increase the therapeutic relation and prevent attrition (45).

Considering the before described topics we suggested that e-health could well be a vehicle of providing an intervention aiming for recovery and illness self-management for persons with SMI. E-health interventions for people with SMI are accepted and feasible (46), and can deliver effective education (47). (45). Conclusions on the effectiveness of e-health for persons with SMI can not yet be drawn (46,48).

The development of the e-IMR intervention, and trial preparation

We took up the challenge to provide knowledge about e-health for persons with SMI. All the before described topics are coming together in the development and testing of the effectiveness of an e-health intervention on recovery and illness self-management for people with SMI. To contribute to consumer oriented development, delivery, and effectiveness of self-management e-support programs; we developed a blended version of the IMR: the e-IMR intervention. This e-IMR study was part of the project 'Self-Made and Sound' on development and evaluation of self-management e-support programs, funded by ZonMW. Within this project, other e-support interventions were developed for people with rheumatoid arthritis (49) and cardiovascular diseases (50), and for parents of children with chronic kidney diseases (51). 50,268,269)

The intervention development process was guided by the six steps of the Intervention Mapping protocol (IM), in which the first is a needs-assessment and the sixth is the evaluation of the intervention (52). Just as in the topics of self-management and recovery, in intervention development we also see a more central role for persons with a chronic illness providing experiential knowledge. Orlowski et al. (53) concluded that consumer consultations helped to shape intervention design. We investigated what problems persons with SMI face, what behaviour needs to be changed, how they need to be supported and what they need from an intervention. Next, we developed an Internet platform on which the IMR-curriculum was integrated, and blended the use of this platform to face-to-face delivery of the standard IMR in groups. In the sixth IM step we conducted an exploratory cluster randomized controlled trial to investigate the effectiveness and feasibility of the e-IMR intervention. In order to be able to make a true comparison, we deliberately chose the set up of a trial in which the intervention is controlled by the face-to-face delivery of the standard IMR. In the field of people with SMI, this was, as far as we know, the first trial to investigate the effectiveness of an e-health intervention controlled by the non-e-health version. Most interventions are controlled by waiting lists or care as usual comparisons.

Testing the effect and feasibility of an intervention in a pilot study is recommended by the Medical Research Council as the second stadium of developing complex interventions (54). We evaluated the e-IMR intervention's effectiveness by using statistical analyses. In the second stadium evaluating its feasibility is reckoned to be just as important. Feasibility problems need to be resolved before performing a confirmative trail. The feasibility can be evaluated by using qualitative interviews and analyses. The reported use of qualitative methods in registered trials has increased over time and worldwide (55).

Aims of this thesis

Two main aims in this thesis represent the development and evaluation of the e-IMR intervention. The first aim was the consumer-oriented development and preparation of the e-IMR intervention and trial. The second aim was the evaluation of the e-IMR intervention compared to the face-to-face delivery of the IMR. Related to the second, we planned to explore not only the potential effectiveness of the e-IMR intervention, but also the actual use and added value of the e-IMR intervention, and finally the outcome measures that most likely capture consumers' potential benefits of the e-IMR intervention.

Outline of the thesis

This thesis is divided into two sections representing the two aims. In the **first section** consumer experiences were involved in the development of the e-IMR intervention. This section starts with **chapter 2,** which comprises of an investigation of the needs of persons with SMI. We investigated the perspectives of persons with SMI by doing a literature review of qualitative studies. A thematic-synthesis helped us to identify the nature of self-management support needs of persons with SMI. In **chapter 3**, we conduct a qualitatively evaluation of the standard IMR. We interviewed persons who participated in an IMR program group. We tried to understand which ingredients of the IMR enhanced the participants' recovery. Before being able to investigate the effectiveness the e-IMR intervention, the Illness Management and Recovery Scales needed to be validated in the Dutch context. This study is written down in **chapter 4.** In **chapter 5** we report about the developmental actions and results of the exploration of the six steps of the IM protocol. Throughout the six IM steps, we consulted a group of experts, including people with SMI who participated in an IMR program group, IMR trainers of whom one was a peer-professional, and an informal caregiver. This chapter also describes the applied e-health components of the e-IMR intervention, and the protocol and methods of investigating the before mentioned aims of this thesis.

The **Second Section** comprises of studies that reflect the second aim of the thesis. **Chapter 6** reports about the quantitative exploration of the effect of the exploratory multi-centre cluster randomized controlled trial of the e-IMR intervention for people with SMI who were referred to the standard IMR program. The process evaluation of the e-IMR intervention is reported in **chapter 7**. In this study the added value, barriers, and facilitators of the e-IMR intervention are investigated. In **chapter 8** we identify the outcome measure that most likely capture consumers' potential benefit of the e-IMR intervention. Since the e-IMR platform was used too little we decided to change the focus to the potential benefit of the standard IMR. Here we try to give an answer to the question what outcome measure was capable of identifying the most relevant and meaningful change in the health status of persons that participate in the IMR. Therefore we used the concept of the minimal important difference.

In **chapter 9** we discus the issues from the studies and we identify implications for future practice and research. C**hapter 10** gives a summary of the thesis. The reference list of all the chapters can be found in **chapter 10** of this thesis.

Section I Development and preparation of the e-IMR intervention

Chapter 2.

Self-Management Support Needs from the Perspectives of Persons with Severe Mental Illness: A Systematic Review and Thematic Synthesis of Qualitative Research

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Theo van Achterberg;
Peter J. J. Goossens.

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Abstract

Background:
The development of de-hospitalization policies in mental health have resulted in a growing emphasis on self-management. In the Chronic Care Model, self-management support is an essential element. Because of the episodic nature of severe mental illness (SMI) and its high relapse rates, we assume that the extent of self-management support needs of individuals with an SMI is considerable. However, a clear overview of the nature of the self-management support needs of persons with SMI is missing.

Aims:
This study aimed to identify self-management support needs from the perspective of individuals with SMI.

Method:
A systematic review was conducted using the method of thematic synthesis of qualitative studies. After searching the databases MEDLINE, PsycINFO, CINAHL, and EMBASE, we screened the papers for the eligibility criteria: individuals with an SMI, adequately representing the voice of persons with SMI and describing their self-management support needs. 31 papers were included.

Results:
The main findings showed that participants in the studies described the need for informational support, emotional support, acknowledgement, encouragement, and guidance in order to make sense of their illness experiences, ease suffering, obtain validation and recognition, execute self-management tasks, and be led through an unfamiliar territory.

Conclusion:
The perspectives of persons with SMI can provide a roadmap for constructing a self-management support intervention for persons with SMI. Important others have an essential role in fulfilling support needs. Managing an SMI on your own is difficult. Therefore it is preferable to let important others participate in self-management interventions, and to introduce peer support.

Introduction

Individuals with a severe mental illness (SMI) are diagnosed with a psychiatric disorder that goes hand in hand with serious impairments in social and/or occupational functioning, for at least a couple of years, and requires coordinated multidisciplinary care (1). In most countries in the European Region the number of psychiatric beds has been reduced significantly (5). This policy gives new challenges for persons with SMI especially regarding their self-management. Parallel to this trend, the emphasis on self-management is growing and is incorporated in new perspectives on health, defined as an ability to adapt and to self-manage (16). Self-management is a dynamic and continuous process of self-regulation that refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (13).

In the Chronic Care Model, self-management support is an essential element (56). Supporting self-management means providing information and encouragement to help individuals in maintaining greater control through understanding their condition, and thus become able to monitor and take appropriate action (18). Scientific evidence on supporting individuals' self-management in health care in general suggests that not all mechanisms to support self-management have equal outcomes (57,58). Van Achterberg et al. stated that health professionals should avoid thinking that providing knowledge, materials, and professional support will be sufficient for patients to accomplish change and consider alternative strategies that may be more effective (58). Rygg et al. suggest that it is important to be aware of people's reasons for participating in self-management support programs, in order to maintain a more consistent focus on people's support needs (59). However, self-management support needs have not yet been widely investigated. Van Houtum et al. investigated the extent of the self-management support needs of people with a chronic illness, indicating to what extent individuals feel a necessity to perform self-management tasks and to what extent they feel a need for support with these tasks (19,20). Perceiving self-management tasks does not automatically indicate a higher need for support (19), which can be explained by the fact that individuals might prefer to and/or be able to manage themselves. Also, time since diagnosis is not necessarily related to the number of support needs, which can be explained by the fact that the manifestation of a chronic illness often changes over time, which may lead to continuously altering self-management tasks (20). Thus, there is a relation between the number of support needs and the individual course of the illness, and this is significantly related to whether the individual perceives the illness as episodic and/or progressively deteriorating (20). There is no reason to assume that this is any different in persons with an SMI. Research has identified indicators of mental health deterioration across several SMIs (60) and described the episodic nature of SMI (4,22) with its high relapse rates (23). Therefore, we assume that the extent of the self-management support needs of persons with an SMI is considerable. In this paper, we focus on the nature of the *self-*

management support needs of persons with SMI, for which a clear overview is lacking. We ultimately aim to shed light on the kind of support strategies that are needed in order to be able to perform the necessary self-management tasks, for which an overview of the support needs of persons with SMI is needed. In order to design adequate self-management support interventions, insight into the nature of self-management support needs of persons with SMI is needed.

Objectives

Because user engagement has the potential to uncover unmet needs and preferences (61), we aimed to identify the nature of self-management support needs from the perspectives of persons with SMI themselves.

Methods

In contributing to a new understanding of patient perspectives, syntheses of qualitative research are well-established forms of systematic literature review, and they give a stronger voice to patient perspectives than single studies do (62). A synthesis of qualitative research provides an integrative interpretation of findings from single qualitative studies, and allows for a more substantive description of the phenomena (63). We performed a thematic synthesis of qualitative literature according to the method outlined by Thomas and Harden (64). This method was developed to address questions related to health promotion, for instance about intervention need. The method consist of four stages: 1) searching literature in different databases and screening titles, abstracts, and full texts for eligibility; 2) assessing the quality of relevant publications; 3) extracting data from the results sections of the papers; and 4) thematic synthesis of the extracted data. Furthermore, this study followed the "Enhancing Transparency in Reporting the Synthesis of Qualitative Research" statement (65). In this study we use the word participant, when we mean the participants from the reviewed studies.

Searching

In the first stage, the databases MEDLINE, PsycINFO, CINAHL, and EMBASE were searched to identify relevant peer-reviewed papers, in English, published on paper or online before March, the 1st of 2017. The search terms used were: "Severe Mental Illness," "Self-Management," "Needs Assessment," "Qualitative Research," and possible synonyms (see Additional File). The term "Qualitative Research" was chosen because qualitative research implies hearing personal views, thereby allowing us to stay as close as possible to the perspectives of persons with SMI themselves. We searched for all available studies. Additional records were manually searched from references in the included papers (see Figure 1). We followed this stage by screening titles and abstracts of the papers taking into account the following criteria. The content:

- is about individuals with an SMI, which means being diagnosed with a psychiatric disorder, for more than one year, and being treated in secondary or tertiary settings;

- adequately represents the voice of persons with SMI, which means that it must be clear that the statements were directly reported by participants with SMI and not by other participants, such as relatives or other support providers;
- describes support needs that were reported and directly related to self-management tasks; and
- is gathered and analysed qualitatively.

Once the initial selection was completed, the full texts of the papers were screened using the same criteria.

Quality Assessment

In the second stage, a quality assessment of the eligible papers was performed, for which we used the Qualitative Assessment and Review Instrument (QARI) (66), which consists of 10 items scored “yes,” “no,” “unclear,” or “not applicable.” The QARI was chosen because it supports the synthesis of qualitative research. See Table 1 for the QARI scoring items. We decided to include papers if items 2 to 5 and 8 all scored “yes.” In spite of their relevance, reporting about items 1, 6, 7, and 9 often is missing, and because of our focus on the results section, not on the conclusions, we did not account for items 1, 6, 7, 9, and 10 in the decision to include a paper. To the item 6 we added that researchers could also be located professionally.

Table 1. Scoring items of the Qualitative Assessment and Review Instrument

1	There is congruity between the stated philosophical perspective and the research methodology.
2	There is congruity between the research methodology and the research question or objectives.
3	There is congruity between the research methodology and the methods used to collect data.
4	There is congruity between the research methodology and the representation and analysis of data.
5	There is congruity between the research methodology and the interpretation of the results.
6	There is a statement locating the researcher culturally or theoretically [or professionally].
7	The influence of the researcher on the research, and vice-versa, is addressed.
8	Participants, and their voices, are adequately represented.
9	The research is ethical according to current criteria or. For recent studies, there is evidence of ethical approval by an appropriate body.
10	Conclusions drawn in the research report do appear to flow from the analysis, or interpretation of the data.

Data Extracting

In the third stage, self-management support needs were extracted from the results sections of the included papers. Two researchers (TB and PG) independently extracted data from two papers and discussed the data. The first researcher extracted data from all other papers. We paid close attention to whether or not the described support was related to a self-management task and whether the support was qualified as needed, desired, helpful, missing, valued, or synonyms of these qualifications. All the extracted text fragments were extensively discussed before inclusion. When needed, the data were checked in the full texts to understand the context of the self-management support need. The data were loaded into an Excel sheet, with special care to be able to trace the data back to the original article.

Thematic synthesis

In the fourth stage, the extracted text fragments were coded line-by-line. Inductively, descriptive themes were developed, while remaining close to the primary data. Next, focusing on support needs, analytical themes were generated, representing interpretative constructs, explanations, or hypotheses. After the analyses, a number of papers were excluded in second instance because of informational redundancy (67), which means these papers did not bring in new points of view in relation to other papers. We judged that the remaining sample size was appropriate to support our findings.

Descriptions of self-management tasks could be related to more than one support need. To avoid repetition, we decided not to report the relevant self-management tasks with all support needs in the text of the results section, but to present a matrix showing the links between the major support needs and the related self-management tasks, thematically categorized according to Barlow et al.'s (13) definition of self-management (see Table 2).

Rigor

Because synthesis of qualitative research is a highly interpretative method, which places substantial demands upon the researchers (63), all necessary decisions within the successive stages were made according to the same procedure: two researchers (TB and PG, with extensive mental health nursing and research experience) independently prepared for decisions, and discussed their differences until reaching consensus. When inconclusive, a third researcher (BvG, with generic health services research experience) decided. This procedure was set up to bracket our own experience and prejudice, and to prevent over-interpretations of the data.

Results

Initially, 5,856 papers were assessed on their title and abstract, with the full text of 230 being evaluated; of these: 180 were not eligible, 3 did not pass the quality assessment, 16 were identified as redundant, and 31 were included in the analyses (see Figure 1), in which the voices of more than 548 persons with SMI, coming from 12 different countries were represented. Table 3 gives an overview of the included papers with the authors, countries, topics, data collection methods, qualitative approaches, data analysis methods, numbers and genders of participants, diagnoses, diagnostic instruments, quality assessment scores, and whether the paper reported fulfilment to ethical standards.

Four studies were based on two data sets from 1) Todd et al. (68,69), and 2) Zou et al. (70,71). These sets were analysed a second time with a different focus.

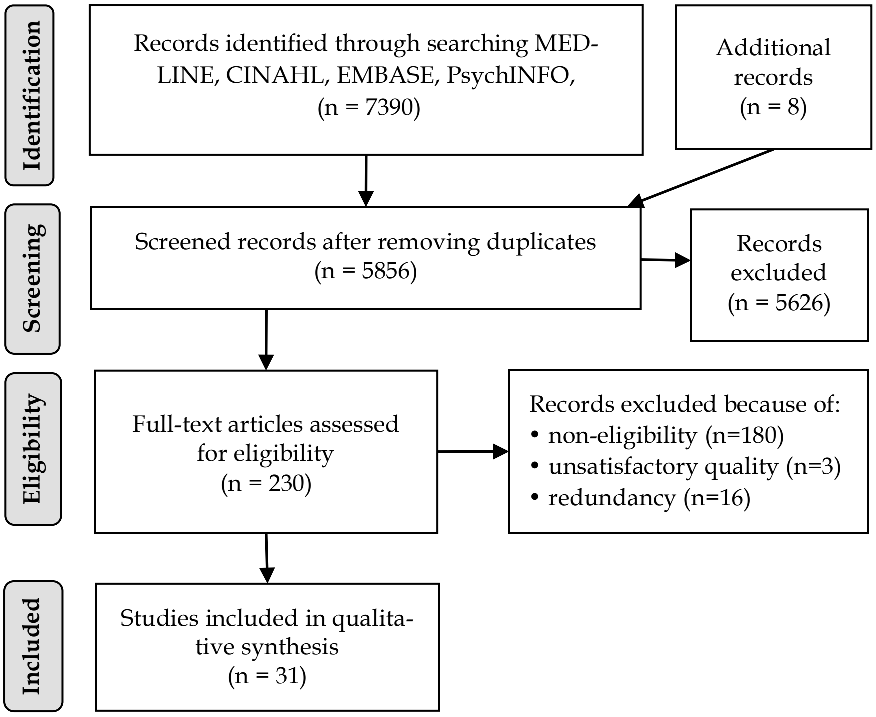

Figure 1. Selection process flowchart

Out of the 31 papers, five main self-management support need themes emerged, describing the need for informational support, emotional support, acknowledgement, encouragement, and guidance, in order to support persons with SMI with their self-management tasks.

When the data gave rise to descriptions of why the support is necessary, the lack of support, the support needs, the results of provided support, and conditional issues, these are reported, in this order. To conclude, we provide examples of illustrative quotes of self-management support needs from the reviewed papers.

Informational Support Needs

In order to be able to perform self-management tasks (see Table 2), participants stated that informational support was necessary because mental illnesses were totally foreign to them (72), they were unaware of what kinds of care were available to them (69), they did not know what to do when things went wrong (68), they were in shock over having a diagnosis, or they were in denial (73). Participants endorsed the need for informational support by stating that they missed getting information from treatment settings (70,72,74–76). Participants described alienating tendencies when

Table 2. Matrix of the support need themes and the related self-management areas categorized according Barlow et al. (4) definition of self-management and a rest-category of managing the illness.

	Self-management areas	Need for information on	Need for emotional support with	Need for acknowledgement with	Need for encouragement with	Need for guidance with
Manage symptoms	Coping symptoms	how to cope with symptoms, stress-management, how to live, manage the illness, daily life (71,73,80,93), how to recognize symptoms and triggers (68,83);	coping with symptoms (76,78–80,82,89–92);	coping with: stress related to illness symptoms (78,80) negative thoughts, rumination, negative self-appraisal (89), crisis (89,90), feeling unwell (72), symptom exacerbation (85), understanding experiences are symptoms (79);	coping with symptoms, and relapse prevention (78,87); getting to and sticking to a regular schedule, stabilizing daily structure and routines (79,80);	Coping with symptoms in general (68,70,72,77–84), keeping up awareness (81);
	Substance abuse	alcohol and drugs, and how to remain sober (83);	coping with craving (77)	understanding difficulties in periods of misuse (79)	staying clean (83);	
Manage treatment	Access	how to access, navigate and talk to services (69);		starting, changing, continuing treatment (72);	pursuing and seeking treatment (72,80,88)	
	Treatment preference	treatment options (75);		making decision (74), getting preferences (72);		getting preferences(85), and needs met (86)
	Medical treatment	that it might take some time and trial and error before its beneficial (88), side effects, risks, interactions (75,76);	accepting adverse reaction, side effects (74):	choosing to take medication (74), tolerating side effects (74), taking medication (80);	taking medication (72,80)	taking medication (72,80), getting ready to take the right medication by evaluating and reorganizing a backlog of two months and several changes in prescriptions (78);

Manage consequences	Psychologically	their own physical condition and limitations (95,96);	relieving the image of being fat (76);		improving physical health (95);	
	Socially	interpersonal skills; how to relate to others, how to tell others about the illness (69), the need for and how to seek support (82);	loneliness (71);			getting insight let others be part of your life (82);
	Exercise	ideas of physical activity (97), a program on smoking cessation and exercise (96); weight management (76), transportation possibilities, swim passes (91);	doing exercise (92);		getting into physical activities (91,95–97), smoking cessation (96), entering a lifestyle program (91,96);	
Manage lifestyle	Healthy eating	how to break patterns (97)	changing behaviour(91)		changing behaviour (91), maintaining routines,	
	Lifestyle changes	how to break patterns (97);	hanging behaviour(91),		changing behaviour (91), maintaining routines,	
Manage the Illness	General	unspecified life areas (70,72,94), what causes the illness (79); what peers experience (71–73,80,81,91,97);	understanding the illness (78);	understanding meaning and impact of the illness (78);	coping with the illness (71,80,87);	accessing, processing (filtering, summarising, screening reliability and credibility, checking accuracy), and using online information (94), coming to terms with illness (80).
	Psychiatric condition	diagnosis (75,82), prognosis (75);	maintaining hope and confidence to manage illness (98);			
	Practical issues	legal rights, managing debt, pregnancy, seasons, time zones (69).	conducting life and daily struggle (82).	executing daily life activities (78)		

lacking knowledge (75,91), and added that clinicians should not automatically assume that individuals with SMI are aware of their mental illness (75). Three subthemes for informational support needs emerged from the data.

The first was *the need for information provision*, which was related to participants' needs for an explanation, understanding (79), validation (72,82,89) normalization (82), and reassurance (94). Being provided with information enhanced their ability to make sense of what was happening (84) and raised awareness (75,96). Participants mentioned that they preferred verbal to written, and hard-copy to online information (72).

> *"(the schizophrenia society) workshops gave me knowledge of what was happening to me, I had mental illness and I didn't even know what that was. I thought it was being retarded . . . the more you know what's going on with you, that's a big part of my staying healthy."* (91)

The second subtheme for informational support needs was *the need for sharing information* (71,80,81,97), which including listening to peers (73,81) and exchanging information (71,80,97) and ideas on how to cope with the illness (97). By sharing information with peers they discovered similarities, found understanding, and therefore felt less strange (80) and lonely (71).

> *"Breaking patterns from my side. And it was easier to do when you could talk to others in the group. You sort of exchanged 'this is what I did' and 'this is what I think' and 'I think this."* (97)

The third subtheme for informational support needs was *the need for educational support*, (68,69,91) and related to participants' needs for knowledge (96), understanding (68,83,91), and learning skills (68,69,76,83). Participants said that education facilitated changing behaviour (76,83,91,95,96), awareness, acceptance (73), and the confidence to change illness perceptions (93).

> *"learn techniques to recognize triggers and understand their symptoms… it is when things start to go wrong what do I do then because nothing seems to be immediate … immediate enough, so something like that would be helpful."* (68)

Emotional Support Needs

When facing self-management tasks (see Table 2) participants reported a need for emotional support, in relation to being overwhelmed by symptoms (76,78–80,85,91,92), experiencing emotional crisis (89,90), the hardship of living with the illness (71), and worrying about a possible relapse (88). Two subthemes for emotional support needs emerged from the data.

The first was *the need for active listening*, such as needing someone to talk to (77), someone who lets you talk freely (89), who listens and actively engages (90), and who allows venting and opens up space in a conversation (80). Participants mentioned that the atmosphere of active listening is non-judgmental, is not meant to fix symptoms (85), and means not rushing into illness-related items too much (80).

> *"I think, 'Who can I talk this [symptom] out with?' and generally it's [a friend]. It is not to fix what's going on [symptoms] but to restore me to where I am comfortable."* (85)

The second subtheme for emotional support needs was *the need for presence*. Participants reported the need for the actual presence of peers, who provided a necessary safe and non-judgmental atmosphere (76), reduced loneliness (71) and anxiousness (91,92), increased acceptance and feeling normal, and boosted self-esteem (76). Presence also included being aware of having available informal support providers (80) who do not let you down (82) and who care and hold hope that you will get through (90). The need for presence included the need for available and accessible medical services in case of necessity (79).

> *"Everybody I've met is sort of like me. They all have the same problems . . . so that we all share . . . we can all share and no one's critical, so that makes it safe."* (76)

> *"And it's that, which is my security, that I can ring her directly when something happens and I can get it out of my head. [. . .] That's enough, I feel better.* (82)

The Need for Acknowledgement

When facing self-management tasks (see Table 2), participants reported a need for acknowledgement, especially when they were in crisis (90) (89) or in stress, when not understanding the illness (78), when scapegoating oneself (80), and when participants desired to play an active role in treatment decisions (74). Participants mentioned that they were often underestimated (74). Participants' reported the need to receive reminders that they were a good (89) and loved person (80), to be believed and be told they are not stupid (90), to obtain validation that their behaviours are symptoms of their illness (78,79,89), to be told the illness is real (80), to be taken seriously (74), and getting time to talk (72), to receive responses to their input (72,79), and to be invited to be involved and engaged in decision making (72,74). The acknowledgement boosted self-esteem (80). Conditionally, participants said that before being able to understand their illness they needed support providers who really understood the illness (98) and who acknowledged the frightfulness (79) and impact of the illness (78,79).

> *"The biggest thing that she tells me is that bipolar is just a snippet of me. It's not who I am, it's just a piece of me, it doesn't make everything. It doesn't make all of me; it's just a snippet of me. That helps me out with my self-esteem big time, because when you first get diagnosed with a mental illness the first thing you think is, "Oh my god, I'm crazy in my head and everybody's gonna think I'm a bad person or this or that," and you know, just being able to hear that "It's just a snippet of you, Rachel. You know, there's so much more to you" —positive things."* (80)

Table 3. Overview of the included papers

Author (reference)	Country	Topic	Data gathering method	Qualitative approach
Arbour-Nicitopoulos et al. (96)	USA	Evaluating a smoking cessation intervention	Semi-structured interviews	NR
Aref-Adib et al. (94)	UK	Online information seeking behaviour	Semi-structured interviews	NR
Barker et al. (98)	UK	Client and family narratives	Semi-structured interviews	NR
Billsborough et al. (90)	UK	Support needs	Semi-structured interviews	NR
Chronister et al. (78)	USA	Social Support	Semi-structured Focus group,	Phenomenological
Cohen et al. (85)	USA	Coping strategies	Person-centred qualitative interviews	Phenomenological
Cruce et al. (79)	Sweden	Recovery promoting care	Semi-structured interviews	NR
Doherty and MacGeorge (80)	USA	Supportive behaviour	Semi-structured interviews	Ethnographical
Fisher et al. (72)	Australia	Experiences of treatment decision making	Semi-structured interviews	NR
Graham et al. (91)	Cana-da	Health Behaviours and Health Behaviour Programs	Focus groups	NR
Hernandez and Barrio (86)	USA	Families and medication use and adherence	Semi-structured interviews	Grounded theory
Johnstone et al. (92)	UK	Physical activity	Semi-structured interview	Phenomenological
Kinter et al. (74)	USA	Patient relevant endpoints	Focus group, individual interviews	Phenomenological
Loughland et al. (75)	Australia	Communication of a diagnosis	Semi-structured interviews	Generic
Luciano et al. (87)	USA	Long-term Sobriety strategies	Semi-structured interviews	Constructivism
Nover (76)	USA	Increased risk of developing secondary physical illnesses	Semi-structured interviews	NR
O'Connor et al. (73)	Ireland	A psycho-education group	Semi structured interview	Phenomenological
Ouwehand et al. (99)	Netherlands	Religious and spiritual experiences	Semi-structured interviews	Phenomenological
Owen et al. (34)	UK	Social interaction	Semi-structured interviews	NR
Poremski et al. (81);	USA	Treatment adherence and metabolic comorbidities,	Open ended interviews	Grounded theory
Rastad et al. (97)	Sweden	Barriers, Benefits, and Strategies of Physical Activity	Semi-structured interviews	NR

Analysis method	n(M)	Diagnosis/comorbid diagnosis	Diagnostic instrument	QARI	Ethical approval
Thematic analysis, constant comparative method	12(0)	Bipolar disorder, schizophrenia, anxiety disorder, major depression	NR	7	yes
Thematic analysis	22(10)	Psychosis (schizophrenia, schizoaffective disorder, bipolar affective, psychosis NOS)	NR	9	yes
Inductive, deductive, strategies from grounded theory, constant comparative analysis.	8(6)	Schizophrenia	NR	9	no
A reflexive-collaborative approach	16(9)	Bipolar disorder	SR	8	no
Consensual Qualitative Research	52(29)	Major depression; bipolar disorder; schizophrenia; PTSD; schizo-affective disorder; anxiety disorder	NR	7	no
Constant comparison analytic approach	20(10)	Schizophrenia	DSM IV	9	yes
General qualitative approach	8(6)	Schizophrenia/SU, bipolar disorder/SU, schizo-typical disorder/SU	ICD-10, DSM IV	7	yes
Qualitative coding methods, constant comparative technique	30(6)	Bipolar disorder	MDQ	7	no
Thematic analysis	19(6)	Bipolar II disorder	DSM 5	7	yes
Grounded theory, Thematic analysis	37(18)	Schizophrenia spectrum disorders, Bipolar and related disorders, depressive disorders, Anxiety disorders, Obsessive-compulsive disorders, PTSD, SU	NR	9	yes
Grounded theory approach, on-going comparative analysis	14 (11)	Schizophrenia	NR	8	yes
IPA	27 (16)	Schizophrenia	NR	6	no
IPA	30 (NR)	Schizophrenia	ICD10	8	Yes
Thematic analysis	14(9)	Schizophrenia	NR	7	yes
Charmaz's constructivist grounded-theory approach	12(12)	Schizophrenia, Bipolar disorder, SU	NR	9	yes
Qualitative approach	9(1)	Schizophrenia, bipolar disorder, schizo-affective disorder, major recurrent depression and comorbid medical illness	NR	7	yes
IPA	11(4)	Bipolar disorder	DSM IV	7	no
Inductive coding	10 (4)	Bipolar disorder	NR	10	yes
Inductive Thematic analysis	20 (7)	Bipolar disorder I & II	DSM IV	7	yes
Constant comparative method	25 (NR)	Schizophrenia, psychotic disorder	NR	9	yes
Conventional qualitative content analysis	20(13)	Schizophrenia, schizo-affective disorder	DSM IV	8	yes

Table 3. continued

Author (reference)	Country	Topic	Data gathering method	Qualitative approach
Roe et al. (93)	Israel	Illness Management and Recovery program	Narrative Evaluation of Intervention Interview	NR
Rusner et al. (82)	Sweden	Conditions that enable a good life	Open interviews	Phenomenological
Thomas and Rickwood (83)	Australia	A journey of recovery	In-depth, semi-structured interviews	Case study
Todd et al. (68)	UK	Expectation of web-based self-management intervention	Focus group	NR
Todd et al. (69)	UK	Support from a self-management intervention	Idem as Todd et al. (68)	
Topor et al. (84)	Different countries	The role of others in the recovery process	Open-ended, narrative interviews	NR
Wärdig et al. (95)	Swe-den	Healthy lifestyle	Semi-structured interviews	NR
Whitley and Campbell (77)	Cana-da	Stigma, agency and recovery	Multiple focus groups, observation	NR
Zou et al. (71)	China	Self-management, facilitators and barriers	Interviews	Phenomenological
Zou et al. (70)	China	Self-management	interviews	NR

ASRM: Altman Self-Rating Mania Scale; BDI: Beck Depression Inventory; DSM IV: Diagnostic and Statistical Manual of Mental Disorders, 4th edition; ICD-10: International Classification of Diseases, 10th edition; IPA: Interpretative Phenomenological Analysis;

The Need for Encouragement

In order to execute self-management tasks (see Table 2), participants stated they needed encouragement because of experiencing symptoms (72,80,97); fear (96); a lack of motivation, energy (80), and memory (78,80); mistrusting oneself (70); not wanting to go alone (92,96); not taking initiatives (97); and inability to stay on track (80). Three subthemes for encouragement needs emerged from the data.

The first was *the need for stimulation* (72,80,83,92,95,96), such as receiving suggestions (97), reminders (70,78,80), a push (83,92,94,97), and professional interest in their physical condition (95). The stimulation enhanced motivations for change (79,91) and taking responsibility (80,83). Conditionally participants mentioned that they did not want to be babied too much (83).

> *"Often a couple of the staff members here have been, if I was having a rough day, which I have had a few, 'Come on Tabitha, let's go and shoot some hoops outside, play some basketball or kick the footy on the oval'. That's been really helpful too . . . I've had a lot of support and encouragement to stay off drugs or to minimize the harm."* (83)

Analysis method	n(M)	Diagnosis/comorbid diagnosis	Diagnostic instrument	QARI	Ethical approval
Grounded theory approach	36(25)	Schizophrenia, psychosis NOS, bipolar disorder, anxiety, personality disorder	NR	8	yes
Structure of whole-parts-whole Dahlberg	10(4)	Bipolar disorder	NR	8	yes
Theory-driven approach, content analysis	1(0)	Psychosis and major depressive disorder	NR	8	yes
Thematic analysis, interpretive analysis	12(7)	Bipolar disorder	MDQ	8	yes
Idem as Todd et al. (68)					
Established qualitative procedures	12(5)	Schizophrenia, major depression/paranoid psychosis	NR	7	no
Conventional content analysis	40 (NR)	Schizophrenia, bipolar disorder, schizo-affective, delusional disorder, unspecified psychosis	ICD-10	8	yes
Grounded theory approach	NR (NR)	Schizophrenia, bipolar disorder, major depression, schizo-affective disorder, SU	NR	8	yes
Collazzi's qualitative methodology	21(11)	Schizophrenia	ICD-10	8	yes
NR	Idem as Zou et al. (71)			7	yes

MSQ: Mood Swings Questionnaire; N(M): number of participants (of whom male); NOS: Not Otherwise Specified; NR: Not Reported; PTSD: Post-Traumatic Stress Disorder QARI: Qualitative Assessment and Review Instrument; SR: Self-Reported; SU: Substance Use Disorder

The second subtheme for encouragement was *the need for presence*. The presence of peers or others was described as an encouraging experience for participants. They mentioned the helpfulness of having a buddy or doing activities in a group (87,91,92,96,97), and that peers showed them the possibilities of achieving a different life (87). The presence of peers enhanced accountability, motivation (91), and courage (92). Participants also described they felt encouraged when having somebody, not necessarily a peer, available to listen to their achievements (83,97). Conditionally, participants want to avoid that the presence of others turn into feeling of being under surveillance (97).

> *"I think being part of a group is motivational for me, you're more accountable that way."* (91)

The third subtheme for encouragement was *the need for confirmation*, including receiving positive affirmations (97), expressing faith and confidence in a person's ability (71,78,80,87), reminding them of accomplishments and progress (80), or getting reassurance such as being told that what one wants to do sounds like the right thing (72). The confirmation enhanced confidence (71), boosted self-esteem (80), and reduced stress (78).

> *"I have an appointment with my doctor every month. She always says: 'You have the ability to manage your illness and your own life, you can have a normal life just like other people do . . . never give up'. I feel so encouraged."* (71)

The Need for Guidance

Because of difficulties in performing self-management tasks (see Table 2) independently, participants expressed the need for guidance (78,94,99). Participants stated difficulties in understanding and recalling information (94), thinking logically, making decisions (72), being proactive (72,80), making one's voice heard (72,84), and expressing oneself (82,86,94). These difficulties were related to a lack of confidence, learning disabilities (94), unawareness of current symptoms (70,77,78,80), a fear of what might happen (70,81,82,99), or being overwhelmed (72,73,78,82,94,99). Four subthemes for the need for guidance emerged from the data.

The first was *the need for feedback* on their current condition and behaviour (68,70,72,77–84,100), such as getting opinions (82), direct comments (80,83), ideas about how to interpret things, a confronting little nudge in the right direction (78), a "red flag" and straightforward instructions to leave an unhealthy situation (80,83).

> *"I've asked for them to both tell me if they see any difference in me to where I'm going downhill. If they see 'Oh Linda, I think you need to get help. Go talk to your therapist' you know. Cause my last episode, they said they sensed it, but they didn't know for sure you know, so I told them from now on to tell me so I can get help right away to talk it out."* (78)

The second subtheme for guidance was *the need for being monitored*. In order to prevent relapses, participants' commented that their symptoms and triggers needed to be monitored (90), because others noticed changes in their condition earlier than the participants themselves (70,72,77,80,83,84). Participants described the need to be watched (70), to be checked (80), for instance about the quality of their decisions They also mentioned the need for a network contract or agreement (78,82) with their verbal or written consent to take over responsibility and take necessary actions in the case of a relapse (72,78,82). Monitoring support was considered to enhance feelings of safety (70,72,77,79,80). Conditionally, participants stated that this being monitored is preserved for persons whom they trust (72,80,82), which is based on being familiar with the individual behind the symptoms (79)

> *"My ex-partner will often ask me questions about the decisions I'm making, to clarify in my own head what's going on. Like she just wants to know that I'm clear about why I'm doing what I want to do . . . there are times when I'm almost incapable of making decisions and it's been helpful for me to have someone that I trust from a personal point of view."* (72)

The third subtheme for guidance was *the need for advocacy*, including being accompanied during medical appointments by someone who provides additional information (72) and clarifies their treatment preferences (72,86), or needing someone who plays an intermediary role to initiate contact with services and acts like a lobbyist on the person's behalf to preserve their individual rights (84).

> *"When I go by myself I don't like it. It doesn't feel good. Because I cannot . . . tell my own way out or like tell them, like, what prescriptions."* (86)

The fourth subtheme for guidance was *the need for counseling*, including reappraising and working through stressful situations (80), future worries, or past painful experiences (82), for instance spiritual or religious experiences during past

psychosis (99). This support enhanced understanding of what happened to them (99) and coming to terms with the illness (80).

> *"These questions, philosophical questions, are very important. I am convinced that if one does not find somebody who can help you with it, you continue to search for meaning and you can often notice that they come back in the next psychosis."* (99)

Discussion

From the perspectives of persons with SMI themselves, in preparing a self-management support intervention, we identified five major self-management support needs: informational support, emotional support, acknowledgement, encouragement, and guidance. *Informational support* needs comprise being provided with illness-related information, sharing it with peers, and education to make sense of experiences and obtain know-how on coping with it. *Emotional support* needs comprise actively being listened to and the actual presence or availability of another person to ease suffering and increase strength to cope with illness-related emotions. *Acknowledgement*-related support needs comprise being validated, recognized, and appreciated as a person behind the symptoms, capable of playing an active role in taking decisions. *Encouragement*-related support needs comprise stimulation, confirmation, and again presence to execute self-management tasks. *Guidance*-related support needs comprise feedback, monitoring, advocacy, and counselling, leading the person with SMI through unfamiliar territory and when performing tasks independently is too difficult.

When looking at what is reported about why the support is needed and what it enhances, we see an overlap among the five types of self-management support needs. For instance, being overwhelmed by emotions or symptoms, scapegoating, alienating tendencies, and enhancing self-esteem are related to different support needs. On the one hand one might conclude that it is a matter of personal preferences whether information support or emotional support fits with the need for support. On the other hand, fulfilling the need for information may not be enough to redirect alienating tendencies, as we identified acknowledgement as a conditional factor before being able to understand the SMI. This is in line with Bodenheimer et al. (101), who stated that didactic education in itself does not improve health-related behaviours or clinical outcomes.

Participants in the studies described the overwhelming alienating impact of an SMI. Persons with an SMI often experience failure and a sense of demoralization, which is characterized by feelings of helplessness, incompetence, diminished self-esteem, hopelessness, entrapment, aloneness and meaninglessness (102). Their attempts to make sense of experiences, related to an SMI, failed and they are confronted with incomprehensibility, frightfulness, and incompetence. Making sense, or 'sensemaking', is an action and a process of giving meaning to experience. Weick et al. portrays sensemaking as: the experience of being thrown into an on-going, unknowable unpredictable streaming of experience in search of answers to the question, "what's the story?" (103). Dervin stated that a gap in sensemaking appears when the continuity of experiences is interrupted (104). In regard to essential self-management activities, Mamykina et al. stated that people make a myriad of daily choices based on sensemaking, including organizing the chaos of lived experiences, finding patterns, and discovering connections and dependencies, which all refer to an orientation system, based on past experiences (105). This focus on sensemaking implies a personal discovery process that starts with having an experience, followed by reflecting, giving meaning, and experimenting to find one's way toward self-managing and experiencing what really works. This process is called "experiential learning," as first described by David Kolb in the 1970s (106,107). The process fits with the self-management support needs we identified: receiving acknowledgement and emotional support when being overwhelmed or in need to cope with emotions, getting information and counseling when needing to understand and discover meaning, receiving encouragement when experimenting to perform self-management tasks, and getting to terms with the illness as a result of this personal process.

How the provided support is perceived and accepted might, as well, be a personal matter. Participants described boundaries of the support needs in conditional factors, such as preferred ways of providing information; not being judged, patronized, or put under surveillance; and the support providers' trustworthiness and empathy. As we saw earlier, the support in itself is not enough. The conditional factors suggest that support providers need to pay attention to their attitude toward the individual with an SMI.

Our findings support the view that self-management does not imply 'doing everything on your own'. Guidance is needed when performing tasks independently is a difficult path to follow. Therefore, self-management also means seeking support from others when necessary (25). Participants described how they depend on the support of others, as they mentioned the need for a network contract in order to prevent relapse. Rusner et el., not in vain, titled her manuscript 'a dependence that empowers' (82). As our review shows, informal support providers can contribute by meeting the needs for emotional, acknowledging, encouraging, and guiding support. However, family interactions are known for both facilitating and impeding recovery

(108). Being confronted with a severely mentally ill relative or friend can cause the same sensemaking gap and evoke both anxiety and sympathy, which can yield emotional ambivalence and awkward interactions (109). In order to enhance the facilitating potency of important others, the participants in the reviewed papers reported the need to educate important others to become better support providers (80) and the need to learn how to talk positively about their SMI and how to involve others in their self-management to get the self-management support they need (69,82).

The last remark we want to make is about peer support. Those who have already bridged the sensemaking gap can support others trying to bridge it. Peers have the conditional knowledge through their own experience and can be excellent support providers, which is promoted in the recovery literature (25,110,111).

Strength and Limitations

One of the strengths of this review is that it makes the voices of many persons with SMI heard with regard to their preferences on support for self-management. The population represents persons with a broad spectrum of mental illnesses, coming from various countries all over the world.

Given the interpretive character of this synthesis of qualitative research (63), we cannot fully exclude that this review also reflects researchers' interpretations to some degree, in relation to both our own analyses and those of the researchers from the original studies. We tried to be careful in our analyses and decisional process. Yet in the papers included in our synthesis, we often missed a report on the issue of bracketing, as described by Tufford and Newman (112), and were therefore unable to assess the researchers' background and their possible influence on the interviews and analyses. Another limitation of our own work is that we did not hold consumer consultations in order to arrive at a more in-depth understanding of the self-management support needs of persons with SMI.

Conclusion

This review provides insight in the nature of self-management support needs of persons with SMI. In order to be able to perform necessary self-management tasks, individuals with SMI reported the need for informational support, emotional support, acknowledgement, encouragement, and guidance. Findings further support the view that managing an SMI on your own is a difficult path to follow, a degree of dependency will remain. Important others and peers can be viewed as having an essential role in fulfilling self-management support needs.

The perspectives of persons with SMI as described in this paper can provide a roadmap for constructing self-management support interventions that account for the needs for informational support, emotional support, acknowledgement, encouragement, and guidance. Healthcare providers, can educate, support and advocate with a focus on personal support needs, while regularly checking whether the provided support truly fulfils the support needs of individuals who try to manage their SMI. Because of their essential role, it is preferable to let important others participate in self-management support interventions. Also, it is preferable to introduce peer support, because of peers' ability to bridge the sensemaking gap.

Additional file. Search terms for searching databases

Search terms	Synonyms
Severe Mental Illness AND	(Severe mental illness[tiab] OR serious mental illness[tiab] OR Mood Disorder*[tiab] OR Affective Disorder*[tiab] OR Affective Psychos*[tiab] OR Bipolar Disorder*[tiab] OR Manic-Depressive[tiab] OR Mania*[tiab] OR Manic State*[tiab] OR Bipolar Depression[tiab] OR Manic Disorder*[tiab] OR Cyclothymic Disorder*[tiab] OR Paranoid Disorder*[tiab] OR Paranoid Psychos*[tiab] OR Paranoia[tiab] OR Paranoias[tiab] OR Schizophrenias[tiab] OR Schizophrenia[tiab] OR Schizophrenic*[tiab] OR Mood Disorders[Mesh] OR Schizophrenia and Disorders with Psychotic Features[Mesh] OR Affective Disorders, Psychotic[Mesh] OR Depressive Disorder[Mesh]) OR Depressive Disorder, Major[Mesh] OR Depressive Disorder, Treatment-Resistant[Mesh] OR Dysthymic Disorder[Mesh] OR Seasonal Affective Disorder[Mesh] OR bipolar I disorder[tiab] OR bipolar II disorder[tiab] OR severe mental illness[tiab])
Self-management AND	(Self management[Mesh] OR Self management[tiab] OR Daily Living Activit*[tiab] OR ADL[tiab] OR Chronic Limitation of Activit*[tiab] OR Self Care*[tiab] OR Activity of Daily Living[tiab] OR Activities of Daily Living[tiab] OR Consumer Participation[tiab] OR Patient Participation[tiab] OR coping[tiab] OR adherence[tiab] OR compliance[tiab] OR coping[Mesh] OR Patient compliance[Mesh] OR self efficacy[Mesh] OR self efficacy[tw] OR Illness management[tw] OR self help techniques[tw] OR self instructional training[tw] OR self determination[tw] OR self evaluation[tw] OR self monitoring[tw] OR self regulation[tw] OR self reinforcement[tw] OR stress management[tw] OR self actualization[tw] OR empowerment[tw])
Needs-assessment AND	(Needs Assessment[Mesh] OR needs assessment*[tiab] OR perspective*[tw] OR support*[tiab] OR preference*[tw] OR recovery goal*[tw] OR psychological assessment[tw] OR psychological needs[tw] OR special needs[tw] OR patient assessment[tw] OR psychosocial support[tw] OR unmet needs[tw])
Qualitative research	(Qualitative research[Mesh] OR focus group[tw] OR interview*[tw] OR Phenomenolog*[tw] OR qualitative research[tw] OR grounded theory[tw] OR observation methods[tw])

Section I. Development and preparation of the e-IMR intervention

Chapter 3.

How the Illness Management and Recovery Program Enhanced Recovery of Persons with Schizophrenia and other Psychotic Disorders: A Qualitative Study

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Abstract

This study aims to describe how the Illness Management and Recovery program enhanced recovery of persons with schizophrenia and other psychotic disorders from their own perspective. Participants valued learning how to divide huge goals into attainable steps, how to recognise and prevent a relapse by managing symptoms, practising skills, and talking openly about illness related experience. They learned from the exchange with peers and from the information in the IMR textbook. Nurses should have continuous attention and reinforcement for progress on goals, skills practice and exchange of peer information. A peer-support specialist can contribute to keep this focus.

Introduction

Schizophrenia and other psychotic disorders (PDs) are characterized by the presence of delusions and hallucinations (113) and when it lasts longer than a couple of years belongs to the category of Severe Mental Illness (SMI) (1). Like other SMI a PD can cause—and is due to—serious impairments in social and/or occupational functioning, and need coordinated multidisciplinary care (1). Persons with a PD often experience failure and a sense of demoralisation, which is characterised by feelings of helplessness, incompetence, diminished self-esteem, hopelessness, entrapment, aloneness and meaninglessness (102). The treatment of this chronic condition is focussed on clinical as well as on personal recovery (25). Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (4).

The Illness Management and Recovery (IMR) program is a complex intervention that aims to help persons with a PD and other SMI's to develop personal skills for managing their mental illness and moving forward in their lives (31). The program includes five evidence based methods: psycho-education, cognitive-behavioural approaches to medication adherence, relapse prevention, social skills training and coping skills training (27,31). The IMR program is developed as a standardised curriculum-based program containing 11 modules concerning clinical and personal recovery (Box 1.).

The IMR program, which is tailored to individual needs, requires approximately nine months, when delivered in weekly sessions. Each session follows a uniform structure facilitating education of illness management skills and making progress towards recovery goals. The program is provided by IMR certified professionals and peer-support specialists (114).

Box 1. IMR Modules

1. Recovery Strategies
2. Practical Facts about Mental Illnesses
3. The Stress-Vulnerability Model
4. Building Social Support
5. Using Medication Effectively
6. Drugs and Alcohol Use
7. Reducing Relapses
8. Coping with Stress
9. Coping with Persistent Symptoms
10. Getting Your Needs Met in the Mental Health System
11. Healthy Lifestyles

In randomised controlled trials (RCT) (35–37) and in quasi-experimental trials (114–117) the IMR program has shown significant improvements in illness management, psychosocial functioning, knowledge about the illness and goal-setting skills (36). Next to the effectiveness of the IMR program, one wants to understand how this complex intervention enhances the recovery of persons with an SMI in order to reinforce this focus. Recently McGuire et al. investigated critical elements of the IMR program from the perspective of sixty-seven experts who rated 16 IMR elements (118). But, the call for qualitative analysis of complex interventions is growing, which allows in-depth exploration of the pathway of change and active ingredients which are too complex to be captured quantitatively (54). Only one study of the IMR program obtained qualitative data (93) which identified attributed improvements and the uniqueness of the IMR program. However, so far there is no study that provides insights about the active ingredients within the IMR program from the viewpoint of people with an SMI themselves and how the program exerts its effects. Because of our sample of persons with a PD, the aim of our study was to gain insights into the IMR program's ingredients that enhanced recovery from the perspective of persons with a PD, who completed the IMR.

Methods

A descriptive phenomenological design was used to explore personal retrospection on experiences with the IMR program. Phenomenological inquiry is an approach that can be used to examine and recognise the lived experience that is commonly taken for granted (119). The personal experiences were registered in one-to-one interviews with persons who attended the IMR program in the past.

Participants

Participants were recruited in one outpatient unit for persons with a PD in the Netherlands. All participants took part in one of three separate IMR-program groups that finished one, 13 or 19 months before the interview. Two certified IMR trainers, a mental health nurse and a peer-support specialist, provided the IMR groups. This outpatient clinic was audited in 2011 and evaluated with an excellent implementation score on the IMR Fidelity Scale and General Organisation Index (120).

Persons were included in the study when they met the criteria: having schizophrenia or another psychotic disorder (113), a period of two years since onset of the illness before they started the IMR program, and having completed the IMR program. We defined completers as having an attendance rate of at least 70%, as a 100% is not realistic in a weekly IMR-program group, which took approximately nine months. Persons with a lower attendance rate might have missed too many sessions and ingredients of the IMR program. After missing a session, participants received individual attention of a trainer to be able to catch up with the group again. Persons who experienced difficulties in communication due to substance use or psychotic experiences at the time of the interview were excluded from the study.

From the list of persons who attended the three separate IMR-program groups, the IMR trainers identified 14 potential participants meeting the in/exclusion criteria. These potential participants were asked to participate by their mental health nurse and received oral and written information about the study. The researcher phoned these persons to provide further information and made an appointment for the interview. A total of eight persons were willing to participate in this study.

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki. After consulting the Dutch Central Committee on Research Involving Human Subjects, we concluded that ethical approval was not obliged because participants did not receive treatment, nor were they asked to behave in a particular way (121). Approval for this study was obtained from the Board of Directors of the mental health organisation involved in this study. Before starting the interview participants signed an informed consent.

Data Collection

Open interviews were executed in the period of September 2013 - January 2014, with an average duration of one hour. Each interview was guided by a topic list, which was used as an Aide Mémoire, to guide the participants back when distracted from the main subject: the IMR program. The topic list was developed after reviewing recovery literature, a pilot interview and discussions within the research group. Two open questions were asked in each interview: "You have participated in an IMR program; how did you experience this program?" and "What does recovery mean to you?" Together with the participants, the interviewer took special attention to investigate whether or not experiences were the results of the IMR program. After the data analysis of the first three interviews, the topic list was modified in consequence of the first results. The interviews took place at the locations of the participants' preferences where they felt at ease; at home or in the outpatient unit. The interviewer ensured that the interview was not disturbed by a telephone call or another one's presence.

All interviews were voice recorded and transcribed verbatim. At the end of each interview the findings were summarised and checked with the participant to ensure that the accuracy of the experience was grasped.

Data Analysis

In this study, the Colaizzi's data analysis method was used as described by Holloway and Wheeler (122) and supported by the MAXQDA® computer software. The first step, following Colaizzi's method, started with a thorough reading and rereading of the transcripts in order to obtain a general idea about the whole content. The second step was the extraction of significant statements of each interview. The researcher (first author), a peer researcher (LvdM), and the supervising researcher (second author) coded the first three interviews independently and discussed their differences until consensus about the code text was reached. The two researchers independently coded three more interviews.

After analysing the sixth interviews, data saturation seemed to be achieved, which was confirmed in the two last interviews. Statements were formulated in significant codes, sorted into categories and clustered into themes. Different opinions were discussed with all researchers to clarify the categories and challenge subjectivity. The results were summarised in a thick description.

In the final step we executed a member check. Each participant received a document with the findings of the study and a summary of their own interview by e-mail or post. Seven out of eight participants responded and recognised themselves in the findings.

Authenticity, Trustworthiness and Credibility

Prior to conducting the interviews, the interviewer (WvL) described her own presuppositions in a logbook and discussed these with the research supervisor as a part of bracketing. A pilot-interview with a peer-support specialist was conducted, videotaped, and evaluated for critical reflection of the interview style. A logbook was kept throughout the entire research process, in order to record all the researcher's thoughts, reflections, ideas and observations. Data analysis including the records from the logbook have been discussed and supervised in order to enlarge dependability and credibility. Close attention was paid during data analysis to ensure every step could be traced back to the original data.

The 2nd up to the 5th author published multiple qualitative papers. Only the first author was not experienced in the phenomenological field. To be sure the first author performed the right approach we arranged a private course in qualitative research by an experienced teacher (SvdH).

Results

Participants

In total, eight participants participated in this study: four men and four women in the age range of 24 to 56 (Table 1). The participants completed one of three different IMR program groups, with an attendance rate of 70% - 100%. The IMR groups finished one, 13 or 19 months before the interview. All but one of the participants succeeded in finishing the IMR-program group. One participant missed the last two sessions because of getting a paid job, which didn't fit with the program schedule.

Table 1. Participants' characteristics

Participant	Age	Gender	Diagnosis	Number of months after completing the IMR program
1	36	male	Unspecified Psychosis	13
2	46	female	Schizophrenia	19
3	24	male	Schizophrenia	19
4	51	female	Schizoaffective disorder	13
5	56	male	Unspecified psychosis Delusional disorder	1
6*	30	female	Unspecified Psychosis	19
7	27	male	Unspecified Psychosis	19
8	45	female	Schizoaffective disorder	1

**missed the last two sessions*

Emergent Themes

In the interviews, participants described a number of IMR-program ingredients that enhanced their recovery. Five main themes emerged from the data. Two themes captured the skills the participants learned: goal-setting skills and symptom management skills. Three themes represented what contributed to learning these skills: sharing peer information, the IMR textbook, and practice.

Goal-Setting Skills

All participants mentioned that learning goal-setting skills in the IMR program was one of the most important achievements in their recovery process. Some participants said that before the IMR program, they did not know how to achieve their huge goals, like having paid employment, accomplishing a training, finding a partner, and restoring family links.

> *I always did put a lot of pressure on myself. The goals I had were far too big. (Participant 4)*

The IMR program taught them how to break down their huge personal goals into a number of shorter-term achievable goals and defining concrete and specific steps. At the start, the participants struggled with setting short-term goals because they were not used to doing this. The participants mentioned that the IMR program taught them how to achieve their goals by working step by step. They became aware that a goal could be achieved in different ways, and they could make a balanced choice about which way suited them best and set the first step.

> *It's all right to have a big goal, but if I don't make all the steps in between, I won't get there. (Participant 3)*

Most participants changed the way they set goals in their lives. They mentioned they continued to break down long-term goals into attainable proximal goals even after ending the IMR program 19 months ago.

> *Make things manageable. When I have a huge goal, it's complicated. I still divide this goal in smaller parts, that's how it becomes attainable. (Participant 7)*

Symptom Management Skills

Seven out of eight participants mentioned they learned more about how to manage their symptoms by identifying triggers and stress-vulnerability.

> *When I looked back during the IMR program, I realised I endured too much stress: problems in my relationship, difficult childhood, no sleep for three nights and still working … it became too much. (Participant 6)*

The IMR program provided knowledge and insight into how to prevent a relapse by recognising early symptoms, managing stress, and asking for support. Participants reported they experienced more grip in coping once they knew what to do when these symptoms reoccurred.

> *When I am tense, I have to do more physical exercise like walking. I have learned I get more relaxed that way. (Participant 8)*

> *Now, I don't do nightshifts anymore and I recognize the signs of a relapse. When I start to see different colors I call two friends and my nurse. (Participant 6)*

Sharing Peer Information

All participants mentioned sharing information with peers as a valuable element in their recovery process. Six participants stated that, before entering the IMR program, they didn't talk about their illness related experiences.

> *I didn't talk to people about my experiences. I thought about it of course but didn't talk about it with others. (Participant 5)*

> *There is a peer group for people with psychosis and schizophrenia, but I don't talk about my experiences there while drinking a cup of coffee. I just don't talk about it easily. (Participant 2)*

They mentioned the IMR program sessions to be the only places where they could talk openly about their illness related experiences. Participants mentioned this disclosure was a reassuring experience.

> *In the IMR program I finally could talk about what I experienced during my psychosis. (Participant 2)*

> *Talking about my psychotic episodes in the group felt more comfortable, compared to talking to people who don't have the same experiences. In doing so I could deal with my past. (Participant 3)*

Participants mentioned that talking about symptom experiences openly in the IMR program led to recognition, growing acceptance, and reconciliation of the illness. Psychotic experiences were no longer seen as an alien element of their own identity but as symptoms of an illness other people suffered as well.

> *During the IMR program I heard similar stories and my own experiences became less strange one way or the other, because I no longer was the only one … after all I am not the illness, I am a whole person and the illness is just a little part of who I am. … Due to the IMR program I have learned not to be ashamed about what happened to me. (Participant 3)*

Four participants mentioned that sharing experiences during the IMR program helped them to change their illness-dominated identity. In their own social environment participants experienced that symptoms were seen as deviant. They experienced the effects of stigma and self-stigma.

> *People reacted strangely when I told them about my experiences. They said I was wrong or abnormal, things like that. I still notice that some of these people don't trust me; they are worried what I might do. (Participant 2)*

Before attending the IMR program, three participants perceived of themselves as different compared to other people. They alienated themselves because they thought themselves to be the only people with psychotic symptom experiences.

> *I thought these weird things, you know … yes, I had some psychotic episodes. I thought I was the only one who experienced this. When I was back to normal I thought how strange my behaviour had been. Yes, totally strange, which made me feel uneasy. (Participant 5)*

The participants who didn't feel shame about their illness took the lead in disclosing experiences. But they too found it difficult in the beginning because of negative social responses in the past.

> *I told you before about people [from her own social context] who responded strangely after I told them about my experiences … in the IMR program this was different; they took me seriously and asked relevant questions, so I felt free to talk about my experiences. ... After that, more people started to talk. The trainer told me he appreciated I often took the lead in sharing my experiences. (Participant 2)*

Most participants appreciated the fact that the peer-support specialist shared his personal experiences. This role model paved the way for them to share their own experiences.

> *I appreciated that the peer-support specialist shared his on-going struggle. I admired his strength to work as a trainer while still experiencing difficulties. This made me learn too. (Participant 6)*

Participants mentioned that they appreciated the exchange of tips from peers about useful strategies to achieve their goals, cope with symptoms, and prevent relapse, which created hope for the future. These peers became role models. They said they also learned from the coping experiences of others.

> *The other participants gave me handy tips and tricks; we could share our experiences. Seeing others coping in different ways made me learn too. (Participant 7)*

> *… a lot of people in my group did voluntary work or had a fulltime job …. This confirmed my opinion that it is possible to get a job, even with my experiences. (Participant 6)*

> *He (the peer-support specialist) tried to help others with his experiences this gave me the strength to believe I could progress too…I wanted more than an eight hours voluntary work and enrolled in a job as trainee employee. (Participant 3)*

Participants appreciated the recognition, understanding and equality while sharing experiences with peers, which made them feel free to make their own decisions. They often missed this perceived freedom in sessions with professionals.

> *… Practitioners learned from what they have heard or read. Some knowledge you can only gain by experience … when a peer-support specialist tells about his experiences and actions, it is just like I feel more freedom to make my own choices. (Participant 7)*

The IMR Textbook

Six participants mentioned that the IMR textbook provided useful information, especially about practical facts of the illness, medication, the stress-vulnerability model and relapse prevention.

> *I thought it was good to read all the information in the textbook; to me this was a great help. For me the textbook was a kind of manual. Especially the information about psychosis, schizophrenia, medication and about recovery helped me. (Participant 1)*

> *To get the information about medication on paper was very useful. I could read about it in the textbook and then we talked about the medication with the psychiatrist and with the others. I have learned about the risk for a relapse; this is a lot higher when I don't take medication. (Participant 6)*

> *The textbook content broached the subject of personal illness related experiences. ... sometimes it is difficult to explain what happened to me, but now … because of the textbook it is easier for me to give words to my experiences … we talked about the information in the textbook, what I knew from my own life, my experiences. (Participant 5)*

Reading the practical facts about the illness mentioned in the textbook helped to change the idea of being the only one with psychotic symptoms.

> *I found out this illness exists more often, otherwise they don't write about it; that gave relief. (Participant 5)*

Practice

Six participants reported that they learned by practising skills in daily life, which was ensured by the structure of the IMR program. In every session there was continuous attention and reinforcement for progress of individual goals and steps made between the sessions.

> *I liked the whole structure of the IMR program with setting personal goals, working towards them and talking about your strategies and progress every session. (Participant 2)*

The first experiences of success generated positive feelings and hope. The feeling of being able emerged. Participants regained control of their life and self-confidence.

> *I wanted to try out the effect of getting out of bed early in the morning and taking my medication regularly. After a while I found out that doing this made me feel a lot better. This way I had more time to enjoy activities. … I started to play tennis with a friend; that kept me in shape and doing this I got more social contact. … I felt more competent to deal with negative consequences of my illness as losing my job, stress, isolation. I feel able to get on with my life …. This increased my self-confidence. (Participant 1)*

Discussion

Although the IMR program is internationally provided, this is the first descriptive phenomenological study on the experiences of persons with PD who completed the IMR program about how the IMR program enhanced their personal recovery. This study identified five main themes of IMR program ingredients that enhanced participants' recovery: learning goal-setting skills, symptom management skills, sharing peer information, the information from the IMR textbook, and practising skills.

Goal-Setting Skills

All participants in this study experienced learning goal-setting skills as one of the most important elements of the IMR program. They learned to set attainable goals, search for possible coping strategies, make a balanced choice, and set steps towards personal goals. Roe et al. (93) categorised goal setting as part of the program structure of the IMR. The participants in our study stated that goal setting has a more central place in the IMR program. Also in the study of McGuire et al. (118) goal-setting skills and follow up was identified as one of three critical elements of IMR. Identifying personal recovery goals, breaking them down into short-term goals, focussing on practice, and encouraging persons with an SMI to set the necessary steps is embedded throughout the whole IMR program (31). This is in accordance with what Latham and Locke (123) state: a clear focus on the goal, strategies, practice, and repeated evaluation of effort and progress leads to a higher performance. This could explain why the participants perceived learning goal-setting skills as very important for their recovery.

Symptom Management Skills

The psycho-educational elements in the IMR program improved the symptom-management. By getting more knowledge and insight in their symptoms, participants got more grip and were able to take adequate action in order to prevent relapses. This matches with the study of Roe et al. who mentioned that participants considered coping and self-management as an important domain of improvement (93).

The IMR program also aims for medication adherence and readapting to society. Because participants reported these experiences in relation to sharing peer information, the IMR-textbook, and practice, we did not report on these items as emergent themes.

Sharing Peer Information

All participants experienced sharing information with peers and the peer-support specialist as a valuable element of the IMR program. Sharing peer information led to reassuring disclosure experiences, and exchanging hopeful tips and tricks. Participants experiencing peer information made them change their illness perception, which stopped alienating tendencies in participants. They learned that experiences were no longer signs of being different, but symptoms of an illness. This could be related to the domain of social support within the group, which Roe et al. attributed as a unique component of the IMR program (93). Our findings provide a deeper explanation of this social support within the group. One aspect of sharing peer information was sharing illness related experiences with peers within the IMR program, which led to mutual recognition, understanding, feeling 'not being alone anymore', and resolving illness-dominated identities. With respect to the trainers, the peer-support specialist boosted this process by disclosing his own illness related difficulties. Our findings underline the reassuring effect of disclosure because the worry and concern over secrecy is reduced (124). Another aspect of sharing peer information is the effect of social comparison. This human tendency to compare oneself with others influences self-perception and self-esteem (125). Before attending the IMR program, participants compared themselves with others in healthy mental and social conditions. These others are their first reference group in which people often cannot or do not want to understand psychiatric symptoms. This can evoke feelings of alienation and self-stigma (126). Talking with peers about having psychotic features resolved this alienation because of the similar peer experiences to which they could compare themselves. The IMR program creates a sense of community and a new norm group for self-evaluation.

Sharing experiences with peers and a peer-support specialist also contained the aspect of modelling. Peers can enhance their value as pro-social models (127) as two participants in this study mentioned that peer models stimulated them to get paid jobs. This modelling in the IMR created a sense of hope for the future and overcoming the 'why-try' effect. In the 'why-try' effect, self-stigmatisation functions as a barrier to achieving life goals (3). Avoidance is used as a coping strategy for devaluation (124) and diminishes hope and future perspectives (128).

This finding does not match with the study of McGuire et al. in which the item 'enlisting mutual support' among group members was identified as an element of lower importance (meeting some essential and impactful criteria) (118). This might be due to the missing information in McGuire et al. about how the IMR program was performed: in group or individual sessions (118).

The IMR Textbook

The IMR textbook structured all the information, provided ideas, and broached several subjects to be discussed. For instance, medication was addressed in the IMR textbook and discussed with a psychiatrist, which strengthened insight in the role of medication adherence for relapse prevention. This finding matches with the study of McGuire et al. (118) in which the IMR curriculum was identified as a defining element of the IMR program. Roe et al. (93) also mentioned the IMR materials gave ideas of how to cope and that the workbook has a lot of potential to change things.

Practice

During the IMR program, participants observed peers practising new skills, exchanging ideas, sharing experiences of success and resolving illness-dominated identities, which encouraged them to take steps towards their personal goals. One participant mentioned improvement in social contact by experimenting in getting up early and starting to play tennis. The focus on practising skills in daily life, attaining personal goals and having reinforcement in the structure of the IMR program gave participants feelings of hope and regained control. This finding matches with the development of a sense of agency, which the illness often takes away. This sense of agency can be rediscovered when hope is fostered, strength is identified, and achievements are experienced (25).

Limitations

A number of limitations of the study should be noted. The first limitation is the trainer effect on findings while only two trainers within one unit trained the participants. The results of this study might have evaluated the trainers' roles instead of the IMR program. However, the excellent IMR fidelity rating of this centre increases the generalizability of the findings. The second limitation is the possible selection bias because trainers selected the potential participants, although selection criteria were clear. The third limitation is including only participants who completed the IMR program. Persons who dropped out of the IMR program could have reported other or negative experiences.

Conclusion

Programs for persons with schizophrenia and other psychotic disorders should contain education of goal-setting and symptom management skills, sharing peer information, the IMR textbook and a focus on practising skills to enhance their recovery. In the IMR program participants learned how to achieve recovery goals, found ways to prevent a relapse and defined a more personal identity apart from their illness. The findings underline the value of the IMR program's focus on exchange of peer information, which enables social comparison and modelling.

Practice Implications

Recovery programs that promote learning goal-setting skills, symptom management skills, and sharing peer information like the IMR-program should be promoted in the treatments for persons with psychotic disorders. These skills and peer information should also be incorporated in the daily work of all nurses working persons with PD. The efficacy of these potential changes should be evaluated on a regular basis. Encouraging the exchange of peer information enables social comparison and modelling, which can lead to changing illness-dominated identities. Without sharing experiences, the IMR program becomes a standard course and loses its power to reach a more positive identity. A peer-support specialist IMR trainer contributes to this focus and is of value because of the model he or she is representing.

Section I. Development and preparation of the e-IMR intervention

Chapter 4.

Investigating the reliability and validity of the Dutch versions of the illness management and recovery scales among clients with mental disorders.

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Abstract

Background

The Illness Management and Recovery scales (IMRS) can measure the progress of clients' illness self-management and recovery. Prior studies have examined the psychometric properties of the IMRS.

Aims

This study examined the reliability and validity of the Dutch version of the IMRS.

Method

Clients (n=111) and clinicians (n=40) completed the client and clinician versions of the IMRS, respectively. The scales were administered again 2 weeks later to assess stability over time. Validity was assessed with the Utrecht Coping List (UCL), Dutch Empowerment Scale (DES), and Brief Symptom Inventory (BSI).

Results

The client and clinician versions of the IMRS had moderate internal reliability, with α=.69 and α=.71, respectively. The scales showed strong test-retest reliability, *r* =.79, for the client version and *r*=.86 for the clinician version. Correlations between client and clinician versions ranged from *r* =.37 to .69 for the total and subscales. We also found relationships in expected directions between the client IMRS and UCL, DES, and BSI, which supports validity of the Dutch version of the IMRS.

Conclusions

The Dutch version of the IMRS demonstrated good reliability and validity. The IMRS could be useful for Dutch-speaking programs interested in evaluating client progress on illness self-management and recovery.

Introduction

The Illness Management and Recovery program was developed by integrating effective psychosocial interventions to teach clients with severe mental illness techniques to manage mental illness and work towards recovery (27,129). The Illness Management and Recovery program has been proven effective in randomized controlled trials (35–37) and in quasi-experimental trials (114–117).

Along with the program, scales were developed to evaluate the effectiveness of the program. The Illness Management and Recovery Scales (IMRS) (32) were designed to measure progress in activities and outcomes considered to be related to the program, including knowledge about the illness, social support, medication adherence, relapse prevention, coping and substance abuse. These domains can be monitored from client and clinician viewpoints using parallel versions of the same scale. Overall the IMRS have shown moderate to good internal reliability, test-retest reliability, and reasonable support for convergent validity (130–132).

Although each scale is used as a one-dimensional measure, the IMRS were initially developed to measure recovery progress in multiple domains. In their psychometric study Hasson-Ohayon et al. (131) identified three dimensions in the IMRS: 1) ‘Coping’ - the extent to which the clients coping reduces symptom relapse, symptom distress and impairment of functioning; 2) ‘Knowledge and Goals’ - the extent to which the client is skilled in obtaining knowledge about the illness and is able to set and strive for personal goals; and 3) ‘Medication’ - the extent to which the client is using medication effectively and is able to reduce the abuse of alcohol and drugs. A recent study supported the existence and reliability of three factors, but only examined the clinician version. Sklar et al. (133) showed a similar factor structure to that of Hasson-Ohayon et al. (131) on the IMRS clinician version. However, a few items loaded differently and they changed the naming of the factor structure to ‘Management’, ‘Recovery’ and ‘Substance’, corresponding to the factors ‘Coping’, ‘Knowledge and Goals’ and ‘Medication’ of the Hasson-Ohayon et al. (131) study respectively.

In addition to factor structure, some studies have examined the correspondence between client and clinician report. Three studies (130–132) found low to moderate correlations between client and clinician perspectives (ranging between .23 and .58), suggesting that the scales may be tapping different dimensions or perspectives of recovery. For example, Hasson-Ohayon et al. (131) found subtle differences that suggest that the client perspective might be more related to coping whereas the clinician perspective is more focused on the self-management aspect of recovery.

In terms of convergent validity, IMRS have been linked to a variety of constructs in the expected direction, including symptoms (rated by self or others), perception of recovery, quality of life and coping (130–133). Given the focus of the Illness Management and Recovery program on managing illness, determining the relationship with empowerment, symptom distress, and coping would appear particularly salient. Hasson-Ohayon et al. (131) assessed coping as a one-dimensional construct with the Coping Efficacy Scale (CES) (134) and showed that more efficacious coping was related to higher scores on the IMRS. However, coping was assessed specifically in terms of how clients were dealing with symptoms. Previous research suggests that coping can be a cognitive style or trait of how people deal with problems beyond symptoms, and different coping styles have been identified (135). Despite criticism to the approach vs. avoidance dichotomy (136), a passive avoidant coping style is most strongly associated with severity of mental health problems, across a range of mental health conditions (137–141). Given the strong link between coping and illness management and recovery skills, one would expect that efficacious coping with symptoms and less passive avoidant coping would be associated with better scores on the IMRS.

The Illness Management and Recovery program is currently being implemented in the Netherlands, and although English, Swedish, and Hebrew versions of the IMRS have been developed and evaluated (130–133), a Dutch psychometric study is currently lacking. Before using the IMRS in a Dutch population, its psychometric qualities should first be established, including how the total IMRS and underlying dimensions relate to measures of self-management and coping. The aim of this study was to investigate the psychometric properties of the Dutch version of the IMRS from perspectives of both clients and clinicians. Because of the emphasis of the Illness Management and Recovery program on coping skills and self-management skills, and prior differences between the client and clinician versions of the IMRS, we examined the relationship between the client and clinician IMRS and explored the relationship of the IMRS with measures of coping and self-management.

Method

Participants

Participants were 111 adults recruited from one of two psychiatric institutes in the Netherlands providing regular supportive housing or outpatient care. Participants were not attending an Illness Management and Recovery program. Clients were recruited by posters and information provided by clinicians. Inclusion criteria were: age 18 – 65 years, a good understanding of the Dutch language, and a diagnosis of a mental disorder made by a psychiatrist according to the DSM-IV criteria (see Table 1 for an overview of participants' demographic characteristics). Also, participants had to be able to provide informed consent, and psychiatrically stable enough to participate in the study as assessed by the case manager.

Clinicians

Forty case managers working in the same psychiatric institutes were asked to fill out the clinician version of the IMRS for his or her participating client (ranging from 1 to 8 clients per clinician). No personal data was collected from the clinicians.

Instruments

IMRS. The IMRS include parallel client and clinician versions (32). Each version contains 15 items, rated on a 5-point scale. The client and clinician version of the IMRS were double translated into Dutch and back translated by a native speaker into English to control for translation accuracy and validity. Differences between the translations were discussed with two experts in the field of IMR. All changes were made involving the original author Kim Mueser in the decision making process.

The designers of the original IMRS used a one-dimensional scale summing or averaging items into a total score. In accordance with Salyers et al. (132), we used a mean instead of sum for our analysis. Previous psychometric studies found a strong to moderate internal reliability ranging form .82 to .55 for the client version of the IMRS (131–133), and .73 to .80 for the clinician version (131,132). We based our calculations on the factor analysis from Sklar et al. (133), using the factor Recovery (items 1, 2, 4, 8 and 12), Management (items 6, 7, 9 and 11) and Substance (item 14 and 15). We chose the Sklar et al. (133) factors because of good fit in their study, and we agreed with the rationale for adding item 12 to the Recovery Factor and excluding item 13 from the Substance Factor.

Coping. The Utrecht Coping List (UCL) (135) was administered to measure client coping style. The UCL is a 47-item questionnaire measuring seven different coping styles: active approach, palliative reactions, avoidance/abide, searching for social support, passive coping, expression of emotions, and using reassuring and comforting thoughts. Cronbach's alpha levels indicate good internal reliability for the subscales of the UCL ranging from .67 to .82, and previous research has shown support for adequate concurrent validity (135). In our sample the Cronbach's alpha of the subscales of the UCL ranged from .67 to .86.

Recovery. The Dutch Empowerment Scale (DES) (Nederlandse Empowerment Lijst) (142) is a self-report questionnaire to determine the degree of empowerment in psychiatric clients. The DES consists of 40 items tapping six dimensions: professional support, social support, headstrong, belonging, self-management, and involved community. Each item is rated from 1= strongly disagree to 5 = strongly agree. A psychometric study of the DES showed good internal consistency (Cronbach alpha = .93) and correlations with other measures indicating acceptable construct validity (142). In our sample the Cronbach's alpha of the DES was .86.

Symptom List. The Brief Symptom Inventory (BSI) is a self-report questionnaire to assess psychopathology (143). The BSI consists of 53 items covering a broad range of psychosocial problems. Each item is rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). Additionally, the BSI also measures three global indices of distress, the Global Severity Index, measuring the overall psychological distress level, Positive Symptom Distress Index, measuring the intensity of the experienced symptoms, and the Positive Symptom Total, measuring the total number of symptoms. Prior studies show good internal reliability for the subscales of the BSI ranging from .63 to .89 and good support for concurrent validity (143,144). The focus of the

BSI is on experienced stress and not on actual number of symptoms. In our sample the Cronbach's alpha of the subscales of the BSI ranged from .77 to .91.

Procedure

The study was conducted in accordance with the declaration of Helsinki. However, according to Dutch legislation full ethical approval was not obliged because participants did not receive treatment or asked to behave in a particular way (www.ccmo.nl/en/). Data collection was not related to an intervention study. Only questionnaires were administered, and those "would not in principle come within the scope of the Act, unless either the frequency with which a subject was asked to complete a questionnaire were sufficient to bring about a temporary change in the subject's lifestyle or the (psychologically probing) nature of the questions were such that the subject could be regarded as having received a particular treatment or having been asked to behave in a particular way." Approval for this study was obtained via the management boards and the client council of the institutes.

Clients were recruited for participation in the study by their case managers and with information leaflets and posters that were presented at the different health care locations. Client and their case managers both completed the IMRS at a two-week interval. Clients also completed the other measures at Time 1. Case managers and researcher coordinators were present for instruction and questions concerning the study.

Analysis

We used SPSS version 20 (145) to examine the IMRS on internal reliability, test-retest reliability, and concurrent validity. Confirmatory factor analysis was not appropriate because of the small sample size. First, internal reliability was examined by calculating Cronbach's alpha on the total IMRS score and for each of the subscales. Test-retest reliability was examined by Pearson's correlations calculated between the two administrations. We also examined Pearson's correlation between the clinician and client versions of the IMRS to examine the level of correspondence between them.

Pearson's correlations were also calculated between all measures (BSI, UCL, and DES) and the total IMRS score and the IMRS subscales to examine construct validity.

Because passive coping and avoidance style have been associated with mental health problems and decrease of self-efficacy (137,138,146) we expected negative correlations with passive coping and avoidance coping style and positive correlations with active coping style for the IMRS-Total and the IMRS-Management factor. We also expected high correlations between the IMRS total score and the DES dimensions of headstrong, belonging and self-management. At the subscale level, we expected self-management to be strongly related to the IMRS-Management factor, and we expected social support, headstrong and belonging to be related to the IMRS-Recovery factor. As professional support is aimed at the caregiver perspective on recovery, and involved community is aimed at the perspective of society, we expected close to zero correlations between the IMRS total score and the DES' dimensions professional support and involved community, which will demonstrate divergent validity. We expected that clients showing more recovery and self-management would score lower on experienced distress (i.e. negative correlations between IMRS total score and the BSI total and subscales and the UCL avoidance abide and passive coping.

Table 1. Demographic characteristics of the participants

Variables	N	%	Variables continued	N	%
Psychiatric diagnosis	111		Employment	103	
Pervasive development disorder	21	18.9	Paid job	21	20.4
			Volunteer	22	21.4
Attention disorder	2	1.8	Education	4	3.5
Personality disorder	13	11.7	Adult Day Care program	21	18.6
Anxiety disorder	5	4.5			
Mood disorder	8	7.2	None	35	34.0
Psychotic disorder	11	9.9	Income	102	
Mental retardation	1	.9	Salary	22	21.6
Addiction	3	2.7	Paid benefits	78	76.5
Axis II and Axis I combined	25	22.5	Scholarly benefits	2	2.0
Multiple Axis I diagnoses	11	9.9	Born in the Netherlands	105	
Other/Not specified	11	9.9			
Gender	108		Yes	98	93.3
Male	55	48.7	No	7	6.7
Female	53	46.9	Independent living	105	
Education	101		Yes	88	83.8
Primary School	11	10.9	No	16	15.2
Lower Secondary	43	42.6			
Upper Secondary	11	10.9			
Post-secondary non-tertiary	22	21.8			
Bachelor-Master or equivalent	14	13.9			

Results

Internal reliability

Cronbach's alpha using all the items was α=.61 for the client version and α = .69 for the clinician version of the IMRS. When excluding item 13 (regarding medication use) from the reliability analysis, internal reliability improved, with Cronbach's α=.69 for the client version and Cronbach's α=.71 for the clinician version. We omitted item 13 from the remainder of the analyses. Because 18% of respondents omitted item 13 we examined diagnoses to better understand the omission: nine had a pervasive development disorder, four had a personality disorder, one had attention deficit

Table 2. Pearson correlations between the clients and clinician total IMRS and factors

Diagonals between parentheses represent internal reliability coefficients.	Client IMRS-Total	Client IMRS-Management	Client IMRS-Recovery	Client IMRS-Substance	Clinician IMRS-Total	Clinician IMRS-Management	Clinician IMRS-Recovery	Clinician IMRS-Substance
Client IMRS-Total	(.69)							
Client IMRS-Management	.74**	(.77)						
Client IMRS-Recovery	.78**	.35**	(.53)					
Client IMRS-Substance	.33**	.04	.12	(.57)				
Clinician IMRS-Total	.63**	.51**	.56**	.11	(.71)			
Clinician IMRS-Management	.61**	.66**	.46**	.04	.78**	(.74)		
Clinician IMRS-Recovery	.45**	.32**	.51**	-.07	.80**	.46**	.(28)	
Clinician IMRS-Substance	.08	-.10	.09	.37**	.40**	.15	10	(.61)

IMRS: Illness Management and Recovery Scales; **p<0.01

disorder, one had a diagnoses deferred on Axis II, and two had 'other conditions that my be a focus of clinical attention'.

Of the three subscales, only IMRS-Management showed acceptable Cronbach's alpha levels, with α = .77 and α = .74 for the client and the clinician versions respectively. All other alpha levels were questionable to poor for all subscales (see Table 2 for exact values).

Test-retest reliability

Correlations between two week administrations showed strong test-retest reliability with r =.79, p<0.001 (n=92) for the client version of the IMRS and r =.86, p<0.001(n=89) for the clinician version of the IMRS. Test-retest reliability was also strong for all subscales except for the client subscale Recovery and Substance with r =.64, p<0.001 (n=92) and r =.67, p<0.001(n=85), respectively.

Correlations between clinicians and clients on the total and subscale scores of the IMRS

Table 2 shows the correlations between clients and clinicians on the IMRS total and subscale scores. Overall, client and clinician versions were significantly correlated for the total and subscale scores. The client and clinicians ratings on Management (r =.66) correlated higher than their ratings on Recovery (r =.51). The magnitude was much lower for the subscale Substance (r = .37).

Table 3. Pearson correlations between the Utrecht Coping List and the IMRS

	active approach	palliative reactions	avoidance abide	searching for social support	passive coping	expression of emotions	reassuring comfortting thoughts	UCL Total
Client IMRS-Total	.39**	.08	-.37**	.20*	-.46**	-.01	.20*	-.01
Client IMRS-Management	.22*	-.05	-.37**	.03	-.66**	-.06	.18	-.22*
Client IMRS-Recovery	.33**	.19	-.18	.28**	-.17	.12	.12	.17
Client IMRS-Substance	.20*	.04	-.10	.14	-.16	-.09	.19	.06
Clinician IMRS-Total	.21*	.04	-.17	.09	-.19	-.00	.06	.01
Clinician IMRS-Recovery	.19	.09	-.11	.11	-.15	.03	.06	.04
Clinician IMRS-Management	.17	.04	-.17	.07	-.34**	.02	.02	-.07
Clinician IMRS-Substance	-.06	-.14	.02	.07	.12	-.00	-.07	-.01

IMRS: Illness Management and Recovery Scales; *p<0.05 **p<0.01

Construct validity

Correlation with UCL. As shown in Table 3, as hypothesized, there were moderate to strong correlations between the client rated IMRS total scale, IMRS-Management, and IMRS-Recovery scales and the UCL coping dimensions of active approach, avoidance, and passive coping. However, the clinician scales performed differently. The clinician-rated IMRS total scale was associated with client reports of active approach, but not with avoidance and passive coping. The clinician subscale IMRS-Management was negatively associated with passive coping, but no association was found with active approach and avoidance coping.

Correlation with DES. As expected, and shown in Table 4, the client IMRS total score correlated significantly with the DES dimensions Belonging, Self-management, and Total score. Unexpectedly, a moderate significant correlation was also found with Involved Community (r = .37; p< .01). The Client IMRS-Management subscale correlated highest with DES Self-management, and the Client IMRS-Recovery subscale correlated highest with the DES dimension Belonging.

Clinician IMRS total score correlated with Self-management, Involved community and Total score. The Clinician IMRS-Management subscale correlated highest with Self-management and the Clinician IMRS-Recovery subscale correlated highest with Involved Community.

Correlation with BSI. Moderate to strong negative correlations were found between IMRS total score, both client and clinician versions, with the BSI scales. IMRS client total score showed a significant relationship with the Global Severity Index and the number and severity of symptoms (see Table 5). The client IMRS-Management subscale also correlated strongly negatively with these indices, whereas the IMRS-Recovery and IMRS-Substance subscale correlations were weaker.

Table 4. Pearson correlations between the DES and the IMRS

	Professional support	social support	Head-strong	Belonging	self-management	involved community	DES Total
Client IMRS-Total	.03	.23*	.06	.52**	.50**	.37**	.54**
Client IMRS-Management	-.06	.19	.16	.35**	.49**	.40**	.50**
Client IMRS-Recovery	.01	.13	-.01	.39**	.35**	.23*	.36**
Client IMRS-Substance	.07	.00	.00	.17	.12	.08	.08
Clinician IMRS-Total	.07	.23*	.03	.23*	.34**	.35**	.36**
Clinician IMRS-Management	.03	.15	.14	.18	.36**	.28**	.33**
Clinician IMRS-Recovery	.03	.25*	-.06	.24*	.30**	.33**	.33**
Clinician IMRS-Substance	.17	.03	-.21	-.07	-.07	-.01	-.01

DES: Dutch Empowerment Scale; IMRS: Illness Management and Recovery Scales; * $p<0.05$ **$p<0.01$

IMRS clinician total score also showed a significant, albeit weaker, relationship with Global Severity Index and the number and severity of symptoms. Clinician IMRS-Management subscale also correlated strongly negatively with these indices, whereas IMRS-clinician Recovery subscale correlations were weaker. Clinician-rated IMRS-Substance was not significantly associated with any of the BSI scales.

Table 5. Pearson correlations between Brief Symptom Inventory (BSI) and IMRS

	Positive Symptom Total	Positive Symptom Distress Index	Global Severity Index
Client IMRS-Total	.51**	.58**	.58**
Client IMRS-Management	.54**	.57**	.60**
Client IMRS-Recovery	.28*	.34**	.33**
Client IMRS-Substance	.16	.29**	.23*
Clinician IMRS-Total	.29**	.33**	.38**
Clinician IMRS-Recovery	.24*	.29*	.32*
Clinician IMRS-Management	.37**	.35**	.39**
Clinician IMRS-Substance	.01	.05	.04

* $p<0.05$ **$p<0.01$

Discussion

The aim of this study was to evaluate the psychometric properties of the Dutch translation of the IMRS. Our results support the reliability and validity of the Dutch version of the IMRS, similar to prior studies on the psychometric properties of the English (132,133), Hebrew (131), and Swedish (130) versions of the IMRS.

The Dutch translations of both the client and clinician version of the total IMRS scores had strong test-retest reliability and reasonable internal consistency, somewhat similar to previous psychometric studies. The internal consistency varied between client and clinician and also differed because of frequent omission of item 13 on medication use in our study sample. Without item 13, the internal consistency for the total score increased to an acceptable level, for both versions of the questionnaire. We found moderate correlations between the total scores of the client and clinician versions, similar to those found by (130). Lower correlations between the client and clinician versions were found by Hasson-Ohayon et al. (131), and Salyers et al. (132). Differences in client and clinician ratings are similarly found in other areas (147), posing the question of which perspective is more accurate or whether both are accurate. Future research could include qualitative investigation to better understand differences between clients and clinicians in how they use the IMRS.

When considering subscales, only IMRS-Management showed adequate internal consistency, and the IMRS-Recovery and IMRS-Substance showed moderate to low internal consistency for both versions of the scale. However, Cronbach's alpha coefficient is dependent upon the number of items used in its calculation. Due to the small number of items (respectively 3 and 2) of the two scales we considered their internal consistency acceptable. Our results contrast with Sklar et al. (133) who showed an internal consistency of .83 for the items in IMRS-Management, .76 for the items in the IMRS-Recovery and .69 for the items in the IMRS-Substance for clinicians. Hasson-Ohayon et al. (131) found values ranging from .47 to .83 for these subscales. However direct comparisons are difficult because of the different items that were used for the IMRS-Substance and IMRS-Recovery and the fact that Sklar et al. (133) studied the clinician version only. Cronbach's alpha levels, due to differences in variances between large and small samples, could also be related to the sample size of the studies (148). Sklar et al. (133) included 9,142 clients for the reliability analysis. Therefore, our study may underestimate internal consistency due to the smaller sample size.

Searching for another explanation for the moderate to low internal consistency of the IMRS subscales, we executed post-hoc analyses. A post-hoc analyses of the subscale Recovery identified item 12 on involvements with self-help activities as the most problematic. However, deleting this item resulted in little improvement (client version improved from .53 to .56 and in the clinician version improved from .61 to .66).

Another post-hoc analysis showed that clients who omitted item 13 scored higher on the mean score of all remaining items of the IMRS than clients who completed all items. It is likely that clients omitted item 13 because no medications were prescribed to them given the majority of respondents' diagnoses (e.g., pervasive development disorders, personality disorders may not have medications prescribed. Similarly, the IMRS-Substance items 14 and 15 might also appear problematic because there is no clear option for consumers to score when they want to report no problematic use of alcohol or drugs. We suggest adding an option in items 13, 14, and 15 in which clients can report no medication is prescribed to them and that they do not use alcohol and drugs, which would be scored a 5. Adding these options might clear possible misunderstanding for respondents and improve the internal consistency of the IMRS subscales.

The IMRS-Total scale scores showed reasonable support for concurrent validity. As expected, there was a relation with coping on the UCL, showing that clients scoring high on the IMRS also reported more active coping styles. Our results are consistent with Hasson-Ohayon et al. (131) and extend their results by showing a relationship between coping styles, particularly passive coping and avoidance style, which are associated with mental health problems and experienced burden (149). On the other hand the differential patterns of correlations we found between the clinician rated IMRS (IMRS total scale and IMRS-Management) and the active, avoidance, and passive coping styles support Skinner's et al. (136) criticism on the approach vs. avoidance coping styles cannot be the extremes of one action category.

The IMRS total scale score correlated significantly with several DES scales as expected. However, although we predicted that IMRS would not be related to the Involved Community, this subscale actually was correlated with the IMRS. It might be that when clients have a greater feeling of acceptance from the community, they need less social support and are less dependent on actively seeking help from others. Future research of the total IMRS should focus more specifically on how social support and feeling of empowerment is related to clients' recovery.

The medium to strong correlations between the IMRS and the BSI are promising. Self-reported overall psychological distress, as well as the number and intensity of symptoms were related lower scores on the IMRS total scale and IMRS subscales. These findings are in line with results from Stewart and Kopache (150) who show that patients who are recovering well from their illness also show less symptom distress.

Our study included a relatively small sample of psychiatric clients, which limits generalizability and our ability to conduct confirmatory factor analyses. In addition, our study showed lower internal reliability on the subscales than in the prior sample using similar scoring (133). Generally low internal reliability on a scale puts an upper limit on correlations that one might find with the scale. However, even with lower reliability, some of the subscales showed significant correlations with other variables supporting validity of the constructs. Further research in a larger sample is necessary to determine the confirmatory factor structure of the Dutch translation of both the client and the clinician version of the IMRS.

Conclusion

Overall our study shows that the Dutch version of the client and clinician IMRS has good test-retest reliability, acceptable internal reliability and medium to strong client clinician reliability, particularly when used as a one-dimensional scale. The lower reliability of the subscales and the poor functioning of the IMRS-Substance subscale suggest caution in using the subscales. This study also shows new evidence for the concurrent validity of the IMRS, extending to additional measures. Our findings support the Dutch version of the IMRS for use in evaluating recovery-orientated care in the Netherlands or other Dutch-speaking locales. However, further research is needed to determine whether subscales can be used.

Section I. Development and preparation of the e-IMR intervention

Chapter 5.

Development of an E-Supported Illness Management and Recovery Program for Consumers with Severe Mental Illness Using Intervention Mapping, and Design of an Early Cluster Randomized Controlled trial.

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Abstract

Background:

E-mental health is a promising medium to keep mental health affordable and accessible. For consumers with severe mental illness the evidence of the effectiveness of e-health is limited. A number of difficulties and barriers have to be addressed concerning e-health for consumers with severe mental illness. One possible solution might be to blend e-health with face-to-face delivery of a recovery-oriented treatment, like the Illness Management & Recovery (IMR) program. This paper describes the development of an e-health application for the IMR program and the design of an early clustered randomized controlled trial.

Method/Design:

We developed the e-IMR intervention according to the six-step protocol of Intervention Mapping. Consumers joined the development group to address important and relevant issues for the target group. Decisions during the six-step development process were based on qualitative evaluations of the Illness Management & Recovery program, structured interviews, discussion in the development group, and literature reviews on qualitative papers concerning consumers with severe mental illness, theoretical models, behavioural change techniques, and telemedicine for consumers with severe mental illness. The aim of the e-IMR intervention is to help consumers with severe mental illness to involve others, manage achieving goals, and prevent relapse. The e-IMR intervention consists of face-to-face delivery of the Illness Management & Recovery program and an e-health application containing peer-testimonials on videos, follow up on goals and coping strategies, monitoring symptoms, solving problems, and communication opportunities.

We designed an early cluster randomized controlled trial that will evaluate the e-IMR intervention. In the control condition the Illness Management & Recovery program is provided. The main effect-study parameters are: illness management, recovery, psychiatric symptoms severity, self-management, quality of life, and general health. The process of the IMR program will be evaluated on fidelity and feasibility in semi-structured interviews with participants and trainers.

Intervention Mapping provided a systematic procedure for the development of this e-health intervention for consumers with severe mental illness and the preparation of an early randomized controlled trial.

Introduction

Dutch policy makers proclaimed the development of e-mental health to be a cornerstone of their policy to keep mental health affordable and accessible in the future. E-mental health applications hold promise to expand access to care (43), and they are expected to be efficient both economically and socially (42). Current applications are most frequently aimed at adults with depression or anxiety disorders and some interventions have demonstrated effectiveness in early trials (43).

For consumers with severe mental illness (SMI) the evidence of the effectiveness of e-health is limited (48). According to Delespaul (1) consumers with SMI are diagnosed with a psychiatric disorder that causes—and is due to—serious impairments in social and/or occupational functioning, which last longer than at least a couple of years, and necessitates coordinated multidisciplinary care. E-health interventions for consumers with SMI are considered to have potential for delivering effective education (47,151). But, a number of difficulties and barriers have been addressed concerning e-health for consumers with SMI, e.g. cognitive impairments and lower technology experience (152). Ben-Zeev et al. (48) advises that future development of e-health interventions must be coupled with examining barriers and possible solutions. One possible solution might be to blend face-to-face and e-health delivery of recovery-oriented treatment programs. This blending is considered to be the most optimal practice to non-SMI consumers (45).

An evidence-based recovery-oriented intervention is the Illness Management & Recovery (IMR) program (31), which has proven effectiveness in three random controlled trials in different countries (35–37). The IMR program is a standardized curriculum-based approach designed to provide consumers with SMI information and skills necessary for managing their illnesses effectively and working towards achieving personal recovery goals (31). The educational material is a hard copy textbook organized in eleven modules (See Box 1). IMR was introduced in the Netherlands in 2009 and is mostly co-facilitated by a peer-support specialist and a psychiatric nurse.

We developed an e-health supported Illness Management & Recovery program (e-IMR intervention), which blends the possibilities of e-health and the standard face-to-face delivery of the IMR program. In this paper we describe the development of the e-IMR intervention and how we will evaluate this intervention.

Methods/Design

Developing the e-IMR intervention

The development of the e-IMR intervention followed the six steps of the Intervention Mapping protocol (IM), a systematic approach to develop health promotion interventions (52). IM helps the development of more effective behavioural change interventions (153) and has successfully been used for the development of various health programs (154–156). Table 1 shows the six IM steps with their objectives and the used methods. During the development process we presented the results to five IMR-experts (see acknowledgement) and they confirmed the results.

Table 1. Intervention Mapping steps, objectives and methods

Steps		Objectives	Methods
1.	Needs Assessment	Gain insight into health problems and underlying determinants of consumers with SMI;	Problems analyses using PRECEDE model; Resources: • Qualitative literature • Internet forum discussions • IMR resources and literature • Development group discussions
2.	Preparing Matrices of Change Objectives	Set intervention outcomes; Specify performance objectives and changeable determinants; Identify proximal change objectives;	Content analyses; Resources: • Qualitative literature • Internet forum discussion • IMR resources and literature • Development group discussions
3.	Selecting Theory-Informed Intervention Methods and Practical Implications	Identify and select theoretical models; Select methods that address change objectives; Select evidence-based interventions and design of practical implications;	Content analyses; Resources: • Literature on behavioural change theories • IMR resources and literature • Qualitative IMR evaluation • Literature on telemedicine and SMI • BCT Classification
4.	Producing Program Components and Materials	Compile an intervention;	Choosing an e-health platform partner; Constructing and pretesting the e-IMR intervention; Resources: • Literature on telemedicine and SMI
5.	Planning Program Adoption and Implementation	Preparing implementation;	Resources: • Literature on telemedicine and SMI • Interviewing consumers on computer literacy (n=52)
6.	Planning for Evaluation	Setting up an evaluation plan;	Designing an early RCT; Resources: • The MRC guideline • Literature on questionnaires

SMI: Severe Mental Illness; PRECEDE: Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation; IMR: Illness Management & Recovery program; BCT: Behavioural Change Techniques; RCT: Random Controlled Trial; MRC: Medical Research Council

Step 1: Needs Assessment

The intervention mapping protocol starts with assembling a development group to assure that the project addresses important and relevant issues for the target group (52). Our group consisted of six consumers with SMI who previously completed the IMR program, an informal caregiver, and two professionals acquainted with the IMR program, of which one is a peer support specialist. Two researchers (TB, BvG) completed the group. The group members brought in their own knowledge, based on experience, profession, or science and thus contributed to group discussions and brainstorm sessions.

Further, the aim of this step is to get insight into health problems and underlying determinants of consumers with SMI. Therefore, we used a number of methods. 1.) We reviewed literature on health problems of consumers with SMI. The MEDLINE, PsychINFO, EMBASE, and CINHAL databases were searched for articles between 2003–2013, retrieving 42 eligible papers. Only qualitative papers were included to be able to stay close to what consumers reported themselves. 2.) We searched on Google for consumers' testimonials in Dutch Internet forums where people with SMI share their problems and needs with peers. 3.) We studied IMR resources (31,157). 4.) We discussed the findings in the development group.

To analyse all the data, we used the PRECEDE model (158) to relate health problems to consumers' health behaviour and their determinants, and environmental factors and their determinants. We identified three important health problems that are influenced by the consumers' behaviour and environmental factors, including caregivers' behaviour and their determinants (See Figure 1). The health problems of consumers with SMI are isolation, relapse of psychiatric symptoms, and hopelessness. Members of the development group stated that these problems are intertwined.

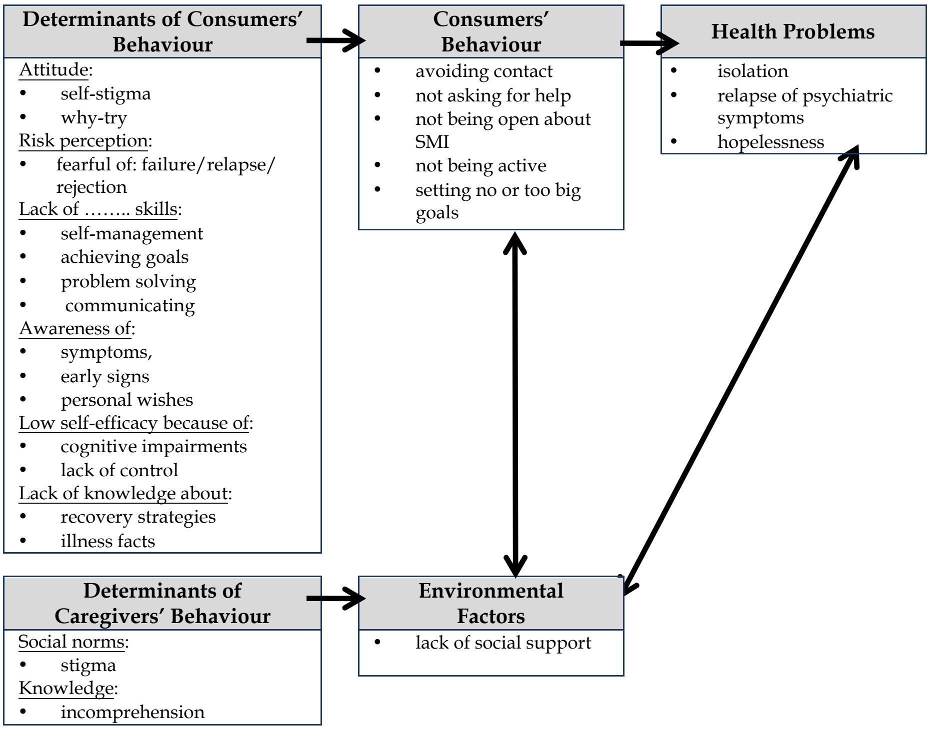

Figure 1. PRECEDE model of health problems of consumers with SMI

Isolation is described as feelings of exclusion and loneliness. Consumers report feelings of having no one to talk to about their problems and feelings of being misunderstood by other people. Consumers are susceptible for relapse of being overwhelmed by psychiatric symptoms like anxiety, depression, mania, and psychosis. This is related to an unstable balance between their biological vulnerability and stress. Problems with hopelessness are described as having a life that is marked with suffering and limitations, never-ending uncertainties, feelings of uselessness, and meaningless.

The underlying consumers' behaviour that causes—and is due to—these health problems are avoiding contact with others, not asking for help, and not being open about issues related to their SMI, resignation such as choosing not to be active, and setting no goals at all or unrealistic goals for the future. These behaviours have determinants in common. The first determinant is attitude, like self-stigma and 'why try' (3). Self-stigma includes feelings of shame, being different, or being the only one with a SMI. The 'why try' attitude is characterized by the question 'why should I try?', which affects goal-related behaviour. The second determinant is risk perception, like fear of being rejected by others, expecting to fail, and fearing relapse. The third determinant is the lack of skills, such as skills to cope with symptoms, skills to set and achieve recovery goals, problem-solving skills, and communicating skills, e.g. how to tell people about their condition. The fourth determinant is awareness. Consumers have difficulties in recognizing early warning signs and lost awareness of things they would like to achieve. The fifth determinant is self-efficacy, influenced by cognitive impairments, such as little concentration and attention, and the lack of control or mastery over one's behaviour. The last determinant is lack of knowledge about the illness and recovery possibilities.

The main environmental factor that influences behaviour problems is lack of social support, such as lack of acknowledgement and ineffective encouragement. Often consumers get infeasible suggestions of how to solve problems. This is determined by the social norms related to stigma and lack of knowledge that causes incomprehension. Other people cannot understand the difficulties that come along with experiencing psychiatric symptoms.

Step 2: Preparing Matrices of Change Objectives

The second step aimed to identify the intervention objectives. First, we described the behavioural outcomes. Second, we formulated performance objectives and their changeable determinants of what consumers need to do to attain the outcomes. Next, we created a matrix by crossing performance objectives with determinants and change objectives. The change objectives describe what consumers need to learn to execute the performance objectives. For this purpose we studied the same resources as in the first step, and searched for descriptions of healthy behaviour that could be linked to the results of the first step and discussed in the development group.

Table 2. Matrix of behavioural outcomes, performance objectives, determinants, and proximal change objectives

Behavioural Outcomes	Performance Objectives	Personal Determinants and the Related Proximal Change Objectives				
		Knowledge	Perceived Norms	Attitude	Skills /Self-Efficacy	Awareness /Outcome Expectation
Having connections with other important people	Disclose about having a SMI	Lists people that respect him or her;	Recognize others need information to understand his or her SMI;	Acknowledge equality to others; Acknowledge stigma in others;	Express confidence in ability to explain to others about his or her SMI; Express confidence in ability to solve problems related to social relations;	Expect disclosure will neutralize isolation;
Achieving personal recovery goals	Plans and executes attainable steps to achieve personal recovery goals	Defines what recovery means to him or her; Identifies personal long-term recovery goals; Identifies short-term goals and attainable steps	Recognize people with SMI can achieve goals and have strength;	Acknowledge it is worth trying to achieve goals; Acknowledge personal pros and cons of being active; Acknowledge there is hope for the future; Acknowledge that failure is common; not your fault;	Express confidence in ability to break down long-term recovery goals into short-term goals and attainable steps; Express confidence in ability to solve problems related to executing the steps;	Estimate personal wishes and goals; Monitor goal achievements; Expect that achieving goals will help coping with the illness;
Reducing relapse of psychiatric symptoms	Active coping (early) symptoms and stressors	Define correlation between stress and biological vulnerability, symptoms, and relapse; Lists personal (early) symptoms and stressors; Lists personal management strategies in a relapse prevention plan;	Recognize peers have similar symptoms and problems; Recognize peers are respectful people;	Acknowledge that he or she is the expert on his or her SMI; Acknowledge his or her stress vulnerability; Acknowledge personal pros and cons of active coping;	Express confidence in ability to manage stressors actively according to relapse prevention plan; Express confidence in ability to solve problems related to coping with symptoms and stressors;	Monitor symptoms; Expect active coping will prevent relapse and help to achieve goals; Monitor successful coping strategies;
Achieving goals and reducing relapse	Arrange support regarding coping with symptoms and achieving goals	Lists the people that are able to support him or her;	Acknowledge dependence (on others) that empowers	Acknowledge dependence (on others) that empowers	Express confidence in ability to explain (and ask for) what people can do to support them;	Expect social support helps to achieve goals and cope actively;

As a result, we formulated three main behavioural outcomes of the intervention. The first behavioural outcome is having connections with other important people. The connected performance objective is learning to disclose their SMI. The second outcome is achieving personal recovery goals and relates to the objective planning and executing attainable steps towards recovery goals. The third outcome is reducing relapse of psychiatric symptoms, which relates to the objective coping actively with symptoms and stressors. Another performance objective is 'arranging social support', which relates to the second and third outcomes. Consumers learn to instruct others on what really supports them and what is not feasible for them. The determinants of the performance objectives are the same as in step 1. In order to influence the determinants we formulated proximal change objectives. Table 2 shows the matrix of the outcomes, performance objectives, determinants, and proximal change objectives.

Step 3: Selecting Theory-Informed Intervention Methods and Practical Applications

The third step aimed to identify and select theoretical models and evidence-based methods that could address the change objectives that were described in the second step. For this purpose we studied the literature on theoretical models of behavioural change (52,159) and the underlying theories and methods of the IMR program (31). In the development group we discussed the findings of two qualitative evaluations of how consumers experienced the IMR program (93,160). Next we matched the change objectives with evidence-based methods using the manual for Behavioural Change Techniques Classification (BCT) (161). To select practical applications we studied peer-reviewed literature on telemedicine and SMI about examples of e-health interventions for consumers with SMI.

As a result, we concluded that the IMR program is based on the theories Stress-Vulnerability Model (SVM) and the Trans Theoretical Model (TTM) (31). These theories are also applicable for e-IMR intervention. The SVM (28) describes how the balance between stress and biological vulnerability can be disturbed and that consumers actively keep or restore the balance. This relates to the problem of susceptibility for relapse as described in step 1 and the active coping objectives as described in step 2. The TTM describes that the process of change includes increasing knowledge, raising awareness, changing attitudes, changing perceived norms, and increasing self-efficacy (30). This process matches the content of the determinants of the problem as described in the first step and the determinants of the performance objectives as mentioned in Table 2.

As a result of discussing the components and applications of the e-IMR intervention, we will provide peer information and social comparison to affect consumers' attitudes and perceived norms by applying peer testimonials on videos. Modelling will be used applying these peer testimonials that will show examples of how skills can be performed. Opening the intervention for important others will help consumers to disclose and involve others in order to get the proper social support by executing coping skills. Therefore, the intervention contains communication options with peers, trusted persons, and IMR trainers.

To enhance the consumers' achievements of recovery goals we will use the methods of setting graded task of attainable steps and reinforcements of progress. In the intervention consumers will keep track of the goals and the goal achievements. To enhance self-efficacy consumers need to keep track of successful attempts of coping with symptoms. This enlarges the chance that the new behaviour will be used again. Setting graded tasks and weighing pros and cons will also be used in the problem-solving method. To raise awareness of symptoms and enhance insight into the course of their symptoms the intervention applies monitoring symptoms.

To get familiar with the applications, such as keeping track of goals and the problem-solving method and to maintain its use, the intervention will continuously provide these applications. We assume that repeated use will increase consumers' confidence and ability to execute the performance objectives.

Step 4: Producing Program Components and Materials

The fourth step aimed to design the e-IMR intervention with components and materials that match the proximal change objectives and methods that were identified in the previous steps. For this purpose (1) we studied peer-reviewed literature on telemedicine and SMI to determine design issues, (2) we gathered information about information and communication technology (ICT) partners who could deliver the desired components on a protected e-health platform. Designing the e-IMR intervention was completed after pretesting the intervention thoroughly on legibility, usability, and bugs.

As a result, we chose an ICT partner because of their broad experience in developing e-mental health modules and their ability to provide login data. The website of the e-IMR intervention was designed according to the Flat Explicit Design Model in order to increase user-friendliness for people with cognitive impairments and lower technology experience (152). Therefore, we avoided the use of mandatory fields, the need to scroll back and forth on the website, the need to go to different pages for additional content, and the use of large text fragments.

The e-IMR intervention uses the same routeing as the IMR program: 11 modules (see Box 1), all together 56 chapters, for approximately 40 weekly sessions.

The e-IMR intervention uses a hard copy textbook along with the website in which the videos and practice at home assignment options are provided. At the end of the first module the goal follow-up system is introduced and provided in all later chapters. At the end of the second module and in all the later chapters, the coping skill follow-up system is provided. When the second module is completed, the consumers will be alerted via weekly e-mail to register their symptoms. The problem-solving method is presented as a practice at home assignment option in the last chapter of each module. Each chapter will finish with an evaluation of the chapter.

Within the intervention, the IMR trainer is able to start a discussion with the consumer. During face-to-face sessions the trainer will open the website and discuss the content of each session. Furthermore, the consumers select a trusted person with whom they will share the content of the e-IMR intervention. When the e-IMR intervention is provided via group sessions, the trainer will use a group e-mail to start a discussion with group members.

Step 5: Planning Program Adoption and Implementation

The fifth Intervention Mapping step aimed to prepare the adoption and implementation of the e-IMR intervention in the Netherlands. For this purpose we studied the literature on telemedicine for consumers with SMI to identify implementation barriers, and we conducted structured interviews with 52 Dutch consumers with SMI regarding the use of computers and the Internet.

As a result, we decided to implement the e-IMR intervention in institutions that already provide the IMR program. These institutes are assembled in the Dutch IMR network. Saxion, University of Applied Sciences supports this network and educates trainers to carry out the IMR program. This network facilitates the implementation and provides trainers that will be able to execute the e-IMR intervention after being instructed how to use the applications of the e-IMR intervention.

Implementation could not only be hindered by cognitive impairments and lower technology experience of consumers with SMI (152), but also by not having access to a computer. The results of the structured interviews showed that approximately 40% of consumers with SMI had no computer, mostly because of financial problems. Therefore, we will assess the consumers' computer skills before they enter the e-IMR intervention. When necessary we will help the consumer to search for a place where he or she can use a computer and support him or her to learn to use the website of the e-IMR intervention.

Step 6: Planning for Evaluation

The sixth and last step aimed to develop an evaluation plan to determine whether the e-IMR intervention contributes to the recovery process of consumers with SMI and matches the consumers' preferences. For this purpose we studied the Medical Research Council (MRC) guidance (162).

As a result, we decided to test the e-IMR intervention in an exploratory cluster randomized controlled trial with a twelve-month follow-up from baseline. This trial will not be powered as it will aim to (1) explore the potential effectiveness and effect-size, (2) to identify outcome measures that most likely capture consumers' potential benefits of the e-IMR intervention, (3) to explore the actual use and added value, and (4) to evaluate continued participation or dropping out of the e-IMR intervention.

Participants in the experimental condition will receive the e-IMR interventions containing the use of the hard copy textbook and the program components described in step 4. Participants in the control condition will receive the IMR program only using the hard copy textbook. Both conditions will be provided in individual or group sessions. All participants will also receive care consisting of extensive in- and/or outpatient psychiatric services including case management and guideline-based psychiatric treatments.

Before randomization, we stratified institutions within types (outpatients/ inpatients clinics). Due to risk of contamination, units that could contaminate each other were combined in one cluster. Because of high attrition rates in the IMR program (38) and e-health (44) we need 50 participants in both conditions. .

The inclusion period has been closed in October 2015. The follow-up will last until the end of October 2016 followed by the results at the end of December 2016.

Settings and Eligibility

Settings are eligible if trained and experienced trainers provide the IMR program. Consumers who are referred to the IMR program by their clinician will be eligible to participate. Consumers that meet the following criteria will be included: above 18 years of age, capable of giving informed consent, and meeting the SMI criteria: having a diagnoses of schizophrenia, schizo-affective disorder, bipolar disorder, or major depression, with a duration of one year since onset, and a disability that is sufficiently severe to cause serious impairment of functioning in family responsibilities, occupation, and accommodation (163).

Data collection

At baseline we will collect the participant characteristics: age, gender, living situation, social economic status, diagnosis, time since diagnosis, previous treatment, latest relapse, relapse frequencies in the past, and computer/internet availability and literacy. Also at baseline we collect the trainer characteristics: profession, highest education, gender, age, years of experience in mental health, and the number of executed IMR programs in the past.

At baseline and at twelve months the trainers will be interviewed and rated according to the IMR Fidelity Scale (164) to assure that the IMR program is executed as it is meant to be.

To measure the effect we will examine the following parameters at baseline, six, and twelve months: illness management, recovery, psychiatric symptoms severity, self-management, quality of life, and general health. Respectively, we use the following measurements:

1. the clinician and consumer version of the Illness Management and Recovery Scales (132,165);
2. the Mental Health Recovery Measure (9,166);

3. the Brief Symptom Inventory (167,168),;
4. the Patient Activation Measure (169,170),;
5. the Manchester Short Assessment of Quality of Life (171);
6. the RAND 36-Item Health Survey (172).

At 12 months we will gather login data on the frequency of participants' use of the website of the e-IMR intervention. When participants and trainers completed the 12-month questionnaires, we will interview them qualitatively about the added value of the e-IMR intervention, the actual use and continued participation, or dropping out.

Analyses

Quantitative analyses will be executed according to the intention to treat principle. Multilevel regression with a random setting effect and repeated measures will be used to explore the effectiveness of the e-IMR intervention. Baseline measures and participants' characteristics will be added as covariates. The relevance of the frequency of participants' use of e-IMR intervention, consumer characteristics, trainer characteristics, and IMR Fidelity Scale ratings will be explored by performing subgroup analyses.

The process of interviewing and analysing the qualitative data will be guided by the modified method of Stevick–Colaizzi–Keen (173).

Ethics

The ethical approval for conducting the e-IMR trial was provided by the Committee on Research Involving Human Subjects, Arnhem-Nijmegen (NL49693.091.14). The trial is registered in the Dutch Trial Register (NTR4772).

Discussion

In this paper we described the systematic development of the e-IMR intervention. This intervention blends the use of e-health and face-to-face delivery of the IMR program in order to mitigate problems with isolation, relapse, and hopelessness of consumers with SMI. The e-IMR intervention will help these consumers to involve other important people, manage achieving personal recovery goals, and reduce relapse.

The focus on learning self-management skills and taking the lead in their treatment addresses development in the mental health policy in the Netherlands. E-mental health is a promising medium (42) and the e-IMR intervention matches the changes in the future profile of the nursing profession in the Netherlands (174). Nurses need to focus on estimating what is necessary to support and teach the consumer self-management skills.

The use of the Intervention Mapping Protocol assured a systematic approach of the development of the intervention, including participation of the target population. In the sixth step of this protocol we designed an early-randomized controlled trial to evaluate the intervention. The use of an exploratory trial is advised in the Medical Research Counsel's framework for the development and evaluation of complex interventions (162). The choice of using the IMR program in the control group allows evaluating the added value of the e-health components to this IMR program. As Ben-Zeev et al. (48) advises this study is coupled with examining barriers and possible solutions. Therefore, this study will add new information to the body of knowledge in the field of e-health to consumers with SMI.

We conclude that the Intervention Mapping protocol provided a systematic procedure for the development of the e-IMR intervention for consumers with SMI. Estimating the added value of e-health will be possible because it is controlled by the standard IMR program.

Section II. Evaluation of the e-IMR intervention

Chapter 6.

e-IMR: e-health added to face-to-face delivery of Illness Management & Recovery programme for people with Severe Mental Illness, an Exploratory Clustered Randomized Controlled Trial

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Abstract

Background:
E-mental health holds promise for people with severe mental illness, but has a limited evidence base. This study explored the effect of e-health added to face-to-face delivery of the Illness Management and Recovery Programme (e-IMR).

Method:
In this multi-centre exploratory cluster randomized controlled trial, seven clusters (n = 60; 41 in intervention group and 19 in control group) were randomly assigned to e-IMR+IMR or IMR only. Outcomes of illness management, self-management, recovery, symptoms, quality of life, and general health were measured at baseline (T_0), halfway (T_1), and at twelve months (T_2). The data were analysed using mixed model for repeated measurements in four models: in 1) we included fixed main effects for time trend and group, in 2) we controlled for confounding effects, in 3) we controlled for interaction effects, and in 4) we performed sub-group analyses within the intervention group.

Results:
Notwithstanding low activity on e-IMR, significant effects were present in model 1 analyses for self-management ($p = .01$) and recovery ($p = .02$) at T_1, and for general health perception ($p = .02$) at T_2, all in favour of the intervention group. In model 2, the confounding covariate gender explained the effects at T_1 and T_2, except for self-management. In model 3, the interacting covariate non-completer explained the effects for self-management ($p = .03$) at T_1. In model 4, the sub-group analyses of e-IMR-users versus non-users showed no differences in effect.

Conclusion:
Because of confounding and interaction modifications, effectiveness of e-IMR cannot be concluded. Low use of e-health precludes definite conclusions on its potential efficacy. Low use of e-IMR calls for a thorough process evaluation of the intervention.

Introduction

In spite of the growing interest in e-mental health, evidence for the effectiveness of e-health for people with a severe or serious mental illness (SMI) is limited (46,48). Naslund et al. (46) found that e-health interventions for people with SMI have high feasibility and acceptability. Van der Krieke et al. (175) found that people with psychotic disorders were able and willing to engage in e-health, and found larger effects for medication management (175). However, one should be cautious about drawing conclusions regarding the effectiveness (46,175). E-health is used in a wide range of interventions for people with SMI on (1) illness self-management and relapse prevention, (2) promoting adherence to medications and/or treatment, (3) psycho-education, supporting recovery, and promoting health and wellness, and (4) symptom monitoring (46). E-health interventions make use of personal digital assistance, medication tracking devices, home monitoring systems, smartphone applications, SMS, and web-based interventions (46).

Also in general mental health, e-health approaches show great potential and offer the possibility of expanding access to care while being economically and socially efficient (42). But e-health interventions in mental health have high attrition rates (44). The addition of face-to-face contact to e-health is supposed to increase the therapeutic relation and prevent attrition (45)..In the case of people with SMI, e-health components could be added to an evidence-based face-to-face recovery-oriented intervention. Such an intervention is the Illness Management & Recovery programme (IMR) (38). The IMR is a standardized curriculum-based approach designed to provide people with SMI the information and skills necessary for managing their illnesses effectively and working towards achieving personal recovery goals. In addition to the standard face-to-face delivery of the IMR, an e-health intervention (e-IMR) was designed which follows the IMR-curriculum, and was further developed with the end-users of the intervention (176). The aim of this study was to explore the effect of the e-IMR for people with SMI who were referred to the Illness Management & Recovery programme.

Methods

The e-IMR was tested in an exploratory multi-centre cluster randomized controlled trial. According to the Medical Research Council guidance (177), an exploratory trial evaluated an intervention before testing it in a confirmative trial. In this study, a cluster was a subdivision of a mental health institute. The cluster randomization prevented contamination between the intervention and control group participants. Data were collected at baseline (T_0), halfway (T_1) and endpoint (T_2). The inclusion period was between January and October 2015. Data collecting lasted until October 2016.

Eligible clusters delivered the IMR-programme as a whole package with an experienced trainer-couple meaning that at least one trainer completed the IMR-total-training organized by the Dutch IMR-network and executed at least the first five modules of the IMR-programme before starting the IMR-programme in the trial.

Trial monitoring

An employee of the 'Radboudumc Technology Center – Clinical Studies' monitored the process of trial administration. The administration of Trial Master Files, both paper as well as computerized files, was independently checked for completeness and accuracy.

Randomization

A statistician generated a randomization schedule using Statistical Analysis System®, version 9.4. The allocation to the intervention or control group was communicated after the participating institutional board provided their consent to participation. Because of the nature of the intervention, blinding was not possible.

Sample size

Because of the exploratory character of this study, a power calculation was considered unnecessary.

Participants

Eligible participants met the following criteria: above 18 years of age; capable of giving informed consent; and meeting the Dutch SMI criteria according to Delespaul (1) (being diagnosed with a psychiatric disorder that causes, and is due to, serious impairments in social and/or occupational functioning which lasts longer than at least a couple of years and necessitates coordinated multidisciplinary care. Persons who were overwhelmed by disability, including dependence, denial, confusion, anger or despair, were excluded from participating.

Care as usual

All participants, in both the intervention and control group, received care consisting of extensive inpatient and/or outpatient psychiatric treatment including case management. They also received the IMR-programme, which was provided in weekly, 2-hour, face-to-face group sessions according to the Dutch version of the IMR 3.0 programme (178) using the hard-copy version of 11 modules.

Intervention

On top of this care as usual, participants in the intervention group had the opportunity to use the e-IMR intervention (176). The e-IMR intervention started with a 'welcome page' explaining the use of e-IMR and leading participants to the 11 modules. The e-IMR intervention included the same fill-in forms as in the hard-copy version of the IMR-programme. E-IMR added illustrative videos showing peer testimonials to encourage participants to talk more freely about themselves and to take steps in their recovery process. E-IMR also added problem-solving forms at the end of each module, registration of successful coping strategies, and a symptom-monitoring page.

The e-IMR was introduced to the trainers and participants of the intervention group by the first researcher in the second group session. Individuals who did not provide informed consent were allowed to join the e-IMR without participating in the research. The trainer-couples were supported in learning how to support participants in the use of e-IMR; how to install e-IMR on a computer in the session room and how to use e-IMR during the sessions.

In e-IMR, the registration forms of successful coping strategies and the symptom-monitoring page were introduced after the second module 'practical facts about mental illnesses'. Weekly emails with a link to the e-IMR platform led the participants to the symptom-monitoring page. After closing each module, one of the trainers gave feedback to the participants via the platform and guided the participants to the next module.

Data collection

Data were collected in face-to-face interviews by the researcher or a researcher assistant at three time points: at baseline, a week before starting the IMR-programme (T_0); halfway, after completing the 5th module (T_1); and endpoint, at least a week after finishing the IMR-program (T_2). The data were recorded on paper and later transferred into a LimeSurvey® (179) database. The original recorded data as well as the transferred were double-checked for accuracy and completeness.

Outcome measures

At baseline, independent demographic and clinical characteristics were recorded. At all three time points, six dependent outcome domains were gathered.

At T_0 the following participant characteristics were collected: age, gender, physical comorbidities, treatment history, cultural background, social economic status, education level, computer/Internet availability and use. At T_0, the participant's case manager provided their diagnostic classification according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition.

The participant's ability to manage their illness was measured with the consumer version of the **Illness Management & Recovery Scales** (IMRS), consisting of 15 items (32). The response anchors, on a five-point Likert scale (1-5) vary depending on the item. The IMRS total-up score ranged between 15 and 75. The IMRS' Cronbach's alpha is .55-.83 (130–132,165).

The participants' self-management ability, which refers to the individual's knowledge, skill and confidence for managing his/her own health and healthcare, was measured with the **Patients Activation Measure** (PAM) (17), consisting of 13 items. The response anchors on a five-point scale, vary from not applicable (0), 'strongly disagree' (1) to 'strongly agree' (4). The term 'doctor' in the items five and six was explained as their mental health clinician, which includes a nurse and/or case manager. Raw scores were transformed into standardized activation scores ranging between 0 and 100. The PAM's Cronbach's alpha is .84-.88 (170,180–182).

The Mental Health Recovery Measure (MHRM) assessed the participants' progress in their recovery process. The MHRM consists of 30 items with response anchors, on a five-point scale, varying from 'strongly disagree' (0) to 'strongly agree' (4), and 'neutral' (2) in between (9). The MHRM total-up scores ranged between 0 and 120. The MHRM's Cronbach's alpha is .93 (183).

The participants estimated the level of burden of symptoms they experienced using the **Brief Symptom Inventory** (BSI), consisting of 53 items (167). The response anchors, on a five-point scale, vary from 'not at all' (0) to 'extremely' (4). The mean BSI scores ranged between 0 and 4. A negative time trend for the BSI means a reduced level of burden. The BSI's Cronbach's alpha is .96 (168).

The participants' subjective satisfaction with life was measured with the **Manchester Short Assessment of quality of life** (MANSA), consisting of 12 items (171). The response anchors on a seven-point scale vary from 'couldn't be worse' (1) to 'couldn't be better' (7). The mean MANSA score ranged between 1 and 7. The MANSA's Cronbach's alpha is .81 (184).

The participants' general health status was measured with the **Rand 36-item Health Survey** (Rand-36), consisting of eight subscales: physical functioning (Rand-PF), social functioning (Rand-SF), role limitations due to a physical (Rand-RLPP) and an emotional problem (Rand-RLEP), mental health (Rand-MH), vitality (Rand-V), pain (Rand-P), and general health perception (Rand-GHP) (185). The response anchors vary between yes/no to Likert scales with three, five, and six options. Raw scores of all the concepts were transformed into scores ranging between 0 and 100. The Cronbach's alpha of Rand-36's eight concepts are .71 and .92 (172).

The extent of participants' activity on the e-IMR platform was determined by counting the number of completed modules and number of log-ins. An e-IMR user is identified by having completed at least module one or having logged in at least five times. Users were regarded as having had the opportunity to benefit from the e-IMR.

As in other studies on IMR (186), participants who attended the face-to-face IMR programme sessions less than 50% were considered to be non-completers. In our study, this resembles stopping the IMR programme before T_1.

Statistical methods

The Statistical Package for the Social Sciences®.23 (145) was used to carry out the analyses. Mixed model multilevel regression analyses were used to examine the main effects on the outcome measures, taking into account clustering of participants and repeated measures. This method automatically uses the 'missing at random' assumption to handle missing data. Random effects on cluster, trainer-couple, and individual participants nested within the cluster were included in the model. Model 1 included fixed main effects for time trend and group. The analyses were executed according to the intention-to-treat principle to prevent bias caused by the loss of participants (187) and to reflect the normal practice (188) of high attrition rates in treatments of people with SMI (38) and e-health (44).

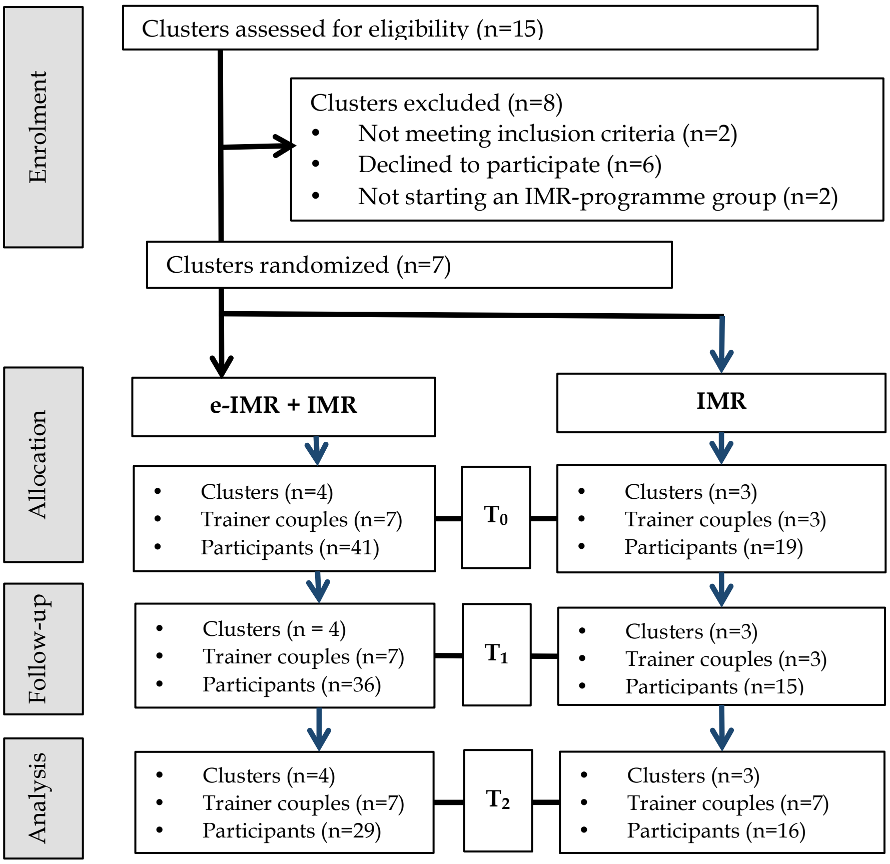

Figure 1. Participants flowchart

Post hoc analyses of effect differences were performed to control for covariates. We considered the covariate gender to be a potential confounder because of its known differences in exposure and reactions to stress and health (189). The covariate was included in model 2, controlling for confounding time trend effects.

In model 3, covariates were included that were expected to interact with the effect differences.

Non-completion of the face-to-face IMR-programme sessions was expected to interact with the effects because being a non-completer is correlated to lower functioning; for instance, lower social functioning (190) and higher emergency room visits and hospitalization (117). In addition, we searched for correlations in T_0 scores between the groups of completers and non-completers.

Because of the known low adherence-rate to Web-based interventions (44), additional subgroup analyses were performed within the intervention group to investigate whether actual use compared to non-use of the e-IMR leads to outcome differences. Thus in model 4, two groups of e-IMR users and non-users were included according to the aforementioned adherence measurement.

Results

Participant flow

Nine institutions with potentially 15 clusters were screened for eligibility. Two clusters were not eligible because they did not deliver the IMR-programme as a whole. Two clusters did not start an IMR-programme group. Four clusters declined because of organizational problems. Seven clusters were included: four were allocated to the intervention group and three to the control group. In three intervention clusters, a second trainer-couple started a second IMR group. So in total, ten IMR-programme groups (seven in the intervention and three in the control group) trained 60 participants: 41 in the intervention and 19 in the control group (see Fig. 1).

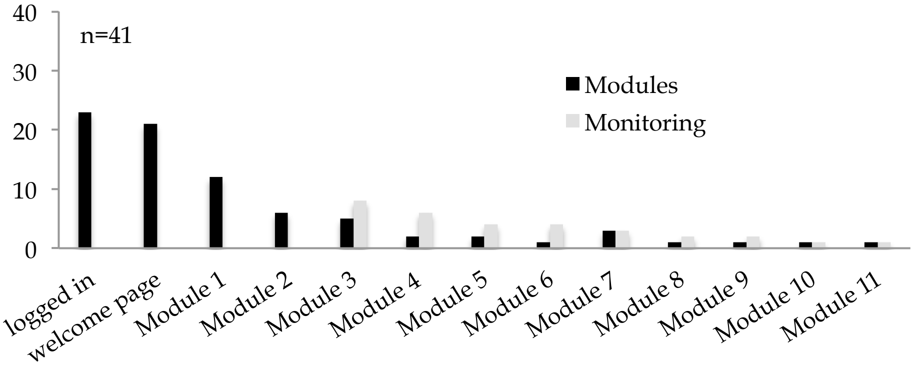

Figure 2. Participants' activity on the e-IMR platform

Out of the total of 60 participants, eighteen (30%) were identified as a non-completer: participants who attended the face-to-face IMR programme sessions less than 50%. Eight participants (20%) in the intervention group and ten participants (58%) in the control group were non-completers, which differed significantly (p = .01). Of these non-completers, 14 participants entered the intention-to-treat analyses, eight in the intervention group and six in the control group at T_1, and seven in both groups at T_2.

Table 1 shows baseline characteristics and distribution over the two groups. The characteristics 'gender' and 'inpatients/outpatients' were unequally distributed over the groups, p = .002 and p = .02 respectively. All ten IMR-programme groups completed the trial. In the intervention group, 12 out of 41 participants were lost in the follow-up measures in the study. We lost five at T_1 and another seven at T_2. In the control group, four out of 19 participants were lost in the follow-up at T_1 and T_2. We have missing data at T_1 for one participant in the control group. Participants either refused to be interviewed because of being too burdened by the interviews, or they did not respond to attempts to get in touch with them. Out of the 60 participants, 51 (36 and 15) participants were interviewed at T_1, and 45 at T_2 (29 and 16) (See Fig. 1).

Table 1 Demographic and clinical characteristics at baseline per group

Groups	Intervention		Control	
	n(%within group)		n(%within group)	
Variables		Mean (SD)		Mean (SD)
Participants	41		19	
Age		46.9 (11.6)		40.7 (10.6)
Gender**				
Female	30 (73.2)		6 (31.6)	
Male	11 (26.8)		13 (68.4)	
Diagnoses				
Psychotic disorders	14 (34.1)		6 (31.6)	
Mood/anxiety disorders	15 (36.6)		10 (52.6)	
Other disorders	12 (29.3)		3 (15.8)	
Global Assessment of Functioning		50.86 (8.2)		49.8 (10)
Having a somatic comorbidity	23 (56.1)		7 (36.8)	
Having a psychiatric comorbidity	27 (65.9)		11 (57.9)	
Treatment history				
Years ago since first treatment		17.15 (12.3)		16.17 (9.9)
Number of admissions		4.15 (3.9)		3.94 (3.3)
Never admitted	7 (17)		2 (10.5)	
Cultural Background				
Dutch	37 (90.2)		19 (100)	
Turkish, Maroc, Surinam, or English	4 (9.8)		0 (0)	
In/outpatients*				
Independent living	30 (73.2)		8 (42.1)	
Supported housing	11 (26.8)		11 (57.9)	
Netto income				
≤ Minimal income	31 (75.6)		16 (84.2)	
> Minimal income	10 (24.4)		3 (15.8)	
Highest graduated education				
≤ Middle school	26 (63.4)		12 (63.2)	
≥ High school	15 (36.6)		7 (36.8)	
Computer availability / usage				
I don't have a computer/laptop	8 (19.5)		3 (15.8)	
I never use a computer/laptop	6 (14.6)		2 (10.5)	

n: number; SD: Standard Deviation; $^{*}p < .05$; $^{**}p < .01$ (2-tailed)

Table 2 Mixed Model analyses, effect differences for outcome domains

		Model 1 Main group effects		Model 2 Confounder analyses of covariate gender				
Outcome domains	Parameter	T_1*Group	T_2*Group	T_0*Male	T_1*Male	T_2*Male	T_1*Group	T_2*Group
Illness management:	effect	2.55	3.06	4.89	-2.31	-3.26	2.26	2.42
IMRS	p	.13	.07	.00**	.19	.08	.19	.17
Self-management:	effect	7.95	3.90	4.40	.75	1.76	8.71	5.04
PAM	p	.01*	.22	.19	.82	.62	.01*	.14
Recovery:	effect	7.23	5.06	12.69	-7.02	-3.55	5.35	4.42
MHRM	p	.02*	.11	.00**	.03*	.28	.10	.19
Symptoms:	effect	-.07	-.13	-.60	.28	.31	-.02	-.07
BSI	p	.58	.30	.00**	.03*	.02*	.90	.62
Quality of Life:	effect	.15	.11	.37	-.22	-.36	.10	.00
MANSA	p	.35	.52	.07	.18	.04*	.57	.99
Rand-PF	effect	6.61	5.21	19.87	3.57	-6.59	8.73	3.63
	p	.16	.27	.00**	.45	.18	.07	.46
Rand-SF	effect	-.02	.93	15.91	-1.24	-14.26	-1.67	-2.24
	p	1.00	.88	.02*	.13	.04*	.80	.74
Rand-RLPP	effect	9.47	7.88	29.85	-3.43	-13.61	9.98	4.68
	p	.39	.48	.01*	.76	.26	.39	.69
Rand-RLEP	effect	-25.58	9.47	29.18	-9.99	-17.38	-21.33	11.43
	p	.03*	.43	.01**	.46	.22	.09	.37
Rand-MH	effect	-2.40	-1.09	15.11	-6.73	-5.80	-3.85	-2.17
	p	.57	.80	.00**	.13	.21	.39	.64
Rand-V	effect	-.26	.91	15.11	-3.18	-7.04	.55	.35
	p	.96	.85	.00**	.53	.19	.92	.95
Rand-P	effect	1.63	-3.46	21.37	2.74	-1.11	6.01	-3.74
	p	.82	.63	.00**	.72	.21	.42	.62
Rand-GHP	effect	7.84	1.10	15.21	-2.91	-13.97	7.13	5.31
	p	.07	.02*	.00**	.50	.00**	.10	.23

BSI: Brief Symptom Inventory; e-IMR: e-health application to Illness Management & Recovery programme; IMRS: Illness Management & Recovery Scales; MANSA: Manchester Short Assessment of Quality of Life; MHRM: Mental Health Recovery Measure; p: p-value; PAM: Patient Activation Measure; Rand-GHP: Rand General Health Perception; Rand-MH: Rand Mental Health; Rand-P: Rand Pain;

Out of the 41 participants in the intervention group, 23 (56.1%) logged in on the e-IMR platform, twelve of whom completed the first online module and eight of whom visited the symptom-monitoring page (See Fig. 2). In total, 14 (34.1%) participants were identified as e-IMR users.

Outcomes and estimation

The mean scores and standard deviations of the outcomes in both groups are presented in the additional file. Since the random effect of cluster was zero in nearly all the analyses, this factor was excluded from the analyses models. The relevant results of the mixed model analyses are shown in Table 2. In model 1, the participants in the intervention group scored significantly higher compared to the control group for the measures PAM ($p = .01$), MHRM ($p = .02$), and Rand-RLEP ($p = .03$) at T_1, which faded at T_2. At T_2, the effect on the Rand-GHP was significant ($p = .02$) in favour of the intervention group

Model 3					Model 4	
Interaction analyses of covariate non-completer					Sub-group analyses within intervention group	
T_0* completer	T_1*Group	T_1*Group* completer	T_2*Group	T_2*Group* completer	T_1*e-IMR-users	T_2*e-IMR-users
1.57	1.12	.62	2.38	.74	1.89	1.71
.38	.70	.86	.41	.84	.32	.44
1.52	*17.72*	*-15.13*	6.80	-4.81	-.73	3.03
.67	.00*	.03*	.21	.48	.81	.40
6.89	13.36	-10.90	8.09	-3.85	3.27	.84
.13	.01*	.10§	.14	.57	.32	.82
-.13	.08	-.12	.06	-.24	-.18	-.22
.47	.72	.66	.77	.39	.19	.17
.10	.49	-.58	-.04	.24	.10	.12
.65	.08	.09§	.90	.50	.57	.55
-3.92	13.2	-13.01	6.1	-3.17	-.48	6.78
.58	.11	.20	.46	.76	.93	.26
1355	2.04	-7.55	-3.39	5.04	.35	9.07
.04*	.85	.58	.76	.71	.96	.24
-11.85	29.73	-32.31	11.28	-6.33	-6.56	4.99
.36	.12	.17§	.55	.79	.59	.73
8.18	-28.77	5.24	-21.27	44.85	-18.90	23.40
.47	.16	.84	.31	.08*	.15	.13
8.07	-.50	-5.33	-4.94	5.65	2.24	-.83
.13	.95	.56	.50	.54	.61	.87
8.76	14.76	-22.9	8.6	-8.36	-7.62	-9.42
.11	.07	.03*	.30	.42	.11	.09
-10.34	-4.51	2.84	-6.01	.68	2.14	-1.73
.19	.72	.85	.63	.97	.80	.28
1.65	9.28	-3.13	9.44	3.43	-3.01	5.26
.76	.22	.73	.21	.71	.53	.35

Rand-PF: Rand Physical Functioning; Rand-SF: Rand Social Functioning; Rand-RLEP: Rand Role Limitation due to Emotional Problems; Rand-RLPP: Rand Role Limitation due to Physical Problems; Rand-V: Rand Vitality; §p-value < .20; *p-value < .05; **p-value <

Post hoc analyses

In model 2, the analyses accounting for the covariate gender showed that the significant effects above could be explained by confounding except for the remaining effect for PAM (p = .01) at T_1. At T_0, male participants scored significantly higher on nearly all the measures except for the PAM. The same exception occurred in the time trends, but contrarily in favour of female participants.

In model 3, the analyses showed that the interaction of the covariate non-completer was significant for the measures: PAM, (p = .03) and Rand-V (p = .03) at T_1which faded at T_2. As an illustration of the interaction, the graphic in Fig. 3 shows the scores for the PAM, which resembles the scores of the Rand-V. We did not find significant correlations in PAM scores at T_0 between the completers and non-completers (p = .77).

In model 4, the subgroup analyses within the intervention group between the groups of e-IMR users and non-users showed no significant effect differences at T_1 and T_2.

Harm

No serious adverse events were reported during the trial.

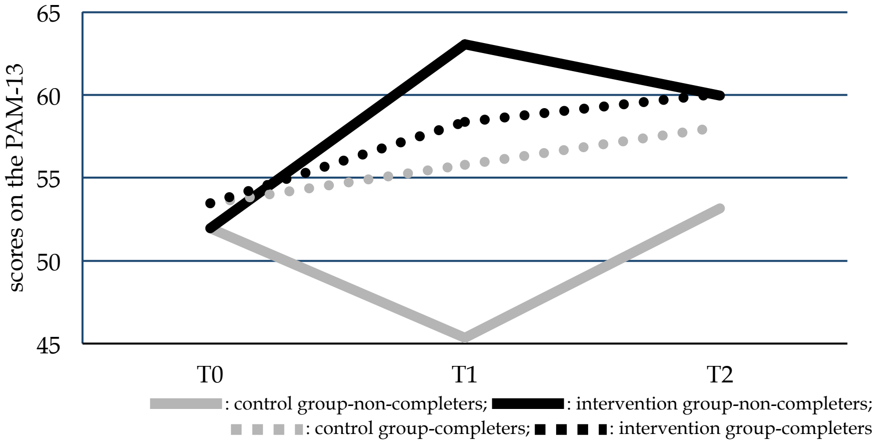

Figure 3. The scores for the PAM

Discussion

This study shows significant differences in main effects for the parameters self-management (PAM), recovery (MHRM), and role limitation due to emotional problems (Rand-RLEP) in favour of the intervention group at T_1, which faded at T_2. At T_2, a significant effect for general health perception (Rand-GHP) occurred, also in favour of the intervention group.

Post hoc analyses showed that the confounder gender explained the effects for recovery and role limitation due to emotional problems at T_1, and for general health perception at T_2. The confounding effects of gender were based on three types of differences: first, the baseline distribution showed significantly more females in the intervention group; second, at T_0 males scored significantly higher on most of the measures; and third, time trends were in favour of female participants. In general, women do differ from men in a number of ways; for instance, exposure and reactions to stress (189), needs and care (191,192), and coping styles (193). With regard to coping styles, women could benefit more from a problem-solving-focused intervention and men from an emotion-focused one (194). IMR, with its emphasis on learning how to manage an illness in a context of pursuing recovery goals (27), has a greater focus on problem-solving- than on emotional strategies. Therefore, women could have benefitted more from the IMR-programme than men.

Post-hoc analyses showed that the confounder gender did not explain the effects for the parameter self-management. Also in studies with people with diabetes II (195) and other chronic illnesses (196), no relations were found between gender and self-management, measured by the PAM.

The interaction covariate non-completer significantly modified the effect for the parameter self-management (PAM) and vitality (Rand-V) such that a large intervention effect was seen in the non-completers and a small effect in the completers. Apparently, stopping the IMR-programme was based on differences in their improvements. In this study, improvements in conditions of people who dropped out of the IRM-programme were unequally distributed over the groups, which modified the effects. The unlikeliness of the effects is confirmed by the subgroup analyses within the intervention group, which showed no significant effect differences between the groups of e-IMR users and non-users.

A last issue to discuss is the low use of the e-IMR platform by the participants in the intervention group which resulted in a minor contrast in the treatments provided to the participants in the intervention and control group and further calls into question the validity of ascribing the effects observed to the e-IMR. The modest use of the e-IMR matches with 6% of consumers using e-health in general mental health in the year of this study (197).

A number of limitations should be noted. Unfortunately, the planned sample size was not achieved and a lower number of participants entered the control group. This might have caused the unequal distribution of some covariates. Due to the small sample, we could not control for more than one covariate in the mixed models without risking over-fitting. Notwithstanding the small sample, a number of non-completers did not withdraw from the study. The overall non-completer rate of 30% is similar to other IMR studies (38). Therefore, the intention-to-treat analyses resemble normal practice.

Conclusion

Finally, this study precludes definite conclusions on the potential efficacy of e-health for people with SMI. This leaves us with many questions about the barriers and facilitators of the e-IMR intervention and its implementation. Against the backdrop of the great promise of e-mental health (5), the modest use of the e-IMR platform might be an interesting outcome which needs to be further investigated. Before deciding how to continue studying the effectiveness of e-IMR, we will investigate barriers and facilitators of the e-IMR and its implementation.

Additional File: Mean scores and standard deviation of the outcome domains per group at baseline (T_0), halfway (T_1) and post treatment (T_2)

	Time point	T_0	T_1	T_2
Measure	Group	Mean (SD)	Mean (SD)	Mean (SD)
Illness management: IMRS	Control	53.1 (7.5)	53.8 (7.3)	54.6 (5.9)
	Intervention	51.6 (6.3)	55.1 (6.0)	56.7 (5.9)
Self-management: PAM	Control	54.4 (13.5)	52.9 (9.9)	58.3 (15.5)
	Intervention	52.5 (10.0)	59.1 (14.0)	60.4 (13.1)
Recovery: MHRM	Control	71.4 (14.9)	70.9 (15.7)	77.2 (17.4)
	Intervention	66.6 (16.4)	74.0 (14.7)	79.2 (15.9)
Symptoms: BSI	Control	1.0 (0.7)	0.9 (0.6)	0.9 (0.6)
	Intervention	1.1 (0.7)	0.9 (0.6)	0.8 (0.7)
Quality of Life: MANSA	Control	4.3 (0.7)	4.4 (0.8)	4.4 (0.6)
	Intervention	4.2 (0.9)	4.6 (0.8)	4.6 (0.7)
General Health Status: Rand-PF	Control	78.4 (26.0)	73.3 (31.6)	80.3 (22.3)
	Intervention	72.3 (24.6)	77.2 (25.0)	78.6 (23.5)
Rand-SF	Control	61.2 (23.9)	64.2 (23.1)	60.2 (22.9)
	Intervention	61.0 (25.3)	64.2 (23.9)	61.6 (26.3)
Rand-RLPP	Control	55.3 (45.3)	51.7 (45.8)	57.8 (49.8)
	Intervention	45.7 (44.0)	53.5 (46.0)	54.3 (44.9)
Rand-RLEP	Control	36.8 (45.7)	62.2 (37.5)	43.8 (33.8)
	Intervention	44.7 (39.2)	40.7 (39.9)	60.9 (44.6)
Rand-MH	Control	56.0 (20.9)	58.7 (17.3)	59.0 (17.6)
	Intervention	56.7 (18.2)	58.4 (19.0)	61.8 (21.0)
Rand-V	Control	47.4 (23.1)	50.3 (24.5)	50.3 (19.4)
	Intervention	48.7 (19.5)	51.9 (16.5)	53.8 (17.7)
Rand-P	Control	71.9 (27.3)	70.1 (32.9)	75.1 (23.7)
	Intervention	61.7 (27.8)	67.7 (28.2)	66.9 (29.6)
Rand-GHP	Control	55.5 (19.3)	49.7 (16.0)	52.8 (16.9)
	Intervention	46.6 (18.0)	51.0 (21.0)	57.1 (17.1)

BSI: Brief Symptom Inventory; IMRS: Illness Management & Recovery Scales; MANSA: Manchester Short Assessment of Quality of Life; MHRM: Mental Health Recovery Measure; MHRM-SE: MHRM self empowerment; MHRM-LN: MHRM learning and new potentials; MHRM-S: MHRM spirituality; PAM: Patient Activation Measure; Rand-PF: Rand-GHP: Rand general health perception; Rand-MH: Rand mental health; Rand-P: Rand pain; Rand-PF: Rand physical functioning; Rand-SF: Rand social functioning; Rand-V: Rand vitality; SD: standard deviation.

Section II. Evaluation of the e-IMR intervention

Chapter 7.

The Blended Electronic Illness Management and Recovery Programme for People with Severe Mental Illness: A Qualitative Process Evaluation Alongside a Trial

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Abstract

Background:
Against the backdrop of the great promise of e-health, we conducted a trial to test the electronic Illness Management and Recovery (e-IMR) intervention to provide conclusions on the potential efficacy of e-health for people with severe mental illness (SMI). The e-IMR intervention used the standard IMR programme content and methodology and combined face-to-face sessions with Internet-based strategies on the constructed e-IMR Internet platform. During the trial the e-IMR platform was used too little

Objective:
This study aimed to evaluate the added value of the e-IMR intervention as well as the barriers and facilitators that can explain the low use of the e-IMR platform.

Method:
This process evaluation was designed alongside a multi-centre cluster randomised controlled trial. In this study we included all the available participants and trainers from the intervention arm of the trial. Baseline characteristics were used to compare the users and non-users. Qualitative data were gathered at the endpoint in semi-structured interviews. With theoretical thematic analyses the data were analysed deductively using a pre-existing coding frame.

Results:
Out of 41 eligible participants and 14 trainers, 27 participants and 11 trainers were interviewed. Ten of the 27 participants were identified as users. e-health components that had added value were the persuasive nature of the goal-tracking sheets, monitoring and the peer testimonials, which had the potential to enhance group discussions and participants' disclosure. The low use of the e-IMR platform was influenced by the platform's inflexibility, the lack of information technology (IT) resources, the group context, the participants' low computer skills and disabilities, and the hesitant e-health attitude of the trainers.

Conclusion:
The extent of e-health readiness and correlations with vulnerabilities in persons with SMI need to be investigated further. This study shows that flexible options were needed for the use of e-IMR components and should be provided only in response to a participant's need. Use of the e-IMR intervention in the future is preconditioned by checking the available IT resources (such as tablets for participants) providing computer/Internet guidance to participants outside the group sessions, evaluating the e-health attitude and skills of trainers, and tailoring e-health training to increase the skills of future e-IMR trainers.

Introduction

In mental healthcare, e-health is expected to have great potential to increase access to care while being economically and socially efficient (42). e-health can be defined as making use of information technology (IT). In meta-analyses, e-health interventions for persons with depressive and anxiety disorders are accepted and proven to be effective (198). e-health also is used for persons with severe mental illness (SMI). Persons with SMI are diagnosed with a psychiatric disorder that causes, and is due to, serious impairments in social and/or occupational functioning that lasts longer than at least a couple of years and necessitates coordinated multidisciplinary care (1). e-health for persons with SMI is used in a wide range of interventions, such as self-management, relapse prevention, promoting adherence to medications and/or treatment, psycho-education, supporting recovery, and promoting health and wellness, and symptom monitoring (46). e-Health interventions for people with SMI are accepted and feasible (46), potentially delivering effective education (47). Unfortunately, conclusions on their effectiveness cannot be drawn (46,48). A number of difficulties and barriers have been addressed concerning e-health for persons with SMI (e.g. cognitive impairments, lower information technology (IT) experience (199), which may explain the high attrition rates (44). Blending face-to-face contact with e-health is supposed to increase the therapeutic relationship and prevent attrition (200).

To contribute to consumer-oriented development and delivery of self-management electronic-support programmes, we developed and tested a blended version of the standardised curriculum-based Illness Management and Recovery programme (IMR) for people with SMI (176,201). The standard IMR provides information and teaches the skills necessary for managing an SMI effectively and working towards achieving personal recovery goals (31). In accordance with the Intervention Mapping protocol (52) and in collaboration with target group members, we developed the electronic IMR (e-IMR) intervention to evaluate whether persons with SMI could benefit more from the IMR when making use of e-health strategies in combination with face-to-face sessions (176). On the e-IMR Internet platform the IMR curriculum was integrated and we blended the use of this platform with face-to-face, group-wise delivery of the standard IMR programme (176). To evaluate the effectiveness of the e-IMR intervention compared to the standard IMR, we conducted a multi-centre cluster randomised controlled trial (176,201).

The most striking finding of the trial was the low use of the e-IMR platform (201), therefore we could not conclude the effectiveness of the e-IMR intervention. Sieverink et al. reported that many e-health evaluations show no or limited positive effects, which is strongly related to not using technologies in the desired way (202). Ben-Zeev et al. (48) advise that the development of e-health interventions for people with SMI must be coupled with examining the barriers and possible solutions. Also, the Intervention Mapping protocol advises testing the effectiveness of an

Table 1. Conceptual framework based on the barriers and incentives for change of different levels of healthcare (203),

Conceptual framework Factors	Determinants	Determinants definitions
e-IMR intervention	Added value	The extent to which the components of the e-IMR platform had added value to the users and were easy and pleasant to use.
	Accessibility	The extent to which the e-IMR platform is accessible
	Implementation fidelity	The extent to which the implementation of the e-IMR platform is executed as planned
	Feasibility	The extent to which the e-IMR platform is practical and fits with current practices
Participants	Attitude	The perceptions, including preferences, motivations, and self-efficacy that the participants have regarding to using internet, computers, and the e-IMR platform.
	Compliance	The extent to which the participants intend to adhere to using the e-IMR platform
	Skills & Knowledge	The extent to which the participants have knowledge, expertise, and skills they need to be able to use the e-IMR platform.
	ICT-Resources	The resources that participants have in order to be able to use the e-IMR platform:
Participants' Social context	Social support	The extent to which the participants have support from others in their social context when having difficulties in using the e-IMR platform.
	Group effect	The extent to which the participants were influenced by other participants in the group in using the e-IMR platform
Trainers	Attitude	The perceptions, including preferences, motivations, and self-efficacy that the trainers have regarding to using internet, computers, and the e-IMR platform.
	Skills & Knowledge	The extent to which the trainers have knowledge, expertise, and that they need to be able to use the e-IMR platform.
Trainers' professional context	Policy	The extent to which organizational regulations influence the use of the e-IMR platform.
	ICT-Resources	The resources that organizations have in order to be able to use the e-IMR platform.
	Work flows	The extent to which trainers are able to adapt their workflow.

General in-depth questions in semi-structured interviews: Can you tell more about why (why not)? What kind of feeling came up? How did you experience ….? What do you think about …..? Can you give an example?

intervention as well as conducting a process evaluation in order to understand why an intervention did or did not work (52). Therefore, we conducted this process evaluation alongside the randomised controlled trial to gain insights that will ultimately help to make adjustments in order to facilitate proper use of the e-IMR intervention specifically or of e-health for people with SMI in general.

Objectives

This study aims to identify the added value of the e-IMR and the barriers and facilitators that can explain the low use of the e-IMR platform.

interview items, data source.

Interview items/questions	Data source P	 T
Did you use the e-health components and how did you estimate the ease or pleasantness of use?	E	E
What was your experience in using the e-health components? Can you describe the added value of the components?	E	E
Did you access (log-in) the e-IMR platform, at home and in the sessions? What made you couldn't?	E	E
How did you implement the e-IMR platform? What was your experience regarding the implementation?	E	E
What was your experience in using the e-health components? How user-friendly was the e-IMR platform?	E	E
What do you think about using the computer related to your health?	B, E	E
You stopped using (or did not use) the e-IMR platform. What made you do so?	E	E
Do you have good computer skills; do you need guidance?	B, E	E
What was your experience in using the computer?	E	E
Do you have a computer, laptop, smartphone, WIFI, and finances?	B, E	E
Did you get help at home? What was your experience?	E	E
What did you experience in the group sessions regarding the use of the e-IMR platform?	E	E
What do you think about using the computer in the e-IMR intervention and in your contacts with persons with SMI?	E	E
Do you have e-health experience?		B
Do you have enough computer skills and knowledge about the e-IMR intervention?		E
What helped or hindered you in using the e-IMR interventions?	E	E
What helped or hindered you in using the e-IMR interventions?	E	E
What helped or hindered you in using the e-IMR interventions?	E	E

B: Baseline; E: endpoint; P: Participants; T: Trainers

Methods

Study design

We conducted a theoretical thematic analysis (204) alongside the trial. This qualitative method makes use of a pre-existing coding frame and is able to provide a detailed analysis of the data (204). Data were derived from semi-structured interviews with participants and trainers that were held at the endpoint of the trial. We used the framework of Grol and Wensing (203,205–207), which frames the factors that potentially influence the effect of an intervention (see Table 1) (203). We thereby focused on the e-IMR intervention itself and its implementation, the trial participants and their social context, the IMR trainers who provided the intervention and their organisational context.

Study Population

In this process evaluation study, we included all available participants and IMR trainers from the intervention arm of the e-IMR trial (201) (see Fig. 1). Information about inclusion, exclusion and eligibility criteria and the effect of the e-IMR trial can be found elsewhere (201). Participants in the intervention arm of the trial who completed at least the first module on the e-IMR platform or had logged into the e-IMR platform at least five times were defined as 'users'. Non-users either did not use the e-IMR platform or used it less than five times. Users were regarded as having had the opportunity to benefit from the e-IMR intervention and to reflect on it. The trainers of the group-wise-delivered e-IMR intervention were psychiatric nurses and peer professionals. A peer professional is a person with a lived experience of a mental illness, educated and trained to become a professional capable of transferring knowledge and counselling other persons with a mental illness.

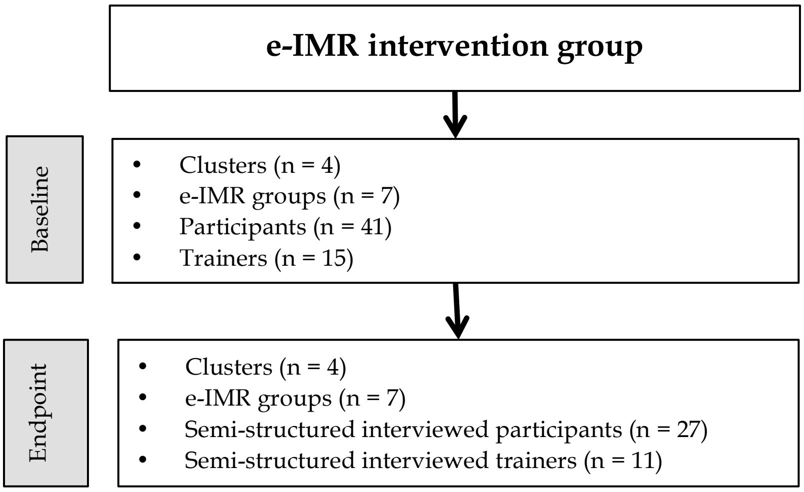

Fig. 1. Study Flow Diagram

The e-IMR Intervention

The e-IMR intervention started with a 'welcome page' explaining the use of the e-IMR platform and leading participants to the 11 modules. On the e-IMR platform, participants could fill in e-versions of the forms in the standard IMR, such as goal-tracking sheets, problem-solving sheets, sheets for tracking successful coping strategies, and a symptom-monitoring page. Also, the e-IMR platform contained illustrative videos showing peer testimonials to encourage participants to talk more freely about themselves and to take steps in their recovery process. Further detailed information about the e-IMR intervention can be seen in Table 2.

Table 2. An overview of the e-health components of the e-IMR intervention

e-IMR components implemented in standard IMR modules			e-health components presence			
	Modules	PTV	GTS	CSS	PSS	SMP
	e-IMR Welcome page	X				
1.	Recovery strategies	X	X			
2.	Practical facts about mental illnesses	X	X	X	X	
3.	The stress-vulnerability model	X	X	X	X	X
4.	Building social support	X	X	X	X	X
5.	Using medication effectively	X	X	X	X	X
6.	Drugs and alcohol use	X	X	X	X	X
7.	Reducing relapses	X	X	X	X	X
8.	Coping with stress	X	X	X	X	X
9.	Coping with persistent symptoms	X	X	X	X	
10.	Getting your needs met in the mental health system	X	X	X	X	
11.	Healthy lifestyles	X	X	X	X	

Explanation of e-health components:	
e-IMR Welcome page	Information about the use of e-IMR and leaded participants to the 11 modules and chapters. Participants could fill in their name after which the platform addressed the participants using their name. The e-IMR chapters of the modules were planned to be used parallel to chapters in the face-to-face sessions.
PTV: Peer Testimonial Videos	Illustrative videos in every chapter showing peer testimonials to encourage participants to disclose themselves and engage in recovery. The testifying peers were members of the developing group.
GTS: Goal Tracking Sheets	Every online chapter automatically reminded the participants to evaluate their personal recovery goals and planned actions.
CSS: Coping Strategies Sheets	Introduced after module 1, in every chapter participants were asked to describe successful coping strategies and they were automatically reminded of these strategies in the later chapters.
PSS: Problem-Solving Sheets	At the end of each module a problem solving sheet was provided to help to resolve remaining problems within the module,
SMP: Symptom Monitoring Page	Introduced after module two (practical facts about mental illnesses) until module nine (coping with persistent symptoms), participants could estimate their burden related to groups of symptoms representing the chapters of module nine: depression, anxiety, hallucinations, delusions, sleep problems, low energy, anger, and concentration problems. Weekly emails with a link to the e-IMR led the participants to the symptom-monitoring page. There symptom estimations were charted in a graph over time.
Workflow	At home, or a another place of their convenience, participants enter the e-IMR platform and make the home-work assignments, keep track of their recovery goals, successful coping strategies, work on problem solving sheets, and monitor symptoms. In the sessions, via a computer and projection, the e-IMR platform was opened to show and discuss the peer-testimonials, sheets in which participants completed home work assignments, goal tracking, coping strategies, problem solving, and monitoring. After finishing a chapter within a module, participants could continue and open the next chapter. They were able to look back to the chapter but could not amend their notes. After closing a module, one of the trainers gave feedback to the participants via the platform and guided the participants to the next module. Participants could not proceed on their own in order to prevent participants are working ahead and loose the parallelism with the group sessions.

Implementation of the e-IMR Intervention

The e-IMR platform was introduced to the trainers and participants by the first author at the second group session. Participants were invited to use the e-IMR platform but were not obliged to use it at the home, because of the possible lack of resources. The trainers were educated on how to support participants in the use of the e-IMR platform, how to install it on a computer in the session room and how to use it during the sessions. The registration forms on successful coping strategies and the symptom-monitoring page were introduced after the second module on 'practical facts about mental illnesses'. Weekly emails with a link to the e-IMR platform led the participants directly to the symptom-monitoring page. After finishing any module, one of the trainers provided feedback to the participants via the platform and guided the participants to the next module. Further detailed information about the implementation of the e-IMR intervention can be seen in Table 3.

Halfway through the trial, we discussed the low use of the platform with the trainers and asked them to re-introduce the platform in the sessions and to motivate and guide the participants to use it at home in order to get as much experience with it as possible. In reaction to this request and in addition to the original implementation strategy, in four out of the seven groups, extra e-IMR lessons were organised outside the IMR sessions (see Table 3**)**.

Table 3. An Overview of the Implementation Strategies of the e-IMR Platform.

Implementation and evaluation of the e-IMR trail	
Implementation of the e-IMR	• Before the start of the trial preparative talks were held with the local IMR-coordinators
	• In the second IMR session within the intervention group information about the e-IMR was provided to the group members and trainers; and email addresses were collected of the members of the group. All group members were allowed to enter the platform. Participating on the e-IMR was not mandatory for participants, because of the known problems with computer availability.
	• Participants who stated the need for guidance with using a computer and had problems with computer availability were offered help from research assistants with using the website of the e-IMR intervention and finding a place to access a computer.
	• The trainer-couples were supported in learning how to support participants to use e-IMR, how to install e-IMR on a computer in the session room, and how to use e-IMR during the sessions. One of the trainers was assigned to use the e-IMR platform and communicate with participants via the platform.
	• At T_1 interviews were held with trainers in order to re-introduce the use of e-IMR in the sessions and the participants at home. In reaction to this request, in four out of the seven sites extra e-IMR lessons were organized outside the group sessions.
Process Evaluation	An early (explorative) multi center cluster RCT was performed between January 2015 and October 2016. An early (explorative) multi center cluster RCT was performed between January 2015 and October 2016. At baseline personal characteristics of participants and trainers were gathered. Log-in data were derived from the e-IMR platform. Qualitative data were collected at the endpoint from participants and trainers. Interview items: the e-IMR intervention and implementation, participants, social context of the participants, trainers, and organizational context of the trainers.

Data Collection

Data were collected between January 2015 and October 2016. Three types of data were gathered: participants' characteristics, log data of the use of the e-IMR platform, and qualitative data from semi-structured interviews at the endpoint of the trial.

At baseline, the following data on participants' characteristics were gathered: age, gender, diagnostic classification according to the *Diagnostic and Statistical Manual of Mental Disorders* (4th edition) (113), physical comorbidities, treatment history, cultural background, socio-economic status, highest education, computer/Internet availability and use, computer literacy, perceived computer skills and the need for guidance when using a computer or the Internet. The last two items were scored on a five point Likert scale with the answer options of 'strongly disagree' (1) to 'strongly agree' (5). In addition, data from trainers were collected at baseline and used for this study: age, gender, profession, highest education, years of experience in mental health, and e-health experience.

Log data about the actual use of the e-IMR intervention were derived from the e-IMR platform. These data were used to identify 'users' and 'non-users'.

We conducted semi-structured interviews at the endpoint of the trial with all available participants and trainers. After the halfway discussions with the trainers about the low use of the e-IMR platform, we discussed the potential influential factors and adapted the framework of Grol and Wensing (203). Within each factor we formulated a number of relevant determinants and accordingly set up the interview questions (see Table 1). The framework and questions were used as the interview topic list in semi-structured interviews at the endpoint. The first author (T.B.) and research assistants performed the interviews with participants at their preferred location. The first author performed the interviews with the trainers. All semi-structured interviews were audio recorded and transcribed verbatim. The transcripts were uploaded in Microsoft Excel®.

Data Analyses

Descriptive statistics were used to present the outcomes for the groups of users and non-users. Chi-square and Student's *t*-tests were carried out to compare the baseline characteristics and IT attitudes of the groups of users and non-users. Quantitative data from the structured interviews at baseline and endpoint were analysed using the Statistical Package for the Social Sciences®, Version 23 (145).

Data from the transcripts of the semi-structured interviews were analysed deductively, by using theoretical thematic analysis (204). We used the following seven steps: (1) all three authors (T.B., B.v.G., and P.G.) independently read and reread the transcripts from the participants and from the trainers for one e-IMR group and identified meaningful statements; (2) all three authors grouped the statements into the categories of the modified coding frame of Grol and Wensing (203); (3) all three authors triangulated their analyses thoroughly until consensus was reached, which means that discussions lasted until all agreed without any doubts; (4) the first author completed the analyses of the subsequent e-IMR groups according to the first two steps; (5) the first author formulated a description of the findings within each determinant and added verbatim examples; (6) all three authors discussed the description of the findings thoroughly until consensus was reached; (7) finally a composite description of the experiences and use of the e-IMR intervention was written and discussed with all authors.

Results

Characteristics of participants and trainers

From the seven groups, characteristics at baseline were collected from 41 participants and 15 trainers (see Table 3**).** The mean age of participants at baseline was 46.9 years (n=41, SD = 11.6) and the majority had minimal income. The mean age of the trainers at baseline was 46.7 years. Nine trainers were psychiatric nurses and five were peer professionals. Of the 41 participants, 14 (34%) were identified as e-IMR users. The groups of users and non-users only differed significantly according to gender (p<.05), with more men being non-users.

Table 4. Personal characteristics of participants and trainers

	Total group		Users		Non-Users	
Variables	n (%)	Mean (SD)	n (% within group)	Mean (SD)	n (% within group)	Mean (SD)
Participants at baseline	41(100)		14(34.1)		27(65.9)	
Age		46.9(11.6)		45.2(11)		50.14(12.4)
Male*	11(27)		1(7)		10(37)	
Diagnoses						
Psychotic disorders	14(34)		4(29)		10(38)	
Mood/anxiety disorders	15(37)		5(36)		9(33)	
Other disorders	12(29)		5(36)		8(30)	
GAF		50.9(8.2)		51.4(8.9)		50.5(8)
Having a psychiatric comorbidity	27(66)		10(71)		17(63)	
Having a somatic comorbidity	23(56)		9(64)		14(51.9)	
Treatment history						
Years ago since first treatment		17.2(12)		14.4(11)		18.6(12.9)
Number of admissions		4.2(4)		4.2(3.7)		4.1(4.5)
Cultural Background						
Dutch	37(90)		14(100)		23(85)	
Other	4(10)		0(0)		4(15)	
In/outpatients						
Independent living	30(73)		12(86)		17(63)	
Supported housing	11(27)		2(14)		10(37)	
Netto income						
≤ Minimal income	31(76)		11(79)		20(74)	
> Minimal income	10(24)		3(21)		7(26)	
Highest graduated education						
≤ Middle school	26(63)		9(64)		17(63)	
≥ High school	15(37)		5(36)		10(37)	
Participant computer resources						
I never use a computer agree	6 (15)		2 (15)		4 (15)	
disagree	35 (85)		12 (85)		23 (85)	
I don't have a computer agree	8 (20)		1 (7)		7 (26)	
disagree	33 (80)		13 (93)		20 (74)	
Participants' activity on the e-IMR platform						
logged in on the e-IMR platform	23 (56)					
completed module 1	12 (29)					
visited monitoring page	8 (20)					

Participants' attitude towards computers at baseline					
Answering options	strongly disagree	disagree	neutral	agree	strongly agree
I need guidance with using a computer	10	12	5	11	3
Users	5	5	0	3	1
Non-users	5	7	5	8	2
I have good computer skills	6	8	11	11	5
Users	2	5	3	2	2
Non-users	4	3	8	9	3

Table 4. Continued

Baseline Trainer Characteristics		
Variables	Total group n (%)	Mean (SD)
Trainers	15(100)	
Age		46.7(8.8)
Male	6(40)	
Highest graduated education		
≤ Middle school	8(53)	
≥ High school	7(47)	
Profession		
Peer professional	5(33)	
Psychiatric Nurse	9(60)	
Social worker	1(7)	
Years of experience in mental health		17.6(11.4)
Having experience with e-health	1(7)	

n: number; SD: Standard Deviation; GAF: Global Assessment of Functioning; n: number; SD: Standard Deviation; * difference between groups of users and non-users is significant (p<0,05)

Process Evaluation

At the endpoint, 27 participants (10 of whom were a users), and 11 trainers were available to be interviewed (see Fig 1 and Table 3). A total of 14 participants (four of whom were users) were not interviewed because they were too burdened by being interviewed. From all the e-IMR groups, at least one trainer was interviewed. Four trainers were unavailable because of busy work schedules. In the following paragraphs, the findings are reported according to the framework (see Table 1). In our findings, we use the terms 'users' or 'non-users' to make it clear that among the participants only users or non-users reported the mentioned statement. We use the term 'participants' when both users and non-users reported the statement. The below detail the findings for the e-IMR intervention and its implementation, the trial participants and their social context, and the IMR trainers who provided the intervention and their organisational context. The determinants for these factors are illustrated by quotes from participants coded with a P followed by four digits and either U or N (standing for 'user' or 'non-user'), and by quotes from trainers coded with a T followed by five digits and either Pe or Nu (standing for 'peer professional' or 'psychiatric nurse').

The e-IMR Intervention and its Implementation

Regarding the e-IMR intervention, the following determinants are described: added value; accessibility; implementation fidelity; and feasibility.

Added value. Users and trainers reported that the components of the e-IMR intervention had added value. One user stated that because of the platform, the standard IMR curriculum was easier to understand. Explanations on relevant subjects in the different modules, for instance about symptoms, were easy to find using the buttons on the platform. A trainer mentioned that the time-consuming search in the textbook was not necessary anymore. In four out of the seven groups, peer testimonial videos were shown during the group sessions. Watching these videos was of great value to trainers and participants, enhancing discussions and disclosure. Participants found the peer testimonials very interesting and experienced recognition but also fear when reminded of their own psychotic experiences.

> *Yes, those videos … I liked them. Watching them was the first we did, and it became easier to talk about the subject. (T31002Pe)*

Trainers and users reported the added value of the repetitive character of the goal-tracking sheets on the platform. Users easily tracked and celebrated their achievements. When using the hardcopy module only, the paper goal-tracking sheets often got lost, which hindered the monitoring of achievement over time.

> *So, your goals appear; that's not in the book. … it's not possible to drop your focus. You're reminded of them … (P1202U)*

One user reported that the results of the weekly reminders to monitor symptoms led to a more objective interpretation of varying emotions, which increased personal insight. Another user did not benefit from this. A different user thought that the focus on symptoms was too strong and one peer professional trainer mentioned that he experienced aversion to this assignment because of this focus on symptoms.

> *In every chapter it appears: How much did symptoms burden you? … it's too negative. I know it is meant to be positive …. But, huh [shivering], these symptoms again; fuck off! (T51003Pe)*

The users and trainers reported that they did not use the 'coping strategies' and 'problem-solving sheets'.

Accessibility. Most of the participants reported that the e-health components were not easy to find. Six out of 14 users reported having problems with logging into the e-IMR platform at home. In five of the seven groups, participants and trainers reported that accessing the platform during the sessions was problematic, due to bugs when using certain browsers, problems with accounts, problems with logging in, and not having the appropriate IT resources.

> *Someone from technical services helped them, but the trainers couldn't get it running. The enthusiasm in the group to work with it was very low. So they stopped trying, and we worked with the book the rest of the time. (P1106U)*

Implementation fidelity. Trainers stated that they gave enough attention to motivate participants to use the e-IMR platform. The trainers and participants both reported that due to problems with accessing the platform and the aversive reaction of non-users, the actual use of the platform during the sessions was low, apart from the peer testimonial videos. Moreover, participants reported that using the e-IMR platform at home was not discussed in later sessions. Some users felt that the trainers did not stimulate them and that they linked this to the fact that use of the e-IMR platform was not obligatory.

> *It was like: 'It is no obligation, I can do it, but ….' I think that when it got more attention, you'll be able to see what it's bringing you. (P1202U)*

Feasibility. The participants and trainers reported the non-feasibility of working on one computer with a projector and screen during the sessions. They estimated that it would be too time-consuming to switch from one participant's account to another. Furthermore, participants could not read their own homework notes when together watching another participant's account on the projection screen. They thought the use of a personal laptop or tablet could overcome this problem.

> *I wondered how a session would go when we do everything in the e-IMR, and nothing on paper. What if someone else is active on the screen, and then I can't see my own notes? What did I write down at home? I won't remember, unless we all have a tablet or laptop. (P4202N)*

Trainers and users reported inflexibility of the platform, such as not being able to amend notes or skip a non-interesting module or change the module order. Because the platform was not used adequately during the sessions, participants easily lost synchronicity: doing the e-IMR intervention on the platform at home and during the group sessions became two separate things. Non-users reported that they stopped or did not start using the platform in order to avoid duplication of effort and to prevent getting confused by using two ways of working with the IMR.

> *There are two things ... I was afraid to mix them up … So, you do double work. You choose either the book or the platform … not both. (P3104N)*

The Participants

Regarding the participants, the following influencing determinants can be described: attitude; compliance; skills and knowledge; and resources.

Attitude. With regard to computers, non-users reported that they postponed the use of computers, were not interested, did not have an affinity, felt that working with computers was impersonal, were too easily overstimulated by the overload of content on a computer screen, experienced a lack of control over what was happening in the computer, and had a preference for tangible paper and face-to-face communication. Some non-users experienced fear and mistrust in the privacy protection of the e-IMR platform, not wanting to take the risk of others being able to read their notes.

> *I don't know where my information goes when I am on the world wide Internet. I need control, always and ever. … I will get overstimulated, all those things in my site, they really distract me. (P4207N)*

Compliance. Some users said that they got lost and confused when confronted with the platform's inflexibility or when they wanted to get through a backlog after a short period of not using the platform. Users missed additional stimuli from trainers to deal with this backlog. Not using or stopping use was related to vulnerability, such as wanting to avoid burdens because of duplication of effort, not feeling well enough, having sensory overload, a lack of concentration, dyslexia, perfectionism, or fear of failure.

> *Yes, in the group you can talk it out right away; that's easy … I did not like doing it on the computer. I think because of the upcoming emotions … and being alone here at home, no one to talk with … It just was too much for me, and I decided to stop using it. (P1207N)*

In terms of vulnerability, the trainers added that the participants recently experienced psychosis, lived a chaotic life, lacked inquisitiveness and initiative, had low intelligence, or had learning disabilities. Learning new skills was reported to be too difficult when not feeling well. The opposite also was reported: feeling better halfway through the trial and then being able to use the platform.

> *First I thought: This looks handy; I can do it. I really intended to do so. But I got those mood swings and thought: Let me do it on paper; it's … what I am used to do … and I will do it later when I feel well enough – then I will. But that did not work. (P4103N)*

Skills and knowledge. At baseline, six participants (15%) reported that they had never used a computer, and most participants (66%) scored neutral or agreed that they had good computer skills. At the endpoint, participants reported not being familiar with computers, being afraid of Internet viruses, not knowing how to log in, and not being able to imagine how computers process their input.

> *I cannot work on the computer …. I did try to learn, but ... no. Terrible, I might be able in a year or so. Now I really cannot. (P1103U)*

At baseline, 34% of the participants did not agree that they needed guidance in working with computers. Out of these participants, 29% became a user. At the endpoint, participants with a need for guidance reported reluctance in asking for help. Three participants became a user halfway through the trial with considerable support from the trainer. One trainer illustrated how a user was helped with working on the e-IMR platform:

> *Well, I (trainer) was at the computer. She (a user) was sitting next to me, and I asked: 'Shall I click here or there?' I typed the text and repeatedly asked: 'Is this correct?' (T41001Nu)*

IT resources. Eight participants (20%) reported having no computer but one of them did become a user. Moreover, not having Internet, an email account, or finances to afford these resources were reported. The majority (76%) of the participants had minimal income.

> *No, really, I was angry; at that time, I had lost my computer. I did it the old-fashioned way. I was fed up with that damned computer… (P3101N)*

The Social Context of the Participants

Within the social context of the participants, the following determinants can be described: social support; and group effect.

Social support. A user reported that getting help to use a computer from her partner caused irritation. She preferred the help of someone outside her family. Other participants reported that they had a non-computer-skilled partner. Three participants became users after getting help from relatives, friends, or trainers outside the group session.

> *I'll tell you, I just met him, and he fixed the necessary update. I did not dare to open it, and that's over now … (P1204N)*

Group effect. In four out of the seven e-IMR groups, the participants decided not to use the e-IMR platform during the sessions. A non-user decided not to use the e-IMR platform at home because another person in the group (a user) was struggling obsessively with using the e-IMR at home. The users and trainers experienced a negative group attitude towards the e-IMR platform, for instance when non-users expressed their irritation when the e-IMR platform was discussed during the sessions.

> *Yes, those participants who were not active on the e-IMR platform were irritated and said: 'Why talk about the e-IMR again? … (T11003Nu)*

The Trainers

Regarding the trainers the following determinants can be described: attitude; and skills and knowledge.

Attitude. Most trainers reported not being computer minded and having a preference for face-to-face contact and tangible paper.

> *I'm not that Internet-minded; nor is my colleague. … My colleague prefers working with these flipcharts. (T42002Pe)*

The trainers estimated that helping participants with the use of the platform during the sessions would take too much time. They differed on whether offering individual guidance to the participants was part of their job as an IMR trainer. The trainers doubted, and some did not offer lessons on using the e-IMR platform outside the group.

> *Yes, ... a participant had intentions to start, but had troubles with the computer firewall …. I was wondering, … what can I do to lower barriers? One option was to install things on her computer, but I considered this was going too far. (T12001Pe)*

Some trainers reported that they observed vulnerabilities, disabilities, lack of concentration, easy loss of self- esteem, lack of discipline, and struggle with computers in participants. The trainers suggested that participants belonged to a low-computer-experienced generation and thought that this was influential. Thus, some trainers stated that to combine e-health and SMI is a complete misfit, and they blamed the policy makers for this.

> *This trend is politically grounded … this e-mental health, blah, blah. Well, I think people from behind their desk invented this. They do not know what people with SMI go through. (T11003Nu)*

The trainers reported that working with the e-IMR intervention and motivating participants was an extra burdensome effort. They felt that working with the e-IMR intervention disturbed the group sessions and that doing the IMR regularly and working with a group were already difficult enough. The trainers reported cautiousness in opposing the resistance of non-users to the e-IMR intervention. Their priority was working with the IMR content and preventing participants' attrition from the sessions and the e-IMR platform became an afterthought.

> *I think most important in the group is that we go on and follow the book. In fact, working on the e-IMR platform was a sideshow. (T12003Nu)*

Skills and knowledge. At baseline, one trainer had e-health experience. Some trainers reported having had enough tools butothers reported not having heard enough about the e-IMR intervention and the trial. The trainers gave differing reports on whether they had enough skills; some said they did not.

> *My colleague explained to me how to start the e-IMR platform, but when I am alone, like today, I can't manage. (T42001Nu)*

The Organisational Context of the Trainers

Regarding the organisational context of the trainers, the following determinants can be described: policy, IT resources, and workflow.

Policy. The trainers had difficulty logging onto the platform because of a privacy policy in their organisation. The Internet system of the organisations had firewalls to protect the organisations' IT environment for Internet viruses. Because of this, some websites and email addresses were identified as unsafe and were blocked.

> *Here [via our intranet], I can't enter LinkedIn or Dropbox …you can't enter hardly anything. … They're afraid of viruses. (T31001Nu)*

IT resources. At the start of the trial, one organisation had an IT environment that was compatible with the e-IMR intervention but the other organisations did not. The session rooms often lacked a computer, a soundcard in the computer, Wi-Fi, a projector, and a screen. The trainers sought help from IT help-desks in their organisation but could not resolve these problems. Some trainers were creative and determined to find a bypass outside the local IT environment.

> *Shit, to get the video's work, the sound card was blocked, but I thought: 'I won't quit trying. I want to show them'. … In the end, we made it. (T42002Pe)*

Workflow. In the search for another session room, trainers were confronted with overly strict schedules. Another issue was about starting IMR groups and assigning IMR trainers on time. In a number of organisations, IMR groups could only be organised shortly before closing the trial period. The trainers reported that such workflow problems are 'business as usual'. In order to fulfil the participants' need for guidance with the e-IMR intervention, a number of trainers reported not having enough time in their work schedule.

> *But this person needs guidance every day. I do not know how to manage that. I don't have time to do so. (T52001Nu)*

Discussion

Principal Results

In this study, we evaluated the added value of the e-IMR intervention as well as the barriers and facilitators that can explain the low use of the platform. The users and trainers had negative and positive experiences with the e-IMR intervention. The added value of the e-IMR intervention consisted of the peer testimonial videos, the persuasive nature of the monitoring page, and the weekly confrontations with their personal recovery goals. Barriers were located in the platform's inflexibility, the infeasible group-wise provision of the intervention, the hesitant attitude towards e-health of the participants and trainers, the participants' lack of IT resources, their low skills and knowledge of using the Internet, and their being too overwhelmed by symptoms or disabled cognitive functioning, causing problems with using the e-IMR platform.

Strength and Limitations

The strength of this study is that its sample included people with low computer use, which enabled us to obtain a broad picture of the added values, barriers, and facilitators. A limitation of this study is that we cannot draw conclusions about the potential feasibility of the e-IMR intervention in individual treatment settings. The e-IMR intervention might work better in individual sessions were it can be better tuned and tailored to the personal needs of the person with SMI. We estimate that the influence of the group attitude and the e-IMR intervention's infeasibility in group settings were considerable. Unfortunately, the institutes where IMR is provided individually declined to participate in the trial.

Comparison with Prior Work

The weekly monitoring page worked out well for some users but for others, including a trainer, these reminders were disliked because of too strong a focus on symptoms. For users, the weekly confrontations with personal recovery goals and actions worked better than the paper version. The peer testimonial videos were highly appreciated because of their potential to enhance group discussions and the disclosure of the participants. Peer testimonials do fulfil the need for peer-information and acknowledgement (208), thus watching this kind of video can be a pivotal experience that enhances reflection and discussion (209).

Users and trainers were confronted with the platform's inflexibility when they wanted to amend previous notes, to skip uninteresting modules or the monitoring page, and to change the order of the modules. Therefore, the next version of the e-IMR intervention should be flexible to fit individual needs. Addressing personalisation seems to be a key issue for future e-health interventions for people with SMI (210). The group-wise provision of the e-IMR intervention was experienced as infeasible because it was too time-consuming to switch between the accounts of participants and the fact that participants were not able to look at their own notes. In addition, because of their e-IMR-averse attitude, participants chose not to use the e-IMR platform during the sessions. Unintentionally, the e-IMR platform and the face-to-face IMR session became two separate things. To overcome this group barrier, providing a tablet to participants was a widely heard suggestion. Providing devices to persons with SMI is known to support engagement in e-interventions (209). This may also overcome the lack of IT resources in persons with SMI, which in our study group was present in 20%, which is comparable to percentages found by Thomas et al. (211). A lack of IT resources was also present in the participating institutes. Future e-IMR-providing institutes need an open IT environment, open soundcards, strong computers and Wi-Fi for multiple tablets, an available projector plus screen, and a help desk. Technological resources are necessary to facilitate e-health interventions (210).

The lack of computer skills and the preference for tangible paper and face-to-face communication of the participants can also be seen as a barrier. Belonging to a generation with less computer experience might be an influence because low computer literacy is associated with higher age (212). Similar to Williams et al. (209), we identified log-in problems and problems with finding e-components on the platform, which contributed to low use of the e-IMR platform. The participants in our study thought that their problems with learning and using the e-IMR platform were due to being too overwhelmed by their symptoms or a disability in their cognitive functioning. Executive functions, working memory, and sustained attention have an important role in using websites (199) and these functions are also highly associated with psychiatric illnesses (24,213). To gain a clear picture of the correlation between the psychiatric health status of persons with SMI and their e-health readiness, more research is necessary. Taking our findings regarding the participants' attitudes, compliance, and skills and knowledge, we concluded that most participants in our study were not yet ready to engage with e-health. Berry et al. (214) drew a comparable conclusion that persons with SMI have relatively low interest in and willingness to engage with e-health interventions. We also concluded that there is a need for guidance in persons with SMI. Implementation of the renewed e-IMR intervention must coincide with an e-health support intervention for participants. Successful use of Internet-based interventions for persons with SMI is facilitated by training, support, and encouragement (209).

The e-health attitudes, skills and knowledge of trainers towards the e-IMR intervention are also barriers. Their hesitant attitude towards e-health is based on their preference for tangible paper and face-to-face contact and their own low computer skills. The trainers in our study stopped promoting the e-IMR intervention so they would not burden the participants and to avoid causing the participants to withdraw from the sessions. Identification with the participants' struggles and vulnerabilities might also have influenced the process. To illustrate, some of the trainers questioned the appropriateness of e-health for people with SMI, blaming the policy makers. Dutch mental health nurses indicate that e-health is not in line with the educational level, cultural background, or digital skills of mental health patients (215). Williams et al. (209) suggested a paternalistic attitude when workers determine the suitability of using e-health interventions for persons with SMI. In our study, in four out of the seven groups, trainers strived creatively to find solutions for showing the peer testimonial videos and for organizing e-IMR lessons outside the group sessions. Thanks to this effort, three of the non-computer-minded participants became ‘users’. Worker engagement is essential to successful implementation of e-health for persons with SMI (209). Before implementing the renewed e-IMR intervention it might be necessary to teach trainers how to use e-health, to become experienced, and to resolve their hesitancy.

Despite our findings, the development of Internet-based interventions is ongoing in our increasingly digitalising society and also in healthcare. Strand et al. (210) stated that the Internet can play a transitional role in recovery-oriented practices and Williams et al. (209) identified its potential to elicit the personal values of persons with SMI and their treatment preferences. These promising statements make further development of the e-IMR intervention worthwhile

Conclusions

The e-health components of the e-IMR intervention that have added value are the persuasive nature of using goal-tracking sheets and monitoring as well as the potential of the peer testimonial videos to enhance group discussions and the disclosure of the participants. The low use of the e-IMR platform was influenced by its inflexibility, the lack of IT resources, the group context, the lack of computer skills of the participants and their disabilities, and the hesitant e-health attitude of the trainers. The extent of e-health readiness and the correlations with vulnerabilities in persons with SMI need to be investigated further. Providing the e-IMR intervention in the future is preconditioned by flexible use of components in response to a participant’s needs, checking the available IT resources in institutions, providing tablets to participants in group settings, providing computer/Internet guidance to participants outside the group sessions, evaluating the e-health attitude of trainers, and providing the necessary e-health training to increase the skills of e-IMR trainers.

Section II. Evaluation of the e-IMR intervention

Chapter 8.

Identifying the Minimal Important Difference in Patient Reported Outcome Measures in Persons with Severe Mental Illness, a Pre-Post Analysis of the Illness Management and Recovery Program

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Abstract

Purpose:

Complementary interventions for persons with severe mental illness (SMI) focus on both personal recovery and illness self-management. This paper aimed to identify the patient-reported outcome measures (PROMs) associated with the most relevant and meaningful change in persons with SMI who attended the Illness Management and Recovery Programme (IMR).

Methods:

The effect of the IMR programme was measured with PROMs concerning recovery, illness self-management, burden of symptoms and quality of life (QoL). From the QoL measures, an anchor was chosen based on the most statistically significant correlations with the PROMs. Then we estimated the minimal important difference (MID) for all PROMs using an anchor-based method supported by distribution-based methods. The PROM with the highest outcome for effect score divided by MID (the effect/MID index) was considered to be a measure of the most relevant and meaningful change.

Results:

All PROMs showed significant pre–post effects. The QoL measure 'General Health Perception (Rand-GHP)' was identified as the anchor. Based on the anchor method, the Mental Health Recovery Measure (MHRM) showed the highest effect/MID index, which was supported by the distribution-based methods. Because of the modifying gender covariate we stratified the MID calculations. In most MIDs, the MHRM showed the highest effect/MID indexes.

Conclusion:

Taking into account the low sample size and the gender covariate, we conclude that the MHRM was capable of showing the most relevant and meaningful change as a result of the IMR in persons with SMI.

Introduction

In recent decades, the focus of treatment for persons with severe mental illness (SMI) changed from decreasing the burden of symptoms towards living a meaningful life (25). In the 1980s, the concept of recovery was introduced, defined as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles (4). In the 1990s, as a result of better general health care, life expectancy grew, illnesses became chronic, the challenge to manage chronic illnesses and their consequences increased and the term 'self-management' was introduced (13).

In the field of persons with SMI, self-management and symptom reduction represent the clinical orientation whereas recovery is used as an orientation for personal issues (4,25). In this field, a dismissive attitude towards labelling mental illnesses can be heard because of the stigmatizing tendencies (25,216). Several interventions with a single focus on recovery have been developed to help persons with SMI to choose, acquire and keep valued roles. Complementary interventions provide both illness self-management and personal recovery-orientated strategies (26). An example of a complementary intervention is the Illness Management and Recovery (IMR) programme (31). Internationally the IMR programme is criticized for its too dominant clinical orientation and McGuire et al. (38) recommend exploring the effects of the IMR programme on recovery and severity of symptom outcomes. In different trials, the IMR programme showed effects on patient-reported outcome measures (PROMs) in domains of recovery (27,217,218), symptom reduction (27,115) and illness self-management (35–37).

A PROM is defined as any report coming directly from patients about how they function or feel in relation to a health condition and its therapy (219). PROMs are considered to be able to measure clinically relevant pre–post effects from a patient perspective. To assess if a change in pre–post measures is relevant and meaningful, the concept of minimal important difference (MID) is introduced (220–222). Guyatt et al. (39) defined the MID as the smallest difference in outcome in the domain of interest that patients perceive as important, either beneficial or harmful. Knowing that an intervention can enhance an important difference in a desired outcome domain may help patients, caregivers and professionals when considering shared decision-making processes. King (223) states that MIDs can convince clinicians to change their treatment practices and convince policy-makers to change their treatment guidelines. The concept of MID has become a standard approach in determining the clinical relevance of changes in PROMs. No scientific literature on MID for PROMs concerning persons with SMI are available. In this study we want to contribute to knowledge about MID in the field of SMI.

Considering the discourse of a clinical versus personal recovery orientation in the field of persons with SMI, this paper aimed to identify the PROM that captures the most relevant and meaningful change as a result of the IMR programme in persons with SMI. If we are aware of this we are able to measure more uniformly in clinical practice and in research.

Methods and materials

Trial design, settings, and study population

We performed pre- and post-tests to measure the effect of attending the IMR programme on different PROMs. To examine which PROM captured the most relevant and meaningful change, we used the concept of the MID (221,223–225). Estimating MIDs of the PROMs was based primarily on an anchor-based method but supported by distribution-based methods. We used an additional index to assess whether the effect of the IMR programme in a given PROM was large or small seen from a patient perspective, hence in terms of the MID. In this way we arrived at the effect/MID as an index. An effect/MID of ≥ 1 indicates that the effect is at least the MID: the higher the index the more patients have a change score above the MID. Typically, within-patient changes are normally distributed around the mean change at group level. By comparing the index across different outcome measures we could identify on which PROM the participants improved the most from the IMR programme. We considered that the PROM with the highest outcome for effect score divided by MID (the effect/MID index) represents the most relevant and meaningful change as a result of the IMR programme. The study population consisted of participants from the e-IMR trial (176,201). Eligible participants met the following criteria: above 18 years of age, capable of giving informed consent and meeting the Dutch SMI criteria according to Delespaul (1): being diagnosed with a psychiatric disorder that causes, and is due to, serious impairments in social and/or occupational functioning that lasts longer than at least a couple of years and necessitates coordinated multidisciplinary care. The IMR programme was delivered groupwise in Dutch mental health institutions and the programme lasted about 1 year for all the groups. Further information on the e-IMR trial is published elsewhere (176,201).

Data collection and outcome measures

In this study, we used the pre–post data that were gathered in the e-IMR trial between January 2015 and October 2016 (201). The first author and research assistants sampled all data in structured interviews. Face-to-face interviews were held because we estimated that too many participants would not respond to telephone or online questionnaires. In the population of people with severe mental illness low computer experience, skills (152) and availability (176) exists. Furthermore this population is known for their cognitive impairments (213). We decided to use the advantages of face-to-face interviewing: spoken language that can be better understood; the possibility of responding to misunderstanding and probing for complete answers and using cards with answering options to overcome memorizing difficulties (226). The interviewers tried to create an easy-going atmosphere by using small talk between the different questionnaires. The interviews took 30-60 minutes and data were sampled using the following six PROMs:

1. Illness management was measured with the *Illness Management and Recovery Scales* (IMRS), consisting of 15 items. The response levels, on a five-point scale (1–5), vary depending on the item. The total score ranges from 15 to 75 and a higher score indicates a higher level of illness management (32)The test–retest coefficient (r_{xx}) for the IMRS varies between 0.79 and 0.84 (130–132,165).
2. Self-management was measured with the *Patient Activation Measure* (PAM), consisting of 13 items (17). The response levels, on a four-point scale, vary from 'strongly disagree' to 'strongly agree', and the fifth option is 'not applicable'. Raw scores were transformed into scores ranging between 0 and 100 and a higher score indicates a higher level of self-management (17). Coefficient r_{xx} for the PAM is 0.76 (181).
3. Recovery was measured with the *Mental Health Recovery Measure* (MHRM), consisting of 30 items (9). The response levels, on a five-point scale, vary from 'strongly disagree' (0) to 'strongly agree' (4), with 'neutral' in between (2). The total score ranges from 0 to 120 and a higher score indicates a higher level of recovery (9). Coefficient r_{xx} for the MHRM is 0.92 (183).
4. Burden of symptoms was measured with the *Brief Symptom Inventory* (BSI), consisting of 53 items. The response levels, on a five-point scale, vary from 'not at all' (0) to 'extremely' (4). The mean score ranges from 0 to 4 and a higher score indicates a higher level of burden and a lower level of mental health (167). Coefficient r_{xx} for the BSI is 0.90 (168).
5. Quality of life (QoL) was measured with the *Manchester Short Assessment of Quality of Life* (MANSA) (171), rating satisfaction with your life as a whole as the first item (MANSA-1) and 11 other items focusing on social, physical and mental health domains on a seven-point scale, varying from 'couldn't be worse' (1) to 'couldn't be better' (7). The mean score ranges from 1 to 7 and a higher score represent a higher level of QoL (171). Coefficient r_{xx} for the MANSA is 0.82 (227).
6. Quality of Life was also measured in terms of general health with the *Rand 36-Item Health Survey*, consisting of 36 items assembled into nine concepts. Raw scores in all the concepts were transformed into scores ranging between 0 and 100, in steps of 5. A higher score indicates a higher level of health (185). In this study we used only two concepts: General Health Perception (Rand-GHP) and Health Change (Rand-HC). Rand-GHP consists of five items that estimate the participant's current perception of general health (bio-psycho-social): (1). how many times the participants' health status hindered them in social activities, which was scored on a five point scale (*all, most, some, a little, none of the time*); (2) whether they estimate that they become ill more easily than other people; (3) whether they estimate that their health status is just like other people they

> know; (4) whether they expect their health status to decline; and (5) whether they estimate that their health status is excellent. Items 2-5 were scored on a five-point scale (*definitely true, mostly true, don't know, mostly false, definitely false*). Coefficient r_{xx} is 0.80 for Rand-GHP (172). Rand-HC consists of one item that estimates health compared to a year ago on a five-point scale (*much better, better, the same, worse, much worse*). At the endpoint of our study, this 'year ago' was the start of the IMR programme. Coefficient r_{xx} is 0.40 for the Rand-HC (172).

During the pre-test, participant characteristics were also sampled: age, gender, psychiatric diagnoses conforming to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) criteria, psychiatric and somatic comorbidities, treatment history, cultural background, housing, socioeconomic status and highest education (see Table 1). At the endpoint, non-completers were identified as those who attended fewer than 50% of the IMR programme sessions.

Method for investigating pre–post effects

Analyses were conducted using SPSS software, version 23 (145). To determine the pre–post effects of the IMR programme on all PROMs we performed mixed-model multilevel regression analyses, taking into account the clustering of participants. Because the IMR programme was delivered via group sessions, the participants were clustered in these groups. This method automatically uses the 'missing at random' assumption to handle missing data. Random effects on cluster and individual participants nested within the cluster and fixed main effects for time trend were included in the model. The analyses were executed according to the intention-to-treat principle. To take into account the influence of covariates, the pre–post effects were controlled for the participant characteristics one by one, including for non-completers. The pre–post effects in the PROMs were used to estimate the effect/MID index.

Methods for investigating the MID

To estimate an MID, both anchor-based and statistical distribution-based methods are recommended (221,223–225). The anchor-based method uses a criterion that measures a concept that health professionals are familiar with and is widely used in assessing patients' health status (223), such as clinical endpoints, global transition questions or QoL measures (221). As there is no such widely used criterion in mental health, we searched for a criterion in our own data that captures the richness and variation of the construct of a QoL measure (221). We examined four QoL anchor candidates: the endpoint data on the Rand-HC global transition question and the change scores on the first item of the MANSA estimating satisfaction with your life as a whole (MANSA-1), the total MANSA and Rand-GHP. Rand-HC and MANSA-1 were only used in the search for an anchor. The strength of the association between the anchor and the PROM needs to be determined because low or no correlation can provide misleading information (221,228). A correlation of at least 0.30–0.35 is recommended (221), therefore Spearman's correlation coefficients between the anchor candidates and the PROMs were calculated. Outliers should not drive a correlation to a significant level. In SPSS, scores above 2.58 times the standard deviation (SD) are assigned as probable outliers (229). Probable outliers were assessed on their appropriateness and impact on the correlation and a decision was made about removing or recoding to a reasonable level (188,230). The anchor candidate with the highest correlation with the change scores in most PROMs was considered to be the best anchor and therefore will be used in the MID-anchor calculations.

Estimation of the MID based on an anchor proceeds as follows: the scores on the anchor were used to categorize participants into five groups that reflected relevant and meaningful change *(large negative, small negative, no, small positive, large positive)*; the mean of the four differences between change scores in the PROMs for two succeeding change groups is the PROM's MID-anchor (223). The MID-anchor was used to estimate the effect/MID-anchor index.

It is recommended that the MID be estimated primarily by anchor-based methods (221,231) and to use distribution-based methods as supportive information (221). Therefore, we examined two statistical distribution-based MID methods based on the effect size (ES) and standard error of measurement (SEM) of the PROM (221). The ES of an intervention estimates the effect of the intervention related to the SD with ½ES as standard for estimating the MID (221,223–225,232). In MID studies, the SDs of the baseline scores and change scores are used to estimate the ES (224,232). A change score is the endpoint score minus the baseline score of a participant. The SD of the change scores (SDc) relates to between-patient variation in change scores. To justify our choice for the ½SDc instead of ½SD on baseline scores, note that the MID based on SDc (MID-SDc) is ½SDc and SDc is one measure of the responsiveness of change that could measure improvement seen from the patients' perspective. Our index (effect/MID-SDc) is 2 × effect/SDc, which is also known as the standardised response mean (228,233). To calculate the effect/MID-SDc index we used the estimated effects from the mixed-model analyses.

The SEM is computed using the SD and the test–retest coefficient index: $SD \times \sqrt{(1 - r_{xx})}$ (188,223,226,234). To estimate the SEM of the PROMs used in our study, we used the SD and r_{xx} reported in psychometric studies of the PROMs in populations comparable to ours as much as possible. A change smaller than the SEM is likely to be a result of the measure's unreliability rather than a true observed change, therefore the PROM's MID based on the SEM (MID-SEM) is equal to the SEM of the PROM. The MID-SEM and the estimated effects from the mixed-model analyses were was used to estimate the effect/MID-SEM index.

When covariates modified the effects, we re-estimated the effect/MID indexes and stratified the participants according to the modifying covariate.

Results

Participant flow

Ten IMR programme groups entered the trial, totalling 91 potential participants, 60 of whom participated. Baseline characteristics of the participants are presented in Table 1. Out of the 60 participants, fifteen (25%) were lost to follow-up, because of being too burdened by the interview. In total, 45 participants completed post-test measurements, 25 (56%) of whom were female; 14 (23%) were non-completers, meaning that they attended less than 50% of the IMR programme sessions. (See Figure 1).

Table 1. Baseline participants' demographic and clinical characteristics

Variable	n(%)	Mean (SD)
Participants	60(100)	
Female	36(60)	
Age		45(11.6)
Diagnoses		
Psychotic disorders	20(33)	
Mood/anxiety disorders	25(42)	
Other disorders	15(25)	
Global Assessment of Functioning	50.5(8.7)	
Having a somatic comorbidity	30(50)	
Having a psychiatric comorbidity	38(63)	
Treatment history		
Years ago since first treatment		16.9(11.5)
Number of admissions		4(3.7)
Never admitted	9(15)	
Housing		
Independent living	38(63)	
Living in supported housing facility	22(37)	
Netto income		
≤ Minimal income	47(78)	
> Minimal income	13(22)	
Highest graduated education		
≤ Middle school	38(63)	
≥ High school	22(37)	

n: number; SD: standard deviation

Pre-post effect analyses

Table 2 shows the estimated effects, which were significant for all the PROMs: illness management (IMRS), recovery (MHRM), self-management (PAM), burden of symptoms (BSI), QoL (MANSA) ($p < .01$) and general health perception (Rand-GHP) ($p < .05$). Only the gender covariate modified effects significantly for Rand-GHP ($p < .01$). For males, the estimated effects were significant only for the MHRM ($p < .05$), whereas for females they were significant for all the PROMs ($p < .01$; see Table 2).

Table 2. Analyses of Mixed model effects, standard deviation of the change scores and analyses of Minimal Important Differences, and effect/MID indexes in total population and genders separately

Measures	Mixed model estimated effects	Mixed model estimated effects on gender	SD_c	MID-anchor	Effect/MID-anchor index	MID-ES	Effect/MID-ES index	MID-SEM	Effect/MID-SEM index
Analyses for total population									
IMRS	3.36**	-2.01	6.62	2.9	1.14	3.3	1.02¶	3.2	1.07¶
PAM	5.70**	2.0	12.32	5.7	1.00	6.2	.92	7.0	.82
MHRM	7.93**	-2.30	11.90	6.1	1.29¶	6.0	1.33¶	5.7	1.40¶
BSI	-.17**	.28	.51	.25	.89	.29	.75	0.46	.47
MANSA	.22**	-.27	.58	-.23	.74	.26	.66	0.23	.74
Rand-GHP	4.73*	-11.54**	17.43	15.5	.31	8.7	.54	10.2	0.47
Analyses for males									
IMRS	.92		5.61	3.22	.28	2.81	.33	3.2	.29
PAM	5.70		14.28	6.48	.88¶	7.14	.80	7.0	.82
MHRM	5.02*		12.11	7.44	.67	6.06	.83¶	5.7	.89¶
BSI	.03		.30	.16	-.19	.15	-.19	0.46	-.13
MANSA	.01		.55	.35	.04	.28	.05	0.23	.03
Rand-GHP	-4.31		15.80	16.67	-.26	7.90	-.55	10.2	-.42
Analyses for females									
IMRS	5.08**		6.99	2.28	2.23	3.50	1.45	3.2	1.61
PAM	5.55**		10.80	4.79	1.16	5.40	1.03	7.0	.80
MHRM	9.93**		11.62	3.78	2.63¶	5.81	1.71¶	5.7	1.76¶
BSI	-.31**		.60	-.29	1.09	.30	1.03	0.46	1.37
MANSA	.37**		.56	.15	2.37	.28	1.29	0.23	.80
Rand-GHP	11.52**		16.33	9.44	1.22	8.16	1.41	10.2	1.14

MID= Minimal Important Difference; IMRS= Illness Management and Recovery Scales; PAM= Patient Activation Measure; MHRM= Mental Health Recovery Measure; MANSA= Manchester Short Assessment of Quality of Life; BSI= Brief Symptom Inventory; Rand-GHP= Rand General Health Perception; SDc= Standard deviation of the change scores; ES: Effect-size; SEM: Standard Error of Measurement.
** Effect is significant at the $p < .01$. *Effect is significant at the $p < .05$. ¶Highest effect/MID index.

Analysis of the MID

The results of the MID analyses are shown in Table 2. The health change measure (Rand-HC) showed no significant correlations to the other PROMs and was therefore considered to be a non-feasible anchor. Compared to the QoL measures MANSA-1 and the MANSA, the general health measure Rand-GHP showed the most frequent, highest and statistically significant ($p < .01$) correlations with the following measures: illness management (IMRS), self-management (PAM), recovery (MHRM), burden of symptoms (BSI), and QoL (MANSA) (see Table 3). Two outliers drove the correlation between Rand-GHP and the BSI. Examination identified the outliers as true scores and to assess their impact on correlation they were recoded into twice the SD_c (= 1.02), after which the correlation remained significant ($p < .01$; see Table 3). Rand-GHP was selected as the anchor.

Table 3. Spearman's correlations between change scores of Patient Reported Outcome Measures.

				Quality of Life measures			
Measures	PAM	MHRM	BSI	MANSA-1	MANSA	Rand-HC	Rand-GHP
IMRS	.246	.499**	-.428*	-.069	.570**	.183	.532**
PAM		.433**	-.242	-.003	.162	.112	.511**
MHRM			-.540**	.147	.340*	.208	.480**
BSI				-.140	-.346*	-.121	-.390**
BSI¶				-.138	-.350*	-,120	-.384**
MANSA-1					.308**	-.059	.104
MANSA				.		-.023	.477**
Rand-HC							.204

IMRS= Illness Management and Recovery Scales; PAM= Patient Activation Measure; MHRM= Mental Health Recovery Measure; MANSA-1= first question of the Manchester Short Assessment of Quality of Life; MANSA= Manchester Short Assessment of Quality of Life; BSI= Brief Symptom Inventory; Rand-HC= Rand Health Change; Rand-GHP= Rand General Health Perception; **Correlation significant at the $p < 0.01$ (two-tailed). *Correlation significant at the $p < 0.05$ (two-tailed). ¶BSI with outliers corrected to 2*SD$_c$.

We categorized the participants in five change groups. The change scores in the Rand-GHP vary from –35 to +40 in steps of 5 (see Table 4). To form the five change groups, we estimated that each group consists of participants that have three consecutive scores in steps of 5, so the score difference between succeeding change groups was 15, which is comparable to the SD$_c$ of 17.4. In the 'no change' group we categorized participants with change scores around zero (–5, 0, 5). We subsequently defined the other groups and the remaining score +40 was assigned to the 'large positive change' group. This resulting five change groups are: large negative (n = 3), small negative (n = 7), no (n = 18), small positive (n = 10), and large positive change (n = 7) (see Table 4).

Table 4. Participants' change scores on Rand-GHP categorized in five subgroups of the total population, and in four gender subgroups

	Effect	Frequency		Male		Female	
Change groups			Cumulative		Cumulative		Cumulative
Large negative change	-35	1		1		0	
	-30	0		1		0	
	-25	2	3	1	3	0	0
Small negative change	-20	2		1		1	
	-15	1		0		1	
	-10	4	7	3	4	1	3
No change	-5	6		4		2	
	0	7		3		4	
	5	5	18	3	10	2	8
Small positive change	10	4		0		4	
	15	5		2		3	
	20	1	10	0	3	1	8
Large positive change	25	1		0		1	
	30	1		0		1	
	35	4		1		3	
	40	1	7	0		1	6
Total		45	45	20	20	25	25

Rand-GHP: Rand General Health Perception

The effect/MID-anchor index was highest in the recovery measure (MHRM), with a value of 1.29.

Regarding the supportive MIDs, the MID-SD_c was calculated for the PROMs (see Table 2) and the effect/MID-SD_c index was highest in the MHRM with a value of 1.33. The MID-SEM values for the PROMs were equal to the SEM, which we calculated for the PROMs with data from referent studies (see Table 5). The effect/MID-SEM index was also highest in the MHRM with a value of 1.40.

Owing to the modifying effect of the gender covariate, we also stratified the MID calculations (see Table 2). For the stratified calculations of the MID-anchor we reorganized the change groups into four groups based on the 15-point difference, because the male/female proportions in the different change groups were skewed (see Table 4). Males were overrepresented in the negative change groups and females were overrepresented in the positive change groups. Only one male was present in the large positive change group and females were absent in the large negative change group. For the groups with male participants we merged the two positive change groups, resulting in large negative (n = 3), small negative (n = 4), no (n = 10) and positive (n = 3) change groups; for the groups with female participants we omitted the large negative change group, resulting in small negative (n = 3), no (n = 8), small positive (n = 8) and large positive (n = 7) change groups. The mean differences between the four change groups estimated the MID-anchors for males and females separately. The effect/MID-anchor index was highest for males (0.88) in the self-management measure (PAM) and for females (2.63) in the recovery measure (MHRM).

For the supportive MIDs the MID-SD_c was stratified for males and females. The effect/MID-SD_c indexes for both males (.83) and females (1.71) were highest in the MHRM. The MID-SEM for males and females separately was not calculated because the referent studies did not provide data for males and females. The effect/MID-SEM indexes for both males (.89) and females (1.76) were highest in the MHRM.

Table 5. Analyses of the Standard Error of Measurement with data from the referent studies (SEM = SD × √(1 - r_{xx}))

Measures (reference)	r_{xx}	SD	SEM
IMRS (165)	.80	6.99	3.15
PAM (181)	.76	14.21	6.96
MHRM (183)	.92	20.00	5.66
BSI (168)	.82	1.08	.46
MANSA (227)	.90	.72	.23
Rand-GHP (172)	.80	22.7	10.15

SEM= Standard Error of Measurement; SD= Standard Deviation; r_{xx}= test-retest coefficient; IMRS= Illness Management and Recovery Scales; PAM= Patient Activation Measure; MHRM= Mental Health Recovery Measure; BSI= Brief Symptom Inventory; MANSA= Manchester Short Assessment of Quality of Life; Rand-GHP= Rand General Health Perception

Discussion

Considering the discourse of a clinical versus personal recovery orientation in the field of persons with SMI, this paper aimed to identify the PROM that captures the most relevant and meaningful change as a result of the IMR programme in persons with SMI. In the whole study population, the recovery measure (MHRM) showed the highest effect/MID index in all the MIDs. Also, in the subgroups stratified by gender, the MHRM had the highest effect/MID index in nearly all the MIDs except for the effect/MID-anchor index for men, which was highest in the self-management measure (PAM). With certain prudence, we conclude that the MHRM captures the most relevant and meaningful change for persons with SMI.

Pre–post scores improved statistically significantly on all the PROMs. The improvements in self-management (PAM) and illness management (IMRS), are bigger than the decrease of burden of symptoms (BSI). The improvements in illness- and self-management might have enhanced their perceived recovery more than symptom reduction. This matches with Slade's statement that self-management is related to recovery because it can be a vital resource for supporting recovery (25). Our findings showed that the IMR programme is capable of facilitating recovery by using both illness self-management and personal recovery-orientated strategies, which is also claimed in previous research (38,118,160). In another earlier study on this population we saw that women scored better than men, as if women could benefit more from the IMR programme than men (201). However, before concluding that the IMR programme should be preserved for females, we suggest re-investigating the possible difference in effect between men and women in a larger trial sample.

The overall results on effect/MID index indicate that participating in the IMR programme brought about an important change in the participants. As stated in the 'Materials and method' section we interpret that an effect/MID index of ≥ 1 indicates that at least half of the participants have a change of at least the MID. However, if the effect/MID index is < 1, there could still be a meaningful number of participants with a change above the MID. On none of the PROMs did the male participants score an effect/MID index of > 1. Considering the concept of the MID, Revicki et al. (228) state that the ½SD magnitude of change is certainly clinically significant but may not be the smallest non-ignorable difference: ½SD in an outcome measure might be too large to be considered minimally important (228). Revicki's et al. statement might also apply for ½SD_c, because in our study the SD_c and the SD on baseline scores differed only slightly. Although the mean change in the male participants in our study was <1MID, we saw that they improved significantly on the recovery measure (MHRM).

On comparing the three calculated MIDs in the PROMs, we conclude that they do not differ by very much. Similarity of the distribution-based MIDs would be expected when the reliability index r_{xx} is 0.75 in a SEM calculation because then both the MID-SD_c and the MID-SEM are equal (234). The r_{xx} in the main PROMs in our study ranged between 0.76 and 0.92. When an r_{xx} is higher than 0.75, the MID-SEM is expected to be lower than the MID-ES. In our study, this is the case in the MHRM and the BSI but not in the QoL measure (MANSA) due to the difference between the SD in the reference study (227) and the SD_c in our study. Nevertheless, in our study the results in the three MIDs are reasonably consistent and therefore we can conclude that the MID-SD_c and MID-SEM support the findings on the MID-anchor.

The anchor-based method is our preferred method, as also recommended by Revecki et al. and Johnstone et al. (221,231). Jayadevappa et al. (219) mention there is no agreement regarding appropriate anchors. The health change (Rand-HC) 'global transition question' anchor-based method appeared to be non-feasible, which is in line with other studies that declared inaccuracy related to response shifts and recall bias (223,235,236). Recall bias might also be responsible for Rand-HC's low test–retest coefficient (r_{xx} = 0.40) found in the study of Van der Zee et al. (172). Nevertheless, this global transition question is still recommended for estimating the MID.

In our study, we found the general health perception measure (Rand-GHP) to be the best anchor. Although this choice was data driven, we also considered that Rand-GHP captures the richness and variation of a construct of QoL. The five Rand-GHP questions contain important issues in estimating one's health status: global estimations of whether their health status hinders them in social activities, whether their health status is excellent, whether they expect deterioration and two questions on whether one's health differs compared to the persons they know. There is considerable evidence that evaluating oneself favourably in comparison with others is associated with having fewer health problems (125). Social comparison also is an important behavioural change technique (161). Because of the groupwise deliverance of the IMR programme in our study, participants became acquainted with peers. Comparing oneself to peers might be more realistic than a comparison to healthy persons. Perceiving one's health status as deteriorating is associated with a higher need for support with self-management tasks (20). We considered that Rand-GHP is a valid measure for investigating the MID as a result of an intervention.

Strength and limitations of the study

The strength of our study is that we contributed to the scientific literature on PROMs and explored the use of MIDs in the field of SMI. We need to be cautious about drawing definite conclusions based on our findings because of the relatively low sample size and the significant gender confounder. The statistical power of the results is low and our sample might not be good representation of the population of persons with severe mental illness. More men living in a supported housing facility might coincidently determine the variance in our observed scores. In a confirmative trial or in other existing datasets with a bigger sample this study might necessarily be repeated. Although our sample size was small, it was large enough (> 40) to detect correlation coefficients of 0.50 or higher with a power of 96% (188) and it therefore properly based the MID-anchor calculations. Another strength of our study is that we were able to include non-completer participants with a low attendance rate, which makes the findings more realistic.

On the one hand, our interviewer-administered method of data collection can be considered as a limitation. The face-to-face interviews might have caused response bias, in terms of acquiescence bias (237), and also social desirability, which is stronger in women compared to men (238). This might have influenced the gender effect difference in our study. Respondents may deliberately answer questions inaccurately, either by underreporting or overreporting of normative or stigmatized issues such as sexual behaviour or eating patterns (239,240). We controlled our results for this bias. We did not find a gender difference in the response to the item of satisfaction with their sexual life in the QoL measure (MANSA), which is an issue that could cause shame and be influenced by social desirable bias. Therefore, we could not conclude that social-desirability bias did lead to the gender difference found in our study and nor could we definitely rule out the presence of this bias. This bias, just as with acquiescence bias, could have occurred in the baseline as well as in the endpoint interviews. Therefore, we expect that the change we saw can be considered a real change. The length of the questionnaires could have caused cognitive fatigue and biased the results because we did not change the order of the different questionnaires. In a confirmative trial, randomizing the order might prevent this bias.

On the other hand, the face-to-face interviews might have prevented non-response bias, by preventing attrition. We estimated that too many of our participants would not respond to self-administered questionnaires. Only participants with a higher level of functioning might have completed the questionnaires, which could have caused bias. We decided we could better use the advantages of face-to-face interviews (226) as mentioned before in the 'Materials and method' section.

Conclusions

Taking into account the low sample size and the gender covariate, we conclude with certain prudence that the MHRM was capable of showing the most relevant and meaningful change in persons with SMI as a result of the IMR programme.

Implications for further research

Our research can be used as an example of how to estimate MIDs in the context of persons with SMI. More research with a larger sample needs to be done to gain a more solid grounding for the MIDs. This research needs to account for the gender covariate. In future research on the effectiveness of interventions for persons with SMI, a recovery measure such as the MHRM should be used.

Implications for further practise

In the search for scientific information that can convince clinicians to change their treatment practices and convince policy-makers to change their treatment guidelines, our findings can be used, with certain prudence, in shared decision-making processes. When an outcome on recovery is desired, a person with SMI can be assigned to the IMR programme. A recovery measure such as the MHRM is able to measure the effect and should be used uniformly.

Chapter 9.

General Discussion

Introduction

The objectives of this thesis were to contribute to consumer-oriented development, delivery and effectiveness of an e-supported self-management intervention for persons with severe mental illnesses (SMI). This thesis was meant to identify strategies that match needs, and to reflect critically on e-support for self-management. This thesis presents the studies executed in phases of development and evaluation of the e-IMR intervention for persons with SMI. The first section of the study focussed on the development and preparation of the e-IMR intervention and trial. The second section focussed on the evaluation of the e-IMR intervention compared to the face-to-face delivery of the IMR.

Main findings

Section 1: Development and preparation of the e-IMR intervention

In the development phase of this study, in **chapter 5**, we define the health problems of persons with a severe mental illness (SMI) as feelings of isolation, relapse of psychiatric symptoms, and feelings of hopelessness. We stated that these problems are intertwined. Treatments for persons with SMI are aiming for symptom reduction and recovery. Recovery means choosing, getting, and keeping valued roles in society. In **chapter 2** we describe self-management support needs of persons who are confronted with the burden of an SMI. When feeling the need to perform a self-management task, persons also can feel the need for support. From reviewing scientific literature we derived self-management support needs. In the process of learning and executing self-management tasks persons with SMI feel the need for: informational support, emotional support, acknowledgement, encouragement, and guidance. Fulfilling the support needs aims to make sense of illness experiences, ease suffering, obtain validation and recognition, execute self-management tasks, and be led through an unfamiliar territory.

The Illness Management and Recovery program (IMR) is a complemented intervention combining the foci on self-management and recovery. In **chapter 3**, from participants in the IMR program we learne that the IMR enhances recovery. Participants reported they learned the skills of goal-setting and symptom management; and that it works because of practising these skills in daily life and getting information via the IMR textbooks and via the exchange with peers in which the peer-professional was of great value. In **chapter 4**, we conclude that the Illness Management and Recovery Scales, used to measure the effectiveness of the IMR, is a valid instrument to measure illness management and can be used in the field of recovery in the Netherlands.

Next, in **chapter 5**, we describe the development of the e-IMR intervention. The e-IMR platform was set up with the content of the standard IMR program. On the e-IMR platform participants could: watch peer-testimonials videos, fill in forms and home work assignments in all the IMR chapters, follow up on goals and successful coping strategies, monitor symptoms, and solve problems. A number of behaviour change techniques (BCT) were implemented in the e-IMR: peer-information, social comparison, modelling, goal-setting, setting graded tasks of attainable steps, reinforcement of progress, weighing pros and cons, and raising awareness. We prepared an exploratory cluster randomized controlled trial.

Section 2: Evaluation of the e-IMR intervention

In **chapter 6** we describe the results of the e-IMR trial, which was executed in institutions, members of the Dutch IMR-network. In the intervention group we blended the use of the e-IMR platform to face-to-face delivery of the standard IMR program. To the participants in the control group only the standard IMR in face-to-face sessions was provided. Seven clusters were randomly assigned to e-IMR+IMR or IMR only. Sixty persons with SMI participated; 41 in intervention group and 19 in control group. Outcomes of illness management, self-management, recovery, symptoms, quality of life, and general health were measured at baseline, halfway, and at the endpoint after twelve months. The data were analysed using mixed model for repeated measurements. Out of the 41 participants in the intervention group 14 (34.1%) participants were identified as e-IMR users, which means having completed at least module one or having logged in at least five times. Halfway, the participants in the intervention group scored significantly higher compared to the control group for the outcomes self-management (Patient Activation Measure (PAM) (17), $p = .01$) and recovery (the Mental Health Recovery Measure (MHRM) (9), $p = .02$). At the endpoint, the effect on the outcome Rand-General Health Perception (Rand-GHP) (172) was significant ($p = .02$) in favour of the intervention group. Unfortunately, the use of the platform was too low to make a relevant difference between the treatments in the intervention and the control group. Because of this, the significant effects that we found could not be realistic. Post-hoc analyses showed that confounding and interactive factors moderated the effects: respectively gender and non-completers. Apparently, women did benefit more from the IMR than men, and stopping the IMR-programme was based on differences in their improvements. These conditions were unequally distributed over the groups, which modified the effects. Thus, this study precludes definite conclusions on the potential efficacy of e-health for persons with SMI

In **chapter 7**, the low use and added value of the e-IMR is evaluated in a qualitative process evaluation. We identified barriers within the intervention itself and its implementation, the participants and their social context, and the trainers and their institutional context. We found that the following barriers were influential: the inflexibility of the e-IMR platform, the lack of IT-resources in participants and in institutes, the context of group-session in which using the platform was estimated as too time consuming, the participants' low computer skills and vulnerability, and a hesitant e-health attitude of trainers. A dismissive attitude towards the e-IMR in participants was present at the start of the trial. Halfway the trial the e-IMR platform was re-introduced. This led to e-IMR lessons outside the group session organized by trainers. Within these lessons a number of participants were able to learn how to use the platform. About the e-IMR components we received different feedback. Added value was reported on the goal-tracking sheets and the peer-testimonials. The latest were highly rewarded for their potency to enhance group discussions and participants' disclosure.

At last, in **chapter 8**, we conclude that the recovery measure MHRM determined relevant change in persons with SMI who participated in the IMR program the most, compared to other outcome measures. Which means that participants in our study improved more in their recovery compared to their burden of symptoms.

The lessons learned from the e-IMR intervention and trial

The e-IMR intervention trial was set up as an exploratory randomized control trial. Our sample was small and not able to prevent bias because of differences in population characteristics (188). Because of this we hesitated to draw conclusions on the significant effects that we found and performed post-hoc analyses on possible confounders and interactive moderators in the population characteristics. These we found in the factors gender and non-completers of the IMR sessions. The confounding factor 'gender' was unequally distributed over the two study groups. Apparently, women did benefit more from IMR than men. In general, women do differ from men in a number of ways; for instance, exposure and reactions to stress (189), needs and care (191,192), and coping styles (193). With regard to coping styles, women could benefit more from a problem-solving-focused intervention and men from an emotion-focused one (194). IMR, with its emphasis on learning how to manage an illness in a context of pursuing recovery goals (27), has a greater focus on problem-solving than on emotional strategies. Therefore, women could have benefitted more from the IMR than men. The interactive factor in our trial was non-completers, defined by persons with an attendance rate of less than 50% (186). We saw that the non-completers in the intervention group had improved contrary to those in the control group who declined. Apparently, a positive and negative motivation to stop the IMR was unequally distributed over the two research groups. At the endpoint, 14 out of 45 participants were non-completers and remained in the trial and entered the intention to treat analyses. We preferred to use the intention to treat analyses because stopping an intervention is ordinary daily practise. High attrition rates appeared in treatments of persons with SMI and in IMR studies (38,186). From this we learned that our sample should be big enough to reach a conventional minimum power of 80% (241). However, low sample power appears to be an endemic problem in biomedical science. (241). Dumas-Mallet et al. (241) found that approximately 50% of studies in different biomedical domains, of which one is mental health, had a power of below 20%.

We qualitatively examined the low use of the e-IMR platform in order to learn how to adapt the e-IMR intervention to increase the use of the e-IMR in the future. Before focussing on the content of the e-IMR intervention we evaluated step 5 of the Intervention Mapping Protocol (IM), which is about examining the potential implementation problems, objectives, and strategies (52). In chapter 7 we concluded that we did not foresee the lack of IT resources in organisations. Implementing the e-IMR platform in the session rooms appeared to be problematic because of highly protected IT-environments and lack of resources. Williams et al. (209) also saw that problems with Internet-based systems in services contributed to the low use of interventions. We identified the precondition that e-IMR-providing institutes need updated resources ready to use the e-IMR platform, which means an open ICT environment, open soundcards, strong computers and WIFI for multiple tablets, available projector and screen, and a help desk.

Unfortunately, we were not able to test whether the e-IMR is feasible in individual sessions. The potential clusters in which IMR is provided individually withdrew from participating in the trial. The use of the e-IMR platform in IMR group sessions appeared to be not feasible because of participants' and trainers' estimation that it would be too time consuming to switch between participant's accounts and not being able to read their homemade notes. Besides, not all group members participated on the e-IMR platform. Participants in the intervention group recommended providing tablets in order to resolve these problems. Providing devices to persons with SMI supports engagement in e-interventions (209), and technical resources facilitate implementation (210).

Participants reported that the e-IMR components goal-tracking sheets and monitoring did have added values, although monitoring was experienced in different ways. Some benefitted from it, and others felt irritated being confronted with symptoms. To focus on the illness was not appreciated by some of the trainers. We learned that the provision of e-IMR components needs to be optional and only provided in response to a specific support need of a participant. Then e-IMR will be able to apply to the general Behaviour Change Techniques (BCT) 'individualization' and 'tailoring' by adapting the intervention to a personal need (161). In response to a certain personal need, future e-IMR trainers must know how to adapt the e-IMR intervention. Other BCTs (161) in the e-IMR applications were 'set graded tasks, goal-setting', and 'reinforcement of progress', which were present in the goal-tracking sheets. Because of the lack of feedback we cannot draw conclusions on the 'problem-solving'- and 'successful coping strategies' sheets. The videos with peer-testimonials on the topics of the chapters in the IMR were highly appreciated by trainers and participants for the provision of peer-information and their added value for its potency to enhance participants' disclosure and group discussions. This matches with Williams et al. (242) findings that watching these kind of videos is a pivotal experience that enhanced reflection and discussions. We conclude that the BCTs 'peer-information', 'social comparison', and 'modelling' had the intended impact. Un-intently, the peer-testimonials also induced the BCT 'participation'. Participants were more involved in the IMR content via the group discussions that were enhanced by the videos.

Reflection on electronic mental health for persons with SMI

In the implementation phase not all potential problems were overlooked. We foresaw a problem with IT resources and competences of persons with SMI, which made us decide not to oblige the use of e-IMR platform at the participants' home. In the implementation phase we planned to offer computer lessons to the participants when necessary. After the introduction of the e-IMR only one participant made use of this opportunity. At the endpoint however, a number of participants said that they had been reluctant to report the need for guidance. In a sense, persons hesitate to concede their imperfection, which we consider a normal facet of life. From this we learned that persons with SMI need guidance with learning to use a computer. This guidance starts with learning how to log in on the platform. Complex log-in procedures contribute to low-use (209). We, just like Van Keulen (243) and Williams et al. (209), saw that participants had great problems logging in into the privacy protected environment.

We also learned that not feeling well enough and having psychiatric symptoms also contributed to the low-use and learning how to use a computer. Learning new skills while not feeling well must have a direct relation to learning how to cope with this 'not feeling well' and not with learning how to use a computer. In our study, in chapter 2, we saw a relation between a need and the provided self-management support. First and foremost this 'not feeling well' needs to be acknowledged and requires presence and active listening. We saw that some of the participants in our study were able to learn how to use the e-IMR platform only later on in the trial when feeling a lot better. This also can be explained by the term 'zone of proximal development'. The term, introduced by Vygotsky (244), describes that the level of development one can reach is bracketed by the learner's current ability. Participants in our study reported having problems with concentration, having a sensory overload, were easily over-stimulated, and lacking control, as if persons lack a theory of mind over what a computer is doing with their input. Obviously their first need is to be able to concentrate well enough before learning how to use a computer. Since SMIs are highly associated with cognitive disabilities, such as impaired attention, learning, memory, and problem solving skills (24), one can imagine the difficulty of learning how to use a computer. We concluded that most participants in our study were not yet ready to engage with e-health. Berry et al. (214) drew a comparable conclusion that persons with SMI have relatively low interest in and willingness to engage with e-health interventions. In order to allow development of interventions tailored to their needs the e-health readiness of persons with SMI needs to be investigated (245).

In our study, trainers with a positive attitude were willing to take a great effort in organizing the e-IMR lessons outside the group. Participants who felt better were more interested in using the computer and participated in the e-IMR lessons. Worker engagement and support of persons with SMI was considered essential for successful use of e-interventions (246). In our study, the attitude of trainers towards the e-IMR was hesitant. Their attitude towards e-health might be based on their preference for tangible paper and face-to-face contact and their own low computer skills. Not to forget, their mean age (46.7) implies that they, like the participants, belong to a low-computer-experienced generation.

Trainers in our study stopped promoting the e-IMR in order not to burden participants and avoid participants' withdrawal from the group-sessions. Identification with the participants' struggle and vulnerabilities is another possible explanation. To illustrate: some of the trainers questioned the appropriateness of e-health for persons with SMI, blaming the policy makers. In general, mental health nurses indicate that e-health is not in line with their education level, cultural background, or digital skills of mental health patients, despite the nurses' general satisfaction with e-health (215). Williams et al. (209) suggests a paternalistic attitude when workers decide on the suitability of persons with SMI to use e-health interventions. The trainers experienced the group pressure against the e-IMR and found it difficult to oppose this and related this to the disabilities of the participants, which, in itself, affirms the mental health stigma. Other trainers strived creatively and found solutions for showing the peer-testimonial videos and additional support outside the group sessions. Notable is that in our study non-computer-minded participants became 'users', thanks to the effort of their trainers, three of whom were peer-professionals. Strand et al. (210) mentioned the facilitating role of peer-professionals and argued that they not only have more time, but relate more readily to personal needs and concerns.

We overall concluded a low e-health readiness in persons with SMI and their need for guidance with e-health. This matches with Apolinário-Hagen et al. (247) who concluded that professional support was essential for help-seeking intentions in case of psychological distress. Therapist-assisted e-health services prevail over unguided programs (247). We considered this could be explained by the self-management support needs. E-health is able to respond to a need for informational support, but is it also able to respond to needs for acknowledgment and emotional support? Is e-health not a too cold technology for warm needs (248)? We do think that e-health needs to respond to a personal need. Chat function or video-calls, might have the ability to bridge the distance between persons in need and the support provider (249). Via e-communities persons might be able to organize face-to-face contacts and practical help close to their homes (250).

Providing the e-IMR in the future is preconditioned by an e-health-friendly attitude and appropriate computer skills of trainers. It might be necessary to organise professional support to teach them to use e-health, get experienced, and resolve their reluctance of using e-health. Successful use of Internet-based interventions is facilitated by the training, support, and encouragement of persons with SMI (209).

Self-management versus recovery

During our study, we often discussed the differences and the similarities between the concepts of self-management and recovery. In our study of self-management support needs we often wondered whether statements fit the concepts of recovery or self-management. An example is a statement about the need for help to engage in public travel.

> *"I could catch the bus, but I didn't know how to go back home. . . . So I learned something new from my daughter and it's nice being able to get around again. To be able to have a real bus pass and use it and enjoy yourself."* (251)

The statement lacked context of the bus' destination. If it was a place of participation, such as work, it would have fitted the recovery concept, but when the destination was a treatment facility it fits the self-management concept. We did not include this statement because of this unclearness. Reviewing the perspectives on self-management that we mentioned in the introduction, we were curious whether we could find comparable descriptions of recovery on the three perspectives of Trappenburg et al. (15): 1) self-management as a paradigm shift from a paternalistic model to a participatory model, 2) self-management as abilities: problem-solving, decision-making, making use of support sources, managing relationships with professionals, planning actions, and self-monitoring, and 3) self-management as an intervention or treatment in which professionals teach persons how and when to make use of the self-management abilities. Such interventions make use of methods like goal-setting, motivational interviewing, and role models (15). In Table 1 we describe the concept of recovery within these three perspectives and compare this to Trappenburg's descriptions of perspectives on self-management as mentioned before, and we add definitions of the two concepts.

The concept of recovery in three perspectives

Paradigm shifts in recovery. The concept of recovery describes the shifts from being a patient into citizenship, from symptom reduction into living a meaningful life, and from disabilities like 'what is wrong with you' into strength, challenges and possibilities (25,252). Deegan's quote *"There is strength in vulnerability"* (253) illustrates the shift away from the normal paradigm of 'showing one's vulnerability is equal to exposing weakness'. The word 'illness' did get a nasty connotation in the recovery movement, in which a dismissive attitude towards the medical orientation can be heard, such as labelling mental illnesses, because of stigmatizing tendencies (25,216). This attitude is caused by the paternalistic attitude in health care in the past and in the present. Over the years persons with SMI are too often not understood, disacknowledged, invalidated, and isolated from citizenship, justified by what is in

Table 1. Comparison of the concepts of self-management and recovery

Perspective	Self-management	Recovery
Concept definition	Self-management is a dynamic and continuous process of self-regulation that refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (13)	Recovery is a deeply personal and unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (4).
Paradigm shift	From the paternalistic model to a participatory model. In the practise of shared-decision, personal needs take a central position instead of what professionals can provide. (15)	• From the paternalistic model to a participatory model. • Identity-change from 'patient' to 'citizenship'. • From decrease of burden of symptoms towards living a meaningful life. • From disabilities towards strength, challenge, and possibilities (25)
Ability	Problem-solving, decision-making, making use of support sources, managing relationships with professionals, planning actions, and self-monitoring (15).	Goal-setting abilities includes: commitment to change, self-efficacy, interests, values, making choices, awareness of identity and social situation, support needs, and the quality of working relation with the professional (254).
Intervention	A self-management intervention aims to enable persons with self-management skills to actively participate in coping with a chronic condition aiming for functioning optimally in daily life. An intervention comprises knowledge transfer and an active stimulation of skills like symptom monitoring, medication management, decision making in case of self-treatments or additional contact with a professional, changes in physical activity and healthy eating and habits (15).	Recovery interventions focus on choosing, getting or keeping a specific valued role; and comprising the recovery values of person orientation, partnership, self-determination, and hope (26). Steps in the CARe-model (255): 1. Building a relationship with the client; 2. Drawing up a strengths assessment; 3. Helping to formulate wishes and goals; 4. Helping to make a recovery worksheet; 5. Helping to execute the recovery worksheet; 6. Adjusting the recovery worksheet.

their own best interest (25,216). To move away from this paternalism a recovery orientated attitude is formulated: the professional is present and listens actively, uses expert knowledge modestly, interacts personally and transparently, recognizes and utilizes the persons strength and social network, and aims for a decrease of suffering and on increase of autonomy (10).

Recovery abilities. In the field of recovery, goal-setting is the central ability. The Dutch foundation of Rehabilitation '92 provides an assessment tool to estimate a person's ability to set and achieve a recovery goal. The assessment tool comprises of the items: commitment to change, self-efficacy, interests, values, making choices, awareness of identity and social situation, support needs, and the quality of working relation with the professional (254).

Recovery intervention. A recovery intervention is identified as counselling of real-life processes focussing on choosing, getting, and keeping a specific valued role; and comprising the recovery values of person orientation, partnership, self-determination, and hope (26). The comprehensive approach to rehabilitation method

(CARe) describes a six steps intervention (255) that comprises of: 1. Building a relationship with the client, 2. Drawing up a strengths assessment, 3. Helping to formulate wishes and goals;, 4. Helping to make a recovery worksheet, 5. Helping to execute the recovery worksheet, 6. Adjusting the recovery worksheet.

Similarities and differences

In the perspective of paradigm shifts we see a broader range of shifts described in the concept of recovery compared to the concept of self-management. In both we recognize the shift from a paternalistic towards a participatory model. The recovery abilities enlighten the more personal attitude and situation related to the recovery goal, where as self-management abilities focus on cognitive decision-making functions in persons related to healthy behaviour. In both self-management and recovery interventions we recognize goal-setting, motivational strategies, and management of the patient-professional relation. Overlooking this discourse, we do see similarities between the concepts of self-management and recovery. Slade (25) describes the relation between the two as that promoting self-management can provide a vital resource for supporting recovery, as if self-management is a smaller concept than recovery. Recovery, indeed, is a broader concept that focuses on deeper levels of a human being, like attitude, values, identity. Self-management focuses on behaviour related to living with the illness and in recovery the ultimate aim is living beyond the mental illness.

Recovery was, and still is, necessary as an emancipatory movement (4). But, we think that the members of the recovery movement must not isolate themselves from the medical orientation, for the illness is a reality. To underline this we mention the DITSMI (Diagnose, Indicate, Treat, Severe Mental Illness) project in which persons with SMI are re-diagnosed, re- indicated, and treated appropriately (256). Many persons with SMI are misdiagnosed and because of that mistreated. Results of the DITSMI project were changes in diagnoses in 49% of the patients, changes in medication in 67%, some improvement in psychosocial functioning, and a 40% decrease in bed utilization (256). Thus, recovery oriented professionals must not neglect the illness self-management aspects of living a chronic illness. Our study (chapter 8) showed smaller improvement in measurements of burden of symptoms than in self-management and recovery. The improvements in self-management might have enhanced their recovery more than that it lowered the burden of symptoms.

This discourse of the two concepts makes clear that self-management and recovery are related and intertwined concepts. The narrative recovery orientation on the personal values beyond the illness should be incorporated in learning to self-manage the illness. Yet, there is no evidence that full recovery of an SMI is preconditioned by executing self-management behaviour. The new definition of health as the ability to manage and adapt (16) reflects the differences between the two concepts of the previous paragraph. The 'manage' item represents the concept of self-management and the 'adapt' item can be related to the concept of recovery, which is about learning how to adapt your life to the consequences of a severe mental illness.

Self-management and/or recovery support needs

One might argue whether the self-management support needs that we described in chapter 2 would differ much from the recovery support needs. One of the recovery tasks that Slade (25) described is the 'framing the illness', which he describes as making sense of the illness to be able to put it in a box: framed as a part of the person but not as the whole person. In this, we recognize the need for acknowledgment as we described in chapter 2. We also recognize this 'framing the illness' in other self-management support needs, which we related to the experiential learning theory of Kolb (106). Persons with SMI mentioned their need to make sense of what they experience. Dervin (104) stated that a gap in sensemaking appears when the continuity of experiences is interrupted by gaps in understanding. The devastating unfathomable experience of an SMI is such a sensemaking gap. With regard to essential self-management activities, Mamykina et al. (105) stated that people make a myriad of daily choices based on sensemaking, including organizing the chaos of lived experiences, finding patterns, and discovering connections and dependencies, which all refer to an orientation system, based on past experiences. This focus on sensemaking implies a personal discovery process that starts with having an experience, followed by reflecting, giving meaning, and experimenting to find one's way toward self-managing and experiencing what really works. This process is called "experiential learning," as first described by David Kolb in the 1970s (106,107). The process fits with the self-management support needs we identified in **chapter 2**: receiving acknowledgement and emotional support when being overwhelmed or in need to cope with emotions, getting information and counselling when needing to understand and discover meaning, receiving encouragement when experimenting to perform self-management tasks, and getting to terms with the illness as a result of this personal process. In a sense the process of dealing with an SMI is a matter of sensemaking, answering the question: *"What's the story?"* (104). The concept of recovery is closer to this narrative orientation than the concept of self-management.

The Illness Management and Recovery Program (IMR)

The IMR is identified as a complementary intervention integrating the recovery and self-management foci of helping persons with SMI to choose, get, and keep valued roles and the reduction of symptoms and effects of the illness itself (26). As we stated in chapter 3 and 8: participating in the IMR enhances the recovery of persons with SMI, just as a Danish qualitative study shows that participants learned much about recovery as a personal experience (257). The IMR has proven effectiveness in three RCT's in different countries (35–37). After reviewing the IMR literature, McGuire et al. (38) concluded that the effects of IMR on consumer-reported recovery and symptom reduction are promising but require further exploration. Since McGuire's et al. review (38) in 2014, international effect studies on the IMR showed different results. In the USA, a pilot cluster randomized controlled trial (RCT) on the implementation of IMR in Assertive Community Treatment (ACT) showed significant effects on the illness self-management, measured by the IMRS, but not on recovery (258). An IMR trial in Denmark did not show significant effects at the endpoint (259,260) and at a one year follow-up (261) on self-management nor recovery. Overall in RCTs minimal effects on subjective recovery have been observed. One explanation is that the currently available rating scales do not sufficiently capture functional and personal recovery (257,262). Unfortunately, the results of the Dutch RCT of Roosenschoon et al. (34) are not yet published. In personal conversation Bert-Jan Roosenschoon reported that he found significant results.

In our study, chapter 8, we compared the outcome measures of self-management, symptom severity, recovery, and quality of life to the concept of General Health Perception (Rand-GHP) of the Rand 36-item Health Survey (172). We concluded that the recovery measure (MHRM) showed the most relevant and meaningful change in the participants and captured the benefits of the IMR program. The highest percentage of participants that scored above the minimal important difference (MID) was in the MHRM. The MID is the smallest difference in change score in the domain of interest that patients perceive as important, either beneficial or harmful, and that help shared decision making in considering a change in treatment (39). The concept of the Rand-GHP appeared to be a valid anchor to which the change scores in the outcome measures could be compared. The Rand-GHP consist of five questions estimating one’s health status: whether their health status hinders them in social activities, whether they estimate their health status is excellent, social comparison in the two questions of comparing ones health to persons they know; and whether they expect a deterioration of health. Social comparison is a ubiquitous social phenomenon (125). There is considerable evidence that evaluating oneself favourably in comparison with others is associated with having fewer health problems (125). Perceiving ones health status as deteriorating is associated with a higher need for support with self-management tasks (20). However, we need to be cautious about drawing conclusions because of the sample size in our study and the variable gender that significant confounded the scores on the Rand-GHP, in favour of women. In this thesis we earlier assumed that, based on gender differences (189,192,193,263), women could have benefitted more from the IMR-programme than men. However, before concluding that the IMR should be preserved for females, we suggest re-investigating the possible difference in effect between men and women in a larger trial sample.

Nevertheless, we cautiously conclude that the Rand-GHP captures the richness and variation of a construct of health perception and is a valid measure for investigating the MID as a result of an intervention. In the Dutch context of persons with SMI, our findings can be used in shared decision-making processes, which is the practical usefulness of the concept of MID. King (223) foresees a future in which MIDs are consolidated in treatment guidelines. Knowing that an intervention can make an important difference in a desired outcome domain can motivate a professional to offer and stimulate a person with SMI to participate in that intervention. In the case of IMR: a person who desires a recovery outcome, as measured by the MHRM, can be recommended to do the IMR program.

Public Stigma

In chapter 5 we mentioned the issue of stigma as a determinant of caregivers' behaviour, which we related to lack of knowledge that causes incomprehension in caregivers without SMI. Persons with SMI have to deal with stigma and consequently experience prejudice and discrimination (2), often resulting in self-stigma and the phenomenon of 'why-try': thus being dissuaded from pursuing life-goals (3). In chapter 5 we also described that persons with SMI often experience that persons without SMI provide infeasible suggestions of how to solve problems and cope with symptoms. In Bos' et al. (109) theory on stigma, a cognitive representation of public stigma lies in the perceived severity of the stigmatized condition, which evokes both anxiety and sympathy and simultaneously can yield emotional ambivalence and awkward interactions. Providing problem solving and coping suggestions can be driven by sympathy, but also by being affected too much by the severity of the symptoms, as if one is infected by the emotional exchange in the relationship. This thesis' opening poem by Okke Jager (264) "*How valuable is a vulnerable human being*" reflects this getting affected when being confronted with human frailty. Providing problem solving and coping suggestions regarding self-management, sets a claim on personal responsibility, another cognitive representation of public stigma (109). With these suggestions healthy persons defend themselves (perhaps unconsciously) for becoming too emotionally involved. This defensive reaction fails to take account for the self-management support need of acknowledgment that we defined in chapter 2. As a result, feelings of rejection and isolation can emerge in persons with SMI. The need for acknowledgment might be responsible for the participants' preferences for talking with peers about the illness, which is reported in the chapters 2, 3, 7 of this thesis, and confirmed by Jensen et al. (257). The exchange in the group was highly valued, and we estimate this is essential. Peers can understand the severity much better. In our review in chapter 2, we wrote that before being able to understand the illness it is necessary to have support providers who really understand the illness and its consequences (98) and who acknowledge the frightfulness (79) and impact of the illness (78,79). One of the informational needs that we defined is to be educated in how to tell others about their illness (69). When a self-management, recovery, or complementary intervention is able to fulfil this need, persons with SMI might become able to educate their caregiver to acknowledge their experience before coming up with problem solving and coping suggestions. Caregivers might then understand their stigmatizing reaction and become better support providers.

Implications for future practice

In spite of our findings concerning the low use of the e-IMR intervention and low e-health readiness of persons with SMI, the development of Internet-based interventions is on-going. This is in line with the progress of the digitalizing society and health care, and is embedded in institutions' policies. Strand et al. (210) concluded that Internet can play a transitional role towards recovery oriented practices. Also Williams et al. (209) identified the potential of Internet-based interventions to elicit personal values of persons with SMI and treatment preferences. Addressing to personalization seems a key issue for future e-recovery research (210). In e-communities persons can report their personal needs and find others who can fulfil this need, all in service of the person in order to empower him or her to keep or restore a sense of agency (265). Such e-communities are in an experimental stadium in a number of cities in the Netherlands (250). In such communities the Illness Management and Recovery (IMR), in the e-IMR or face–to-face only standard version, might be able to fulfil the needs of persons with a mental health problem in all kinds of severities who desire an outcome in the recovery domain. Since the IMR is developed for persons with severe mental illness (SMI) in the USA and knowing that in the USA the SMI-definition is less strict in its duration, we think that the IMR is not restricted to persons with SMI according to the Dutch definition. Also persons treated in the shorter-term mental health care might be able to benefit from the IMR.

The promising statements of Strand et al. (210) and Williams et al. (209) for the future of e-health for persons with SMI make it worthwhile to take up further development of the e-IMR intervention. We learned that future use is pre-conditioned. The trainers and organisations, in which e-IMR will be provided, must have sufficient IT-resources and skills and a positive e-health attitude. Also participants need sufficient IT-resources and skills, or need personal guidance to learn how to use the e-IMR. Learning these skills is often a challenge for persons with SMI. But, it might consequently also resolve isolation from the World-Wide-Web. Mainly older persons with SMI experience digital exclusion (266).

When providing the e-IMR group wise, tablets need to be supplied to the participants. In our study we learned that it is better to use the policy 'all or none' in using the e-IMR. When all participate, the behavioural change technique (BCT) of 'social support' (161) can be applied via e-health, e.g. in a chat-function. In our trial we could not use this technique because the platform we used was not able to provide a chat-function for the group members. The e-IMR intervention should preserve the use of the BCTs 'peer-information', 'social comparison', and 'modelling' (161) in the peer-testimonial videos, and should expand the number of videos using all kinds of models. Not everyone will recognise him- or herself in the current models in the videos. We further encourage the development of peer-professionalism, for the ability to acknowledge and enhance disclosure of persons with a mental health problem.

The use of e-health will grow in the future. Present developments in e-health comprise of using videogames and virtual reality exposure (267). We encourage the future developments of e-health, for the future generation grew up with the technology and will have fewer problems with it (211). By the time this thesis will be published the period of enforced social distancing because of the COVID-19 might be over, or might be reintroduced because of a second wave. We are very curious about how this social distancing encourages the use of e-mental health. The acceptance might grow, but whether the e-health readiness of persons with SMI will grow might depend, in line with our findings, on their condition and on the support with learning the necessary skills. We found that learning and using e-health skills is very hard when one is feeling overwhelmed by the unfathomable and devastating consequences of psychiatric symptoms. An SMI is known for its cognitive disabilities (24). Therefore, we foresee that handling push-messages can be burdensome and will easily be neglected when not being able to concentrate enough because of depression or anxiety. The timing of providing e-health is an issue of concern emerging from our study. So, be cautious, e-health must not be a goal in itself. Learning is bracketed by a person's current abilities, as Vygotsky stated (244). An intervention must respond to a personal need, resolving problems of isolation, fear of relapse, and hopelessness, and aiming for human dignity and a sense of agency.

Implications for future research

From our studies, a number of issues emerge that warrant further investigation. We suggest future research in the items self-management support needs, e-mental health for persons with an SMI, and the illness management and recovery program.

Self-management support needs.

In the process of this study we discussed how to define in-depth a need that is actually behind the support need. We wondered, what are the experienced gaps that need to be resolved, instead of what kind of support needs to be provided. For instance, water quenches thirst; information quenches the need for understanding and sensemaking. We suggest performing a qualitative investigation to find the answer to the question: "What are the personal needs that are violated by an SMI that need to be supported when persons try to recover with an SMI?"

e-Mental Health and Severe Mental Illness (SMI)

In the field of e-health treatment for persons with SMI we recommend to study the e-health readiness of persons with SMI. We question whether much of the e-health research is biased because of not including participants with low computer use and Internet affinity. The actual acceptability, which tends to be high in persons with SMI, is viewed after e-health interventions were delivered (214). Persons with low e-health readiness will not report about the actual acceptability, for they have no actual experience. The issue of e-health readiness in study populations might cause selection bias in trials. In non-SMI e-health literature data on selection bias was often missed (268), or reviewed trials made use of unsystematic and opportunistic recruitment methods (269). To give more insight in the risk for selection bias, we suggest that future research on e-health should take into account the extent of e-health readiness in their study population.

With a study on the e-health readiness in the field of persons with SMI we might find determinants that can help to find solutions to increase the use of e-health in this population.

The Illness Management and Recovery (IMR).

As a follow-up of our IMR studies we suggest future research:

Attrition rates in the IMR. The attrition rate in our study was 30%, which is comparable to other IMR trials (38). There is some consensus that larger attrition rates are associated with younger age, minority race, and substance abuse (186). In our study participants with positive outcomes also withdraw from the IMR session, mainly in the interventions group. We planned to investigate this phenomenon of attrition by gathering information about attrition and continued participation. At the endpoint of our trial we asked the non-completers: why did you step out of the IMR, and to the completers we asked: what made you stay in the IMR. Owing to the lack of time, we have not yet analysed the data on this subject.

The e-IMR intervention. We have not been able to investigate the feasibility of the e-IMR intervention in individual sessions. The e-IMR lessons outside the group sessions give hope that the e-IMR intervention in individual sessions will be feasible. After adapting the e-IMR intervention we need to perform an action research in individual settings to get the necessary feedback before adapting the e-IMR intervention into a final version and prepare a confirmative trial.

Minimal Important Difference. In such a trial the MID of a number of patient reported outcome measures could be investigated by using the method described in chapter 8 with a bigger sample than in our study and accounting for the covariate gender.

Chapter 10.

- **Summary**
- **Samenvatting en Discussie**
- **Data Management**
- **Dankwoord**
- **About the Author**
- **Publication List**
- **Phd Portfolio**
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Summary

Approximately 160.000 persons in the Netherlands suffer from a severe mental illness (SMI) (1), which means having a mental illness that lasts longer than at least a couple of years, that causes—and is due to—serious impairments in social and/or occupational functioning, and that necessitates coordinated multidisciplinary care (1). In **chapter 1**, we explain that SMI's are known for their episodic nature (4,21,22), high relapse rates (23), and high associations with cognitive disabilities, such as impaired attention, learning, memory, and problem-solving skills (24). Persons with an SMI often experience failure and a sense of demoralization, which is characterized by feelings of helplessness, incompetence, diminished self-esteem, entrapment, meaninglessness (102), and they are confronted with social stigma (3).

The treatment of persons with an SMI has changed over the last decades. Dehospitalizing tendencies started in the 1960's led to the increase of community support systems, supported housing, ambulant treatment facilities, and the upcoming of the practise of rehabilitation and recovery (7). Recovery is defined as a unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery implies discovering one's strength and ability to wrestle out of the hopelessness and giving one's life a new turn. With all the challenges recovery implies, making one's own choices and mistakes, and acting accordingly with the support that is needed (7). This is all based on one's life story full of experiential knowledge.

Due to de-hospitalization tendencies and the development of better general health care persons live longer and illnesses have become chronic. The challenge to manage the illness and its consequences increased and the term self-management was introduced in Wagner's et al. Chronic Care Model, which puts the patient in a central position in the healthcare process (14). Self-management can be viewed as a paradigm shift from a paternalistic model to a participatory model in which shared decision-making takes a central role (15). The perspectives on health changed from "not being ill" towards health as an ability to adapt and to self-manage (16), which can be defined as a dynamic and continuous process of self-regulation that refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (13). Self-management can also be viewed as an intervention or treatment in which professionals teach persons how and when to make use of the self-management abilities.

The Illness Management and Recovery program (IMR) is a complementary intervention for persons with SMI that combines the recovery values of person orientation, partnership, self-determination, and hope with the concept of self-management focussing on the reduction of symptoms and the effects of the illness itself (26). The

IMR is a standardized 11 workbooks curriculum-based approach and designed to provide information and skills necessary for managing an SMI effectively and for working towards achieving personal recovery goals (31).

Another development in health care is the use of the growing possibilities of the information technology (IT) as a vehicle for providing or supporting care and treatment at the time and place of personal preference (40). Dutch policy makers proclaimed that the development of e-mental health is their cornerstone policy to keep mental health affordable and accessible in the future (41,42). Electronic mental health (e-health) interventions for persons with SMI are accepted and feasible (46), and can deliver effective education (47). But, e-health interventions have high attrition rates (44) and conclusions on the effectiveness of e-health for persons with SMI can not yet be drawn (46,48). The addition of face-to-face contact to e-health is supposed to increase the therapeutic relation and prevent attrition (45).

We took up the challenge to provide knowledge about e-health for persons with SMI. All the before described topics are coming together in the development and testing of the effectiveness of an e-health intervention on recovery and illness-self-management for persons with SMI. To contribute to consumer oriented development, delivery, and effectiveness of self-management e-support programs; we developed a blended version of the IMR: the e-IMR intervention.

The two aims of this thesis represent the two sections of this thesis: the development and evaluation of the e-IMR intervention. We planned to explore the potential effectiveness of the e-IMR intervention, the actual use and added value of the e-IMR platform, and the outcome measures that most likely capture consumers' potential benefits of the IMR program.

Section 1. Development and preparation of the trial

Self-managing an SMI all by oneself is a difficult task. In **chapter 2** we introduce the concept of 'self-management support needs', which are present when an individual feels the need for support related to the necessity of performing a self-management task (19,20). Here we learn that self-managing an SMI needs to be supported by informational support, emotional support, acknowledgement, encouragement, and guidance in order to make sense of their illness experiences, to ease their suffering, to obtain validation and recognition, to execute self-management tasks, and to be led through an unfamiliar territory.

In **chapter 3** we recognise the self-management support needs in the results of the study in which we evaluated the standard Illness Management and Recovery program (IMR). From this study we learn that the IMR enhances recovery because of learning the skills of goal-setting and symptom management. The IMR worked because of practising these skills in daily life, and getting information via the workbooks and via the exchange with peers. Participants reported that peer-information was a crucial ingredient of this process, followed by social comparison and modelling. Participants could compare themselves with others group members and with the peer-specialist trainer who also provided a social model. Their social norm group changed from their network of healthy persons to a more equal group of persons who represent peer-norms. Peer-information, social comparison and modelling were identified as behavioural change techniques (161). The peer-specialist enables disclosure of persons with SMI in order to exchange experiences and getting to understand them.

In **chapter 4** we investigate the validity the Illness Management and Recovery Scales (IMRS) in the Dutch context. We learned that it is a valid patient reported outcome measure (PRO).

Chapter 5 describes the development process and content of the e-IMR intervention. The six steps of the Intervention Mapping protocol (IM) (52) helped us to develop the e-IMR intervention. In step 1, the needs-assessment, we identified health problems. When entering the mental health system, persons with SMI feel isolated, are afraid of relapses, are overwhelmed by psychiatric symptoms, and experience hopelessness. Because of these problems persons with SMI often enclose their problems, not asking for help, avoiding contact, being passive, and setting no or too big goals. In step 2 of the IM we conducted a matrix of change objectives, which is an excerpt of the matrices we made for the whole IMR-program, which is laid down in the description of IMR as a well-established intervention for persons with SMI in the Netherlands (33). The objectives that we formulated were that participants 1) disclose to others about having an SMI, 2) plan and execute attainable steps to achieve personal recovery goals, 3) cope actively with early symptoms and stressors, and 4) arrange support regarding achieving goals and coping with symptoms. In steps 3 and 4, we applied e-health components to the IMR. In the e-IMR intervention we introduced a number of behavioural change techniques (BCT) (161). With peer-testimonial video's we planned to enhance 'peer information', 'social comparison', and 'modelling'. With goal-tracking sheets and sheets to keep track of successful symptom coping attempts we planned to enhance 'goal-setting', 'setting graded tasks of attainable steps' and 'reinforcement of progress'. With problem-solving sheets we planned to enhance 'setting graded tasks' and 'weighing pros and cons'. With a monitoring page we planned to 'raise awareness' and insight into the course of symptoms. We opted for the introduction of communication possibilities between peers, trusted persons, and IMR trainers to enhance 'social support'. Unfortunately, the platform we used missed functionality to provide this option. In step 5, the implementation step, we investigated the IT-resources and skills of persons with SMI and concluded these were often lacking. Because of this we could not mandatory the use of the e-IMR platform for participants in the trial. The last IM step described the evaluation protocol of the exploratory cluster randomized controlled trial (RCT). To be as naturalistic as possible we planned to control the e-IMR intervention by the standard way of the face-to-face delivery of the standard IMR program.

Section 2. Evaluation of the trial, and thesis aims

In **chapter 6** of this thesis we describe the actual effect of the exploratory clustered RCT. Out of 41 participants in the intervention group fourteen (34.1%) participants could be defined as a user, which means having completed at least module one or having logged in at least five times. These fourteen participants were identified as having had the opportunity to benefit of the e-IMR intervention. We concluded that the platform was used too little to make a meaningful difference in the actual delivered treatments between the intervention and control group. Therefore, the significant improvement on several PROs in the intervention group compared to the control group could not be realistic. In post-hoc analysis we found that the confounding factor gender and the interaction factor non-completers modified the effect. The man/women ratio confounded the results because of unequal distribution over the intervention and the control groups, and the factor non-completers interacted because the results of the non-completers in the two groups differed significantly. Because of these moderators we could not conclude on the potential efficacy of e-health for persons with SMI. The low use of the e-IMR platform called for a thorough process evaluation of the intervention.

In **chapter 7**, we tried to address this call. We found barriers within the intervention itself and its implementation, the participants and their social context, and the trainers and their institutional context influenced the low use of the e-IMR platform. The inflexibility of the e-IMR intervention in for instance not being able to change workbook orders and to go back to amend previous notes, the lack of IT-resources in participants and in institutes, the context of group-session in which using the platform was estimated as too time consuming, the participants' low computer skills and vulnerability owing to which working at the computer and learning new skills was too difficult. Trainers, of whom some had a hesitant e-health attitude, could not turn a dismissive attitude towards e-health in participants. About the e-IMR component monitoring we received different feedback. Some reported its added value and others were irritated by the confrontations with symptoms. The goal-tracking sheets were valued positively because of being persuasive reminders of the goals and the graded tasks of attainable steps. The peer-testimonials were highly rewarded for their potency to enhance group discussions and participants' disclosure. We concluded that the implementation of e-IMR lacked a thorough investigation of the institutions' IT environment and e-health attitude of trainers.

In **chapter 8** we contribute to the discourse of medical versus recovery orientation of a complementary intervention for persons with SMI. With the concept of minimal important difference (MID) we examined the capability of the PROs that we used in our trial to determine the relevant and meaningful change in persons with SMI as an effect of a complementary intervention, in casu the IMR. An MID of a PRO is estimating how big a change in the PRO can be considered as important enough to motivate a switch in treatment. We compared the pre-post effects of the IMR on the

PRO's with three different ways to estimate the MID. The preferred MID method uses a clinical criterion as an anchor. In our study the 'General Health Perception', a concept within the 'Rand 36 item Health Survey' proved to be the best anchor. To support this anchor method we used the MID calculation methods related to the one-half Effect-Size and to the one Standard Error of Measurement. The three methods all gave the same results. Unlike the prejudice of the IMR being a too medical dominated intervention, we concluded that the Mental Health Recovery Measure (MHRM) determined relevant change and captured the benefit of the IMR program, compared to the other PROs on all three MIDs. Which means that participants in our study improved more in their recovery compared to their burden of symptoms.

Summary of the general discussion

In **chapter 9** we discuss the following issues: the e-IMR intervention trail, electronic mental health for persons with severe mental illness, issues regarding the Illness Management and Recovery program, patient reported outcome measures, self-management and recovery concept comparison, living with a chronic illness, and implications for future practise and research.

The e-IMR intervention trail

The low use of the e-IMR platform caused hardly any difference between the interventions delivered to the intervention and control group. Besides this limitation, we reckoned our low sample as one of the major limitations of our study. However low sample power appears to be endemic in biomedical science (241). The low sample caused differences in distribution of population characteristics in the research groups. In post-hoc analyses we saw that the factor gender and non-completers moderated the effects. The IMR's effect on women differed compared to men. In a confirmative trial this issue needs to be reinvestigated.

From the qualitative evaluation we learned that the peer-testimonial videos were highly appreciated by participants and trainers. We consider that the behavioural change techniques (BCT) of peer-information, social comparison, and modelling did show the expected added value. Un-intently, it also induced the use of the BCT of participation. Participants were more involved in the IMR content via the group discussions and their disclosure, which were facilitated by the videos.

We concluded that providing e-IMR in the future is pre-conditioned by: checking available IT-resources in institutions, providing tablets to participants in group-settings, providing computer/Internet guidance to participants parallel to the group-sessions, checking the e-health attitude of trainers, and providing necessary e-health training to future e-IMR trainers.

Electronic mental health for persons with severe mental illness

In the implementation phase we foresaw the problem of having no IT-resources and low computer experience and skills in persons with SMI. The majority of the participants in the trial was neutral or did not estimate they had low computer skills and a need for guidance. Only one participant made use of the offer to get guidance with using the e-IMR platform. At the endpoint of our trial however, a number of participants said that they had been reluctant to report the need for guidance and were happy they did get guidance halfway the trial. In a sense, people hesitate to concede their imperfection, which we consider a normal facet of life. We also learned that not feeling well enough and having psychiatric symptoms influenced the use of a computer and the learning of how to use a computer. We believe that learning new skills while not feeling well must have a direct relation to learning how to cope with this 'not feeling well' and not with learning how to use a computer. This matches with Vygotsky's statement that learning is bracketed by a person's current abilities (244). Participants in our study reported having problems with concentration, having a sensory overload, were easily over-stimulated, were lacking control over the computer, and had no idea over what a computer is doing with their input. Since SMIs are highly associated with cognitive disabilities, such as impaired attention, learning, memory, and problem solving skills (24), one can imagine the difficulties of learning how to use a computer. We saw that many of the participants in our study were not yet ready for e-health.

We wondered whether the issue of e-health readiness is taken into account in research of e-health. Berry et al. reviewed literature and reported that the actual acceptability of e-health treatments for persons with SMI tends to be high (214). But, do research samples contain persons with low computer affinity and skills? Do they enter such studies when recruitment is via advertisements and/or self-referred as in many e-health studies. Do E-health-studies account for this possible selection-bias? Reviews reported that studies did not report about their selection procedures (268) or that selection procedures were defined as unsystematic and opportunistic (269). Therefore, we question whether or not much of the e-health research is biased because of unintentionally excluding participants with low computer and Internet-affinity. We recommend future e-health studies to study and report about the e-health readiness in the study population including a precise report about accounting for this issue in their selection methods.

We also discussed the issue of investigating e-health as a vehicle of an intervention compared to its face-to-face delivery. Carlbring et al (268) reviewed 20 studies in which Internet-delivered cognitive behavioural therapy (CBT) was directly compared to face-to-face delivery. Overall results indicate equivalence (268). As far as we know, in the field of people with SMI, our trial is the first that tried to study the e-health version controlled by the non-e-health version of the intervention. Unfortunately, we could not compare them properly.

In spite of all the efforts of e-health being the cornerstone policy of institutions (41,42), the use of e-health is still moderate to low. In Dutch general mental healthcare, the use of e-health treatments is estimated to be between 5% and 10% rate of the patients (197,248,270). The evidence basement of e-health for persons with SMI is also moderate (46,48).

Overall we conclude the need for guidance with e-health in persons with SMI. Therapist-assisted e-health services prevail over unguided programs (247). We consider this might be linked to the self-management support needs. E-health is able to respond to a need for informational support, but is it also able to respond to needs for acknowledgment and emotional support? Is e-health not a too cold technology for warm needs? (248) Chat function or video-calls, might have the ability to bridge the distance between persons in need and the support provider. Via e-communities persons might be able to organize face-to-face contacts and practical help close to their homes (250).

Issues regarding the Illness Management and Recovery program

The results of our studies show the ability of the IMR program to enhance recovery, in spite of evaluations that commented on the dominant medical orientation within the IMR. The results of the review on self-management support needs motivated us to review the IMR and wright the new 4.0 version. In the 4.0 version participants are invited to make sense of their experiences by describing their own story and their own thoughts about the background, consequences, and circumstances of their experiences. Strategies from positive psychology, aspects of determination, headstrongness, and knowledge by experience were added because of the need for encouragement and recognition of existing abilities. The first evaluation of the 4.0 version were promising. We conclude therefore that the IMR 4.0 strengthens the balance between recovery and the illness management domains. The process of providing an international version of the IMR 4.0 is on-going.

Patient reported outcome measures

In this thesis, we discuss the contextual validation of two patient reported outcome measures: the Illness Management and Recovery Scales (IMRS) and the Mental Health Recovery Measure (MHRM). Considering the items of drugs and alcohol use or misuse in the IMRS and considering the item of the extent of spiritual support in the MHRM, the Dutch context is not responsive. In the Netherlands persons with an addiction as a primary problem are treated in other institutes. Spirituality is not a big issue in the Netherlands, which is regarded a highly secularized country.

We also discuss the concept of minimal important difference (MID) in change scores in the domain of interest that patients perceive as important, either beneficial or harmful, and that help shared decision making in considering a change of treatment. The concept of General Health Perception of the Rand 36-item Health Survey (Rand-GHP) (172) appeared to be a valid anchor. We conclude that the Rand-GHP captures the richness and variation of a construct of health perception and that it is an excellent measure for investigating the minimal important change as a result of an intervention. Compared to the Rand-GHP participants in our study improved the best in their recovery when measured by the MHRM. Therefore, a person who desires a recovery outcome can be recommended to do the IMR program. This investigation also is limited by the low sample and needs to be repeated in a bigger sample.

Self-management and recovery concept comparison

In the analyses phase of our review on self-management support needs we often discussed whether a statement matched the concept of self-management or recovery. This motivated us to have a closer look at the two concepts and compare them. We conclude that self-management and recovery are related and intertwined concepts. Both concepts describe perspectives of paradigm shift, abilities, and intervention. The concept of recovery is a broader concept, which focuses on deeper levels of a human being, like attitude, values, identity, etc. Self-management focuses on behaviour related to living with the illness, but in recovery the ultimate aim is living beyond the mental illness. Recovery was, and still is, necessary as an emancipatory movement, in which the word Illness is having a negative connotation. This might be caused by the paternalistic attitude in mental health care in the past and in the present. Over the years persons with SMI are too often not understood, dis-acknowledged, invalidated, and isolated from citizenship. But, we think that the members of the recovery movement must not isolate themselves from the medical orientation, for the illness is a reality. Many persons with SMI are too often misdiagnosed and because of that mistreated. A proper diagnose and treatment decreases use of medication, minimizes treatment stagnation, and leads to decrease of healthcare consumption and costs (271). Our study shows that the improvements in self-management may have enhanced participants' recovery more than that it lowers their burden of symptoms. Thus, recovery oriented professionals must not neglect the illness self-management aspects of having a chronic illness. The recovery orientation on the personal values beyond the illness should be incorporated in learning to self-manage the illness. The IMR, as a complementary intervention, combines the two concepts.

Living with a chronic illness

The combination of the two concepts is reflected in the new definition of health as an ability to manage and adapt (16). The 'adapt' item in the definition can be related to recovery, which is about learning how to adapt your life to the unfathomable and devastating consequences of a severe mental illness. In line with the experiential learning theory the process of dealing with a chronic general or mental illness is a matter of sensemaking, answering the question: *"What's the story?"* (104). Any illness can cause a sensemaking gap because the illness experience doesn't fit with the orientation system based on past experiences. An illness can change life too much, which may cause a depression because of not being able to adapt. Implementing a narrative orientation in general healthcare, like the recovery orientation, may be of value for recovering from the devastating consequences of any illness (272). Recovery, not with the aim of restoring the old self and the old values, but to discover a new version of oneself (273). Being acknowledged for the deep personal consequences of an illness may prevent gliding into a depression after a chronic illness is diagnosed. In general health dealing with an illness may be too much a technical story of self-management behaviour. With a narrative orientation, persons can find their own way to understand the illness and consequences from their personal perspectives and values, which may be more decisive in personal treatment decision-making than guidelines (272).

Implications for future practice

In the future, the care for persons with a mental health problem will be organized as close as possible to the homes of persons in need. Thereby enhancing resilience on the long term and community building in which e-mental health is having a central place (265). E-communities are in an experimental stadium in a number of cities in the Netherlands (250). In such communities the Illness Management and Recovery (IMR), in the e-IMR or face–to-face standard version, might be able to fulfil the needs of persons with a mental health problem in all kinds of severities who desire an outcome in the recovery domain. The e-IMR intervention should behold the use of the BCTs ‘peer-information’, ‘social comparison’, and ‘modelling’ (161) in the peer-testimonials, and should expand the number of videos using all kinds of models. Not everyone will recognise him- or herself in the current models in the videos. We further encourage the development of peer-professionalism, for the ability to enhance disclosure of persons with a mental health problem.

The use of e-health will grow in the future. Persons with SMI need to be guided to learn to make use of e-health. Learning these skills is often a challenge for persons with SMI. But, it may consequently also resolve isolation from the World-Wide-Web. The timing of providing e-health is an issue of concern emerging from our study. Since learning and using e-health skills is very hard when one is feeling overwhelmed by the unfathomable and devastating consequences of psychiatric symptoms.

We encourage the future developments of e-health, for the future generation grew up with this technology and will have fewer problems with it. But be cautious, e-health must not be a goal on its own. An intervention must respond to a certain need of a person, resolving the problems of isolation, the fear of relapse, and to steer away from hopelessness towards human dignity and a sense of agency.

Implications for future research

From our studies, a number of issues emerge that warrants further investigation:

- Investigate qualitatively to identify the more in-depth self-management support needs, answering the question: “What are the personal needs that are violated by an SMI that need to be supported?”
- Investigate the e-health readiness of persons with SMI.
- Investigate qualitatively the reasons for attrition from the IMR program. Because of a lack of time, we did not yet analyse our data on the question: “Why did you step out, or continue the IMR?”

- Investigate the effectiveness of IMR in the field of less severe mental illness in the shorter-term treatment settings.
- Perform an action research on the e-IMR intervention in individual settings to get the necessary feedback before adapting the e-IMR intervention into a final version and prepare a confirmative trial.
- In such a trial the minimal important difference of a number of patient reported outcome measures could be investigated with a bigger sample than in our study from chapter 8.
- In such a trial also a confirmatory factor analysis of the IMRS can be executed.

Samenvatting en discussie

Bij benadering lijden 160.000 mensen in Nederland aan een ernstige psychiatrische aandoening (EPA) (1). Dit betekent dat deze mensen een psychiatrische aandoening hebben die langer dan een paar jaar duurt, die ernstige beperkingen in sociaal en maatschappelijk functioneren veroorzaakt dan wel tot gevolg heeft, en waarbij multidisciplinaire zorg geïndiceerd is (1).

In de inleiding van dit proefschrift, **hoofdstuk 1,** wordt uitgelegd dat EPA's episodisch van aard zijn (4,21,22) en gepaard gaan met hoge terugval percentages (23) en cognitieve functiestoornissen, waaronder een verminderd vermogen om aandacht vast te houden, te leren en om problemen op te lossen (24). Personen met EPA ervaren geregeld mislukking en demoralisatie welke gekenmerkt worden door gevoelens van hopeloosheid, onvermogen, verminderde eigenwaarde, het gevoel geen kant op te kunnen en zinloosheid (102). Tevens worden ze vaak geconfronteerd met een sociaal stigma (3).

De behandeling van mensen met een EPA is sterk veranderd de laatste decennia. De tendens van dé-hospitalisering startte in de jaren 1960 en leidde tot de groei van het aantal ambulante behandelvormen, beschermde woonvormen en het opkomen van begrippen als rehabilitatie en herstel (7). Herstel niet in de zin van weer beter worden, maar als een uniek proces van veranderingen in de eigen attitude, waardes, gevoelens, doelen, en maatschappelijke rollen. Hersteld zijn betekent voldoening en hoop halen uit je leven en je eigen steentje kunnen bijdragen ondanks de beperkingen van een aandoening. Herstel impliceert het ontdekken van de eigen kracht en vermogens om zichzelf boven de hopeloosheid van een aandoening uit te tillen en het eigen leven een nieuwe wending te geven. De uitdaging van herstellen is te handelen naar de eigen keuzes en vergissingen met de steun die nodig is (7), wat gebaseerd is op iemands eigen levensverhaal vol met ervaringskennis.

Ook de algehele gezondheidszorg (AGZ) kent de dé-hospitaliseringstendens en door de verbetering in de zorg leven mensen met een chronische ziekte langer. De uitdaging van het leven met een chronische ziekte met zijn consequenties werd groter wat leidde tot de introductie van de term zelfmanagement in Wagner's et al. Chronic Care Model (14). Dit model zet de persoon met een ziekte in een centrale positie in het behandel proces. Dit heeft de betekenis van gezondheid veranderd. Gezondheid betekend niet meer 'de afwezigheid van ziekte', maar 'een vermogen om zich aan te passen en zelf te managen' (16). Zelfmanagement wordt vervolgens gezien als een dynamisch en continue proces van het zelf reguleren van het eigen vermogen om de symptomen van de ziekte, de behandeling, de psychosociale consequenties en de nodige veranderingen in leefstijl te managen (13).

De twee visies op herstel en op zelfmanagement worden gecombineerd in de Illness Management and Recovery training (IMR). Deze interventie voor mensen met EPA combineert de herstel-waardes van op de persoon gericht zijn, samenwerken, zelfbeschikking, en hoop met het zelfmanagement-focus op het verminderen van symptomen en de gevolgen van de aandoening (26). De IMR is een gestandaardiseerde interventie met een curriculum met elf werkboeken waarmee mensen met EPA informatie verkrijgen en vaardigheden aanleren om een EPA effectief te leren managen en hen te helpen om persoonlijke hersteldoelen te verwezenlijken (31).

Een andere ontwikkeling in de gezondheidszorg is het gebruiken van de groeiende mogelijkheden van informatie technologie (IT) wat als een middel ingezet wordt voor verstrekken of ondersteunen van zorg en behandeling op een tijd en plaats van iemands persoonlijke voorkeur (40). Nederlandse beleidsmakers hebben e-health tot een beleidsspeerpunt gemaakt om de Geestelijke Gezondheidszorg (GGZ) nu en in de toekomst bereikbaar en betaalbaar te houden (41,42). E-health interventies voor mensen met EPA blijken te worden geaccepteerd (46), zijn uitvoerbaar en kunnen op effectieve wijze educatie geven (47). Maar e-health interventies gaan gepaard met hoge uitval percentages (44) en conclusies over bewezen effectiviteit bij mensen met EPA kunnen nog niet worden getrokken (46,48). Het vermengen of blenden van e-health met face-to-face contacten wordt geacht de therapeutische relatie te vergroten en het terugtrekken te voorkomen (45).

Al de hiervoor beschreven onderwerpen komen samen in de ontwikkeling en het testen van een e-health interventie gericht op herstel en zelfmanagement voor mensen met EPA. Wij ontwikkelde een versie van de IMR en combineerde e-health met face-to-face contacten: de e-IMR interventie. We onderzochten: de vermeende effectiviteit van de e-IMR, het feitelijke gebruik en toegevoegde waarde ervan en de uitkomstmaten waarin de IMR in potentie de meeste vooruitgang bewerkstelligt. Het ontwikkelen en het testen van de e-IMR interventie vertegenwoordigen de twee delen van dit proefschrift.

Dit onderzoek maakt deel uit van een groter onderzoek naar de cliënt-georiënteerde ontwikkeling, verstrekking en effectiviteit van e-health zelfmanagement interventies, ook voor mensen met vasculair risico en reuma en voor ouders van kinderen met een chronische nierziekte. (49–51).

Sectie 1. Ontwikkeling en voorbereiding van de trial

Het in je eentje managen van een EPA is een schier onmogelijke opdracht. In **hoofdstuk 2** introduceren we het concept van ‘zelfmanagement ondersteunings-behoeften’. Deze zijn aanwezig als iemand de behoefte aan ondersteuning voelt bij het uitvoeren van noodzakelijke zelfmanagementtaken (19,20). Wij leerden dat het uitvoeren en aanleren van zelfmanagementtaken gepaard gaan met de behoeften aan informatie, emotionele steun, erkenning, aanmoediging, en begeleiding. Met deze steun kunnen mensen betekenis leren geven aan wat ze meemaken, kan hun lijden verlicht worden, ondervinden ze validering en herkenning, kunnen ze zelfmanagenttaken uitvoeren en worden ze begeleid in een onbekende wereld.

In **hoofdstuk 3** beschrijven we de resultaten van het onderzoek naar de ervaringen van deelnemers aan de IMR zonder e-health. Hierin herkennen we de zelfmanagement ondersteuningsbehoeften. De IMR bevordert het herstel vanwege het aanleren van de vaardigheden: het stellen en bereiken van persoonlijke doelen en het managen van symptomen. De IMR had volgens de deelnemers resultaat omdat de vaardigheden in het dagelijks leven werden geoefend. In deze evaluatie herkenden we tevens de volgende gedragsveranderings-technieken (Behavioural Change Techniques, BCT) (161): peer-information, social comparison en modelling. Herkenning kwam door het uitwisselen van informatie en ervaringen met lotgenoten (peers). Social comparison is het gebruik maken van de mogelijkheid dat iemand zichzelf kan vergelijken met anderen in dezelfde situatie. Deelnemers konden zichzelf vergelijken met groepsgenoten en met de ervaringsdeskundige trainer, die ook als sociaal model fungeerde. Hun sociale normgroep veranderde van gezonde mensen uit hun sociaal netwerk naar mensen uit een meer gelijkwaardige groep van lotgenoten met hun eigen normen. Een ervaringsdeskundige trainer is een rolmodel, die bevordert dat mensen met EPA zich makkelijker openen, over zichzelf beginnen te praten waardoor ervaringen uitgewisseld kunnen worden en men zich begrepen kan voelen.

In **hoofdstuk 4** is de validiteit van de Illness Management and Recovery Scales (IMRS) onderzocht in de Nederlandse context. De conclusie van dit onderzoek is dat de IMRS een betrouwbaar meetinstrument is om het resultaat van een interventie te meten.

In **hoofdstuk 5** wordt het ontwikkelproces en de inhoud van de e-IMR interventie beschreven. De zes stappen van het Intervention Mapping protocol (IM) (52) werden gebruikt om de e-IMR interventie te ontwikkelen. In stap 1 werd een behoeftepeiling en probleeminventarisatie gedaan. Wij zagen dat mensen met EPA overweldigd worden door psychische symptomen, wat gepaard gaan met een gevoel van hopeloosheid, geïsoleerd komen te staan en angst voor een terugval. Vaak hullen mensen met EPA zich in stilzwijgen, vragen niet om hulp, vermijden contacten, wachten passief af en stellen geen of te grote doelen. In IM stap 2 werden de volgende veranderdoelen opgesteld:

1. open zijn naar anderen over het hebben van een EPA;
2. plannen en uitvoeren van haalbare doelen om persoonlijke hersteldoelen te bereiken;
3. actief omgaan met stressoren en vroege symptomen van terugval;
4. arrangeren van steun in het kader van het bereiken van persoonlijke hersteldoelen en het omgaan met symptomen van terugval.

In de IM stappen 3 en 4 hebben we e-health mogelijkheden ingepast in het IMR curriculum. In de e-IMR interventie hebben we de eerder genoemde BCTs (161) toegepast. In alle hoofdstukken zijn video's te zien met verhalen van mensen met EPA die eerder de IMR gedaan hebben. Hiermee werden de BCTs 'peer-information, social comparison en modelling' ingezet. De BCTs 'doelen stellen', 'opstellen van taken in bereikbare stappen', en 'bevestigen van vooruitgang' werden ingezet middels formulieren met een doelenvolgsysteem, en het bijhouden van succesvolle coping strategieën. Met een monitoringspagina werd de BCT 'verhogen van de bewustwording' ingezet en met het 'problemen oplossen formulier' werden de BCTs 'het afwegen van voor en nadelen' en het 'haalbare doelen stellen' ingezet. Aanvankelijk was het de bedoeling om ook de BCT 'social support' tussen deelnemers onderling en naastbetrokkenen in te zetten middels een chat-functie op het e-IMR platform. Het gebruikte platform had helaas niet de daarvoor benodigde functionaliteit. In de IM stap 5, de implementatie stap, hebben we onderzoek gedaan naar de computer-vaardigheid van mensen met EPA en de beschikbaarheid van computer en Internet. We zagen dat deze laag is, wat ons noodzaakte om het gebruik maken van het e-IMR platform niet verplicht te stellen in de interventiegroepen van de trial. De trial is de laatste en 6^{e} IM-stap, 'de evaluatie'. Hierin werd het onderzoeksprotocol beschreven van de exploratieve cluster gerandomiseerde en gecontroleerde trial. Om een naturalistisch onderzoek te kunnen doen werd de effectiviteit van de e-IMR interventie gecontroleerd door groepen waarin de IMR op traditionele face-to-face manier werd uitgevoerd.

Sectie 2. Evaluatie van de trial en de onderzoeksdoelen

In **hoofdstuk 6** van deze thesis beschrijven we het effect van de trial. De uiteindelijk onderzoeksgroep was klein (n=60), waarvan 41 in de interventiegroep en 19 in de controlegroep. Van die 41 hebben 14 (34,1%) gebruik gemaakt van het e-IMR platform, wat betekent dat zij ten minste één werkboek afrondden en/of minimaal vijf keer inlogden op het e-IMR platform. Zij werden 'gebruikers' genoemd. Zij hebben de gelegenheid gehad om van het e-IMR platform te kunnen profiteren. Wij concludeerden dat te weinig mensen, te weinig gebruik hebben gemaakt van het e-IMR platform om verschil te maken met de behandeling aan de mensen uit de controlegroep. Ondanks dat werd een significant verschil in effect gezien tussen de twee groepen in het voordeel van de interventiegroep. Dit kon dus niet verklaard worden door de e-IMR interventie. In de post-hoc analyses zagen we dat het verschil in effect verklaard kon worden door een verstorend (confounding) verschil in de verhouding vrouwen en mannen in de twee groepen. Vrouwen bleken beter te profiteren van de IMR en in de interventiegroep zaten significant meer vrouwen dan in de controlegroep. Ook bleek er een interacterend effect aanwezig te zijn, welke gerelateerd was aan het eerder stoppen met de IMR. In de controlegroep bleken deelnemers te stoppen omdat het hen te veel nadeel opleverde en in de interventiegroep stopte een aantal deelnemers omdat ze ervoeren dat ze het niet meer nodig hadden. Door deze omstandigheden kunnen we nog niets zeggen over de potentiele effectiviteit van e-health voor mensen met EPA. Het feit dat het e-IMR platform weinig gebruikt werd vroeg om een grondige evaluatie van het onderzoeksproces.

H**oofdstuk 7** geeft de uitkomsten van deze evaluatie. Beïnvloedende factoren zijn gevonden in de interventie zelf, in de implementatie ervan, in de deelnemers en hun sociale context, in de trainers en in de context van de instituten waarin zij werken. Een negatieve invloed had de inflexibiliteit van de e-IMR interventie in bijvoorbeeld het niet kunnen veranderen van de werkboek volgorde en eerder opgeslagen notities. Ook werkte het gebrek aan IT-middelen bij deelnemers thuis en in de instituten niet mee. Tevens werd het gebruik maken van het e-IMR platform tijdens de groepsbijeenkomsten als te tijdrovend ingeschat. Bij de deelnemers zagen we dat het aanleren van nieuwe vaardigheden als te moeilijk ingeschat werd door hun kwetsbaarheid en door een gebrek aan computervaardigheden. Verder zagen we een aarzelende e-health attitude bij trainers en het niet kunnen omdraaien van een e-IMR afwijzende attitude van de deelnemers.

Over de monitoringspagina van de e-IMR waren de meningen verdeeld. Enkelen ervoeren de toegevoegde waarde waar anderen geïrriteerd raakten door de nadruk op symptomen. De doelen-volg formulieren werden positief gewaardeerd vanwege de niet te missen herinnering aan hun doelen en de haalbare taken. De verhalende video’s werden sterk gewaardeerd om hun kracht en stimulerend effect op het starten van groepsdiscussies en het aanzetten tot persoonlijke openheid. We concludeerden tevens dat we in de implementatie fase van de e-IMR interventie onvoldoende gekeken hebben naar de aanwezige IT-omgeving binnen de instituten en naar de e-health attitude van de IMR trainers.

Hoofdstuk 8 kan gezien worden als een bijdrage aan de discussie over herstelgerichte versus medische oriëntatie van zorg aan mensen met EPA. Middels het concept van de ‘minimal important difference’ (MID) onderzochten we hoe responsief de vragenlijsten binnen ons onderzoek waren op veranderingen die relevant en betekenisvol zijn. Dit als reactie op het deelnemen aan de IMR, een samengestelde interventie die aandacht heeft voor beide oriëntaties. Een MID van een vragenlijst zegt iets over hoe groot de te verwachten minimaal belangrijke verandering is, welke kan motiveren tot het wijzigen van het behandelbeleid. De MID berekenden we met drie verschillende methodes. De ankermethode heeft de voorkeur. Het anker is een bepaald criterium, bijvoorbeeld de mate van ‘kwaliteit van leven’. In onze studie bleek de uitkomstmaat ‘Algemene Gezondheidsbeleving’, (Rand-GHP, een maat binnen de Rand 36 item Health Survey) het beste anker te zijn. De andere ondersteunende methodes zijn gebaseerd op de twee statistische maten: de effect-size (ES) en de standaard meetfout (SEM). Vervolgens vergeleken we het effect van de IMR met de MID van de verschillende vragenlijsten. De drie MID-methoden gaven hetzelfde beeld. Ondanks het vooroordeel dat de IMR een te medische oriëntatie heeft, zagen we de grootste en meest relevante verandering op de herstelmaat Mental Health Recovery Measure (MHRM). Dit betekent dat deelnemers meer vooruit gingen in hun gevoel hersteld te zijn dan in de mate waarin zij last ondervonden van symptomen.

Samenvatting van de algemene discussie

Hoofdstuk 9 geeft een overzicht van het gehele onderzoek. Hierin bediscussiëren we de volgende onderwerpen: de e-IMR interventie trial, e-Health voor mensen met EPA, de Illness Management and Recovery training, diverse uitkomstmaten, vergelijk van de concepten van zelfmanagement en herstel, leven met een chronisch ziekte en de implicaties van ons onderzoek voor toekomstige praktijk en wetenschappelijk onderzoek.

De e-IMR interventie trial

Door het beperkte gebruik van het e-IMR platform was er nagenoeg geen verschil in de behandeling tussen de interventie- en de controlegroep. Bovenop deze beperking kan ook de te kleine steekproef in het onderzoek als beperkend gezien worden. Daarentegen, te kleine onderzoeksgroepen blijken veel vaker voor te komen in biomedisch onderzoek (241). Door de te kleine steekproef is het risico op verschillen in de interventie en controle groep groot. Alzo geschiedde in onze studie. De redenen om te stoppen met de IMR en het verschil in de man/vrouw verhouding binnen de onderzoeksgroepen verstoorden het effect. In ons onderzoek bleken vrouwen beter van de IMR te profiteren dan mannen. Dit punt vraagt om een bevestigend onderzoek in een trial met een grotere steekproef.

Uit de kwalitatieve evaluatie leerden we dat de video's met peer-verhalen hoog gewaardeerd werden door de deelnemers en de trainers. De gedragsveranderende technieken 'peer-information', 'social comparison' en 'modelling' bleken dus hun verwachtte werk te doen. Onbedoeld bleek ook de techniek 'participation' van toepassing te zijn. Met name de video's vergrootte bij deelnemers hen bereidheid deel te nemen aan de groepsdiscussies en het geven van openheid over hun persoonlijke ervaringen.

Uit deze evaluatie leerden we dat het uitvoeren van de e-IMR in de toekomst vooraf gegaan moet worden door een aantal acties: het checken van de IT-omgeving in de organisaties, het verstrekken van tablets aan deelnemers in IMR groepssessies, het checken van de e-health attitude van trainers, en het indien nodig het geven van e-health training aan toekomstige e-IMR trainers. Tevens zal vooraf georganiseerd moeten worden dat parallel aan de groepssessies computer/internet begeleiding aan de deelnemers gegeven kan worden.

e-Health voor mensen met een ernstige psychiatrische aandoening

In de implementatiefase voorzagen we het probleem met het gebrek aan IT-voorzieningen en vaardigheden bij mensen met EPA. Bij de start van de trial stond de meerderheid van de deelnemers neutraal tegenover e-health en schatte de meerderheid in dat ze over voldoende computervaardigheden beschikte en dat ze geen behoefte hadden aan hulp bij het omgaan met de computer. Eén enkele deelnemer maakte gebruik van het aanbod voor begeleiding bij het doen van de e-IMR thuis. Aan het eind van de trial vertelde een aantal deelnemers echter dat ze terughoudend waren geweest over hun behoefte aan begeleiding en dat ze later in het onderzoek blij waren toch die begeleiding gekregen te hebben. Mensen blijken nou eenmaal moeite te hebben met het toegeven dat ze iets niet goed kunnen. Wat we op zich als normaal beschouwen. We leerden tevens dat als je je mentaal niet gezond voelt het omgaan met de computer moeilijk is evenals het aanleren van computervaardigheden. We denken dat het aanleren van nieuwe vaardigheden terwijl je je niet goed voelt in het teken moet staan van dit 'niet goed voelen' en niet in het teken van leren omgaan met een computer. Dit past bij de leertheorie van Vigotsky die zegt dat het leren beperkt wordt en moet aansluiten bij de reeds bestaande vaardigheden (244). Deelnemers in ons onderzoek rapporteerden concentratiegebrek, overbelasting, snel overprikkeld zijn, geen controle over de computer hebben en geen idee hebben wat de computer met hun informatie doet. Het is te begrijpen dat mensen met EPA moeite hebben met computers als je bedenkt dat EPA geassocieerd is met cognitieve beperkingen zoals: aandacht vasthouden, leren, onthouden en problemen oplossen (24). Wij zagen dat veel mensen met EPA nog niet klaar waren om e-health te gebruiken in hun behandeling.

Wij vroegen ons af of het onderwerp e-health-gereedheid meegenomen wordt in onderzoeken naar e-health bij mensen met EPA. Berry et al. herlazen wetenschappelijke artikelen en rapporteerden dat mensen met EPA e-health behandelingen goed accepteren (214). Maar, zaten in de onderzoekpopulaties van die artikelen wel mensen met een lage computer affiniteit en vaardigheden? Komen deze mensen in de onderzoeksgroepen terecht als ze gerekruteerd worden via advertenties en/of zichzelf moeten aanmelden voor dit soort onderzoek. Houden deze onderzoeken wel rekening met het risico op selectie-bias? Veel onderzoeken rapporteerden niets over hun selectie procedure (268) of rapporteerden onsystematische en opportunistische selectieprocedures (269). We vragen ons daarom af of mensen met een lage computervaardigheid en -affiniteit wel meedoen aan e-health onderzoeken bij mensen met EPA. Voor toekomstig e-health onderzoek raden we aan om de mate van e-health gereedheid in de onderzoekpopulatie te rapporteren en er rekening mee te houden in de resultaten.

We bediscussieerden in dit proefschrift dat e-health gezien moet worden als vehikel van een interventie welke in onderzoek vergeleken dient te worden met het face-to-face uitvoeren van de interventie. Carlbring et al. (268) herlazen twintig artikelen waarin cognitieve gedragstherapie (CGT) binnen de algemene GGz direct vergeleken werd met face-to-face CGT. Zij zagen gelijkwaardige resultaten (268). Voor zo ver wij weten is in het werkveld van mensen met EPA onze trial de eerste die e-health probeerde te vergelijken met de face-to-face vorm van de interventie. Helaas konden wij deze twee vormen niet goed met elkaar vergelijken.

Ondanks alle aandacht voor e-health en inspanningen in de organisaties, die e-health tot hoeksteen van hun beleid hebben verklaard (41,42), is het gebruik van e-health nog steeds gematigd laag. In de algemene geestelijke gezondheidszorg in Nederland is het gebruik van e-health ingeschat op 5-10% van de patiënten

(197,248,270). Het bewijs voor de effectiviteit van e-health voor mensen met EPA is nog steeds beperkt (46,48).

Ons onderzoek overziend concluderen we dat mensen met EPA begeleiding nodig hebben bij het omgaan en het leren omgaan met e-health en dat ze begeleide e-health interventies liever hebben dan onbegeleide (247). We denken dat dit te maken heeft met de zelfmanagement ondersteuningsbehoeften uit hoofdstuk 2. Met e-health kan aan een behoefte aan informatie worden voldaan, maar is het ook in staat te reageren op de behoefte aan erkenning en emotionele steun? Is e-health niet een te 'koude' technologie voor warme behoeftes (248)? Chat-functies of beeldbellen zou wel in staat moeten zijn om de afstand te overbruggen tussen mensen met EPA en steunverleners. Binnen e-communities zouden hulp en face-to-face contacten dicht bij het eigen huis geregeld kunnen worden (250).

De Illness Management and Recovery training

De resultaten van ons onderzoek laten zien dat de IMR training in staat is om herstel van mensen met EPA te bevorderen, ondanks het commentaar op IMR dat het té medisch is georiënteerd. Een evaluatie van de IMR en de resultaten van ons onderzoek naar zelfmanagement ondersteuningsbehoeften motiveerden ons om een nieuwe versie van de IMR te schrijven: de 4.0 versie. Daarin worden deelnemers uitgenodigd om betekenis te geven aan hun ervaringen en hun eigen verhaal te maken, hun eigen gedachten te hebben over de achtergrond, de consequenties en de omstandigheden van hun ervaringen. In de IMR 4.0 zijn strategieën toegevoegd uit de positieve psychologie, tezamen met aspecten van vastberadenheid, eigenheid en ervaringskennis. De eerste evaluaties zijn veelbelovend. We zien dat de IMR 4.0 balans brengt tussen de domeinen van herstel en ziektemanagement. Het proces om tot een internationale versie IMR 4.0 te komen is gaande.

Diverse uitkomstmaten

In dit proefschrift bediscussieerden we de contextuele validatie van twee vragenlijsten, te weten de Illness Management and Recovery Scales (IMRS) enerzijds en de Mental Health Recovery Measure (MHRM) anderzijds. In de IMRS zijn de items over drugs en alcohol gebruik en in de MHRM is het item spiritualiteit niet responsief. We denken dat de Nederlands GZZ context niet gevoelig is voor deze items, enerzijds omdat mensen met verslavingsproblemen in Nederland in andere instituten behandeld worden en anderzijds omdat Nederland beschouwd kan worden als een sterk geseculariseerd land. Het gebruik van deze vragenlijst in Nederland zal rekening moeten houden met deze ongevoeligheid.

We hebben ook het concept van 'minimal important difference' MID onderzocht. Het concept van algemene gezondheidsbeleving (General Health Perception van de Rand 36-item Health Survey (Rand-GHP) (172) bleek een goede maat om de MID vast te stellen. Vergeleken de Rand-GHP bleken deelnemers het meest te verbeteren op de mate van herstel, gemeten met de MHRM. Dus, de IMR kan zeker aanbevolen worden aan een persoon die op herstel een verbetering wenst. Dit onderzoek kent ook de beperking van de te kleine steekproef en zal herhaald moeten worden in een grotere onderzoeksgroep.

De concepten van zelfmanagement en herstel vergeleken

Tijdens de analyse van ons review in **hoofdstuk 2** vroegen we ons vaak af of een tekst uit een artikel ondergebracht moest worden onder de term zelfmanagement of onder herstel. Deze vraagstelling motiveerde om de twee concepten nog eens nader te bekijken. We zagen dat de twee concepten zeer zeker gerelateerd zijn aan elkaar en ook vervlochten zijn. Beide concepten kunnen beschreven worden vanuit de perspectieven van een paradigmaverschuiving, als een set van vaardigheden en vanuit een interventie. Het concept van herstel is een breder concept dat focust op een diepere laag van het mens zijn, zoals: attitude, waarden, identiteit, etc. Zelfmanagement focust meer op de gedragsmatige kant van het omgaan met een chronische ziekte. Bij herstel is het uiteindelijk de bedoeling om het leven boven de ziekte uit te tillen. Herstel was en is nog steeds een emancipatoire beweging in welke het woord ziekte een negatieve connotatie heeft. Dit lijkt veroorzaakt te zijn door de paternalistische houding binnen de GGZ in het verleden en in het heden. Mensen met EPA worden te vaak niet begrepen, niet erkend, geïnvalideerd en geïsoleerd van burgerschap. Maar de herstelbeweging moet zichzelf niet isoleren van de medische oriëntatie, de ziekte is en blijft een realiteit. Te veel mensen worden fout gediagnosticeerd en krijgen daarom niet de juiste behandeling. Een juiste diagnose en behandeling verlaagt het gebruik van medicatie, voorkomt stagnatie van behandelingen en levert een vermindering van zorgconsumptie en kosten (271). Onze studie laat zien dat de verbeteringen op het gebied van zelfmanagement bijgedragen hebben aan het herstel, meer dan aan het verlagen van de last van symptomen. Dus een herstel georiënteerde hulpverlener moet het zelfmanagement aspect van het leven met een chronische ziekte niet uit het oog verliezen. Evenals dat het herstelgericht werken onderdeel moet uitmaken van het leren omgaan met een ziekte. De IMR vult beide oriëntaties aan en combineert de twee concepten.

Leven met een chronische ziekte

De twee concepten van zelfmanagement en herstel zijn vertegenwoordigd in de meest recente definitie van gezondheid als de vaardigheid om zich aan te passen en te managen. Gezond zijn betekent dat iemand in staat is een eigen regie te voeren in het licht van fysieke, emotionele en sociale uitdagingen van het leven (16). Gezondheid wordt zo een werkwoord in plaats van een toestand. Herstellen gaat over je kunnen aanpassen aan de ondoorgrondelijke en verwoestende gevolgen van het hebben van een ernstig psychiatrische aandoening. Uitgaande van de ervaringsgerichte leertheorie is dit leerproces van omgaan met een chronische ziekte een kwestie van betekenisgeving, dat een antwoord zoekt op de vraag: *"Wat is mijn verhaal?"* (104). Elke ziekte kan een betekeniskloof veroorzaken omdat de ervaring van ziekzijn niet strookt met iemands oriëntatiesysteem gebaseerd op ervaringen uit het verleden. Een ziekte kan iemands leven dermate verstoren dat het een depressie oproept omdat iemand niet in staat is om zich aan te passen aan de uitdagingen van die ziekte. Een narratieve herstelgerichte benadering in een behandeling zou van waarde kunnen zijn om iemand te helpen zich aan te passen aan de consequenties van een ernstige ziekte (272). Herstellen gaat dan niet meer om weer terug willen naar de oude zelf, maar om het ontdekken van een nieuwe versie van zichzelf (273). Erkenning krijgen voor de betekenis van de persoonlijke consequenties van een ziekte zou het wegglijden in een depressie mogelijk kunnen voorkomen. In de gezondheidszorg is het omgaan met een ziekte nog een te technisch verhaal van zelfmanagementgedrag. Een narratieve benadering kan mensen helpen om hun eigen weg te vinden, de ziekte en de consequenties te verstaan en te begrijpen vanuit de persoonlijke waarden. Deze waarden zijn meer beslissend voor het nemen van beslissingen over een behandeling dan de bestaande medische richtlijnen (272).

Implicaties voor toekomstige praktijk

In de toekomst zal de zorg voor mensen met psychische klachten zo dicht mogelijk bij hun huis georganiseerd worden. Gericht op weerbaarheid op de lange termijn en op 'community building' waarin e-health een centrale rol speelt (265). 'e-Communities' zijn in een experimenteel stadium in een aantal steden in Nederland te vinden (250). In zulke gemeenschappen zal de Illness Management and Recovery (IMR) training, in de e-IMR of in de face-to-face versie, in staat kunnen zijn de zelfmanagementondersteuningsbehoeften te vervullen. De e-IMR behoeft nog verdere doorontwikkeling en zou gebruik moeten blijven maken van de gedragsveranderingstechnieken: 'peer-information', 'social comparison' en 'modelling' (161). Het aantal video's met ervaringsverhalen mag uitgebreid worden met nog meer interviews met mensen die model kunnen staan. Niet iedereen zal zich in de huidige video's herkennen. Verder moedigen wij de ontwikkeling van het vak van ervaringsdeskundige in de GGZ aan. Dit is bij uitstek de beroepsgroep die in staat is om mensen te helpen openheid te geven over hun ervaringen met psychische klachten.

Het gebruik van e-health zal toenemen in de toekomst, helemaal in deze tijd van Covid-19. Maar we zien dat mensen met EPA veel begeleiding nodig hebben om te leren omgaan met e-health. Het aanleren van e-health vaardigheden kan een grote uitdaging zijn voor mensen met EPA. Echter, als deze vaardigheden eenmaal aangeleerd zijn, kan het hen helpen om zich minder geïsoleerd te voelen van het World-Wide-Web. Voortvloeiend uit de bevindingen van ons onderzoek, zien we een punt van zorg. Het aanleren van nieuwe vaardigheden is een schier onmogelijke taak als men overweldigd wordt door psychische klachten en zijn consequenties. De timing van het aanbieden van e-health moet dan zorgvuldig gekozen worden. Wij moedigen het door ontwikkelen van e-health aan. De toekomstige generatie zal minder problemen hebben met het aanleren van e-health vaardigheden. Maar let wel op, e-health moet niet een doel op zich worden. Een interventie moet aansluiten bij de noden van een persoon: het oplossen van een isolement, het voorkomen van een terugval, een uitweg uit de hopeloosheid. Deze interventie zal gericht zijn en op het herstellen van de eigen waarden en eigen regie.

Implicaties voor vervolgonderzoek

Uit ons onderzoek komen een aantal onderwerpen naar voren die om vervolgonderzoek vragen:

- Doe verdiepend kwalitatief onderzoek naar de diepere lagen achter de zelfmanagement ondersteuningsbehoeften. Probeer antwoord te krijgen op de vraag: "Wat zijn de persoonlijke behoeften die geschonden worden door een EPA en om ondersteuning vragen?"
- Doe onderzoek naar de e-health gereedheid van mensen met EPA.
- Doe kwalitatief onderzoek omtrent de vraag aan deelnemers: "Wat maakte dat je gestopt bent met de IMR of er juist mee bent doorgegaan?" Wegens gebrek aan tijd is de verzamelde data hierover nog niet geanalyseerd.
- Doe onderzoek naar de effectiviteit van IMR in de kortere termijn specialistische GGz.
- Doe een actie-onderzoek naar de e-IMR interventie in individuele setting. Dit om meer feedback te krijgen op de e-IMR en om de nodige aanpassingen te kunnen doen in voorbereiding van een grotere bevestigende trial.
- Doe onderzoek naar het concept van de Minimal Important Difference bij mensen met EPA in een grotere steekproef.
- Doe een factoranalyse van de Illness Management and Recovery Scales in een grotere steekproef.

Data Management

This thesis is based on human subjects research conducted according to the principles of the Declaration of Helsinki. The ethical approval for conducting the e-IMR trial was provided by the Committee on Research Involving Human Subjects, Arnhem-Nijmegen (NL49693.091.14). The e-IMR trial is registered in the Netherlands Trial Register, NL 4621 (ID old NTR 4772).

The studies directly related to the trial are laid down in chapters 6, 7, and 8. All participants in the trial declared informed consent to participate in this research. No incentives were provided to participants. For the studies in the chapters 2, 3, 4, and 5 no ethical approval was obliged.

In collaboration with the 'Radboudumc Technology Center – Clinical Studies' (RTC-CS) a data management plan was set up. During the trial a Trial Master File (TMF) was logged. In the TMF all trial documents were recorded.

In the studies presented in chapter 6, 7, and 8, the PhD student and research assistants collected data in face-to-face interviews. The data from questionnaires were recorded on paper and later transferred into a LimeSurvey® [12] database. The data from qualitative interviews were audio recorded and transcribed verbatim. The original recorded data as well as the transferred were double-checked for accuracy and completeness. An employee of the RTC-CS) monitored the process of trial administration. The administration of Trial Master Files, both paper as well as computerized files, was independently checked for completeness and accuracy.

The paper-recorded questionnaires are stored in the secured environment of the Radboud Institute for Health Sciences, IQ healthcare, Nijmegen, the Netherlands. The raw data, the digitally processed files and the analyzed data of the studies of chapter 2, 4-8 are stored in secured digital files on a local server of the Radboud Institute for Health Sciences, IQ healthcare, Nijmegen, the Netherlands. The raw and analyzed data of the study of chapter 3 are stored in secured digital files on a local server of the Dimence Group Mental Health Care Centre, Deventer, the Netherlands. The raw and analyzed data of the study of chapter 4 are stored in secured digital files on a local server of the School of Applied Psychology, Saxion University of Applied Science, Deventer, the Netherlands.

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Dankwoord

Graag begin ik dit dankwoord met een citaat van Broeder Julius uit 1941 (274):

> *"Dikwijls heb ik mijzelf afgevraagd wat eigenlijk de reden is dat ik in de krankzinnigen-verpleging gegaan ben. … Veel van mijn medemenschen hebben hulp noodig en de krankzinnigen in het bijzonder; maar terwijl ik meende, hun iets te kunnen geven, is het mij gebleken en blijkt het mij steeds, meer en meer, dat ik steeds van hen ontvang en dat het heel weinige, dat ik voor hen doen kan, nooit kan opwegen tegen datgene wat ik aan hen te danken heb."*

De vraag van broeder Julius is mij bekend. Al jong werd ik, als broer van, geconfronteerd met psychiatrie en mede omdat ik op zoek was naar antwoorden op levensvragen en onzekerheden ben ik, 10 jaar later, de wereld van de psychiatrie in gestapt. In de opvolgende 40 jaar heb ik mijn oor te luister gelegd bij de mensen met psychische klachten en kan ik, met Broeder Julius, zeggen dat ik van hen meer geleerd en gekregen heb dan dat ik voor mijn gevoel aan hun welzijn heb kunnen bijdragen. Analoog aan het gedicht van Okke Jager heb ik de glans van hun kwetsbaarheid mogen zien, hebben zij mij tot schild gevormd en zag ik hoe zij bloeiend kleur geven aan onze wereld.

In de inleiding van dit proefschrift heb ik een schets gegeven van 40 jaar ontwikkelingen in de psychiatrie. Deze lopen parallel aan mijn loopbaan waarin ik de eerste helft op klinische afdelingen werkte en in de tweede helft in de ambulante sector werkte. In de aanloop naar de start van mijn wetenschappelijke carrière zijn een aantal mensen cruciaal geweest. Door ze te noemen wil ik mijn dankbaarheid uitspreken. Peter Koopman, die in 1998 een stokje stak voor een carrière als ambtelijk secretaris van de ondernemingsraad. Nico Oud, die al in 1999 zei dat ik de wetenschap in moest, wat mij bewoog om de opleiding tot verpleegkundige specialist te gaan doen. Anja Stevens, die mij in 2005 uitnodigde voor het Expertise Centrum Bipolaire Stoornissen van Dimence. Peter Goossens, die mij betrok bij zijn promotietraject en mij onophoudelijk stimuleerde om zelf de trap naar de 'ivoren toren' van de wetenschap te beklimmen, wat vervolgens mogelijk gemaakt werd door Peter Bournas, sector-manager, die helaas veel te vroeg is overleden.

In 2009 startte ik de beklimming met het wegwerken van mijn wiskunde deficientie. In de opleiding verplegingswetenschap was Peter Goossens mijn mentor. In die tijd kon ik, op mijn beurt, hem inwijden in de dagelijkse praktijk van het ambulant verplegen van mensen met een bipolaire stoornis. In de opleiding verplegingswetenschap waren Irina Poslawski en Irene Jongerden mijn andere leermeesters. Met hen en Peter heb ik mijn eerste wetenschappelijke artikelen gepubliceerd.

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Bisschop van Utrecht tussen 899-917, zetelde in Deventer en wijdde een groot deel van zijn leven aan studie en wetenschap (275).

Dit 'zijpad' bewandelen is een knipoog naar de volgende persoon aan wie ik grote dank verschuldigd ben: Betsie van Gaal, copromotor en drijvende kracht achter het Self-Made & Sound project. Haar onvermoeibaar structurerend vermogen bracht mij steeds terug op het rechte pad. Zij zag mij talloze zijpaden en mogelijkheden verkennen, en hoofdschuddend floot zij mij terug zeggende dat ik gefocust moet blijven. Inmiddels kan ik rustig zeggen dat dit mij beter af gaat en betrap ik mij erop hetzelfde tegen mijn studenten te zeggen. De derde persoon in het promotieteam aan wie ik dank verschuldigd ben is Ria Nijhuis-van der Sanden. Zij heeft op energieke, gedreven en ideeënrijke wijze het estafettestokje overgenomen van Lisette Schoonhoven, die eerder het stokje overgenomen had van Theo van Achterberg na zijn verhuizing naar Leuven. Zowel Lisette's als Theo's bijdrage aan deze promotie hebben hun beslag gekregen in een van de artikelen. Het promotieteam werd gecompleteerd door Hester Vermeulen na haar benoeming tot professor verplegingswetenschap. Als relatieve buitenstaander heeft zij een kritische blik toe kunnen voegen aan het team. Mijn dank gaat ook uit naar mijn mentor Anne Speckens met wie ik in het eerste jaar mijn onzekerheid over mijn onderzoekskwaliteiten heb kunnen uitpluizen. Dit pluizen heeft mij laten inzien dat ik die onzekerheid vooral zelf creëer.

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Het onderzoek had ook niet mogelijk geweest zonder de deelnemers van de ontwikkelgroep, bestaande uit mensen die de Illness Management and Recovery (IMR) eerder gedaan hebben. De meeste van hen hebben hun verhaal ter beschikking gesteld aan de e-IMR interventie. Zij schrokken er niet voor terug om hun kwetsbaarheid als kracht in te zetten. Zij zijn een aantal levende voorbeelden van het gedicht van Okke Jager: *Hoe kostbaar is een kwetsbaar mens.*

Een andere bron van inspiratie was het lectoraat binnen Saxion Hogelschool waar ik dankbaar mocht aansluiten. Ook hier was het een duiventil. Aanvankelijk werd het lectoraat "Herstel-ondersteunende zorg en Empowerment" geleid door Peter Goossens. Na diens vertrek bij Saxion ging de onderzoeksgroep "Verpleegkunde" verder onder leiding van de lectoren Hilde de Vocht en - na haar overlijden - Jan Jukema. Binnen deze onderzoeksgroep heb ik kunnen sparren met collega's als Yvonne Kerkhofs en Silvio van den Heuvel en Ad Bergsma. Ad raapte het IMR-stokje van Peter Goossens op. Hij gaf leiding aan de ontwikkeling van de IMR naar "Eigen Regie en Herstel" (ERH). Ondertussen is dat stokje weer overgedragen aan Karin Tanja-Dijkstra, associate lector. Binnen Saxion hebben veel studenten mij geholpen met het uitvoeren van het onderzoek. Mijn dank gaat ook uit naar Wilma van

Langen die in haar opleiding tot verpleegkundig specialist GGz een van de deelonderzoeken heeft uitgevoerd.

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Yvonne van der Zee

Over de Auteur

Titus Beentjes is geboren op 20 mei 1958. Na de middelbare school startte hij in 1976 met de opleiding tot A-verpleegkundige in Hoorn. In 1979 begon hij de opleiding tot psychiatrisch verpleegkundige in Deventer. Titus' affiniteit lag bij het werken met mensen met een langer durende psychiatrisch aandoening. Na de opleiding werkte hij op een afdeling waarin gewerkt werd met de principes van een therapeutische gemeenschap. In 1989-91 deed hij de middel-management opleiding wat hem motiveerde toe te treden tot de ondernemingsraad waar hij de functie van secretaris bekleedde. Tussentijds studeerde hij muziektheorie aan de Schumann academie.

Eind jaren 1990 is Titus de opleiding tot senior verpleegkundige gaan doen. Dit was in de tijd dat functiedifferentiatie binnen het verpleegkundige beroep in zwang raakte en de functie eerstverantwoordelijke verpleegkundige zijn intrede deed. Tijdens deze opleiding werd hem al geadviseerd om verplegingswetenschap te gaan doen, maar Titus koos voor de opleiding tot verpleegkundig specialist in de geestelijke gezondheidszorg (GGzVS). Dit opende nog meer mogelijkheden en vergezichten in het vak van psychiatrisch verpleegkundige. Tijdens de opleiding tot GGzVS pakte Titus de onderwerpen verpleegkundige diagnostiek en standaard verpleegplannen op.

In 2005 startte Titus zijn carrière als GGzVS binnen het specialistisch centrum voor bipolaire stoornissen binnen Dimence. Daarnaast was hij betrokken bij het landelijk Kenniscentrum Bipolaire stoornissen waar hij als voorzitter van de werkgroep verpleegkundige zorg meewerkte aan de Masterclass Verpleegkundige Zorg voor mensen met een bipolaire stoornis, aan het format signaleringsplan en standaard verpleegplannen.

In 2009 pakte hij het eerdere advies op en startte hij met het wegwerken van een wiskunde deficiëntie waarna hij toetrad tot de opleiding verplegingswetenschap. Zijn eerste publicaties hadden betrekking op het verplegen van mensen met een bipolaire stoornis en hun naastbetrokkenen. Aansluitend begon hij het promotietraject waarin hij studeerde op de effectiviteit van een e-health versie van het Illness Management and Recovery (IMR) programma, wat resulteerde in dit proefschrift. Tijdens dit promotietraject maakte Titus deel uit van het huidig lectoraat Verpleegkunde, Saxion, Hogescholen. Sinds 2018 coördineert hij samen met Marijke Brugman het netwerk Eigen Regie en Herstel (ERH, voorheen IMR). Titus heeft aan meerdere opleidingen les gegeven en begeleidde hij HBO en Master studenten bij hun afstudeer projecten en stages. In deze periode heeft Titus bijgedragen aan de ontwikkeling van de ERH (IMR 4.0), waarbij internationaal samengewerkt werd met Kim Mueser en Susan Gringerich, de ontwikkelaars van de IMR.

Naast de promotie werkt Titus als GGzVS in een ambulant team voor mensen met een angst- en/of stemmingsstoornis, inclusief bipolaire stoornis binnen Dimence, Deventer.

In zijn vrije tijd is Titus een semi-professionele luitspeler met veel ervaring in het begeleiden van zangers. Hij speelt geregeld de basso-continuo partij in meerdere ensembles.

About the author

Titus Beentjes was born in May 20, 1958. In 1976 he started his education as a nurse in a general hospital in Hoorn, the Netherlands. In 1979 he started his education to become a psychiatric nurse in Deventer. After the educational period Titus took up affinity with persons with a longer-term mental health problem and started working in a ward that was working according to the idea of a therapeutic community. In 1989-91 he did a middle management course, which motivated him to enter the employee council of a predecessor of Dimence, and became the council's general secretary. In the meantime, Titus studied classical music theory at the Schumann academy.

Titus resumed his nursing education to become a senior psychiatric nurse in 1999. These were times when differentiation within the nursing profession came into practise, resulting in the function "First Responsible Nurse". This individual responsibility gave in-depth meaning and position to nursing persons with mental health problems. He was advised to study nursing science but he chose to study Master of Advanced Nursing Practise in Mental Health (MANP-MH). In which he succeeded in 2004. There he took up special interest for nursing diagnoses, and standard nursing plans. In 2005 Titus started working as a MANP-MH in nursing persons with a bipolar disorder in an outpatient clinic. Alongside this job, he participated in the nursing committee of the Dutch Foundation for Bipolar Disorder. Under his chairmanship nurses took up the challenge to produce a format for action plans and standard nursing plans.

In 2009, Titus started eliminated his deficiency on mathematics and subsequently studied nursing science. His first publications were on issues concerning the nursing of persons with bipolar disorders and their informal caregivers. In 2013, he entered this PhD process in which he studied the effectiveness of an e-health application to the Illness Management and Recovery program (IMR), which resulted in this thesis.

Since 2013, Titus joined the Saxion Centre for Recovery Oriented Care and Empowerment, nowadays the Centre for Nursing Research, of Saxion University of Applied Science. Since 2018, together with Marijke Brugman, he coordinates the Dutch IMR network, whose task it is to support Dutch institutes who provide the IMR and to develop the Dutch version of the IMR. The IMR network also provides a research platform for students of the Saxion University of Applied Science. Within this constellation Titus contributed to renewing the IMR into the 4.0 version, thereby working internationally together with the founding fathers of the IMR: Kim Mueser and Susan Gringerich.

Next to his research activities, and presently most of his working hours, Titus has a job as a MANP-MH in an outpatient clinic of Dimence, Deventer, where he nurses persons with anxiety and mood disorders, including persons with a bipolar disorder.

In his leisure time Titus is a semi-professional lute player with an extensive experience in accompanying singers. He also plays the basso-continuo in several ensembles.

Publication list

Listed in this thesis

1. **Beentjes T.**, van Gaal B., van Achterberg, T., Goossens P., Self-Management Support Needs from the Perspectives of Persons with Severe Mental Illness: A Systematic Review and Thematic Synthesis of Qualitative Research, *Journal of the American Psychiatric Nurses Association*, 2020 Sep, 3,26(5), 464-82.
2. van Langen, W., **Beentjes, T.**, van Gaal, B., Nijhuis-van der Sanden, M., Goosssens, P., How the Illness Management and Recovery Program Enhanced Recovery of Persons With Schizophrenia and Other Psychotic Disorders: A Qualitative Study, *Archives of Psychiatric Nursing*, 2016, 30(5):552-7.
3. Goossens, P., **Beentjes, T.**, Knol, S., Salyers, M., de Vries, S., An Investigation of the Reliability and Validity of the Dutch Versions of the Illness Management and Recovery Scales among Clients with Mental Disorders. *Journal of Mental Health*, 2017, 26(6), 489–495.
4. **Beentjes T.**, van Gaal B., Goossens, P., Schoonhoven, L., Development of an E-Supported Illness Management and Recovery Programme for Consumers with Severe Mental Illness Using Intervention Mapping, and Design of an Early Cluster Randomized Controlled trial, *BMC Health Services Research,* 2016, 16:20
5. **Beentjes T.**, Goossens, P., Vermeulen, H., Teerenstra, S., Nijhuis-van der Sanden, M., van Gaal B., E-IMR: e-health added to face-to-face delivery of Illness Management & Recovery programme for people with severe mental illness, an exploratory clustered randomized controlled trial, *BMC Health Services Research,* 2018, 18:962
6. **Beentjes T.**, van Gaal B., Vermeulen, H., Nijhuis-van der Sanden, M., Goossens, P., The blended electronic-Illness Management and Recovery program for people with severe mental illness: a qualitative process evaluation alongside a trial, *Journal of Medical Internet Research, Mental Health*, accepted in October 2020.
7. **Beentjes T.**, Teerenstra, S., Vermeulen, H., Goossens, P., Nijhuis-van der Sanden, M., van Gaal B., Identifying the minimal important difference in patients reported outcome measures in persons with severe mental illness, a pre-post analysis of the illness Management and Recovery programme, *Quality of Life Research,* submitted in November 2020.

Peer-reviewed publications not listed in this thesis

1. Bergsma, A., **Beentjes, T**., van Loon, E., & Brugman, M., Eigen Regie en Herstel, *Nurse Academy GGZ*, 2019, 2, 45-51
2. Bergsma, A., **Beentjes, T.**, & Brugman, M., Zinvol leven met psychiatrische kwetsbaarheid, *Tijdschrift Positieve Psychologie*, 2019, 2, 63-69
3. van der Neut, N., Brugman, M., Bergsma, A., & **Beentjes, T.**, 'Ik denk dat een combinatie beter is', Een kwalitatieve studie naar de samenwerking van IMR trainers mét en zonder ervaringsdeskundigheid. *Participatie en Herstel*, 2017,

26(3), 33–41.

4. **Beentjes, T.**, Goossens, P., & Jongerden, I., Nurses' Experience of Maintaining Their Therapeutic Relationship With Outpatients With Bipolar Disorder and Their Caregivers During Different Stages of a Manic Episode: A Qualitative Study. *Perspectives in Psychiatric Care*, 2016, 52(2).
5. **Beentjes T.**, Goossens P., & Poslawsky I., Caregiver Burden in Bipolar Hypomania and Mania: a systematic review. *Perspectives In Psychiatric Care*, 2012, 48(4), 187-197
6. Goossens, P., Kupka, R. **Beentjes T.** & Van Achterberg T., Recognising prodromes of manic or depressive recurrence in outpatients with bipolar disorder: A cross-sectional study in the Netherlands. *International Journal of Nursing Studies*, 2010, 47(10): 1201-1207
7. Goossens P., **Beentjes, T.**, Daemen P., Het signaleringsplan als instrument voor zelfmanagement bij bipolaire stoornissen. *Psychopraxis*, Bohn Stafleu van Loghem, 2009, 11, (1)18-24
8. Goossens, P., **Beentjes, T.**, de Leeuw, J., Knoppert van der Klein E. & Van Achterberg T., The nursing of outpatients with a bipolar disorder: What nurses actually do. *Archives of Psychiatric Nursing*, 2008, (22), 3-11

Book chapters

1. Bergsma, A., Stevelmans, I., Brugman, M., Sterk, T., **Beentjes, T.**, Droës, J., Schaftenaar, P., Pierik, P., Mueser, K., & Gingerich, S., 2018, Eigen Regie en Herstel, Werkboeken 1 t/m 11, Saxion Hogescholen, Deventer.
2. Bergsma A., **Beentjes T.**, Brugman M., & Goossens P., 2016, Hoofdstuk 16, 249-264, Werken aan klinisch en persoonlijk herstel: de Illness Management and Recovery methode, in GGz-Verpleegkunde in de Praktijk, redactie: van Meyel B., De Tijdstroom, Utrecht.
3. Goossens P., & **Beentjes T.**, Zelfmanagement, 2008, Hoofdstuk 19 van het Handboek Bipolaire stoornissen, redactie: R. Kupka, E. Knoppert v.d. Klein, W. Nolen, De Tijdstroom, Utrecht.

Oral presentations

1. **Beentjes T.**, *Siste utvikling av IMR [Nieuwste ontwikkeling van IMR],* Nasjonal IMR fagkonferanse, Bergen, Norway, 2020-01-13.
2. **Beentjes T.**, & Brugman, M., *Working towards the Illness Management and Recovery programme 4.0,* 5th EAOF conference, Verona, 2019-09-05;
3. **Beentjes T**., van Gaal B., van Achterberg, T., & Goossens P., *Self-management support needs of persons with severe mental illnesses*, 5th EAOF conference, Verona, 2019-09-05;
4. **Beentjes T.**, van Gaal B., Goossens P., Vermeulen H., & Nijhuis-van der Sanden M., *The qualitative evaluation of an e-supported Illness Management and Recovery program for people with SMI*, 5th EAOF conference, Verona, 2019-09-05.

5. **Beentjes T.,** van Gaal B., van Achterberg, T., Goossens P., *Zelfmanagement ondersteuningsbehoeften van mensen met ernstig psychiatrische aandoeningen*, Symposium Zin in de Zorg, een toekomstbestendig beroep creëer je samen, Dimence, Deventer, 2019-05-13.
6. **Beentjes T.,** van Gaal B., van Achterberg, T., Goossens P., *Zelfmanagement ondersteuningsbehoeften van mensen met ernstig psychiatrische aandoeningen*, HersTELT, wat TELT, symposium over herstel, Saxion, Lectoraat Verpleegkunde, Deventer, 2018-11-08.
7. Bergsma, A., Brugman, M., & **Beentjes T.**, *Working towards the Illness Management and Recovery programme 4.0,* XIIIth World Congress "Recovery, Citizenship, Human Rights, Reviewing Consensus", World Association on Psychosocial Rehabilitation, Madrid, Spain, 2018-07-06.
8. **Beentjes T.**, van Gaal B., Goossens P., & Nijhuis-van der Sanden M., *The evaluation of an e-supported Illness Management and Recovery program for people with SMI*, Symposium 1.4, presentation 03, ENMESH, The Context of Mental Health Care, Groningen Groningen, The Netherlands, 2017-10-05.
9. **Beentjes T.,** *Herstelondersteunende zorg in de wijk,* Themamiddag Wijklink, Saxion, Deventer, 2017-04-06.
10. **Beentjes T.**, van Gaal B., Goossens P., & Nijhuis-van der Sanden M., *The evaluation of an e-supported Illness Management and Recovery program for people with SMI,* 5th European Nursing Congress Caring for Older People: How can we do things right? Presentation session F1-S226, Rotterdam, The Netherlands, 2016-10-06.
11. **Beentjes T**., van Gaal B., Goossens, P., & Schoonhoven, L., *e-IMR program for consumers with Severe Mental Illness, Development through INTERVENTION MAPPING,* GGZ+TECH, Amersfoort, 2015-04-30.
12. **Beentjes, T.**, Goossens, P., & Jongerden, I., *Nurses' Experience in Maintaining their Therapeutic Relationship with Patients with Bipolar Disorder and their Caregivers in Different Stages of a Manic Episode: a Qualitative Study*, Steiger Congres voor Verpleegkundigen in de GGZ, 2013-05-13, Arnhem.

Poster presentations

1. **Beentjes, T.**, Goossens, P., Prinsen, J., Rijper, P., Vijfhuizen, R., *Het Nieuwe Signaleringsplan*, Congres 10 jaar KenBIS, een feest met inhoud, KenBIS, Amstelveen, 2019-09-20.
2. van Langen, W., **Beentjes, T.**, van Gaal, B., Nijhuis-van der Sanden, M., & Goosssens, P., *Herstel-ondersteunende onderdelen van de Illness Management & Recovery training: een kwalitatieve studie vanuit cliëntenperspectief.* Phrenos, Den Bosch, 2015-05-21.
3. **Beentjes T**., van Gaal B., Goossens, P., & Schoonhoven, L., *e-IMR program for consumers with Severe Mental Illness, Development through INTERVENTION MAP-*

PING, APNA-congress, Indianapolis, Indiana, USA, 2014-10-22/25;

4. **Beentjes T.**, & Goossens P. *A systhematic approach to support nurses in their care giving tasks.* ISBD conference, New Delhi, India, 2008-01-27/29.
5. Stevens A., **Beentjes T**.; Management of pregnancy and postpartum period in 10 patients with bipolar disorder; *Bipolar Disorders*, 11, (suppl. 1), June 2009.
6. **Beentjes T.**, Goossens P. (2008). A systhematic approach to support nurses in their care giving tasks. *Bipolar disorder*, 10 (suppl. 1), 39
7. Goossens P., **Beentjes, T.**, Knoppert – Van der Klein E., Van Achterberg T. (2007). Nursing processes used in the treatment of patients with bipolar disorder: building a body of knowlegde. *Abstract book, 6th European Conference of ACENDIO.*
8. Goossens P., Stevens A., Van Koningsveld F, **Beentjes T.**, Traas A. (2006). Clinical pathways for bipolar disorder. *Bipolar disorder*, 8 (suppl. 1), 58-59
9. **Beentjes T.**, Goossens P., Houtjes, W. & Assink B. *Common Language in Psychiatric Nursing. Results of a pre-research.* ACENDIO. Bled, Slovenië; 2005-04-7/9.
10. **Beentjes T.**, Kronenberg K., van Hoeve J., Goossens P., Houtjes W., van Ravenswaaij P., Uitslag S., & Hoekstra T., *Common language in psychiatric nursing,* ACENDIO, Parijs, Frankrijk, 2003-03-20/22.

PhD portfolio

Name PhD candidate	T.A.A. Beentjes
PhD Period	01-02-2013 – 11-01-2021
Graduate School	Radboud Institute for Health Science
Department	IQ healthcare
Promotor(s)	Prof. Dr. M.W.G. Nijhuis-van der Sanden, Prof. Dr. H. Vermeulen
Co-promotor(s)	Dr. B.G.I. van Gaal, Prof. Dr. P.J.J. Goossens

Training Activities	**Year(s)**	**ECTS**
a) Courses and Workshops		
• Opfriscursus Statistiek Gedrags- en Maatschappijwetenschappen, Radboud University Nijmegen;	2016	1,5
• Biometrics Radboudumc;	2015 - 2016	3
• Academic writing, Radboud University Nijmegen;	2015	3
• BROK, Basic Course of Instructions and Organization for Clinical Researchers;	2014	1,5
• Summer Course Intervention Mapping: Designing theory-based and evidence based programs, University Maastricht;	2013	1,75
• Illness Management and Recovery Training Total, Saxion Hogelscholen;	2013	1,5
• Advanced conversation in English, Radboud University Nijmegen.	2013	1
b) Seminars and Lectures		
• PhD meetings Verplegingswetenschap, Radboudumc, Nijmegen;	2013 - 2019	0,5
• IMR/ERH Netwerkbijeenkomsten, IMR netwerk, Saxion Hogescholen, Deventer, the Netherlands;	2013 - 2019	0,5
• ZonMW netwerkbijeenkomsten binnen het programma “Tussen Weten en Doen I & II”;	2013 - 2017	0,5
• Study Conference with founding father of the Illness Management and Recovery program: Kim Mueser, IMR-network, Saxion Hogelscholen, Deventer, the Netherlands.	2014	0,5
c) Symposia and Congresses		
• **5th European Conference on Integrated Care and Assertive Outreach, “Shaping the future of community mental health care”, European Assertive Outreach Foundation, Verona, Italy** (oral presentation);	2019	1
• Symposium Zin in de Zorg, een toekomstbestendig beroep creëer je samen, Vakgroep Verpleging en Verzorging, Dimence Groep, Deventer, the Netherlands (oral presentation);	2019	1
• Symposium: “HersTELT, wat TELT”, Lectoraat Verpleegkunde, Saxion Hogelscholen, Deventer, the Netherlands (oral presentation);	2018	1
• XIIIth World Congress “Recovery, Citizenship, Human Rights, Reviewing Consensus”, World Association on Psychosocial Rehabilitation, Madrid, Spain (oral presentation);	2018	1

PhD portfolio continued	**Year(s)**	**ECTS**
• XIIth Congress "The context of mental health care", European Network for Mental Health Service Evaluation, Groningen, the Netherlands (oral presentation);	2017	1
• Themamiddag "Wijklink", Academie Gezondheidszorg, Saxion Hogelscholen, Deventer, the Netherlands (oral presentation);	2017	1
• 5th European Nursing Congress Caring for Older People, "How can we do things right?", The Foundation European Nursing Congress, Rotterdam, The Netherlands (oral presentation);	2016	1
• Nationaal GGz Verpleegkunde Congres, "van presentie tot evidence-based practise", Verpleegkundigen & Verzorgenden Nederland, Ede, the Netherlands (oral presentation);	2016	1
• Rehabilitatie Congres "herstel de voortgang", Phrenos, Den Bosch, the Netherlands (poster presentation);	2015	1
• GGz+ TECH, Amersfoort, the Netherlands (oral presentation);	2015	1
• Klinisch Wetenschappelijke Vergadering, Kenniscentrum Bipolaire Stoornissen, Heerhugowaard, the Netherlands (poster presentation);	2015	1
• Afsluitend Symposium Gezondheid & Technologie, Academie Gezondheidszorg, Saxion Hogescholen, Deventer. (poster presentation);	2014	1
• 28th Annual Conference "Building connections: Psychiatric-Mental Nursing Perspectives", American Psychiatric Nursing Association Indianapolis, USA, (poster presentation);	2014	1
• 2nd Annual Conference of the Association for Researchers in Psychology and Health, Enschede, the Netherlands.	2013	0,3
Teaching activities		
d) Lecturing		
• *Herstelondersteunende zorg,* klinische lessen op een psycho-medische unit, Medisch Spectrum Twente;	2019	1
• *Psychopathologie in de praktijk* S19. Saxion Parttime School;	2019	1
• *e-IMR program for consumers with Severe Mental Illness, Development through INTERVENTION MAPPING*. Les in het kader van de Minor Brain & Technology, Saxion Hogelscholen;	2014 - 2016	1
• *Verpleegkundige diagnostiek*; Als onderdeel van: Masterclass: "verpleegkundige zorg bij patiënten met een bipolaire stoornis"; Kenniscentrum bipolaire stoornissen;	2013 - 2020	1
• *Stemmingsstoornissen*. GGz-differentiatie HBOV, Saxion Hogelscholen, Deventer/Enschede;	2013 - 2015	1
• *Masterclass stemmingsstoornissen*, Stichting GGzVS, Utrecht.	2013 - 2015	1
e) Supervision of Internships / other		
• Supervisie over stages van zeven studenten Toegepaste Psychologie, Saxion Hogelscholen;	2013 - 2016	1
• Supervisie over stages van twee studenten Verpleegkundig Specialist, Stichting GGzVS, Utrecht;	2019, 2020	0,5
• Begeleiding van twee studenten bij de module WK04, onderzoeksartikel, Stichting GGzVS, Utrecht.	2014, 2020	0,5
Total		**36,55**

Reference list

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