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Recovery is up to you

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Recovery is up to you:

Evaluation of a peer-run course

Hanneke van Gestel-Timmermans

Naam kunstenaar: Vera Verkuijlen
Titel kunstwerk: Vriendschap en warmte

Gedicht van kunstenaar bij kunstwerk:

Nestje
Nu wil ik slapen
Lekker op schoot
Er voor elkaar zijn en zorgen
Door warmte en vriendschap
met elkaar verbonden
Jezelf veilig voelen
Door ja en nee te verkennen
Er zijn

Recovery is up to you:

Evaluation of a peer-run course

Proefschrift

ter verkrijging van de graad van doctor
aan de Universiteit van Tilburg,
op gezag van de rector magnificus, prof. dr. Ph. Eijlander,
in het openbaar te verdedigen ten overstaan van
een door het college voor promoties aangewezen commissie
in de aula van de Universiteit
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door

Johanna Antonia Wilhelmina Maria Timmermans,
geboren op 30 juli 1962 te Tilburg

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Chapter 1

General introduction

INTRODUCTION

In the 1980s, a new view on recovery emerged in psychiatry based on the 'consumer's' perspective (1). Here, the focus was not on traditional (medical) outcomes, but on individually defined and more subjective constructs such as personal growth, hope, and autonomy (2). Although interest in this type of recovery is rapidly expanding in Western countries, only a limited amount of research has focused on new outcome measures for recovery, or on how this type of recovery can be achieved and/or promoted.

The new view on recovery has consequences for the organization of mental health care. It demands a more recovery-oriented and demand-driven health care. Peer-run services are an example of how a more recovery-oriented health care might be arranged (3, 4). However, despite their advantages and importance for a recovery-oriented care, peer-run services are still not common as a form of mental health service provision. Moreover, research on the effectiveness of peer-run services has been scarce and poorly controlled (3, 5, 6). In order to develop a more evidence-based recovery-oriented health care, additional knowledge on individually-defined recovery and the effects of peer-run services is required.

Central to this thesis is the evaluation of the peer-run course 'Recovery is up to you'. To this end, the feasibility of the course and its effects on the recovery of participants are investigated. Furthermore, we investigated how individually-defined recovery manifests itself by exploring which factors are related to classes of people with different profiles of recovery. Finally, we examined which factors promote individually-defined recovery.

This chapter presents background information on individually-defined recovery, prevalence of major psychiatric problems, long-term psychiatric services, recovery-oriented care, peer-run services, and research on recovery in psychiatry. The chapter closes with a description of the aims and outline of the thesis.

Medically-defined recovery versus individually-defined recovery

In general, there are two broad definitions of recovery in psychiatry (7, 8). The first definition is related to the conventional use of the term and based on a medical or scientific perspective. Here, recovery refers to cure and is defined as an outcome, based on whether operationally-defined criteria in one or more domains are met, such as readmissions, symptom reduction and improved functioning. In the past, the term 'chronic' was associated with this definition of recovery. It embodied the view that people with severe long-lasting psychiatric problems would not improve and therefore required long-term care (9).

The origin of the second and new concept of recovery lies in various longitudinal outcome studies conducted since 1967, showing that a significant number of people with serious mental illness did improve over time, with outcome ranging from only mild impairment to full recovery (10-12). Furthermore, several (former) clients, for instance Deegan (13), have described their experiences of living with a diagnosed mental illness and how they recovered. The new concept of recovery emerged in psychiatry in the 1980s and was based on the client's perspective (1). From this perspective, recovery was defined as *".... a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness"* (14). This new concept of recovery is more concerned with a sense of meaning in life and personal comfort, and refers to how a person manages his or her life in the presence of an enduring illness (10). It focuses on individually-defined and more subjective factors, such as personal growth, hope, and autonomy (2). This 'individually-defined recovery' is not a static construct but refers to an ongoing change process (15). Therefore, there is no uniform pattern for those who are 'in recovery'.

This new concept of recovery is receiving considerable attention from treatment providers and policymakers, for instance in the USA (16), Australia (2, 17), Canada, the UK, New Zealand (18) and the Netherlands. Recent policy initiatives by the US government (and other governments around the world) aim to re-orient research and clinical practice from a traditional focus on effecting cure to exploring ways to encourage and assist people to live meaningful lives in the face of an enduring mental illness (16). In the Netherlands, despite enthusiasm regarding the transformation of mental health care towards a more recovery-oriented care, the conventional definition of recovery still prevails in psychiatry (7, 8), and current services are mainly based on this perspective. Generally, recovery is still operationalised in terms of symptom reduction and improved functioning. Therefore, mental health professionals may not fully be able to fulfill the health care needs of some people with severe mental illness because these clients (and their professionals) might have a different view on recovery. The need to solve this problem is determined by those who are not receiving mental health services and by those who are not satisfied with these services.

Towards a recovery-oriented mental health care

In the Netherlands, the total group with severe mental illness is estimated to be 160,000 people. More than 50,000 of them do not receive psychiatric care and many of them do not receive any care at all (19). Moreover, 1.8% of the total population (about 297,000 people) report to have an unfulfilled need for care for their psychological problems (20). 107,785

persons are estimated to be in need of long-term psychiatric services. About 60% of the people in long-term care are receiving out-patient services, whereas 13% are hospitalized or in sheltered living, and 25% are receiving a combination of out-patient services and sheltered living. The group of people using long-term mental health care is growing, particularly among the group in sheltered living. In the last decade the total number of service users increased by 32% (19).

The central aim of long-term psychiatric care is to improve the quality of life of people with severe mental illness (19). Symptomatic treatment (psychotherapy and medication), illness management and psycho-education programs, and rehabilitation and skills building (related to e.g. day activity programs, work, living situation and social contacts) are common services. Some clients are not satisfied with their relationship with their health care professional and with their influence on the goals of treatment (18). In order to meet the health care needs of these clients, and of the people with severe mental illness who are not connected to mental health care, our long-term psychiatric services need to change. Services can no longer focus solely on reducing symptoms and suffering; this focus needs to be complemented with an emphasis on the process of developing self-agency for clients (10). In a recovery-oriented care both perspectives on recovery are complementary.

A recovery-oriented care incorporates the attitude that recovery is possible (1). It integrates three types of services: services provided by professionals, services provided by peers, and services provided in collaboration (1). In all these services, individuals with serious mental illness are respected as partners in treatment and rehabilitation.

In the first type of service, provided by professionals, the recovery orientation lies in the attitudes and behaviour of the professionals and clients. Recovery-oriented services are person-centred, offered within the context of a collaborative relationship with the client and supporting the strengths of clients (18). Here, new goals of care are, for instance, partnership, shared decision-making, attention given to the client-practitioner relationship, and the clients' perspectives and goals for treatment. Preferably, decisions are worked out in a partnership between the professional and the client, and are made based on client as well as provider perspectives. The client should have the greatest role possible in defining goals of treatment and planning ways to reach these goals; this promotes choice, self-determination and empowerment of the client (8). Also, shared decision-making is a more effective approach in care than a traditional authoritarian approach (21), and reciprocity in the relationship with the professional is of primary importance to clients (18). Nevertheless, this requires a major cultural shift in service delivery; from a paternalistic, illness-oriented perspective to a

collaborative, autonomy-enhancing approach (17). This also implies a different scope of services, which are becoming more community-oriented and with goals on different life domains.

The second type of recovery-oriented services are the peer-run services. These services are planned, implemented and provided by clients for clients, for instance peer-support programs. Peer-run services have expanded rapidly during the past two decades (3, 4), and the increasing popularity of these services illustrates the demand for this type of treatment. Moreover, clients as mental health care providers may accelerate changing the attitudes of professionals (22), because they give those professionals the opportunity to see peers successfully function in their role as, for instance, a course instructor.

The third type of recovery-oriented services are the collaborative services. These services are provided by and for both consumers and professionals, for instance recovery education and training (1). In the Netherlands, in recovery-oriented mental health institutions, clients, professionals and managers work together as partners in order to promote recovery of clients, and to improve mental health care and policies. The HEE Program (Herstel Empowerment Ervaringsdeskundigheid; Recovery Empowerment Consumer expertise) is an example of the three types of services. This program contains a peer-run course, which stimulates individual recovery of clients and their participation in society. Moreover, the program contains a workshop on recovery for clients and their professional(s), and a course for professionals (23).

Peer support: an answer to the health care needs of people with severe mental illness?

There is evidence that peers might have more influence on patients' attitudes, values and behaviours than traditional health care providers (22, 24). Others have shown that peers have the potential to engage people with serious mental illness, who are alienated from the traditional mental health system, into receiving services (25, 26). Therefore, peer-run services seem to be a meaningful tool for the group of people with severe mental illness that is not using 'standard' psychiatric care.

Peer-run services may promote recovery of people with severe mental illness, because these services enhance the autonomy of clients and are based on reciprocal relationships among peers. Peer support supplies the kind of social support that clients cannot receive from professionals and/or close relatives and friends. Individuals with common experiences can provide better support and safer environments than those who have not had a history of psychiatric treatment (5). They can offer participants acceptance, support, understanding,

empathy, and a sense of community. Compared to clients receiving services from conventional mental health programs, participants in peer-run services can play a more active role in creating their own environment (22, 27). Sharing of experiences enhances empowerment, social status, self-esteem and self-efficacy of participants (28). The presence of role models makes participants more hopeful and optimistic about their future (22), and stimulates their coping and problem-solving skills (9). These factors give participants a feeling of personal responsibility (27).

It has also been shown that peer support improves symptoms, reduces hospitalizations, offers hope, facilitates coping, and increases social networks and quality of life in patients with severe psychiatric disorders (22, 27, 29). Despite their advantages, peer-run services are still not common as a form of mental health service provision. Research on the effectiveness of, for instance, self-help groups is limited and very few randomised controlled trials (RCTs) have been conducted (3, 5, 6). One reason for this is that an RCT is considered to be antithetical to peer services and supports, because these services are voluntary and participation cannot be dictated by the requirements of science (5). Finally, assessing the effects of peer-run services on the recovery of participants is complicated, because little is known about the new concept of recovery and no well-established and/or widely used measures for recovery are available.

Research on individually-defined recovery

Research on the factors associated with individually-defined recovery is limited (8). Also, most studies are qualitative and few quantitative data are available. In recent years, however, more quantitative empirical data on the dimensions and determinants of mental health recovery have become available. Several concepts are commonly regarded as important for recovery: empowerment, hope and optimism, perceived knowledge about illness and services, life satisfaction, regaining self-esteem, self-respect and regaining control over symptoms and stress, connection with others, social relationships and social support (1, 18, 30-34). In addition to these quantitative empirical data, some quantitative studies have explored the development and psychometric evaluation of instruments for measuring recovery or aspects of recovery (30, 35-41). However, only a few recent studies were RCTs (29, 42, 43).

In order to transform today's mental health care system into a more recovery-oriented evidence-based care, more quantitative research is needed. The new concept of recovery should be identified. We need this knowledge to address the question as to how individually-

defined recovery should be operationalised in mental health care. Recovery should be measured as a process rather than as an outcome, and with instruments that incorporate more subjective measures than, for example, readmissions and symptoms. As a consequence of this research, services might also need to be adjusted to a person's phase of recovery. Furthermore, when striving for evidence-based mental health care, it is important that RCTs indicate how individually-defined recovery can be promoted by peer-run interventions.

Aims and outline of the thesis

The work in the present thesis has the following aims:

1. To evaluate the psychometric properties of the Dutch version of the Herth Hope Index (HHI) in a sample of people with severe mental health problems.
2. To evaluate the feasibility of the peer-run course 'Recovery is up to you'.
3. To evaluate the effects of the peer-run course 'Recovery is up to you' by means of a randomised controlled trial.
4. To investigate whether classes of people with major psychiatric problems with comparable profiles of individually-defined recovery can be identified, and to evaluate whether these classes are comparable to the phases of recovery as described by Spaniol and colleagues (44).
5. To evaluate which factors promoted individually-defined recovery.

Chapter 2 deals with the evaluation of the psychometric properties of the Dutch version of the Herth Hope Index (HHI). To this end, the Dutch version of the HHI was used in three samples after a strict forward-backward translation procedure. First, a pilot study was conducted in which the content validity and comprehensibility of the HHI was tested. Then, the reliability and validity of the HHI were examined in a sample of people participating in the peer-run course 'Recovery is up to you' (see also Chapter 4). Finally, the test-retest reliability of the HHI-Dutch version was examined in a sample of people with severe mental health problems working in a sheltered workplace.

Chapter 3 focuses on the evaluation of the feasibility of the peer-run course 'Recovery is up to you'. The feasibility was evaluated by semi-structured interviews and checklists. After each course, interviews were held with course instructors and participants to gain information on their experiences with the course. Course instructors also filled out checklists after each course session. A total of 38 courses were given and analysed. In this study the researchers

and clients worked closely together. Clients were involved in the standardisation of the course manual and workbook and they interviewed participants.

Chapter 4 explores the effects of the peer-run course 'Recovery is up to you' on the recovery of participants, by means of a randomised controlled trial. This study was also conducted in collaboration with clients, who also took part in the research advisory committee. Clients were involved in the standardisation of the course manual and workbook, the pilot study of the measures, the assessments, and they also had an advisory role. Recruitment for the study took place at 13 mental health institutions and client organisations in the Netherlands. Participants had to fill out measures on empowerment, hope, quality of life, self-efficacy beliefs, loneliness, coping and generic health status. Inclusion criteria were: suffering from major psychiatric problems (e.g. psychosis, personality disorder, affective disorder, or anxiety disorder), and reporting to have been through very disruptive times from which the person was now recovering. Exclusion criteria were: illiteracy, not speaking Dutch, being suicidal, having florid psychotic symptoms and/or major addiction problems. Data were collected at five moments: T0 to T4 (see Figure 1).

Chapter 5 investigates whether classes of people with major psychiatric problems and with comparable profiles of individually-defined recovery can be identified by latent class analysis. The study also evaluates if these classes are comparable to the phases of recovery, as described by Spaniol and colleagues (44). Furthermore, the study focuses on whether these classes were also related to other variables. For this study the same sample was used as in the effect study.

Chapter 6 describes the factors promoting individually-defined recovery. Finally, the general discussion in Chapter 7 reflects on the findings, methodological limitations and implications of these studies, and makes some recommendations for future research.
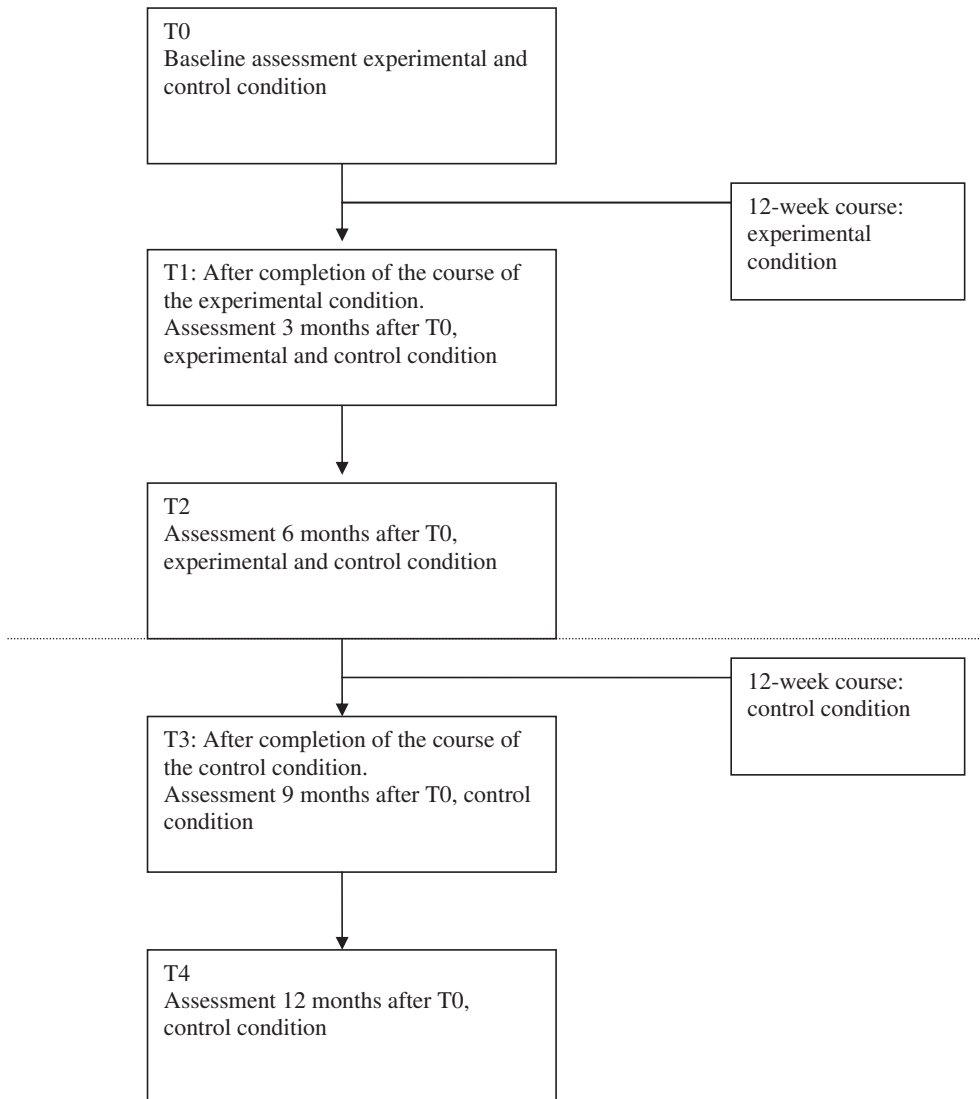
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Figure 1:   **Flow chart of assessments. Assessments at T3 and T4 (below the line) were used for additional information only.**

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Chapter 2

Hope as a determinant of mental health recovery: a psychometric evaluation of the Herth Hope Index-Dutch version

Van Gestel-Timmermans, J.A.W.M., van den Bogaard, J.W., Brouwers, E.P.M., Herth, K. & van Nieuwenhuizen, Ch.

ABSTRACT

Hope is an important aspect of mental health recovery and a major concern in patients with mental illness. Therefore, an instrument to measure hope could be useful for clinical settings and research. The aim of this study was to develop a Dutch version of the Herth Hope Index (HHI-Dutch) and to evaluate its validity and reliability in a sample of people with severe mental illness.

The HHI-Dutch was used in a sample of people with severe mental illness (N = 341). A Principal Component Analysis with varimax rotation was performed and identified two factors. The results also showed a Cronbach's alpha of .84 for the HHI total score and a test-retest reliability of r = 0.79. As for convergent validity, highest correlations were found between hope and health-related self-efficacy beliefs (r = 0.72), perceived quality of life (r = 0.56) and mental health (r = 0.59) and medium correlations between hope and loneliness (r = - 0.47), task-oriented coping (r = 0.45) and the habit to seek company (r = 0.4). As for divergent validity, according to expectations, there was no significant correlation between hope and physical functioning, but there was a positive correlation between hope and general health perception (r = 0.34).

In conclusion, the HHI-Dutch has shown to be an instrument with adequate psychometric properties. It is advisable to use the scale as a whole rather than using the subscales. The HHI-Dutch is appropriate for research in the recovery process of people with severe mental illness. Moreover, the study of hope is important for understanding the concept of hope in relation to mental health recovery. The results of this study may be a step forward and a new impulse to stimulate research on the important 'hope' aspect in mental health recovery.

Keywords: Herth Hope Index, mental health, psychometric, recovery, hope.

INTRODUCTION

The concept of 'hope' is a central aspect in the recovery process of people with severe mental illness (1-3). From the 1970s on, researchers have tried to conceptualise and measure hope, both in healthy and chronically ill adults. Several dimensions of hope were identified in these studies, especially the goal-expectation or goal-achievement dimension, the time- or future oriented dimension and the interpersonal dimension. In the mid-1980s, other conceptual issues were addressed in several studies (4). For example Dufault and Martocchio (5) identified six dimensions of hope: an affective dimension, a cognitive dimension, a behavioural dimension, an affiliative dimension, a temporal dimension and a contextual dimension. In various studies and in different populations, hope has shown to correlate strongly with variables such as well-being (6), quality of life (7), subjective global life satisfaction (8), spirituality and/or religion (6, 9) and measures of resiliency, namely self-esteem, self-confidence and self-transcendence (10). In contrast, there seems to be no strong connection between hope and health status or stage of (somatic) illness (4, 8).

Hope is especially important for individuals when personal resources are exhausted or when they are in a threatening situation with an uncertain outcome (11). Although most research on the experience of hope has been done with cancer patients (7), hope is also very important in the recovery process of people with severe mental illness. Because of new insights in the recovery process there are developments towards a more recovery-oriented mental health care system. In this new orientation, recovery of mental illness goes beyond relief or remission of symptoms and outcome of treatment. This orientation uses a nonmedical, process-oriented model in which recovery ".... is a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness" (12). Rather than meaning symptom-free and without disabilities, recovery here is more concerned with a sense of meaning in life and personal comfort (1). In recent years, some more quantitative empirical data about the dimensions and determinants of mental health recovery have become available and these data have shown that the concept of 'hope' is an important aspect of the process of recovery (1-3). Still, insufficient work has been performed on patients' perspectives about the mechanisms or factors involved in the recovery process, although these perspectives are critical to a fuller understanding of recovery (13).

In line with these developments, in the Netherlands, but also in other European countries, there is a need for a reliable, valid and feasible instrument to measure the 'hope' aspect. This would make the study of hope possible, which is important to understand the relation

between the hope aspect and mental health recovery. The Herth Hope Index (HHI) (4) seemed to be a good instrument for this purpose because it is a brief instrument with good psychometric properties and it has been developed for clinical use. It has been designed to facilitate the examination of hope at various intervals so that changes in levels of hope can be identified. The HHI incorporates the conceptual issues described by Dufault and Martocchio (5) and has been developed and validated for several languages. Published findings, as shown in Table 1, include: a Swedish (14), Japanese (15), Norwegian (7), Spanish (16) and Portuguese (17) version of the instrument. It has been used in different patient groups, for example cardiac patients and patients with cancer, multiple sclerosis, Parkinson's disease (7), ALS (18) and cystic fibrosis (19). At present, the HHI has seldom been used in research on severe mental illness.

The aim of this study is to develop a Dutch version of the HHI and to assess the reliability and validity of this Dutch version in a sample of people with severe mental health problems.

Table 1: **Published articles on development and validation of the HHI in different samples and in different languages**

Author(s) and year	*Sample*	*N*	*Factor-solution*
Herth (1992)	American adults with acute, chronic or terminal illness	70 persons with acute illness; 71 persons with chronic illness; 31 persons with terminal illness	Three factors: 1. Temporality and future 2. Positive readiness and expectancy 3. Interconnectedness with self and others
Benzein & Berg (2003)	Patients in palliative care	40 cancer patients in palliative care; 45 family members of the cancer patients	Two factors: 1. Reconciliation with life situation 2. Religiosity
Wahl et al. (2004)	General population	1893 respondents	Two factors: 1. Positively worded items 2. Negatively worded items
Koizumi et al. (1999)	Elderly people	87 elderly persons who visited a Welfare Centre for the Aged	Two factors: 1. Sense of relatedness and emotions in the hoping process 2. Self-confidence positive readiness and expectancy to hope
Sartore & Grossi (2008)	Chronic disease patients and their caretakers	131 patients and their caretakers, divided in 3 groups: 47 oncology patients; 40 type-2 diabetes patients; 44 caretakers of those patients	Unknown from the English abstract
Pareyra (1996)	Patients and students	126 normal old Argentinean adults; 126 normal Argentinean adults (university students); 150 Argentinean adults (surgical patients)	Unknown from the English abstract

METHODS

Procedure and subjects

Inclusion criteria for all subjects were that they had serious mental health problems (for instance psychosis, personality disorder, affective disorder and anxiety disorder) and that they had moved beyond the acute phase of their disease. They also had to have enough reading skills to complete the questionnaire. After explaining the study in detail (both verbally and in-writing), written informed consent was obtained from each subject.

For this study, the HHI-Dutch was used in three samples. First, the HHI-Dutch was used in a pilot study (N=25), together with other instruments (see instruments), in order to test its content validity and comprehensibility. The subjects attended a Day Activity Centre or were

on a waiting list for this centre (mean age 41.4 years, standard deviation 10.9, percentage female 56 %).

Second, the HHI-Dutch was used, together with other instruments (for example those used for validating), in a sample (N=341) of subjects gathered by advertisements in free local papers, by posters in hospitals, psychiatric care services and in primary care and by the psychiatric care services themselves. These subjects participated in a larger study on recovery of severe mental health problems. Demographic and psychiatric characteristics of the sample are presented in Table 2.

Third, the instrument was used in a test-retest study with 21 people with severe mental health problems working in a sheltered workshop (mean age 39.7 years, standard deviation 9.83, percentage female 38%).

Prior to the start of the study, approval was obtained from the medical ethics committee for mental health institutions in the Netherlands.

Table 2:   Demographic and psychiatric characteristics

Demographic characteristics	Total group N= 341	
	N	(%)
Mean age (S.D.)	43.5 (10.4)	
Age range	17 - 75	
Female	223	(66)
Dutch Nationality		
Born in the Netherlands	312	(92)
Level of education		
Low	95	(28.2)
Average	111	(32.9)
High	119	(35.2)
Principal daily pursuit		
Unemployed	69	(20.3)
Study/School	11	(3.2)
Employed part time	28	(8.2)
Employed full time	13	(3.8)
Volunteer work	137	(40.3)
Living situation		
Living alone	172	(50.6)
Marital status		
Unmarried	191	(56.2)
Married/living together	49	(14.4)
Divorced	94	(27.6)
Widowed	6	(1.8)
Psychiatric characteristics		
Psychotic disorder	112	(33.3)
Affective disorder	122	(36.3)
Anxiety disorder	76	(22.8)
Personality disorder	105	(31.3)

2

Instruments

The Dutch version of the HHI (HHI-Dutch)

In accordance with the forward-backward procedure (20), the HHI was translated into Dutch by three independent translators. Differences were discussed and one consensus-version was constructed. This version was translated back in English by a native speaker. Finally, this last version was approved of by the author of the original instrument. This strict construction process was to the benefit of the content validity of the instrument. Content validity indicates whether particular items are a representative sample of the content area one wants to measure and the extent to which the construction of an instrument is sound and well carried out (21).

The HHI-Dutch was used to assess the overall hope level of the people with severe mental health problems. The HHI-Dutch has 12 Likert scale items, with scores ranging from 1 ('strongly disagree') through 4 ('strongly agree'). The scoring consists of summing the scores for the total scale. Item 3 and item 6 need to be reversed scored. Total scores on the scale are ranging from 12 to 48 points. The higher the score, the higher the level of hope. Cronbach's alpha for the original HHI was found to be 0.97 with a 2-week test-retest reliability of 0.91. The instrument was found to have three factors, each with four items: 1.Temporality and future, 2. Positive readiness and expectancy and 3. Interconnectedness with self and others (4).

Validating instruments for construct validity

Construct validity refers to how well an instrument measures the proposed underlying factors or dimensions; in other words, if the instrument embraces a particular theoretical construct (22). Convergent validity and divergent validity were assessed. According to Cohen (23) a medium correlation ranges from 0.3 to 0.49 and a high correlation ranges from 0.5 to 1.0. Convergent validity was assumed when correlations between hope and another concept were medium to high; i.e. when both concepts were related to each other. Divergent validity was assumed when correlations between hope and the other concepts were low; i.e. when both concepts were not related to each other.

The Manchester Short Assessment of Quality of Life

The Manchester Short Assessment of Quality of Life (MANSA) is an instrument to measure quality of life in people with mental illness. In this study, an abbreviated version of the MANSA was used, consisting of 12 subjective questions to assess satisfaction with life as

a whole and with several life domains. Satisfaction is rated on 7-point Likert scales ranging from 1 ('could not be worse') through 7 ('could not be better'). Cronbach's alpha for the satisfaction ratings in the original English version of the MANSA was 0.74 (24) and for the Dutch version respectively 0.73 for students, 0.78 for older people with severe mental illness and 0.85 for people with severe mental illness currently receiving treatment (Ch. van Nieuwenhuizen, S. Priebe and A. Nugter, 2009, in preparation).

The Mental Health Confidence Scale

The Mental Health Confidence Scale (MHCS) was designed to assess the health-related self-efficacy beliefs of persons dealing with mental disorders. It has a 16-item 6-point Likert scale with scores ranging from 1 ('totally no confidence') through 6 ('full confidence'). The instrument has three subscales: Optimism (six items, Cronbach's alpha = 0.91), Coping (seven items, Cronbach's alpha = 0.90) and Advocacy (three items, Cronbach's alpha = 0.80). The total scale has a Cronbach's alpha of 0.94 (25). In a Dutch study, Cronbach's alphas for the Dutch version were 0.88 for Optimism, 0.87 for Coping, 0.76 for Advocacy and 0.93 for the total scale (26).

The Loneliness Scale

The Loneliness Scale is an instrument to assess a subjectively experienced unpleasant or intolerable lack of social relationships (27). The scale consists of 11 items on 5-point Likert scales, ranging from 1 ('yes, for sure') through 5 ('no, certainly not'). It contains two subscales: the Emotional Loneliness Scale (six items, negatively formulated) and the Social Loneliness Scale (five items and positively formulated). Cronbach's alpha of the total scale ranged from 0.8 to 0.9 (28).

The Coping Inventory for Stressful Situations

The Coping Inventory for Stressful Situations (CISS) assesses coping-behaviour and is also for use with psychiatric patients (29). It is a 48 item 5-point Likert scale instrument with scores ranging from 1 ('not at all') through 5 ('very much so'). The instrument contains three main scales, Task-oriented coping (Cronbach's alpha = 0.87), Emotion-focused coping (Cronbach's alpha = 0.87) and Avoidance (Cronbach's alpha = 0.82). The last main scale has two subscales: Seeking company (Cronbach's alpha = 0.78) and Seeking distraction (Cronbach's alpha = 0.75) (30).

The RAND-36

The RAND-36 assesses general health situation. It contains eight subscales: Physical functioning, Social functioning, Role limitations (physical problem), Role limitations (emotional problem), Mental health, Vitality, Pain and General Health Perception. The scale consists of 36 items. Six subscales have items on 3- through 6-point Likert scales and the other two scales have items that can be answered with 'yes' or 'no'. The Cronbach's alpha of the subscales ranged from 0.71 to 0.92 (31).

The convergent validity of the HHI-Dutch was assessed by correlating HHI-Dutch sumscores with validating instruments:

a. 12 subjective items of the Dutch version of the *Manchester Short Assessment of Quality of Life (MANSA)* (24, 32), because strong correlations have been found between hope and quality of life (7),

b. the total scale and the subscale Optimism of the Dutch version of the *Mental Health Confidence Scale (MHCS)* (25, 26), because strong convergent correlations have been found between hope and measures of resiliency (10),

c. the total scale of the Dutch version of *the Loneliness Scale* (27, 28), because a relationship is an essential component of hope (33) and more general satisfaction with networks is associated with greater hope (1),

d. the scales Task-oriented coping and Seeking company of the Dutch version of the *Coping Inventory for Stressful Situations (CISS)* (29, 30). As hope is important in coping with, or recovering from, chronic illness (34) a correlation was expected between the former behaviours and hope, and

e. the subscale Mental health of the Dutch version of the *RAND-36* (31), while strong relationships have been found between hope and subjective health or subjective global life satisfaction (8). Those concepts are strongly related to mental health.

Based on findings in other studies, high correlations were expected with quality of life, health related self-efficacy beliefs and mental health (7, 8, 10); medium correlations with task-oriented coping and loneliness (1, 33, 34).

The divergent validity HHI-Dutch was assessed by correlating Dutch HHI sumscores with the subscales Physical functioning, Role limitations (physical problem) and General health perception of the Dutch version of the *RAND-36* (31) because low correlations were expected between hope and physical health. Hope has shown to have no strong connections with health-status or symptom severity (8).

RESULTS

Examination of the factor structure of the HHI-Dutch

A Confirmatory Factor Analysis (CFA) was conducted to examine if the factor structure of the Dutch HHI fitted well to the original version (35). It is generally assumed that a Goodness-of-Fit Index between 0.90 and 0.95 indicates a very good fit, but in the literature no cut-off-points are given (36). The CFA in the sample of 341 people with severe mental health problems showed a Goodness-of-Fit Index of 0.89, indicating that the factor structure of the Dutch HHI did not fit well to the original version. Hence, a Principal Component Analysis (PCA) with varimax rotation was performed. First, the suitability of data for factor analysis was assessed by computing the Kaiser-Meyer-Olkin (KMO) value. Small values of the KMO-coefficient indicate poor chances of success in factor analysis because correlations between pairs of variables cannot be explained by the other variables (37). In this study, the coefficient was 0.88, which, according to Kaiser (38), is high. In addition, factorability of the correlation matrix was considered (several coefficients were greater than 0.3) and the Bartlett's test of sphericity was significant. Therefore, a PCA with varimax rotation was performed, in addition to exploring eigenvalues, proportions of explained variance and whether or not factor content was open to interpretation. As a result, the original three-factor solution (4) could not be confirmed in the present study. Instead, a two-factor solution was found accounting for 47 % of the item variance. Eigenvalues for the two factors were 4.5 and 1.1, respectively. Factor 1 (view on life and future) consisted of the items: 1, 2, 3, 6, 10 and 12; $\alpha = .8$. Factor 2 (self-confidence and inner strength) consisted of the items: 4, 5, 7, 8, 9 and 11; $\alpha = .69$. In Table 3, the loadings of the HHI-Dutch items are shown.

Table 3: **Factor loadings of the 12 items of the HHI Dutch after varimax rotation**

Items	*Factor loading F1*	*Factor loading F2*
1. Positive outlook on life	**0.61**	0.48
2. Presence of goals	**0.49**	0.44
3. Feel all alone	**0.69**	0.03
4. Can see possibilities even when in difficulties *	0.29	**0.49**
5. Belief that comforts *	0.23	**0.30**
6. Scared about the future	**0.76**	0.05
7. Recall happy/joyful times	0.05	**0.56**
8. Deep inner strength	0.07	**0.69**
9. Give and receive caring/love	0.15	**0.67**
10. A sense of direction	**0.70**	0.28
11. Each day has potential	0.33	**0.68**
12. Life has value and worth	**0.69**	0.46

* Because of cultural differences items 4 and 5 were freely translated. The expression 'I can see a light in a tunnel' has a different connotation in the Netherlands and could be associated with death. Item 5 'Faith that comforts' was freely translated because religion in the Netherlands is not an integrated, natural part of daily life as it is in the United States (39). Numbers in bold represent items that load on that specific factor.

Reliability of the adapted HHI

Results showed a Cronbach's alpha of .84, indicating adequate internal consistency of the scale as a whole. In the 1-week test-retest study with 21 people with severe mental health problems a test-retest reliability of $r = 0.79$ ($p<0.01$, two-tailed) was found, which is high (23).

Content validity

The construction process of the HHI-Dutch, as described earlier, supports its content validity. The instrument was translated according to a strict forward-backward translation procedure. The pilot study showed no specific problems with the instrument.

2

Construct validity

Convergent validity

Convergent validity was assessed by correlating HHI-Dutch sumscores with our validating instruments. In Table 4 the correlations for the scales and subscales are presented. Highest correlations were found between hope (HHI-Dutch) and health- related self-efficacy beliefs (i.e. the subscale optimism of the MHCS; $r = 0.72$; $p < 0.001$) and between hope and perceived quality of life (MANSA; $r = 0.56$; $p < 0.001$) and mental health (i.e. the subscale Mental Health of the RAND-36; $r = 0.59$; $p < 0.001$). There were medium correlations between coping (CISS) and hope and between loneliness (Loneliness Scale) and hope. The correlation with loneliness was the highest ($r = -0.47$; $p < 0.001$) followed by task-oriented coping (i.e. the subscale Task-oriented coping of the CISS; $r = 0.45$; $p < 0.001$) and seeking company (i.e. the subscale Seeking company of the CISS; $r = 0.40$; $p < 0.001$).

Divergent validity

Divergent validity was assessed by correlating HHI-Dutch sumscores with the subscales Physical functioning, Role limitations (physical problem) and General health perception of the Dutch version of the RAND-36. There were no significant correlations between hope and physical functioning and between hope and role limitations (physical problem), but there was a moderately high correlation between hope and general health perception ($r = 0.34$; $p < 0.001$; see Table 4).

Table 4: Pearson correlations of the HHI-Dutch total scale with total scales and subscales of validating instruments; N = 326

Instruments used for convergent validity	1	2	3	4	5	6	7	8	9	10	11
Instrument / domain											
1. HHI-Dutch total score	-										
2. MANSA total score	0.56*	-									
MHCS											
3. Total score	0.69*	0.58*	-								
4. Optimism subscale	0.72*	0.58*	0.85*	-							
5. Loneliness Scale, total score	-0.47 *	-0.63 *	-0.47*	-0.5*	-						
CISS											
6. Task-oriented coping	0.45*	0.31*	0.48*	0.45*	-0.21*	-					
7. Seeking company	0.4*	0.39*	0.33*	0.39*	-0.42*	0.5*	-				
RAND-36											
8. Mental Health	0.59*	0.62*	0.61*	0.63*	-0.47*	0.37*	0.33*	-			
Instruments used for divergent validity											
Instrument/domain											
RAND-36											
9. Physical functioning subscale	0.06	0.14	0.17	0.14	-0.1	0.05	-0.03	0.07	-		
10.Role limitations (physical problem)	0.12	0.3*	0.2*	0.2	-0.21*	0.05	0.04	0.22*	0.47*	-	
11.General health perception	0.34*	0.46*	0.39*	0.36*	-0.3*	0.23*	0.17	0.42*	0.46*	0.46*	-

Note. Bonferroni correction (α*= .05/55; p* $\leq$ 0.0009)

DISCUSSION

In this study the validity and reliability of the HHI-Dutch were assessed. It showed that, with respect to construct validity, the original three-factor structure could not be confirmed. Instead, a two-factor structure was found: factor 1: view on life and future and factor 2: self-confidence and inner strength. High correlations were found with health-related self-efficacy beliefs (MHCS), especially with optimism, with quality of life (MANSA) and with mental health (RAND-36). Moderately high correlations were found with loneliness (Loneliness Scale; a negative correlation) and task-oriented coping (CISS), as expected, but also with seeking company. According to expectation, no significant relationship was found with physical functioning, but a moderately high correlation was found with general health perception.

There are several explanations for the fact that, in the present study, as well as in most other studies that have adapted the HHI, different factor structures were found than in the original version. First, cultural differences might have been responsible for problems we encountered in the translation process. In the present study, a free translation was used for items 4 ('I can see a light in a tunnel') and 5 ('I have a faith that gives me comfort'). With respect to item 5, this was performed because religion in the Netherlands is not an integrated, natural part of daily life as it is, for instance, in the United States (39). Item 4 was translated more freely because this item otherwise might have caused primarily associations with death for respondents. In the Swedish study (14), both items were literally translated, and therefore item 5 kept a religious meaning. Those differences in the translation procedure in both studies might have caused different factor structures. In the present study, the items 4 and 5 loaded stronger on the factor that also consists of the items concerning self-confidence and inner strength. In the Swedish study (14), the items 4 and 5 formed one, separate factor, labelled 'religiosity'. A second explanation is that, for different groups of respondents, hope can have a different meaning, resulting in different response patterns. As can been seen from Table 1, four out of the six published studies on the HHI had different samples and different factor structures. The two-factor solutions differed from the HHI-Dutch factors. Nevertheless, the scale as a whole has a good internal consistency for the different populations in all studies.

Most findings in this study are corresponding with other studies. The strong relationship between hope and perceived quality of life and between hope and health-related self-efficacy beliefs is corresponding with the study of Phillips-Salimi et al. (10) and with the findings in the Norwegian study of the HHI (7). The relationship between higher levels of loneliness and

lower levels of hope was less strong, which corresponds with findings of Byrne et al. (33) and Corrigan and Phelan (1). The relationship between hope and task-oriented coping corresponds with Miller's description that hope is important in coping with, or recovering from chronic illness (34). But the present study is also showing a moderate correlation between hope and the habit to seek company. This can be explained by the importance of social relationships for people with severe mental illness. More social support can result in higher levels of hope. Herth (4) and Landeen et al. (8) describe that there seems to be no strong connection between hope and health status or stage of (somatic) illness. Findings of this study are showing no correlation with physical functioning, but a moderate correlation with general health perception. An explanation could be that there are high correlations between hope and mental health. General health has a mental and a physical component and probably the mental component is a dominating factor for people with severe mental illness.

Limitations and strengths

In discussing the results, several limitations of the present study need to be addressed. The first limitation of this study is that it was not designed as a psychometric study *per se*; for instance, three different samples were used for this study, instead of one. However, for all samples, the inclusion criteria were the same and there is no reason to believe this has affected the results. A second limitation is that the instrument was used in a sample of people with severe mental illness and there is a possibility that the use of the HHI in other groups of patients, for instance, in palliative care, could result in other conclusions. However, other studies are showing us that the instrument can be used for different groups of patients. Moreover, it can also be viewed as strength of the study that it was conducted in a population with mental health problems, because hope is an important aspect of mental health recovery. Lack of hope is a major concern in patients with mental health problems. Therefore, the HHI-Dutch could be a useful tool in clinical interventions and could also stimulate research on hope in the area of mental health. Further research of the applicability of the current form of the HHI-Dutch to various groups of people is necessary.

Conclusion

In conclusion, the HHI-Dutch has shown to be an instrument with adequate psychometric properties. The results of different studies suggest that the interpretation of subscales is difficult and it varies across the studies, but the scale as a whole has adequate psychometric properties. Therefore, it is advisable to use the scale as a whole instead of using the

subscales. Furthermore, the HHI-Dutch is appropriate for research in the recovery process of people with severe mental health problems. Its briefness and suitability for clinical use make the instrument also an appropriate tool for research and clinical interventions regarding hope in people with severe mental illness. More research on hope in this recovery process will give a better understanding of the relationship between hope and mental health recovery. It will also offer new insights into the recovery perspectives of people with severe mental illness, which is important for the development of a recovery-oriented mental health system. The results of this study may be a step forward and a new impulse to stimulate research on the important 'hope' aspect in mental health recovery.

Author contributions

Hanneke van Gestel-Timmermans, M.Sc., was first author and responsible for the data collection, the statistical analyses and the first draft of the manuscript. As co-authors, Prof. Chijs van Nieuwenhuizen, Ph.D., Evelien Brouwers, Ph.D., Joop van den Bogaard, Ph.D. †, and Kaye Herth, Ph.D. (author of Herth Hope Index) contributed by critically reviewing the paper and the statistical analyses.

Conflict of interest inserted after online publication:

No conflict of interest has been declared.

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Feasibility of the peer-run course 'Recovery is up to you' for people with major psychiatric problems

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ABSTRACT

Objective

This feasibility study was conducted to get more insight in the experiences of course instructors and participants with the peer-run course 'Recovery is up to you'. Furthermore the (dis)advantages of the course, the compliance with the course protocol and important factors in implementing the course were evaluated.

Methods

Recruitment of people with major psychiatric problems took place at 13 mental health institutions and client organisations in the Netherlands. The feasibility of the peer-run course was evaluated by semi-structured interviews and by checklists. After each course, interviews were conducted with course instructors and participants (drop-outs also) to gain information on their experiences with the course. Course instructors filled out checklists after each course session, indicating their protocol compliance, satisfaction with and opinion on process related aspects. Contents of the interviews were systematically analyzed to reveal core concepts.

Results

Participants and course instructors had very positive experiences with the course. Course instructors were important as a role model and participants felt inspired and supported by them. The course instructor, the group process (especially the openness and safety in the group) and the course material were mentioned as important factors for the recovery of participants. Course instructors adhered closely to the course material and were highly motivated.

Conclusion

The course 'Recovery, is up to you' is a promising tool, because it is easy to implement and the experiences with the course were highly positive. The written course material was clear and there were no major structural problems concerning adherence to the protocol.

INTRODUCTION

Peer-run services for people with major psychiatric problems have expanded rapidly during the past two decades, and the increasing popularity of these services illustrates the demand for this type of treatment (1, 2). Peer-provided services fit well into today's changing care for people with major psychiatric problems, which is becoming more recovery-oriented in Western countries, such as the United States, Australia and the Netherlands (3, 4). This recovery-oriented care emphasizes the potentialities of clients and it defines recovery as a process. It represents a major shift in service delivery because of its autonomy enhancing approach (4). Peer services are recovery-oriented because these services engender empowerment and are based on the principle of self-determination. The assumption of peer support is that individuals who share common experiences can provide better support and safer environments than others who have not had a history of psychiatric treatment (5). Peer providers can communicate positive regard, understanding and acceptance to clients and they may have more influence on patients' attitudes, values and behaviours than traditional health care providers (6, 7). Furthermore, being easily accessible, peer providers may engage more people with serious mental illness into receiving services, leading to greater motivation for further treatment (7, 8).

There is ample theoretical support for the beneficial effects of peer support on the recovery of individuals with major psychiatric problems. Peer support groups for instance increase social networks of participants and offer them acceptance, support, understanding, empathy, and a sense of community (9). As such, peer support enhances participant's empowerment (10). By helping one another, participants' experience increases in social status, self-esteem and self-efficacy (10, 11). Relationships are important for the recovery process and consequently it is important for participants to have the experiences of being respected the way they are (12). Moreover, the presence of role models makes participants more hopeful and optimistic about their future and stimulates them to develop their own coping and problem-solving skills (10, 13).

In spite of the theoretical support for peer-run services, limited research on the actual benefits of these services for the recovery process of people with major psychiatric problems has been conducted. Review studies showed that a consistent finding from feasibility and effectiveness studies on consumer-run services has been that consumers can adequately provide services to others with serious mental illness (9) and that their results are comparable to interventions ran by professionals (1).

Recently, it was shown that the course 'Recovery is up to you' (a peer-run, recovery-oriented service for people with major psychiatric problems) enhances empowerment, hope and self-efficacy beliefs of its participants (14). In the present study the feasibility of this course is evaluated. The purpose is to get more insight in: (a): experiences of course instructors and participants with the course, (b): the advantages and disadvantages of this peer-run service, (c): compliance of the course instructors with the protocol and (d): important factors in planning and implementing of this service.

METHOD

The feasibility study was explored as part of a larger study in which the effectiveness of the course on the recovery of participants was assessed (14). Recruitment for the study took place in the Netherlands between 2006 and 2008 at 13 mental health institutions and client organisations. In this period 38 courses were conducted. The participating sites had to meet two criteria: they had to have at least two course instructors at their disposal and they had to have one person available to support them. Prior to the start of the study, approval was obtained from the medical ethics committee for mental health institutions in the Netherlands. The trial registration number was: ISRCTN47331661.

Participants

People with major psychiatric problems were recruited by means of advertisements in free local papers, posters in hospitals, psychiatric care services and in primary care, by mental health care providers, and by fellow patients involved in the research project. Course instructors or their supervisors conducted interviews with participants on admission to the course, in order to check if the person was able to participate and to give more detailed information about the course. Inclusion criteria were: presence of serious psychiatric problems (e.g. psychosis, personality disorder, affective disorder, or anxiety disorder), being 'in recovery' after having experienced major life disruptions and being prepared to take more responsibility for one's life. Furthermore participants had to be able to discuss experiences with others. Exclusion criteria were: illiteracy, not speaking Dutch, being suicidal, having florid psychotic symptoms or major addiction problems. After complete description of the study to the participants, written informed consent was obtained. The demographic and psychiatric characteristics of the sample are presented in Table 1.

Table 1: **Demographic and psychiatric characteristics of participants and demographic characteristics of course instructors**

Demographic characteristics	Participants		Course instructors	
	N= 333	%	N=37	%
Age				
Mean age (S.D.)	44 (11)		43 (9)	
Age range	17 - 74		25-65	
Gender				
Female	220	66	27	73
Male	113	34	10	27
Nationality				
Born in the Netherlands	306	92	36	97
Different	27	8	1	3
Level of education				
Low	103	31	4	11
Middle	111	34	9	24
High	115	35	24	65
Principal daily pursuit				
Unemployed	68	21		
Study/School	10	3		
Employed part time	25	8		
Employed full time	13	4		
Volunteer work	135	41		
Housekeeping	32	10		
Living situation				
Living alone	168	51		
Living with parents	14	4		
Living with partner, child(ren)	37	11		
Living with partner, no children	26	8		
Single parent	18	5		
Hospital setting	15	5		
Sheltered living	46	14		
Hostel	2	1		
Different	6	2		
Marital status				
Unmarried	186	56		
Married/cohabiting	47	14		
Divorced	93	28		
Widowed	6	2		
Major DSM-IV-classifications				
Psychotic disorder	109	33		
Affective disorder	119	36		
Anxiety disorder	74	23		
Personality disorder	104	32		
Number of hospital admissions during the last year				
0	273	85		
1	32	10		
≥2	16	5		

Number of visits to psychologist/ psychiatrist during the last year	N	%
0-5	195	59
6-10	61	18
11-20	25	8
≥21	27	8

The course 'Recovery is up to you'

The course 'Recovery is up to you' was developed in 1996 by clients and two mental health professionals and is meant for people with major psychiatric problems. Prior to this study, the course had been given over 50 times at 12 different locations in the Netherlands, and a pilot study indicated high patient satisfaction with the course (15). The course consists of twelve weekly two-hour sessions for groups consisting of five to ten participants. Groups are led by two trained course instructors, who are in an advanced state of their recovery process and are prior course participants. They closely follow a detailed standardized manual. They receive a training-on-the-job and learn by experience while working together with experienced course instructors. All course instructors receive supervision by the national coordinator in regular meetings and by their organisation. Each organisation or institution has their own course instructors. For demographic characteristics of the course instructors: see Table 1. The participants use a standardized workbook. They get a certificate for their participation in the course if they have been present at ten sessions. [1]

Each session has the same structure and is organised around a specific recovery-related theme, following the text of the manual and workbook. These are: the meaning of recovery to participants, personal experiences of recovery, personal desires for the future, making choices about care or daily problems, setting up goals, participation in society, roles in daily life, personal values, how to get social support, abilities and personal resources, and empowerment and assertiveness. Important elements of the course are the presence of role models, psycho-education and illness management, learning from each other's experiences, social support, and homework assignments. In each session, a recovery-related theme is being discussed in a group setting, individuals share their experiences with the group, and skills are practiced. In several sessions the participants receive homework assignments.

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[1] Manual and workbook are available at: Knowledge Centre for Self-Help & Consumer Expertise (www.kenniscentrum-ze.nl).

Procedure

The feasibility of the peer-run course 'Recovery is up to you' was evaluated by semi-structured interviews and by checklists for instructors. Checklists were assembled after every four sessions of the course. The interviews were conducted by the researchers and peer research assistants at the participating sites. The peer research assistants were (ex-)patients who were specially trained in interview skills and reporting by professionals from the Knowledge Centre of Self-help and Consumer Expertise and Tilburg University. Afterwards they got trained-on-the-job and were supervised by the researchers, by evaluation meetings and by regular checks and discussions of interview reports.

Measures

Participant satisfaction and instructors' protocol adherence were measured. First, after completion of each course one course instructor and one or two participants (depending on the size of the course group) were randomly selected and interviewed to gain information on their experience with the course. In order to get a complete picture of the experiences with the course, participants who dropped-out were also interviewed. Second, the course instructors filled out a checklist after each course session, indicating their protocol compliance, their satisfaction with and opinion on process-related aspects. The items of the checklist were filled out by both course instructors on a ten-point scale, ranging from 1 (very little compliance or very negatively valued) to 10 (much compliance or very positively valued).

Data analysis

All interviews were transcribed verbatim. To increase the validity of the interview texts, these were sent back to the interviewees to check the interview contents. For data reduction the six-step coding scheme of Cresswell was used (16). Data were explored to identify concepts by grouping individual experiences with the course into categories. Furthermore, the number of categories was limited and text fragments were bundled with similar codes. Their contents were systematically analyzed to reveal the core concepts. Hence, it was possible to develop insights across the cases on experiences with the course on different topics. For the analysis of the checklists we used the mean scores on all checklists per organisation.

RESULTS

In the 38 courses, the mean number of participants was 7 (SD 2.1; range 3-12). The mean number of drop-outs per course group was 2 (SD 1.2; range 0-4). The mean number of attended sessions was 9 (SD 3.3; range 1-12). Main reasons for drop-out were personal or family problems, mental or other illness, unmet expectations of the course or not being prepared to participate in the course. Of about 40 % the reason for drop-out was unknown.

The results of the interviews and checklists are presented below. First, the results of interviews with a total of 61 participants are presented. Second, the results of interviews with 37 course instructors are presented (one course was not evaluated) and the results of the checklists, which were filled out by all course instructors (two courses were not evaluated).

Participants' opinions and experiences with 'Recovery is up to you'

The main reasons why people enrolled in the course were that they wanted to learn about themselves and their recovery process, to share experiences, to work on their social contacts and because the course appealed to them. About 80% of the respondents reported that the course had met their expectations. Participants spontaneously expressed that they had learned about themselves, their specific needs, their social contacts and their influence on their personal recovery. About 30% of the participants had learned to stand up for themselves, make choices, set goals and take steps to achieve their aims. About 25% of the participants spontaneously mentioned that their self-confidence had increased, and a smaller group was planning to improve their social contacts. Nevertheless, a few participants were disappointed as they had expected to be cured after the course. To them, the difference between recovery and cure had not been clear and as a result they had expected to be cured after the course.

More than 90% of the participants were inspired and felt supported by the course instructor. The fact that the course was peer-led created openness in the group and made it easy for participants to talk about their own situation. About one fifth of the participants explicitly mentioned that the course instructor acted as a role model and more than a quarter of the participants spontaneously mentioned the course instructor as a stimulating factor for their active participation in the course and for their recovery process.

Concerning the group process, the majority of the participants indicated to have received social support (over 80 %) and personal attention (over 60%) from other participants. About half of the participants experienced safety, openness and acceptation in the group and strong ties with other participants. Safety and openness were also (spontaneously) mentioned as stimulating factors for active participation in the group and the recovery process by one third

of the participants. Social support, being understood by other participants and the course material were mentioned less frequently. About one third of the participants mentioned not to have had enough opportunity to speak, because of dominant peers in the group. Some participants knew that they had difficulty with taking part in conversations, but they did not inform the course instructor about this. Nevertheless, about 80% of the participants judged their own participation as active.

Organisational aspects were also judged very positively. The majority of the participants (more than 85%) was satisfied about all organisational aspects: information about the course, topics, the workbook and other materials and the duration of the course. Participants appreciated the variation in assignments. Also a majority (two third) of the participants was satisfied about duration and location of the meetings and about the presentation, attention and guiding capacities of the course instructor (more than 80 %).

More than half of the participants mentioned ways to improve the course. A more in depth discussion of the course topics was mentioned by about one fifth of the participants. Some participants would have liked to learn more about recovery related themes not included in the course, such as use of medication and social relationships. Note: Drop-out participants were also interviewed, but they did not mention specific problems with the course.

Course instructors' opinions and experiences with 'Recovery is up to you' and results of checklists

Course instructors judged the organisational aspects positively and only mentioned a few problems. More than half of the course instructors mentioned that the recruitment and intakes of participants were time consuming and about 40% was not satisfied about the use of different rooms for one course and about disturbing noises. Nevertheless, the course instructors were satisfied about almost all organisational aspects.

Most course instructors were satisfied about their own guidance as a course instructor. Over 95 % of the course instructors mentioned that they were able to stimulate and guide the group process properly and judged their conversational skills and ability to cope with emotions within the group as sufficient. Course instructors indicated the ideal group size to be about seven or eight participants.

The checklists showed high protocol adherence and no major problems. In Table 2, the results of the checklists are presented. The mean adherence to the structure of the sessions was high: 8.6 (SD 1.4; range 1-10), as was adherence to the course content per session: 8.8 (SD 1.2; range 1-10). The large range in scores indicates that occasionally course instructors

were less satisfied with: reaching the goals of the session, investment of time on each part of the session, leading capacities and disturbing factors (mostly noises). Generally, the atmosphere in the groups was judged as positive (mean: 8.8; SD 1.1; range 4-10). The interviews also showed minor structural problems with the protocol among about one sixth of the course instructors. These problems were that some participants needed more time than available for filling out tables, course instructors sometimes had problems with the explanation of a topic and with the program of the last session, which was too large. Nevertheless, these problems arose occasionally.

Table 2: Average scores on all checklists (and Standard Deviations) for different institutes of mental health care (IMHC) and client organisations (CO)*

	IMHC 1	IMHC 2	IMHC 3	IMHC 4	CO 1	IMHC 5, location 1	IMHC 5, location 2	IMHC 6	IMHC 7	IMHC 8, location 1	IMHC 8, location 2	IMHC 9	CO 2	CO 3 **	IMHC 10**
Protocol adherence															
Kept to structure of session	8.3 (0.9)	9.2 (0.5)	8.8 (0.4)	9.7 (0.8)	8.2 (1.6)	8.1 (1)	9 (2)	7.2 (2)	8.9 (0.8)	7.7 (0.7)	8.7 (0.5)	8.7 (0.8)	9.8 (0.5)	7.1 (0.7)	7.3 (2.9)
Kept to content of session	8.6 (0.8)	9.3 (0.4)	8.9 (0.3)	9.7 (0.6)	9.3 (0.5)	8.1 (0.9)	9.2 (1.5)	7.4 (2)	9.4 (0.8)	7.7 (0.9)	8.7 (0.8)	8.7 (0.7)	9.3 (1.5)	7.8 (1.1)	8.4 (2.2)
Met the goals of the session	8.5 (0.8)	9.0 (0.7)	8.3 (0.5)	9.8 (0.4)	9.3 (0.5)	8.5 (0.9)	8.4 (0.8)	7.7 (1.6)	8.9 (1.1)	7.9 (0.7)	8.7 (0.8)	8.2 (1.1)	9 (0.8)	7.9 (1)	9.2 (1.6)
Judgement of group process															
Atmosphere within group	8.4 (1.1)	9.8 (0.4)	8.8 (0.4)	9.7 (0.8)	9.1 (0.7)	8.4 (1.1)	8 (0.9)	8.9 (0.8)	9.1 (1.1)	7.3 (0.9)	8 (0.7)	8 (1.2)	9 (0.8)	7.8 (1)	9.2 (0.9)
Social relationships within group	8.3 (1)	9.8 (0.4)	8.8 (0.5)	9.8 (0.6)	9.4 (0.5)	8 (1)	8.3 (0.9)	8.8 (0.7)	9.3 (1.1)	7.4 (0.7)	8 (0.6)	7.9 (1.2)	9.1 (0.7)	7.5 (0.9)	9.8 (0.4)
Social support within group	8.1 (1.1)	9.7 (0.5)	8.6 (0.7)	9.8 (0.5)	9.3 (0.6)	7.5 (0.9)	8.1 (0.8)	8.4 (0.8)	9 (1.3)	7.5 (0.9)	8.2 (0.6)	7.9 (1.3)	9.1 (0.9)	7.4 (0.8)	9.9 (0.3)
Openness within group	8.3 (0.8)	9.7 (0.5)	8.6 (0.7)	9.8 (0.4)	9.5 (0.5)	8.2 (1)	7.8 (0.7)	8.5 (0.7)	8.9 (0.9)	7.3 (0.6)	8.1 (0.8)	8.2 (1.1)	9.3 (0.7)	7.2 (1)	9.5 (0.8)
Course instructor's abilities															
Investment of time on each part of the session	8 (1.2)	8 (0.8)	8.3 (0.4)	9.5 (0.9)	8.9 (1.1)	7.6 (1)	6 (2)	8 (1.4)	8.2 (1.3)	7.4 (1.2)	8.4 (0.5)	8.7 (0.5)	8.8 (1.5)	7.3 (1.3)	7.7 (2.5)
Equal contribution of participants	7.6 (1.2)	8 (0.7)	8.2 (0.5)	9.3 (0.9)	8.8 (0.8)	7.2 (0.7)	6.7 (1)	7.7 (1)	8.6 (1.2)	7.2 (0.8)	7.5 (0.8)	8 (0.7)	8.7 (0.9)	6.2 (1)	9.3 (1)
Cope with emotions	8.2 (1)	9.3 (0.7)	8.7 (0.5)	9.8 (0.5)	9.4 (0.5)	8.7 (0.9)	7.6 (0.9)	8.3 (0.9)	9.2 (1)	7.2 (0.8)	8.7 (0.5)	8.5 (0.7)	9 (0.9)	7.3 (1)	9.4 (0.8)
Listen	8.4 (0.7)	9.3 (0.5)	8.7 (0.5)	9.7 (0.5)	9.3 (0.7)	9 (0.9)	8.2 (0.7)	8.5 (0.8)	9.5 (0.7)	7.3 (1)	8.4 (0.5)	8.6 (0.7)	9.2 (0.8)	6.9 (1.4)	9.6 (0.7)
Leading capacities	8.1 (0.8)	9.1 (0.8)	8.8 (0.4)	9.7 (0.6)	9.4 (0.6)	8.7 (1.1)	7.1 (0.9)	8.1 (0.9)	9.2 (0.9)	7.1 (1)	8.1 (0.7)	8.5 (0.6)	9.2 (0.6)	6.2 (0.4)	8.8 (1.3)
Intervene	8.1 (0.8)	9 (0.8)	8.2 (0.5)	9.6 (0.7)	9 (0.6)	8.7 (0.8)	6.9 (0.9)	8 (1)	8.3 (1.1)	7.1 (1)	8.3 (0.5)	8.3 (0.9)	9.2 (0.8)	7 (0.7)	8.7 (1.2)
Social support	8.1 (0.9)	9.4 (0.5)	8.8 (0.5)	9.7 (0.5)	9.3 (0.5)	8.7 (0.9)	7.1 (0.9)	8.1 (0.6)	8.7 (1.1)	7.3 (0.9)	8.4 (0.5)	8.5 (0.7)	9 (1)	7.2 (1)	9.5 (0.8)
Course instructor's satisfaction about															
Disturbing factors	7.8 (1.5)	7.9 (0.8)	8 (0.5)	8.9 (1.2)	9.3 (0.7)	7.4 (0.7)	8.7 (0.7)	7.3 (1.4)	9.5 (0.7)	7.2 (0.8)	8.9 (0.5)	9.3 (1.1)	9.5 (0.9)	7.5 (1.2)	6.5 (2.7)
Total course	7.9 (1.8)	9 (0.9)	8.9 (0.3)	8.9 (1.4)	9.1 (0.8)	8.2 (1.4)	8.6 (0.5)	8.8 (1.1)	7.2 (2.5)	7 (1.3)	8.1 (0.5)	9 (0.7)	9.1 (1.3)	4.7 (1.3)	8.4 (2.1)

* Scales ranged from 1 (for instance: very little compliance or very negatively valued) to 10 (for instance: much compliance or very positively valued)
** All organisations filled out every checklist except for the marked ones; they filled out only 50% of the checklists

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DISCUSSION

In general participants and course instructors had very positive experiences with the course. For participants, the course instructor, the group process and the course material were important factors for their recovery. Course instructors had been important as a role model and participants felt inspired and supported by them. Furthermore, especially the openness and safety in the group were mentioned as important factors for recovery. The course material and social support were also mentioned. The course instructors adhered closely to the course protocol and were highly motivated.

The present study showed that participants highly appreciated peers as course instructors because they created openness and inspired them. Prior studies also showed that the atmosphere of non-judgemental acceptance (5, 17) and the positive regard, understanding and acceptance in the relationship of peer providers with clients (7) are valued elements of peer-support. A consistent theme in the recovery narratives about professionals is reciprocity (18). Patients want empathic, collaborative and mutually trusting relationships with their provider (19). Furthermore, participants have stated repeatedly that peer-run services changed their lives (9, 21) and are a cornerstone of recovery-oriented care (1, 2). The group process (sharing experiences and social support) was also mentioned as a promoting factor for the recovery of participants. In prior studies role models, sharing experiences and social support are mentioned as critical ingredients of peer support (1, 9, 10, 20). Furthermore participants valued the course material as important for their recovery. Important elements of the course are psycho-education and illness management, which are well-known and evidence-based methodologies (22).

The course is easy to implement because of the available structured workbook and manual. Nevertheless, in this study several points of interest arose concerning the implementation of the course. First, participants need a safe environment. A quiet course room is required, which is available for every session of the course and located in an easily accessible (threshold-free) building. Second, to avoid drop-out and disappointment, a systematic intake of participants is recommended, to inform participants about the goals of the course (for example no in depth discussion of the course topics) and the meaning of recovery. Another issue is that course instructors are advised to be very attentive to the problems of introvert participants and that participants have to feel at ease in the group. Finally, support of the course instructors will contribute to a good progression of the course. This support can be given by their supervisor as well as by a coach from a coordinating centre, such as the Knowledge Centre of Self-help and Consumer Expertise.

In discussing the results of the study, several issues need to be addressed. First, all subjects participated on a voluntary basis and therefore they were highly motivated, which may partially explain the high satisfaction with the course. Course instructors were also highly motivated. Both factors might have influenced the positive results. Nevertheless, drop-out participants were also interviewed, but they did not mention specific problems with the course. Another issue is that at present, the course is only available in Dutch. However, adaptations of the course material in other languages are in preparation. Finally, although the course is easy to implement and a prior study showed its effects, further research has to show which elements of this course and other peer-run services are important for the recovery process of participants.

Conclusion

The course 'Recovery, is up to you' is easy to implement and the experiences of both participants and course instructors with the course were highly positive. The written course material was clear and there were no major structural problems concerning adherence to the protocol. The course is a promising tool because a recent study showed its effects, it is recovery-oriented and peer-run, and because it could provide an opportunity for many people, whether or not able to gain access to the mental health system, to make an active start in their recovery process.

Declaration of interest

None, except for the first author. At the time of the study, she was employed at the centre which coordinates the course.

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Effects of a peer-run course on the recovery of people with major psychiatric problems: a randomised controlled trial

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Submitted

ABSTRACT

Objective

Research on the effectiveness of peer-run services on the recovery of people with major psychiatric problems has been limited and poorly controlled. In the present study, the effects of a peer-run course on recovery are evaluated.

Methods

Recruitment of people with major psychiatric problems took place in the Netherlands between 2006 and 2008. The effects were evaluated in a Randomised Controlled Trial (RCT) design. A total of 333 people were randomized to the experimental condition (N=168) or control condition (N=165). Assessments took place at baseline, after 3 months (i.e. at the end of the course) and after 6 months. Data were analyzed using multilevel analysis.

Results

After three months, participants in the experimental group had significantly higher scores on key elements of recovery: empowerment, hope and self-efficacy beliefs. There was evidence for a weak positive effect on quality of life, task-oriented coping and general mental health and a weak negative effect on emotion-focused coping. There were no effects on physical health, loneliness and avoidant coping. The effects of the intervention persisted three months after finishing the course. Similar results were found for those initially placed on a waiting list (control condition) when they participated in the course six months later.

Conclusion

The findings imply that the peer-run course contributes to the improvement of important domains of recovery. Peer-run services, such as 'Recovery is up to you', are of added value for recovery-oriented mental health care because they offer participants an opportunity to make an active start with their recovery.

Keywords: Randomized Controlled Trial, recovery, peer-run services, peer support, major psychiatric problems.

INTRODUCTION

In the 1980's, a new point of view on recovery emerged in psychiatry, based on the consumer's perspective (1). Here, the focus is not on traditional (medical) outcome, but on individually defined and more subjective constructs such as personal growth, hope, and autonomy (2). At present, little research has been conducted on how such recovery can be achieved or promoted.

   A potentially powerful tool to enhance the recovery of people with major psychiatric problems is peer support. Several studies showed that peer support improves symptoms, reduces hospitalizations, offers hope, facilitates coping and increases social networks and quality of life in people with severe psychiatric disorders (3-6). Peers also have the potential to engage people with serious mental illness into receiving services (7). Moreover, the majority of people with mental disorders do not get professional help while many of them need this care (8).

   Peer-run services have expanded rapidly during the past two decades (9, 10), and the increasing popularity of these services illustrates the demand for this type of intervention. Despite their advantages, peer-run services are still not common as a mental health service and research on the effectiveness of for instance self-help groups has been limited and poorly controlled (9, 11, 12).

   The aim of the present longitudinal study was to evaluate the effects of a peer-run course on the recovery of people with major psychiatric problems using a RCT design. To operationalize recovery, proxy measures were used, i.e.: empowerment, hope, quality of life and self-efficacy beliefs. In addition, loneliness, coping and generic health status (mental health and physical health) were assessed. The hypothesis was that the course would result in higher levels of recovery, except for physical health.

METHOD
Participants

   Recruitment took place in the Netherlands between September 2006 and July 2008. People with major psychiatric problems were recruited by means of advertisements in free local papers, posters in hospitals, psychiatric care services and in primary care, by mental health care providers, and by fellow clients involved in the research project. There were two inclusion criteria: suffering from major psychiatric problems (e.g. psychosis, personality disorder, affective disorder, or anxiety disorder), and reporting to have been through very

disruptive times in life from which the person was recovering. Exclusion criteria were: illiteracy, not speaking Dutch, being suicidal, having florid psychotic symptoms and/or major addiction problems. Demographic and psychiatric characteristics are presented in Table 1.

Table 1: Demographic and psychiatric characteristics of the experimental and control condition at baseline

Demographic characteristics	Total experimental condition N=168		Total control condition: N=165	
	N	%	N	%
Age				
Mean age (S.D.)	43 (11)		44 (10)	
Age range	19 - 74		17 - 71	
Gender				
Female	114	68	106	64
Male	54	32	59	36
Nationality				
Born in the Netherlands	151	90	155	95
Different	17	10	8	5
Level of education				
Low	52	31	51	31
Middle	63	38	48	30
High	52	31	63	39
Principal daily pursuit				
Unemployed	30	18	38	23
Study/School	5	3	5	3
Employed part time	16	10	9	6
Employed full time	7	4	6	4
Volunteer work	64	38	71	43
Housekeeping	20	12	12	7
Living situation				
Living alone	73	44	95	58
Living with parents	10	6	4	2
Living with partner, child(ren)	20	12	17	10
Living with partner, no children	11	7	15	9
Single parent	12	7	6	4
Hospital setting	9	5	6	4
Sheltered living	27	16	19	12
Hostel	1	1	1	1
Different	5	3	1	1
Marital status				
Unmarried	90	54	96	59
Married/cohabiting	25	15	22	13
Divorced	49	29	44	27
Widowed	4	2	2	1
Major DSM-IV-classifications [*]				
Psychotic disorder	48	29	61	38
Affective disorder	61	37	58	36
Anxiety disorder	34	20	40	25
Personality disorder	56	34	48	30
Number of hospital admissions during the last year				
0	137	85	136	86
1	17	10	15	9
≥2	8	5	8	5
Number of visits to psychologist/ psychiatrist during the last year				
0-5	96	61	99	65
6-10	39	25	22	15
11-20	7	4	18	12
≥21	15	10	12	8

[*]These were self-reported DSM-IV classifications; participants could have reported more than one diagnosis

Procedure

Assessments took place at 13 different mental health care institutions and patients' associations across the Netherlands. When the study was explained (verbally and in writing), written informed consent was obtained from each participant. At baseline, participants were randomly allocated to the experimental or control condition. Researchers and research assistants were blinded for the condition of the participants by assigning numbers to the questionnaires. Data were gathered at baseline (T0), after 3 months (T1) and after 6 months (T2) for both conditions. Participants in the experimental condition started the course within one week after randomization at T0, and completed the course after three months at T1. Participants in the control condition were placed on a waiting list and enrolled in the course after T2. Data for the control condition were also gathered 3 (T3) and 6 (T4) months after the start of their course. This way, the effect of the intervention could be evaluated by (a) comparing recovery in the experimental and control condition at T1, (b) assessing whether a potential difference in recovery between the two conditions would persist three months after the course at T2, and (c) assessing recovery longitudinally in the control condition from T0 to T4.

Participants from the experimental and control condition were both free to participate in other recovery related activities and continued their treatment as usual. All participants were remunerated with € 7,50 for each assessment. Prior to the start of the study, approval was obtained from the medical ethics committee for mental health institutions in the Netherlands. The trial registration number was: ISRCTN47331661.

Intervention

The course 'Recovery is up to you' was developed in 1996 by clients and two mental health professionals. It consists of twelve weekly two-hour sessions. Groups were led by two trained course instructors who were in an advanced state of their recovery process and were prior course participants. They closely followed a detailed standardized manual.

Each session had the same structure and was organized around a specific, recovery-related theme, following the text of the manual and workbook. Examples of themes were: personal experiences of recovery, making choices about care or daily problems, and getting social support. The participants used a standardized workbook and received homework assignments. Important elements of the course were the presence of role models, psycho-education and illness management, learning from each other's experiences, social support, and homework assignments. In each session, themes were discussed in a group setting,

individuals shared experiences with each other, and skills were practiced. To assess protocol adherence of the course instructors in the study, they were asked to fill out a checklist after each session.

Outcome measures

The primary outcome measure was recovery. Because no Dutch instrument for the assessment of recovery was available, four self-report instruments were used to measure key elements of recovery: hope, quality of life, self-efficacy beliefs and empowerment (1, 13, 14). Secondary outcome measures were generic health status (mental health and physical health), loneliness and coping (task-oriented, emotion-focused and avoidant coping).

To assess *hope* the Herth Hope Index (HHI) was used (15, 16). *Quality of life* was assessed using the 12 subjective items of the Manchester Short Assessment of Quality of Life (MANSA) (17, 18). *Self-efficacy beliefs* were measured with the Mental Health Confidence Scale (MHCS) (19, 20). *Generic health status* was measured with the SF-36 (21-23). In the present study, the *Mental Component Scale* (MCS) and *Physical Component Scale* (PCS) were used (21). *Loneliness* was assessed using the Loneliness Scale (24-26). *Coping* was measured with the Coping Inventory for Stressful Situations (CISS) (27, 28). In the present study, the three main scales (Task-oriented coping, Emotion-focused coping and Avoidance) were used. All aforementioned instruments are well-known and have good psychometric properties. Finally, *empowerment* was assessed using a newly developed instrument, the Dutch Empowerment Scale (29).

On all instruments higher scores indicate more recovery, except for loneliness, coping and physical health. Here, higher scores indicate higher loneliness, increased coping behaviour, and better physical health. In the present study, we used the mean score on the scale or subscale as dependent variables in the analyses. The average Cronbach's alpha at T0 to T4 was sufficient: .83 for HHI, .88 for MANSA, .93 for MHCS, .91 for MCS, .91 for PCS, .92 for Loneliness scale, .91 for Task-oriented coping, .89 for Emotion focused coping, .82 for Avoidance and .94 for the Dutch Empowerment Scale.

Statistical analysis

Preliminary analyses

Means and standard deviations were calculated for all dependent variables on all occasions, for both conditions. Cohen's *d* (30) was calculated and the corresponding one-tailed independent- and dependent samples *t*-tests were performed, in order to assess the effect of

the course at T1 and for the control condition at T3, and to assess the persistence of the effect three months after the course at T2 and for the control condition at T4. Power analysis indicated that at least 50 participants in each condition were needed to obtain a power of .8, assuming no dependence of observations within the same course group, a small effect size of $d = .2$ and an alpha of .05.

Multilevel analyses

Multilevel analysis was used to analyze within and between individual differences in recovery scores over time (31). The main independent variables were condition (experimental or control condition) and time of measurement. In addition, the effects of educational level, gender, and marital status were tested. To increase statistical power, equal averages of recovery were assumed at T1 and T2 and at T3 and T4, since the d values at these occasions indicated that the effects of the course persisted for at least three months (see Table 2a and 2b).

The effect of the peer-run course on each of the ten dependent variables was tested by two different multilevel analyses. In the first multilevel analysis, both a random intercept and random slope model were estimated on the data of T0 to T2. The random intercept model assumes that participants differ on recovery at baseline, but that the effect of the intervention is the same for all who received it. The random slope model allows for inter-individual variation in improvement of recovery in the experimental condition. In the second multilevel analysis, because of insufficient data, only a random intercept model could be estimated using the data at T0 to T4 of participants of the control condition.

Course group was not included as an additional level in the analyses since it explained only up to six percent of the total variance of a recovery measure. Data of all participants who had a value on the dependent variable on at least one occasion were included in the analyses. The multilevel analyses were carried out using maximum likelihood of the procedure MIXED of SPSS 17.0.

RESULTS
Therapy participation

In total, 38 separate courses were given at 13 different locations across the Netherlands. Each location had its own course instructors. The mean number of individuals per course group was 7 (SD=2.1; range 3-12). The mean number of attended sessions by individuals in

the experimental group was 9.0 (SD=3.3; range 1-12). Results of the checklists indicated that the course instructors' mean adherence to the protocol was high (32, 33).

Of all 333 people that participated in the study, 168 were randomized to the experimental condition (see Figure 1). Chi-square tests of independence and *t*-tests showed no significant differences between the two conditions at baseline on demographic and psychiatric characteristics. Sample size at T3 and T4 was smaller because many participants dropped out and a minimum of 5 per group was required.

4
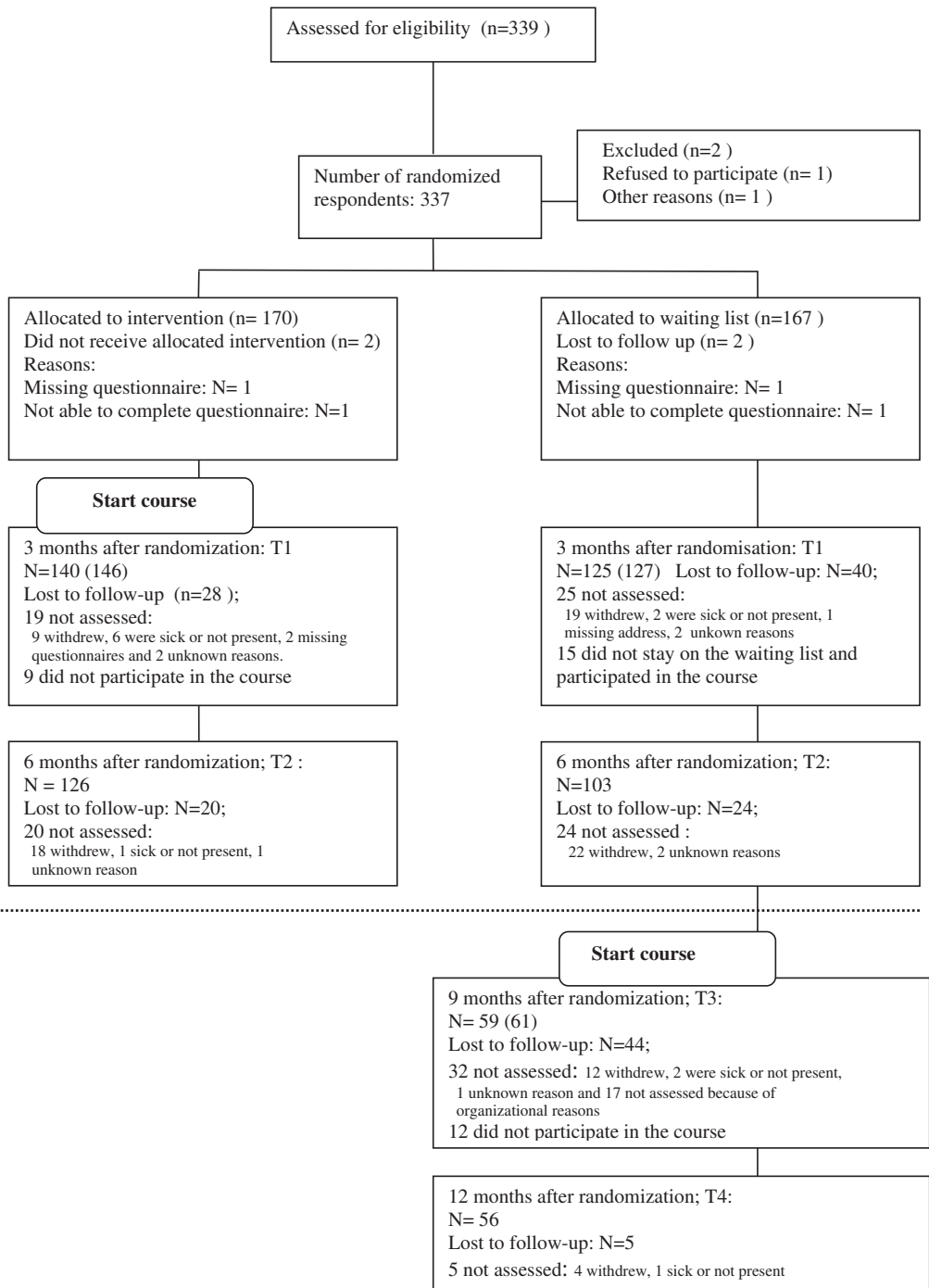
Figure 1: **Flow chart of respondent numbers at each moment; the assessments at T3 and T4 below the dotted line were for additional information**

Preliminary analyses

The means, standard deviations and sample sizes for all dependent variables on all occasions are shown in Table 2a and 2b. On average, the correlation between scales was .38, .35, .43, .43 and .41 for T0 to T4, respectively. The results of the *t*-tests suggest that there was an effect of the peer-run course on empowerment, hope, and self-efficacy (see columns corresponding to T1 in Table 2a and T3 in Table 2b, respectively), and that this effect persisted after three months (see columns corresponding to T2 and T4 in Tables 2a and 2b, respectively). Cohen's *d* indicates that the effect of the treatment was small to moderate on empowerment, hope, self-efficacy beliefs and task-oriented coping, small on quality of life, and small or absent on loneliness, mental health, emotion-focused coping, avoidance and physical health. Finally, the similar *d* values at T1 and T2 and T3 and T4 suggest that if there was an effect then it persisted after three months.

After dealing with missing values, 920 observations remained of in total 327 subjects. On these data, all multilevel analyses were carried out.

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Table 2a: **Mean (SD), sample size, Cohen's d and significance of one-tailed t-tests for all dependent variables in the intervention and control condition for T0 to T2** [1,2]

Outcome measures	T0		T1		T2	
	Intervention	Control	Intervention	Control	Intervention	Control
Empowerment	**3.40** (.49) N=155	**3.37** (.51) N=152	**3.55** (.48) N=136 d = .32**	**3.38** (.53) N=117	**3.59** (.50) N=121 d = .38**	**3.40** (.56) N=99
Hope	**2.78** (.47) N=157	**2.76** (.48) N=151	**2.91** (.47) N=132 d = .26*	**2.79** (.53) N=118	**2.97** (.46) N=120 d = .50***	**2.73** (.48) N=97
Quality of life	**4.32** (.88) N=153	**4.23** (1.00) N=151	**4.49** (.96) N=124 d = .13	**4.36** (1.07) N=114	**4.63** (.97) N=111 d = .24*	**4.39** (1.05) N=97
Self- efficacy beliefs	**4.38** (.82) N=161	**4.33** (.89) N=152	**4.65** (.81) N=134 d = .33**	**4.35** (.97) N=116	**4.71** (.93) N=121 d = .35**	**4.40** (.88) N=100
Loneliness	**6.40** (3.56) N=166	**6.87** (3.40) N=161	**5.89** (3.61) N=138 d = .11	**6.27** (3.55) N=122	**5.45** (3.87) N=125 d = .28*	**6.49** (3.68) N=102
Task- oriented coping	**3.19** (.69) N=166	**3.17** (.73) N=163	**3.00** (.71) N=140 d = .20	**2.86** (.71) N=124	**3.01** (.73) N=126 d = .22*	**2.86** (.61) N=103
Emotion- focused coping	**2.82** (.67) N=166	**2.76** (.69) N=163	**2.43** (.67) N=140 d = .13	**2.52** (.72) N=124	**2.34** (.71) N=126 d = .15	**2.45** (.72) N=103
Avoidant coping	**2.64** (.66) N=166	**2.67** (.69) N=163	**2.48** (.61) N=140 d = .20*	**2.35** (.67) N=124	**2.44** (.58) N=126 d = .12	**2.37** (.67) N=103
Mental health	**34.4** (12.1) N=164	**34.9** (12.9) N=162	**35.3** (13.8) N=129 d = .05	**36.4** (13.2) N=131	**38.7** (13.2) N=126 d = −.09	**37.1** (12.3) N=102
Physical health	**48.0** (10.5) N=164	**47.8** (10.6) N=162	**48.8** (11.0) N=129 d = −.03	**47.4** (10.6) N=131	**48.3** (9.7) N=126 d = −.14	**47.6** (10.2) N=102

[1] *$p < .05$; ** $p < .01$; *** $p < .001$.
[2] Independent-samples t-tests were performed for T1 and T2 by comparing means in the experimental and control condition at the same occasion. Cohen's d corresponding to these t-tests are also reported, but not for T0. Cohen's d is positive if its value is in the expected direction.

Table 2b: **Mean (SD), sample size, Cohen's d and significance of one-tailed t-tests for all dependent variables in the control condition for T3 and T4** [1,2]

Outcome measures	T3 Control condition	T4 Control condition
Empowerment	**3.50** (.45) N=57 **d = .33**[**]	**3.49** (.47) N=54 **d = .53**[***]
Hope	**2.89** (.46) N=53 **d = .51**[***]	**2.81** (.51) N=51 **d = .25**[*]
Quality of life	**4.51** (1.03) N=55 **d = .22**	**4.60** (1.09) N=51 **d = .42**[**]
Self- efficacy beliefs	**4.58** (.84) N=55 **d = .30**[*]	**4.56** (.87) N=55 **d = .33**[**]
Loneliness	**6.05** (3.75) N=59 **d = .06**	**6.16** (4.08) N=56 **d = −.02**
Task- oriented coping	**2.96** (.80) N=58 **d = .19**	**2.98** (.79) N=55 **d = .27**[*]
Emotion- focused coping	**2.35**(.70) N=58 **d = .16**	**2.41** (.69) N=55 **d = .01**
Avoidant coping	**2.41**(.74) N=58 **d = .10**	**2.40** (.66) N=55 **d = .19**
Mental health	**38.9** (12.1) N=57 **d = −.09**	**38.5** (13.2) N=55 **d = −.05**
Physical health	**47.7** (9.7) N=57 **d = −.03**	**47.0** (10.6) N=55 **d = .05**

[1] [*] $p < .05$; [**] $p < .01$; [***] $p < .001$.
[2] Dependent-samples *t*-tests were performed for T3 and T4 by comparing the mean at these occasions with the mean at occasion T2 in the control condition. Cohen's *d* corresponding to these t-tests is also reported. Cohen's *d* is positive if its value is in the expected direction.

4

Multilevel analyses: differences between experimental and control condition

In Table 3, the second column presents the change in recovery on the dependent variables for the control group. These results indicate that quality of life and loneliness improved significantly and all forms of coping decreased significantly without intervention in the control condition. The third column compares the effects for the control and experimental condition and shows that the experimental condition improved significantly more than the control condition on empowerment, hope, self-efficacy beliefs, task-oriented coping and emotion-focused coping. For instance, the .136 for empowerment signifies that the average empowerment at T1 and T2 combined is .136 higher in the experimental condition than in the control condition in the same period (and .026 + .136 higher than at baseline). No difference in improvement for the two conditions was observed for quality of life, loneliness, avoidant coping, mental health, and physical health.

The intra-class coefficients were high for the MCS and PCS scales (.38 and .40, respectively) and very high for the other scales (from .69 for the HHI and MHCS to .75 for the MANSA). Some of these large individual differences could only be explained for physical health, but not for the other dependent variables. Finally, individual differences in the effect of the intervention on recovery were only observed for self-efficacy beliefs, and task-oriented and avoidant coping. None of these individual differences could be explained by demographic variables.

Multilevel analyses: effect of the intervention in the control condition only

The last column of Table 3 shows the change in average recovery between the two periods T3 to T4 and T0 to T2. The average score was higher on empowerment, hope, quality of life, self efficacy beliefs, and mental health and lower on emotion-focused coping after they participated in the course than before. No effect of the intervention was observed on loneliness, task-oriented coping, avoidant coping, and physical health. Values of intra-class coefficients were similar to those of the analysis on the first three occasions. Agreeing with the results on T0 to T2, only effects of the control variables were found on physical health. The observed effects were similar as well.

Table 3: **Results of multilevel analyses on the effect of the intervention on all recovery variables [a]**

Outcome measure	Change in recovery in control condition (S.E) at T1 and T2 [b]	Difference in change in recovery between experimental and control condition at T1 and T2 (S.E) [c]	Change in recovery between the periods T3 toT4 and T0 to T2 in control condition (S.E) [c]
empowerment	.026 (.030)	.136 (.039)[***]	.154 (.033)[***]
hope	.019 (.028)	.142 (.038)[***]	.111 (.033)[***]
quality of life	.114 (.054)[*]	.106 (.072)	.257 (.064)[***]
self-efficacy beliefs	.082 (.096)	.247 (.069)[***]	.220 (.062)[***]
loneliness	−.470 (.20)[*]	−.311 (.27)	−.220 (.213)
task-oriented coping	−.284 (.040)[***]	.137 (.055)[**]	.013 (.053)
emotion-focused coping	−.320 (.040)[***]	−.101 (.053)[*]	−.170 (.050)[***]
avoidant coping	−.274 (.037)[***]	.080 (.053)	−.065 (.048)
mental health	1.35 (1.00)	1.47 (1.25)	2.41 (1.15)[*]
physical health	.036 (.79)	.757 (.99)	−.124 (.91)

[a] [*] $p < .05$; [**] $p < .01$; [***] $p < .001$.
[b] two-tailed test, since no change in a particular direction was expected.
[c] one-tailed test, since an improvement as a result of the course was expected.

DISCUSSION

In this study, the effects of a peer-run course on recovery were longitudinally assessed in a large group of people with major psychiatric problems in a randomized controlled trial. Confirming our hypothesis, we found a positive effect of the peer-run course on participants' empowerment, hope and self-efficacy beliefs. Moreover, there was evidence for a weak positive effect on quality of life, task-oriented coping and mental health, and a weak negative effect on emotion-focused coping. There were no effects on physical health, as expected, but also no effects on loneliness and avoidant coping.

The main effects of the course on important elements of recovery, empowerment, hope and self-efficacy beliefs, are comparable to the results of two recent studies. Both studies also assessed the effects of a 12-week peer-run intervention based on a recovery workbook. A Canadian RCT (N=33) (34) showed effects on hope, empowerment and recovery and no effect on quality of life. Another study (N=47) (35), showed improvement on self-esteem, self-efficacy, spiritual well-being, social support and psychiatric symptoms. Furthermore, other studies on peer-run services and self-help groups have found similar results (10, 19, 36, 37). Several factors can explain the effects found in the present study: the presence of role models, sharing of personal experience in dealing with serious mental illness (4, 6, 9, 37) and also the elements of psycho-education and illness management in the course, which are well-known evidence-based methodologies (38). Furthermore, peer education, peer support and a clear structure of the intervention are common elements in peer-run interventions with similar results.

As mentioned, there was evidence of a weak positive effect on quality of life and general mental health. The small effects on quality of life may be judged as significant for the practice of psychiatry and justify wider use of an intervention (39). The weak effect on general mental health can be explained by the fact that the mental component of the SF-36 might be too generic. The intervention only had an effect on vitality and mental health. General mental health also comprises other components that were not affected by the course, such as social functioning and role limitations due to emotional problems.

As expected, there was evidence for a weak negative effect of the course on emotion-focused coping and a weak positive effect on task-oriented coping. The unexpected finding that task-oriented coping decreased in the experimental condition is supported by a review study on clinical use of coping in affective disorder (40). This study showed a gap between

coping theory and clinical use of coping, because of the complex interaction between life stressors, coping, personality and affective disorders.

No effects were found on loneliness, while one would expect loneliness to decrease after participation in the course. This was not the case, probably because it takes a longer time to develop social networks, as was also found in other studies on self-help groups and peer support (5, 6).

This study also showed that the control condition improved significantly between T0 and T2 on quality of life and loneliness. Reasons for these changes could be a statistical phenomenon known as 'regression to the mean', and anticipated treatment.

In discussing the results, several limitations of the present study need to be addressed. Methodologically, the absence of an attention placebo control condition in order to identify an attention effect in the experimental group (Hawthorne effect (41)) is a limitation of the study. However, it is unlikely that this effect is responsible for the positive effects found, because these effects were found only on a few outcome measures, and persisted for at least three months. A second methodological limitation is that, due to missing data of 24 participants, we could not perform an intention-to-treat analysis (42). By mistake, only baseline data of these participants, who did not comply with the randomization, were gathered. Another limitation is that it is unclear what ingredients exactly have caused the effect of the peer-run course. Further research is necessary on peer-run services to get more knowledge about their useful ingredients for recovery. Fourth, all instruments were self-reported. Although the subjective outcome measures were deliberately chosen, more objective outcome measures such as for employment would have added valuable information. Finally, it is a limitation that no information was gathered on additional recovery-related interventions participants engaged in during the research period.

Conclusion

The peer-run course 'Recovery is up to you' improved important domains of recovery (i.e., empowerment, hope and self-efficacy beliefs), and these effects persisted for at least three months. At present, peer run services, such as 'Recovery is up to you', are of added value for recovery-oriented mental health care because they offer participants an opportunity to make an active start with their recovery.

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Declaration of interest

None, except for the first author. At the time of the study, she was employed at the centre which coordinates the course.

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4

Profiles of individually-defined recovery of people with major psychiatric problems

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ABSTRACT

Background

Research on factors associated with individually-defined recovery is limited. Several phases of recovery have been described in the literature. Individuals in these distinct phases have different characteristics and problems.

Aims

To identify classes of people with major psychiatric problems having comparable profiles of individually-defined recovery, to relate these classes to the phases of recovery as described by Spaniol and colleagues (1), and to associate the classes to demographic and psychiatric characteristics, and health-related variables.

Methods

Data of 333 participants with major psychiatric problems were used. A latent class analysis was conducted on mean scores of four proxy measures of recovery.

Results

Three well-defined classes were found which differed on the recovery measures. The classes differed significantly on variables corresponding to Spaniol's phases of recovery (1) and on health care utilization, health care needs and anxiety disorder, but not on demographic variables.

Conclusions

It is possible to identify classes of people with major psychiatric problems having comparable profiles of individually-defined recovery which seem to correspond to phases of recovery. More knowledge of the characteristics of people in different phases of recovery will contribute to a more fine-tuned and recovery-oriented health care.

Keywords: recovery, major psychiatric problems, severe mental illness, latent class analysis, profiles of recovery.

INTRODUCTION

In the 1980s, a new point of view on recovery emerged in psychiatry, based on the consumer's perspective (2). From this perspective recovery was defined as ".... a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness" (3). The focus was not on traditional (medical) outcomes such as readmissions, symptom reduction and improved functioning, but on individually defined and more subjective factors, such as personal growth, hope, and autonomy (4). This so-called individually-defined recovery is not a static construct but refers to an ongoing change process (5). Therefore, there is no uniform pattern for those who are 'in recovery'.

Research on the factors associated with individually defined recovery is limited (6). Several concepts are commonly regarded as important for recovery: empowerment (2, 7-9), hope and optimism (2, 8, 9), perceived knowledge about illness and services, life satisfaction (9), regaining self-esteem, self-respect and regaining control over symptoms and stress (2, 8), connection with others, social relationships and social support (2, 8, 10-12).

In the recovery literature, different phases of recovery are described. Although the number of phases differs, the properties of the phases are comparable (13). For instance, Spaniol and colleagues (1) described four phases of recovery. In the first phase, called 'being overwhelmed by the disability', the person is disconnected from the self and others, powerless to control his or her life and lacks self-confidence. The second phase is characterized by 'struggling with the disability', i.e.: the person recognizes the need to develop ways of coping with the disability, but the fear of failure can be very deep. Medication can be helpful, but is not sufficient for progressing beyond this second phase. In the third phase, called 'living with the disability', the person is able to use effective coping strategies to deal with the disability, and there is a stronger sense of self and confidence in having control over life. The fourth phase is called: 'living beyond the disability'; the disability has become a small part of the person's world and does not significantly interfere with having a satisfying and contributing life (1). Individuals can move back and forward from one phase to another. People in the different phases have different characteristics (1). In phase one, the lack of close social contacts seems to be a central problem. In phase two, the role of medication seems to become less important while coping behaviour and generic health status seem to improve. In phase three individuals seem to have effective coping strategies, sense of self and confidence and in phase four the disabilities are not a central problem anymore.

Different phases of recovery imply individual differences in recovery. Indeed, van Gestel-Timmermans et al. (14) found considerable variation in recovery in a study on the effectiveness of the course 'Recovery is up to you.' The aim of the present study, using the same data, was to investigate whether classes of people with different profiles of individually-defined recovery could be identified by latent class analysis. More specifically, the study aimed to discover:

1. Whether it is possible to identify classes of people with major psychiatric problems having comparable profiles of individually defined recovery.

2. Whether these classes are comparable to the phases of recovery, as described by Spaniol and colleagues (1).

3. Whether the classes are related to other variables, such as demographic and psychiatric characteristics and health-related variables. In particular, we explored whether the classes differed on loneliness, close social contacts, utilization of psychiatric medication, generic health status (social functioning, mental health) and task-oriented coping.

METHOD

Procedure

This study was part of a larger study in which the effectiveness of the course 'Recovery is up to you' was assessed (14). The data of 333 participants were available. Assessments took place at 13 different mental health care institutions and patients' associations across the Netherlands. When the study was explained (verbally and in writing), written informed consent was obtained from each participant. Prior to the start of the study, approval was obtained from the medical ethics committee for mental health institutions in the Netherlands.

Participants

Recruitment took place in the Netherlands between September 2006 and July 2008. People with major psychiatric problems were recruited by means of advertisements in free local papers, posters in hospitals, psychiatric care services and in primary care, by mental health care providers, and by fellow clients involved in the research project. These people were recruited to participate in a course on recovery (15) and were 'in recovery'. There were two inclusion criteria: suffering from major psychiatric problems (e.g. psychotic disorder, personality disorder, affective disorder, or anxiety disorder), and reporting to have been through very disruptive times in life from which the person was recovering. Exclusion

criteria were: illiteracy, not speaking Dutch, being suicidal, and having florid psychotic symptoms or major addiction problems. Mean age was 44 (age range: 17-74), 66% was female, 92% was Dutch, 35% had high education, 16% was married, 81% was living independently, 54% was working or studying and 77% had a minimum income or less. Most people had mood disorders (36%), followed by psychotic disorders (33%) and personality disorders (31%). The demographic and psychiatric characteristics of the sample are presented in the second column of Table 1.

Proxy measures of recovery

Since no well-established Dutch instrument to measure recovery was available at the time this study was conducted, proxy measures of recovery were used. Self-report instruments were used to assess four key elements of recovery: hope, quality of life, self-efficacy beliefs and empowerment (2, 7-9). To assess *hope* the Herth Hope Index (HHI) was used, consisting of 12 Likert-scale items, with scores ranging from 1 ('strongly disagree') through 4 ('strongly agree') (16, 17). *Quality of life* was assessed using the 12 subjective items of The Manchester Short Assessment of Quality of Life (MANSA) with 7-point Likert scales ranging from 1 ('could not be worse') through 7 ('could not be better') (18, 19). *Self-efficacy beliefs* were measured using the 16-item Mental Health Confidence Scale (MHCS), with 6-point Likert scales with scores ranging from 1 ('totally no confidence') through 6 ('full confidence') (20, 21). All aforementioned instruments are well-known and have good psychometric properties (16-21); Cronbach's alpha of these instruments ranged from .84 to .91. *Empowerment* was assessed using a newly developed instrument, the Dutch Empowerment Scale. The scale consists of 40 items on 5-point Likert scales ranging from 1 ('strongly disagree') through 5 ('strongly agree') (22). Cronbach's alpha of the scale was .93. In this study for all measures the mean scale scores were used.

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Table 1: Scores on recovery measures, demographic and psychiatric characteristics and other variables of the total sample and class Low, Middle and High

	Whole sample		Class low (l)		Class middle (m)		Class high (h)		Effect size (Cramers V/ Eta squared)[b]
	N=330		N=76		N=175		N=79		
Scores on recovery measures	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Hope	2.77	.47	2.2	.35	2.8	.27	3.26	.33	.6 l<m<h***
Quality of life	4.28	.94	3.29	.65	4.23	.63	5.32	.57	.57 l<m<h***
Self efficacy beliefs	4.35	.85	3.33	.60	4.39	.49	5.32	.43	.65 l<m<h***
Empowerment	3.39	.50	2.78	.32	3.39	.3	3.96	.28	.64 l<m<h***
Recovery-related variables									
1. Demographic characteristics[a]	N	%	N	%	N	%	N	%	
Age (329)									.01
Mean age (S.D.)	44 (10)		44 (10)		43 (10)		45 (11)		
Age range	17 – 74		23-71		17-74		20-65		
Gender									.06
Female (330)	218	66	51	67	119	68	48	61	
Nationality									.07
Born in the Netherlands (328)	303	92	71	93	158/174	91	74/78	95	
Level of education (326)									.06
Low	101	31	28	37	48/173	28	25/77	33	
Middle	111	34	23	30	60	35	28	36	
High	114	35	25	33	65	38	24	31	
Marital status (329)									.14
Unmarried	184	56	42	55	109/174	63	33	42	
Married	53	16	9	12	26	15	18	23	
Divorced	92	28	25	33	39	22	28	35	
Living situation (323)									.04
Living independent (alone, with parents, living together or married with/without children)	261	81	60/75	80	141/171	80	60/77	78	
Living in setting or sheltered	62	19	15	20	30	18	17	22	
Principal daily pursuit (317)									.09
Working or studying	172	54	36/73	49	87/169	51	49/75	65	
Not working/studying	145	46	37	51	82	49	26	35	
Income (311)									.09
≤ minimum (€1071)	239	77	61/74	82	125/163	77	53/74	72	
Standard (€1743)	45	14	10	14	24	15	11	15	
>Standard (> €1743)	27	9	3	4	14	9	10	14	

	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
2. Healthcare utilization										
Psychiatric care (330)	2.4	1.4	2.43	1.49	2.55	1.35	2.04	1.4	.02	m>h**
Other care (330)	1.52	0.92	1.63	0.8	1.5	0.99	1.46	0.87	.01	
Psychiatric medication (330)	1.4	1.19	1.68	1.17	1.35	1.21	1.23	1.14	.02	l>m*, l>h*
3. Health care needs (330)	2.45	1.35	2.9	1.28	2.5	1.37	1.89	1.17	.07	l>m*, m>h**, l>h***
4. Use of information concerning recovery (330)	0.93	0.93	0.89	0.92	0.98	0.97	0.84	0.82	.01	
	N	%	N	%	N	%	N	%		
5. Use of selfhelp (327)	38	12	5	7	23/172	13	10	13	.09	
6. Psychiatric characteristics										
Psychotic disorders (326)	109	33	22	29	58/174	33	29/76	38	.07	
Mood disorders (326)	117	36	36	47	56/174	32	25/76	33	.13	
Anxiety disorders (324)	73	23	21/75	28	43/173	25	9/76	12	.15	m>h*, l>h*
Personality disorders (326)	102	31	29	38	56/174	32	17/76	22	.12	
Substance abuse (325)	22	7	7/75	9	10/174	6	5/76	7	.06	
7. Existence of close social contacts (328)	282	86	54	71	149/173	86	79	100	.29	l<m**, m<h***, l<h***
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Recovery-related concepts										
1. Loneliness (327)	6.63	3.49	8.99	2.13	7.08	3.15	3.35	2.85	.33	l>m>h***
2. Coping (329)										
Task-oriented coping	3.18	0.71	2.67	0.65	3.21	0.62	3.62	0.66	.22	l<m<h***
Emotion focused coping	2.79	0.68	3.23	0.5	2.8	0.66	2.33	0.57	.21	l>m>h***
Avoidant coping	2.66	0.68	2.21	0.6	2.67	0.59	3.05	0.68	.18	l<m<h***
3. Generic health status										
Physical functioning (329)	2.53	0.45	2.45	0.46	2.57	0.43	2.53	0.49	.01	
Social functioning (330)	3.25	1.05	2.45	0.95	3.29	0.91	3.93	0.93	.23	l<m<h***
Role limitations (physical problem) (329)	1.51	0.42	1.35	0.39	1.53	0.42	1.62	0.4	.05	l<m*, l<h***
Role limitations (emotional problem) (329)	1.45	0.41	1.19	0.31	1.46	0.4	1.7	0.39	.18	l<m<h***
Mental health (330)	3.68	0.95	2.71	0.7	3.69	0.71	4.6	0.68	.46	l<m<h***
Vitality (330)	3.36	0.99	2.53	0.79	3.37	0.84	4.14	0.79	.32	l<m<h***
Pain (330)	3.99	1.17	3.5	1.24	4.04	1.06	4.35	1.18	.07	l<m***, m<h**, l<h***
General health perception (328)	3.05	0.81	2.52	0.7	3.05	0.73	3.56	0.76	.2	l<m<h***

*p<.05; **p<.01; ***p<.001

[a] Sample sizes are between brackets

[b] Cramer's V for categorical variables and eta squared for continuous variables. An inequality such as 'l<m<h***' denotes that the scores of class High are on average higher than of classes Low and Middle, and higher of class Middle than of class Low, and that these results of all three tests are significant at .001

Variables and concepts related to recovery

Scores on seven main categories of variables and concepts which were assumed to be related to recovery were assessed. The seven main categories of variables were: demographic characteristics, health care utilization, health care needs, use of information concerning recovery, use of self-help, psychiatric characteristics and existence of close social contacts.

Concepts assumed to be related to recovery were: loneliness (emotional and social), coping behaviour (task-oriented coping, emotion-focused coping and avoidance) and generic health status (1, 2, 8, 9). *Loneliness* was assessed using the Loneliness Scale, consisting of 11 items on 5-point Likert scales, ranging from 1 ('yes, for sure') through 5 ('no, certainly not') (23-25). Cronbach's alpha of the total scale was .90. *Coping* was measured using the three subscales of the Coping Inventory for Stressful Situations (CISS) (Task-oriented coping, Emotion-focused coping and Avoidance). It is a 48 item 5-point Likert scale instrument with scores ranging from 1 ('not at all') through 5 ('very much so') (26, 27). Cronbach's alpha of the subscales ranged from: .68 to .92. *Generic health status* was measured using the eight subscales of the RAND-36 (Physical Functioning, Social Functioning, Role Limitations (physical problem), Role Limitations (emotional problem), Mental Health, Vitality, Pain and General Health Perception). The scale consists of 36 items. Six subscales have items on 3- through 6-point Likert scales and the other two scales have items that can be answered with 'yes' or 'no' (28). Cronbach's alpha of the subscales ranged from .75 to .89. These instruments are also well-known and have good psychometric properties (23-28). In the present study, the mean scores on the scale or subscale were used. For all instruments, missing values were treated as described in the manuals.

Table 2 shows the aforementioned variables and concepts, their operationalization, and the literature on which the expected relations with the proxy measures of recovery were based.

Table 2: **Variables and concepts related to recovery, their operationalization and the literature on which the expected relations with the proxy measures of recovery are based**

Recovery-related variables	*Operationalization*	*Expected relation with proxy measures of recovery*
1. Demographic characteristics		
Age		Older age may be linked with more favourable subjective quality of life (Marwaha et al., 2008)
Gender		Men score higher on quality of life (Lehman et al., 1995)
Nationality	Born in the Netherlands or not	Effect of nationality is a result of environmental circumstances and coping (Yanos & Moos, 2007)
Level of education	Low, middle, high	Higher education predicts improved daily functioning and management of illness (Powell et al., 2001).
Marital status	Married, Unmarried, divorced	Social relationships and social support are important for recovery (Schön et al. 2009)
Living situation	Independent, in setting or sheltered	Greater independence in housing situation is related to better life satisfaction (Yanos & Moos, 2007)
Principal daily pursuit	Working or studying (employed parttime or fulltime, volunteer work, school/study) or not working or studying	Employment is correlated with positive outcomes in social functioning, symptom levels, quality of life and self-esteem (Marwaha &Johnson 2004).
Income	≤minimum (€1071), standard (€1743), >standard (>€1743)	A good financial condition may promote recovery (Topor et al., 2009)
2. Health care utilization		
Psychiatric care	Casemanager, traject support, housing support, daycare centre, psychotherapy, psychiatrist/psychologist, admission into hospital, outpatient's treatment	There may be less dependence on the mental health system when someone has more knowledge about one's illness, the range of available treatments and ways to navigate the service system (Mueser et al., 2004) i.e. when a person is in an advanced state of recovery
Other care	Family doctor, social worker, district nurse, physiotherapist, other services	Mental illness and symptoms are among the most powerful factors influencing patients' use of primary and secondary non-psychiatric health care (Steen Hansen et al., 2005; Levinson et al., 2008). More recovery was presumed to be related to less dependence of these services.
Psychiatric medication	Antipsychotics, antidepressive	Medication adherence is a predictive variable of symptomatic remission (Lambert et al., 2008)

		Operationalization	Expected relation with proxy measures of recovery
3.	**Health care needs**	medication, anxiety medication, other psychiatric medication; Needs for help in: day care, work, housing, leisure, taking care of oneself, social contacts	There may be less dependence on the mental health system when someone has more knowledge about one's illness, the range of available treatments and ways to navigate the service system (Mueser et al., 2004) i.e. when a person is in an advanced state of recovery
4.	**Use of information concerning recovery**	Websites, documents, lectures, other information	Getting information is a part of self-help. Self-help involvement predicts management of illness (Powell et al., 2001)
5.	**Use of self-help**		Self-help involvement predicts management of illness (Powell et al., 2001)
6.	**Psychiatric characteristics**		Lower symptom levels are more strongly associated with higher subjective quality of life scores in neurotic than in mood disorders and schizophrenia (Priebe et al, 2010). Diagnosis itself may have no effect on both clinical and social outcomes (Lasalvia et al., 2007). Duration of (psychotic) symptoms at baseline may be associated with symptom remission (Robinson et al., 2004)
		Psychotic disorders	
		Mood disorders	
		Anxiety disorders	
		Personality disorders	
		Substance abuse	Substance use abstinence is a predictive variable of symptomatic remission (Lambert et al 2005)
7.	**Existence of close social contacts**		Having the social supports of family, friends, professionals and peers is a decisive factor in recovery (Schön et al., 2009)

	Recovery-related concepts	*Operationalization*	*Expected relation with proxy measures of recovery*
1.	**Loneliness**		More general satisfaction with social networks is associated with greater hope (Corrigan et al., 2004)
2.	**Coping**		Hope is important in coping with chronic illness (positive correlation; Miller, 1992)
	Task-oriented coping		Illness management or coping with illness and recovery are closely related (Mueser et al., 2004)
	Avoidant coping		Avoidant coping may decrease when illness management increases (Lazarus & Folkman, 1984)
	Emotion-focused coping		Emotion-focused coping may decrease when illness management increases (Lazarus & Folkman, 1984)
3.	**Generic Health status**		No strong connections are expected between recovery and physical health-status (Landeen et al., 2000)
	Physical functioning		Social support may promote recovery (Hendryx et al., 2008); social relationships are the core category of contributing recovery factors (Schön et al., 2009)
	Social functioning		No strong connections are expected between recovery and physical health-status (Landeen et al., 2000)
	Role limitations (physical problem)		

Role limitations (emotional problem)	Role limitations by emotional problems are contradictory to coping with illness or illness management. Illness management and recovery are closely related (Mueser et al., 2004)
Mental health	Strong relationships were found between hope and subjective health (Landeen et al., 2000)
Vitality	Strong relationships were found between hope and subjective health (Landeen et al., 2000)
Pain	No strong association was expected between recovery and physical health-status (Landeen et al., 2000)
General Health perception	Strong relationships were found between hope and subjective health (Landeen et al., 2000)

Statistical analysis

Latent Class Analysis (LCA) (29) was applied to identify subgroups of patients with different profiles based on the four key elements used in this study, i.e.: hope, quality of life, self-efficacy beliefs and empowerment. The primary objective of LCA is to find the smallest number of classes of individuals with similar profiles of recovery. Several indices of model fit were used to determine the appropriateness of a latent class model, as well as the number of classes to retain. To specify the number of classes, LCA solutions with different numbers of classes were tested and compared to model fit indices. The Bayesian information criterion (BIC) is a relative indicator of model fit, with lower values indicating better fit of the model to the data. The Vuong-Lo-Mendell-Rubin likelihood ratio test was used to test whether a model with k classes fits significantly better than a model with k-1 classes. The distinctiveness of the classes was examined using Entropy, which is a coefficient ranging from 0 to 1. Higher values indicate clearer delineation of classes and values of .80 or higher are desirable. The assignment of individuals into a class was based on their most likely class membership.

After identifying classes of recovery profiles, analyses were conducted to identify whether class membership was associated to the phases of Spaniol and colleagues (1) and to the relevant variables and recovery-related concepts. More specifically, we verified if class membership predicted scores on seven main categories of variables and on recovery-related concepts. The omnibus Welch test and post-hoc t-tests (Fisher's LSD approach) were performed on continuous variables. These t-tests are preferred if the homoscedasticity assumption might be violated and group sizes are unequal (30). Chi-square tests were performed on discrete variables and chi-square tests of two proportions when results were significant. A significance level of .05 was used in all tests. Eta squared (for continues variables) and Cramer's V (for categorical variables) were the reported effect size measures. The LCA was performed using M-plus 5.2 (31); all other analyses were run using SPSS 17.0.

RESULTS

Latent Class Analysis

Of the 333 subjects in this study, three dropped out because of systematic missing values. Table 3 presents the results of the LCA solutions of one to six classes. The BIC values decreased across solutions containing two, three, and four classes, suggesting that four classes fit the data best. However, decreases in BIC were much larger going from two to

three classes than going from three to four classes. According to the Vuong-Lo-Mendell-Rubin test, three classes were a significantly better fit to the data than two classes (p<.05), and four classes did not improve model fit significantly beyond that of the three classes (p>.05). Therefore, the three-class solution was retained. The entropy of the three-class model was .80, indicating that the classes were well-defined.

Table 3:   Fit statistics for Latent Class Analysis (N=330)

Number of classes	BIC	Entropy	p-value Vuong-Lo-Mendell-Rubin test
1	2519,319		
2	2128,215	0,79	0.000
3	2005,353	0,80	0.0093
4	1967,744	0,80	0.3271
5	1952,360	0,79	0.0431
6	1963,306	0,81	0.6995

Note: BIC, Bayesian information criteria (Kass & Raferty, 1993). Entropy refers to the average classification accuracy when assigning patients to classes with values closer to 1 indicating greater precision (range = 0-1). Vuong-Lo-Mendell-Rubin test provides a direct test between two models; a low p-value indicates a k-1 class model should be rejected in favour of a model with at least k classes.
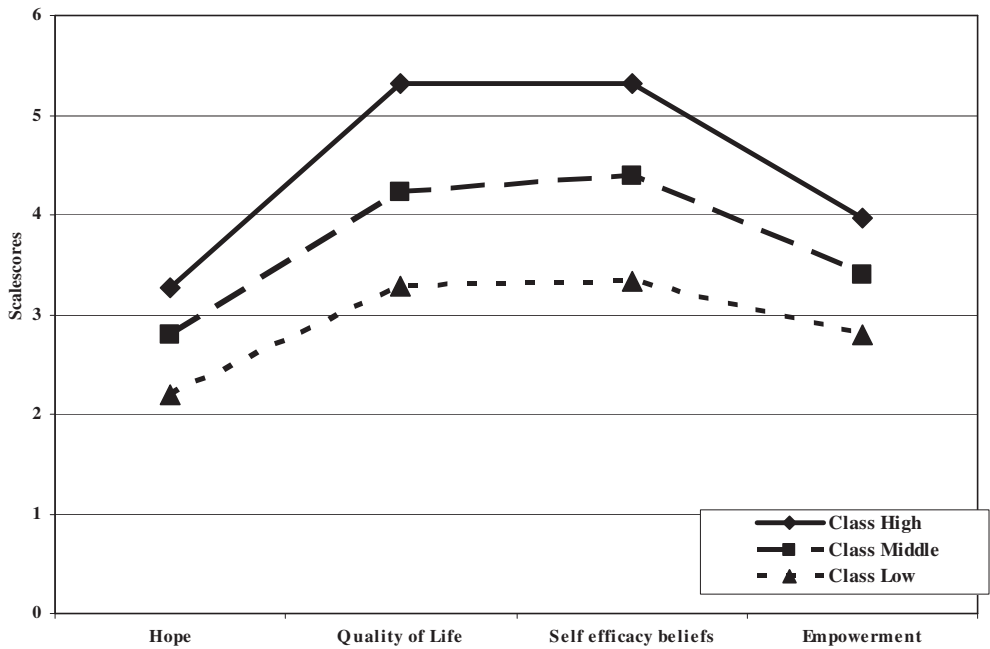
Figure 1: Profiles of proxy measures of recovery
Note: Scale score ranges Hope 1-4; Quality of Life 1-7; Self efficacy beliefs 1-6; Empowerment 1-5

   The profiles of the three classes on the four key measures of recovery are depicted in Figure 1. One class of persons (N=79) with higher scores on the recovery scales was identified (class High). A larger subgroup (N=175) emerged with lower values on the recovery scales (class Middle) and another subgroup (N=76) with the lowest scores (class Low). The mean scores on the recovery scales differed significantly between the three classes (see Table 1). Class membership explained 59.7%, 56.9%, 64.8% and 63.8% of the variance of hope, quality of life, self-efficacy beliefs and empowerment respectively, indicating that differences in the scores on the four key concepts are well represented by the three classes. Table 1 also presents the scores of the classes on relevant variables categorized in seven main categories and on recovery related concepts.

Phases of recovery

Since the three classes differ systematically on the four recovery measures, we examined if these classes corresponded to the phases of recovery, as described by Spaniol and colleagues (1). Based on this description it was assumed that the classes would differ on loneliness, close social contacts, utilization of psychiatric medication, generic health status (social functioning, mental health) and task-oriented coping. The last column of Table 1 shows that the three classes differ significantly on all these variables. As can be seen in Table 1, effect sizes were large (see Cohen, (32)), except for utilization of psychiatric medication. Class Low is characterized by the highest loneliness and the least close social contacts, the highest utilization of psychiatric medication, and the lowest social functioning, mental health and task-oriented coping. Class Middle scored better on all the aforementioned variables than class Low. Class High scored better than class Middle on all variables except psychiatric medication, on which the two classes did not differ significantly.

Other variables

The three classes did not differ on demographic characteristics, use of information concerning recovery and use of self-help. Significant differences corresponding to lower scores for class Low and higher scores for class High were observed on health care needs, emotion-focused coping, vitality, pain, and general health perception. In addition, significant differences were found on utilization of psychiatric care (in class Middle utilization was higher than in class High), anxiety disorders (class High had less people with anxiety disorders than the other classes), avoidant coping (class High had most people with avoidant coping behaviour, class Low had the fewest) and role limitations (physical problems and emotional problems; the highest classes had the highest scores).

DISCUSSION

This study was a first attempt to identify classes of people with major psychiatric problems having comparable recovery profiles. Three classes were identified. Characteristics of the people in the lowest class seemed to correspond with the first phase of Spaniol and colleagues (1), whereas people in the middle class corresponded best with the second phase. People in the highest class matched especially with the third phase of Spaniol and colleagues (1).

Spaniol and colleagues (1) described four phases of which only three were identified in the present study. This can be due to the fact that participants were willing to take part in a

course on recovery and thus were still 'working on their recovery'. This might explain why the fourth phase 'living beyond the disability' was not found in our sample.

The findings in the present study are in line with the results of two quantitative studies (33, 34)), which explored the validity of a Stages of Recovery Instrument (STORI). This is a self-rating instrument, meant for measuring stages of recovery in individuals. Cluster analysis in both studies showed that the STORI was able to detect three stages of recovery, which were comparable to the first three phases of recovery found by Spaniol and colleagues (1).

As mentioned, classes were comparable to the phases of Spaniol and colleagues (1) but were also related to other variables, that is: health care utilization, health care needs and anxiety disorders. One would expect people in the lowest class to have the highest utilization of psychiatric care, because they have the highest health care needs. However, only people in the middle class had a significant higher utilization than the highest class. An explanation could be that people in the lowest class had the fewest social contacts and the lowest scores on task-oriented coping, which might prevent them from seeking help for their problems. A Norwegian study (35) showed that the majority of persons with anxiety disorders and/or depression do not get professional help while many of them are in need of care. The authors concluded that this may be associated with personal and familial suffering, as well as functional impairment. In the present study the lowest and middle class consisted of more people with anxiety disorders than the highest class. The combination of anxiety disorders and functional impairment might explain the lower utilization of psychiatric care in the lowest class.

An interesting finding was that the classes did not differ significantly on demographic variables. For instance, people in the highest class did not differ from people in the lowest class on income or living situation. Therefore, demographic variables did not seem to be related to the recovery of people with major psychiatric problems. These results differ from other studies, which indicated that interventions reducing financial strain may facilitate participation in cultural and social activities and promote recovery (11, 36). However, research on the association between financial situation and recovery is still in its infancy (11). Employment is correlated with positive outcomes in social functioning, symptom levels, quality of life and self-esteem, but a clear causal relationship has not been established (37).

People in the highest and middle class experienced more role limitations, which may seem surprising because role limitations do not seem to be related to their higher scores on recovery measures. However, this finding corresponds well with Spaniol's phase two, called:

'struggling with the disease' (1). When developing new roles, people struggle more with finding coping strategies in order to manage their symptoms, such as cutting back on activities, avoiding stress and getting social support. Moreover, they have to build strength and confidence in the ability to act on their own interest, leading to more consistency in contacts, roles and environments (1).

People in the highest class had the highest scores on avoidant coping. According to the coping theory (38) one would expect scores on emotion-focused coping and avoidant coping to be lower in this class than in the lower classes. The high scores on avoidant coping indicate that people avoid problems instead of dealing with them. However, avoidant coping is not always negative, e.g. social withdrawal can be a positive way to avoid stigma (13).

There are some limitations of the present study that need to be addressed. First, it would be preferable to have one measure for recovery. However, no well-established Dutch instrument to measure recovery was available at the time of the study. Therefore, four proxy measures were used. These measures contributed equally to the different profiles, which suggests that they might be equally important aspects of recovery. Second, in the present study no information was gathered about family support and (age of) onset of symptoms. These are important factors for recovery (1, 12), which should be included in future research. Moreover, with this type of analysis, it remains unknown how long symptoms of participants persisted and how long it took before they reached a certain state of recovery. Finally, the findings of the present study cannot be extrapolated to all clients in mental health care because of the exclusion criteria in the present study. For the present study, people were included who were able to participate in a course on recovery. Therefore people in the fourth phase of recovery were not represented.

CONCLUSION

The present study is a first quantitative orientation in identifying classes of people with major psychiatric problems who are 'in recovery' at one specific moment. Three classes were found, showing characteristics which are in line with phases of recovery as described in the recovery literature. Future research should focus on the characteristics and special needs of people who are in different phases of recovery. More variables, such as symptom levels and vocational functioning, should be included in this research. Specifically, more knowledge about people in a certain phase of recovery and the factors promoting moving from one phase to another is important for a more fine-tuned and recovery-oriented health care.

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Factors promoting individually-defined recovery

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ABSTRACT

Background

Traditionally, recovery refers to the remission of symptoms (1-2). In the eighties, a new view on recovery emerged in psychiatry based on the consumer's perspective, called individually-defined recovery (3). Despite the ample interest in individually-defined recovery, little empirical research has been conducted and instruments to measure recovery are scarce (10, 12, 14, 16).

Aims

The aims of the present study were to investigate whether there is a positive effect of a peer-run course on change in recovery for classes of people with different recovery profiles, which other variables than the recovery profiles contributed to change in recovery over time, and for which persons a peer-run course was most beneficial.

Methods

Latent class analysis (LCA) was used to identify subgroups of patients with different profiles on four key elements of individually-defined recovery i.e., hope, self-efficacy beliefs, empowerment, quality of life, at T0 (N=330). These profiles were based on participants that were either following a peer-run course on recovery of three months, or that were placed in a control condition, without a course. Sequential multiple regression analyses were run to predict changes in recovery between T0 and T1 (N=265).

Results

The course had a positive effect on change in recovery with respect to hope, self-efficacy beliefs, and empowerment, but not on quality of life. Only a few other variables had an effect on change in recovery, and the effect of only a small number of variables differed across classes or condition.

Conclusions

Our findings suggest that the peer-run course in itself is an important contributor to change in recovery. In addition, the course seems beneficial for individuals with different demographic and psychiatric characteristics, and with different recovery profiles.

Keywords: recovery, major psychiatric problems, profiles of recovery, factors promoting individually-defined recovery

INTRODUCTION

During the past three decades, the consumer movement has drawn the attention of mental health providers, researchers and policymakers to the concept of recovery. Traditionally, recovery refers to the remission of symptoms (1-2). In the eighties, a new view on recovery emerged in psychiatry, based on the consumer's perspective (3). Here, the focus was not on traditional (medical) outcomes, but on individually defined and more subjective constructs such as personal growth, hope, and autonomy (4). This so-called individually-defined recovery covers more than the remission of symptoms and can be achieved in spite of the existence of these symptoms (5-9). Several concepts are regarded as important for individually-defined recovery, such as, empowerment (3, 5, 10-12), hope and optimism (3, 11, 12), perceived knowledge about illness and services, life satisfaction (12), regaining self-esteem (3, 10, 11), self-respect and regaining control over symptoms and stress (3, 11), connection with others, social relationships and social support (3, 10, 11, 13-15).

Despite the ample interest in individually-defined recovery, little empirical research has been conducted and instruments to measure recovery are scarce (10, 12, 16); see also Schön et al. (14). Recently, a few randomised controlled trials have been published in which peer-run courses on recovery were evaluated (17, 18). These studies suggest that peer-run courses have positive effects on empowerment, hope, self-efficacy beliefs, self-esteem, quality of life, spiritual well-being, social support and psychiatric symptoms. What the aforementioned studies did not reveal, however, is which variables can explain individual differences on changes in recovery and for which individuals a peer-run course is most beneficial.

Van Gestel et al. (19) identified three classes based on different scores on four key elements of recovery (hope, self-efficacy beliefs, empowerment, quality of life) at baseline. One class (High) scored higher than average on the four elements, one class lower (Low), and one class had values in between the two classes. The classes of people were based on participants that were either following a peer-run course on recovery of three months, or were placed in a control condition without a course. The aim of the present study was to evaluate which factors promote change in recovery. More specifically, the study aimed to discover:

1. Whether there is a positive effect of the course on change in recovery from baseline to the end of the course, for all classes of people with different recovery profiles.
2. Which other variables contributed to change in recovery over time, after controlling for the effect of the course and class differences.
3. For which persons the peer-run course was most beneficial.

METHOD

Procedure

This study was part of a larger study in which the feasibility and effectiveness of the peer-run course 'Recovery is up to you' was assessed (18, 20). Assessments took place at 13 different mental health care institutions and patients' associations across the Netherlands. At each location half of the participants was randomly allocated to the experimental group, the other half to the control group. Participants in the experimental condition started the course within one week after randomisation and completed the course after three months at T1. Data were gathered at baseline (T0) and after 3 months (T1). Participants from the experimental and control condition were both free to participate in other recovery related activities and continued their treatment as usual. All participants were remunerated with € 7,50 for each assessment.

Prior to the start of the study, the study was explained (verbally and in writing), written informed consent was obtained from each person and approval was obtained from the medical ethics committee for mental health institutions in the Netherlands. The trial registration number was: ISRCTN47331661.

Participants

Recruitment took place in the Netherlands between September 2006 and July 2008. People with major psychiatric problems were recruited by means of advertisements in free local papers, posters in hospitals, psychiatric care services and in primary care, by mental health care providers, and by fellow clients involved in the research project. There were two inclusion criteria: suffering from major psychiatric problems (e.g. psychosis, personality disorder, affective disorder, or anxiety disorder), and reporting to have been through very disruptive times in life from which the person was recovering. Exclusion criteria were: illiteracy, not speaking Dutch, being suicidal, having florid psychotic symptoms and/or major addiction problems.

A total of 333 persons participated. Mean age of this group was 43,5 (SD: 10,5; range: 17-74), 66% was female, 92% was Dutch, 35% had high education, 16% was married, 79% was living independently, 55% was working or studying and 75% had a minimum income or less. Most people had mood disorders (36%), followed by psychotic disorders (33%) and personality disorders (32%). Demographic and psychiatric characteristics are presented in Table 1. At T1, 265 participants were still involved in the study (79.6%).

Table 1: Demographic characteristics, psychiatric characteristics, and average scores on recovery-related variables for the experimental and control condition at baseline

	Total experimental condition: N=168		Total control condition: N=165	
	N	%	N	%
Demographic characteristics				
Age				
Mean age (S.D.)	42,9 (10,5)		44,0 (10,4)	
Age range	19 - 74		17 - 71	
Gender				
Female	114	68	106	64
Male	54	32	59	36
Nationality				
Born in the Netherlands	151	90	155	95
Different	17	10	8	5
Level of education				
Low	52	31	51	31
Middle	63	38	48	30
High	52	31	63	39
Principal daily pursuit				
Unemployed	30	18	38	23
Study/School	5	3	5	3
Employed part time	16	10	9	6
Employed full time	7	4	6	4
Volunteer work	64	38	71	43
Housekeeping	20	12	12	7
Living situation				
Living alone	73	44	95	58
Living with parents	10	6	4	2
Living with partner, child(ren)	20	12	17	10
Living with partner, no children	11	7	15	9
Single parent	12	7	6	4
Hospital setting	9	5	6	4
Sheltered living	27	16	19	12
Hostel	1	1	1	1
Different	5	3	1	1
Marital status				
Unmarried	90	54	96	59
Married/cohabiting	25	15	22	13
Divorced	49	29	44	27
Widowed	4	2	2	1
Income				
≤ minimum (€1071)	123	78	118	76
≤ Standard (€1743)	22	14	23	15
> standard	12	8	15	10
Psychiatric characteristics:				
Major DSM-IV-classifications				
Psychotic disorder	48	29	61	38
Affective disorder	61	37	58	36
Anxiety disorder	34	20	40	25
Personality disorder	56	34	48	30
Recovery-related variables				
Loneliness (SD) (N=328)	6.38 (3.56)		6.89 (3.40)	
Coping				
Task-oriented coping (SD) (N=330)	3.18 (.70)		3.17 (.73)	
Emotion focused coping (SD) (N=330)	2.81 (.67)		2.76 (.69)	
Avoidant coping (SD) (N=330)	2.64 (.66)		2.67 (.69)	
Generic health status				
Physical functioning (SD) (N=330)	2.54 (.44)		2.53 (.46)	
Social functioning (SD) (N=330)	3.26 (1.05)		3.25 (1.05)	

Role limitations (physical problem) (SD) (N=330)	1.51 (.41)	1.52 (.43)
Role limitations (emotional problem) (SD) (N=330)	1.43 (.40)	1.47 (.42)
Mental health (SD) (N=331)	3.66 (.92)	3.69 (.98)
Vitality (SD) (N=331)	3.37 (1.01)	3.36 (.97)
Pain (SD) (N=331)	3.96 (1.14)	4.03 (1.19)
General health perception (SD) (N=329)	3.08 (.79)	3.02 (.84)

Intervention

The course 'Recovery is up to you' was developed by clients and two mental health professionals. It consists of twelve weekly sessions of two hours. Groups were led by two trained course instructors, who were (ex-)clients that had followed the course themselves previously and who were in an advanced state of their recovery process. They closely followed a detailed standardized manual. See Van Gestel-Timmermans et al. (20) for a description of the course.

Proxy measures of recovery

Since no well-established Dutch instrument to measure recovery was available at the time this study was conducted, several key elements of recovery were used as proxy measures, i.e., measures of hope, quality of life, self-efficacy beliefs and empowerment. The Herth Hope Index (HHI) was used to assess hope (21, 22). Quality of life was assessed using the 12 subjective items of The Manchester Short Assessment of Quality of Life (MANSA) (23, 24). Self-efficacy beliefs were measured using the Mental Health Confidence Scale (MHCS) (25, 26). All aforementioned instruments are well-known and have good psychometric properties (21-26); Cronbach's alpha of these instruments at T0 and T1 ranged from .84 to .94.

Empowerment was assessed using a newly developed instrument, the Dutch Empowerment Scale (27). The scale consists of 40 items on 5-point Likert scales ranging from 1 (strongly disagree) through 5 (strongly agree). Cronbach's alpha of the scale at T0 and T1 were 0.93 and .94, respectively.

Recovery-related variables, demographic characteristics and psychiatric characteristics

In addition to the proxy measures, recovery-related and other variables that might be associated with recovery were assessed. Recovery-related concepts were: loneliness (3), coping behaviour (11, 12, 28) and generic health status (11). Loneliness was assessed using

the Loneliness Scale (29-31). Cronbach's alpha of the total scale was .90 at both T0 and T1. Coping was measured using the three subscales of the Coping Inventory for Stressful Situations (CISS): task-oriented coping, emotion-focused coping and avoidance (32, 33). Cronbach's alpha's of the subscales ranged from .68 to .92. Generic health status was measured using the eight subscales of the RAND-36 (Physical Functioning, Social Functioning, Role Limitations (physical problem), Role Limitations (emotional problem), Mental Health, Vitality, Pain and General Health Perception) (34). Cronbach's alpha of the subscales ranged from .75 to .90. In the present study, the mean scores on all scales or subscales were used.

Other variables that were taken into account were demographic characteristics (age, gender, nationality, level of education, principal daily pursuit, living situation, marital status and income) and psychiatric characteristics. For the psychiatric characteristics, the four major DSM-IV classifications were used: psychotic disorders, affective disorders, anxiety disorders and personality disorders. Note that these were self-reported classifications. Participants could report more than one diagnosis. See Table 1 for an overview of all variables' categories and their frequency distributions.

Statistical analysis

Latent class analysis (LCA; 35) was applied to identify subgroups of patients with different profiles on the four key elements used in this study, i.e., hope, self-efficacy beliefs, empowerment, quality of life, at T0. The primary objective of LCA is to find the smallest number of classes of individuals with similar patterns of recovery. In the analysis, classes were added stepwise until the model fitted the data well. The number of classes was decided using the BIC (the smaller the better), entropy (the larger the better), and the Vuong-Lo-Mendell-Rubin test. A low p-value of the test indicates that the 'k-1 class model' should be rejected in favour of the 'k-class model'. The LCA was performed using M-plus 5.2 (36).

After identifying classes of recovery profiles, four sets of sequential multiple regression analyses were run to predict change in recovery between T0 and T1, one on each key element of recovery: hope, self-efficacy beliefs, empowerment and quality-of-life. In the first step of the sequential multiple regression analysis, the effect of class membership, condition, and their interaction on change in recovery was estimated. In this way, the first research question whether there is a positive effect of the course on change in recovery, for all classes of people with different recovery profiles, could be answered. To answer the second research question which (recovery-related or other) variables affect change in recovery, the effect of one

(recovery-related or other) variable on change in recovery was estimated in the second step. In this step, we controlled for class membership and condition which means that the effect of each variable was assessed separately.[2] In the last step of the sequential regression analysis, we checked if the effect of each variable interacted with class membership or condition. The last step allowed us to answer the third research question for which people the peer-run course was most beneficial.

The regression analyses were run using SPSS 17.0. Two-tailed tests were used everywhere. In the regression analysis, the variable 'principal daily pursuit' was recoded into 'working or studying' versus 'not working/studying', and the variable 'living situation' was coded into 'living independently' (alone, with parents, living together or married with/without children) versus 'living in setting or sheltered'.

RESULTS

Of the 333 participants in this study, three dropped out because of systematic missing values and thus were not included in the LCA at baseline. The three-class solution was selected since it was more parsimonious and did not provide a worse fit than the four-class solution. While the BIC value for the four-class solution (1967.7) was lower than for the three-class solution (2005.4), the Vuong-Lo-Mendell-Rubin test indicated that the four-class solution did not provide a significantly better fit than the three-class solution ($p = .33$). Finally, the entropy of the two solutions was identical (.80).

The three classes demonstrated unique profiles of recovery at T0. One class, called H (high recovery), consisted of 79 patients with higher than average scores on all four recovery variables at T0. A larger class of 175 patients, called M (medium recovery), emerged with average values on recovery, and a smaller class of 76 subjects, called L (lower recovery), with lower than average scores on recovery. Class membership explained 59.7%, 56.9%, 64.8% and 63.8% of the variance of hope, quality of life, self-efficacy beliefs and empowerment, respectively, indicating that differences in the scores on the four key concepts at T0 are well represented by the three classes.

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[2] The effects of all variables were not estimated simultaneously in one analysis because the number of variables was relatively large to the number of observations.

Table 2: **Average change over time on Hope, Quality of Life, Self-efficacy beliefs and Empowerment in each class for both the control and experimental condition.** *SD* **between brackets**

	Class L		Class M		Class H	
	Control	**Exp.**	**Control**	**Exp.**	**Control**	**Exp.**
Hope	.06 (.41)	.33 (.52)	.09 (.38)	.14 (.32)	-.10 (.38)	-.05 (.36)
	N=32	N=26	N=53	N=72	N=27	N=29
Quality of life	.36 (.56)	.23 (.64)	.07 (.82)	.25 (.71)	-.10 (.55)	-.20 (.57)
	N=32	N=26	N=47	N=62	N=27	N=29
Self-efficacy beliefs	.33 (.66)	.53 (.74)	.01 (.77)	.36 (.67)	-.10 (.34)	-.16 (.75)
	N=32	N=26	N=47	N=62	N=27	N=29
Empowerment	.17 (.40)	.28 (.35)	-.03 (.40)	.16 (.40)	-.06 (.30)	-.10 (.39)
	N=32	N=27	N=52	N=71	N=25	N=31

Table 2 presents the average change score from T0 to T1 of each of the four recovery variables, for each class × condition combination. The regression analyses on the change scores with class and condition as independent variables revealed that the interaction effect was not significant in all four analyses (all *p*-values > .15). Therefore, the class × condition interaction was not incorporated in the subsequent steps of the sequential multiple regression analyses. Class and condition together explained 7.1%, 6.2%, 9.8%, 9.1% of the variance of hope, quality of life, self-efficacy beliefs, empowerment, respectively, representing medium effect sizes. Change in recovery was higher in the experimental condition for hope (*p* = .04), self-efficacy beliefs (*p* = .02), and empowerment (*p* = .02), but not for quality of life (*p* = .77). Differences between the three classes on change in recovery were highly significant (*p*-values of .001 or less). The class low on recovery at T0 showed improvement and the class high on recovery at T0 showed a decline in recovery, for all four recovery variables and both conditions.

Table 3: Results of Sequential Multiple Regression Analyses

Predictor	Hope effect	ΔR^2	Quality of life effect	ΔR^2	Self-efficacy beliefs effect	ΔR^2	Empowerment effect	ΔR^2
Demographic characteristics								
Age	-.04	.002	.07	.004	.04	.002	-.02	.000
Female	-.01	.000	.00	.000	.01	.000	.03	.001
Non-Dutch	.09	.007	.07	.005	.11	.011	.06	.004
Level of education		.030[*]		.019		.021		.009
Middle	.20[+]		.08		.14[*]		.10	
High	.10		-.08		-.01		.02	
Principal daily pursuit								
Participating in society	-.01	.000	.00	.000	.014	.000	-.10	.010
Living situation		.011		.000		.002		.006
Living in institution sheltered	.10		.02		.05		.06	
Living with family	-.02		.00		.01		.07	
Marital status		.007		.004		.000		.006
Unmarried	.09		-.06		.02		.00	
Divorced	.11		-.09		.01		-.08	
Income		.031[*]		.003		.013		.002
Standard	-.17[+]		.01		-.06		-.04	
>Standard	-.07		-.05		-.10		.01	
Psychiatric characteristics: Major DSM-IV-classifications								
Psychosis	-.06	.004	.01	.000	-.02	.000	.02	.000
Mood disorders	.01	.000	-.04	.001	.00	.000	.05	.002
Anxiety disorders	-.05 +.56C[*]	.021	.10	.009	.09	.007	-.05 +.63C[*]	.026[*]
Personality	-.04	.002	-.01	.000	-.04	.001	-.05	.002
Recovery-related variables								
Loneliness	-.08	.004	.02	.000	-.08	.004	-.12	.009
Coping								
Task-oriented	-.05	.002	-.10	.008	-.04	.001	-.04	.001
Emotion focused coping	-.58[+] +1.51M[#] +1.06H[+]	.049[+]	-.39[*] +1.01M[*] +1.03H[*]	.035[*]	-.34[*] + 1.10M[*] +.69H[*]	.029[*]	.04	.001
Avoidant coping	.00	.000	-.03	.001	-.01	.000	-.07	.004
Generic health status								
Physical functioning	.05	.002	.01	.000	-.03	.001	.03	.001
Social functioning	.02	.000	-.12	.012	-.02	.000	.17 -.54C[*]	.024[*]
Role limitations (phys problem)	.02	.000	-.05	.003	.03	.001	.12	.014
Role limitations (emot problem)	-.04	.001	-.17	.022[*]	.05 -.51C[*]	.026[*]	.02	.000
Mental health	-.09	.004	-.06	.002	.13	.002	.22 -1.13M[*] -.38H	.031[*]
Vitality	-.08	.004	.23[*] -.39M[+] -.34H[*]	.037[*]	-.04	.001	.31[*] -.85M[*] -.93H[*]	.029[*]
Pain	.01	.000	.02	.000	-.01	.000	.06	.003
General health perception	.10	.005	-.04	.001	.09	.006	-.02	.000

Shows standardized effect of a predictor (in row) on the dependent variable (hope, quality of life, self-efficacy beliefs, empowerment), controlled for the effect of condition and class. If both the interaction of the predictor with condition and class were not significant then the main effect and the corresponding R^2 change (ΔR^2) is shown, otherwise the estimates corresponding to the model with the significant interaction is shown.

* <.05; + <.01; # <.001

M: class showing medium recovery at t0; H: class showing high recovery at t0; L: reference category

C: intervention condition (control condition is the reference category)

Columns two and three of Table 3 present the standardized effect of a variable on change in hope and the corresponding increase in explained variance, respectively, after controlling for the effect of class and condition. For example, the standardized effect of being a woman on change in hope was -.01, and did not further increase the explained variance, which was 7.1%. Column three shows the increase in explained variance after incorporating both the variable and the interaction effect in the analysis, if an interaction was significant. Columns four to nine represent the effects on the other dependent variables, and have the same structure as columns two and three.

To summarize the results of the multiple regression analyses, most variables did not have an effect on change in recovery. If an effect was present, the effect was small or small to medium with a maximum effect of emotion-focused coping on change in hope (explaining 4.9% of the variance). The effect of emotion-focused coping on change in hope, quality of life and self-efficacy beliefs was negative for the class low on recovery at T0, and positive for those in the other two classes. There was no effect of emotion-focused coping on change in empowerment. Anxiety disorder, vitality and role limitations (emotional problem) affected changes in scores on two key elements of recovery. Improvement in both hope and empowerment was positively affected by anxiety disorder, but only in the experimental condition. Vitality affected quality of life (positive effect for those in class L) and empowerment (positive for class L, and negative for class M). Role limitations (emotional problem) affected quality of life (negative) and self-efficacy beliefs (negative effect, but only in the experimental condition). Some other variables affected only the change in scores on one key element of recovery. Level of education (higher for class M) and income (lower for standard income) affected hope. Improvement in empowerment was affected by mental health in class M (negative).

DISCUSSION

The aim of the present study was to evaluate which factors promote change in recovery. The first research question was whether there was a positive effect of the course on change in recovery for classes of people with different recovery profiles. Results show that the first research question in general can be answered affirmative. The course had a positive effect on change in recovery with respect to hope, self-efficacy beliefs, and empowerment, but not on quality of life. The effect of the course was the same across classes, whereas change in recovery was different across the three classes. The finding that the course had a positive effect in all classes suggests that all individuals, whether scoring low, medium, or high on the

recovery measures at baseline, benefit from the course. The effect of class on change in recovery, however, could be attributed to a statistical artifact. Our finding that individuals in the high, middle and low classes on recovery at T0 score on average negative, average and positive on change in recovery is exactly what can be expected from the statistical regression towards the mean phenomenon (37).

The second and third research question were which other variables than the recovery profiles contributed to change in recovery over time, and for which persons a peer-run course was most beneficial. Only a few factors had an effect on change in recovery and the effect of only a small number of factors differed across classes or condition. Moreover, if an effect was present, this effect was small or small to medium. The fact that few and small effects on change in recovery were found, suggests that the peer-run course in itself is an important contributor to change in recovery. In addition, the course seems beneficial for individuals with different demographic and psychiatric characteristics, and with different scores on recovery-related variables.

The effect of the course depends on whether persons have an anxiety disorder. Participants with anxiety disorder showed more improvement on two out of four key elements of recovery, suggesting that the course might be most beneficial for people with anxiety disorders. Furthermore, a few variables only had an effect on change in recovery for some people. Emotion-focused coping had a negative effect on recovery for people in an early phase of recovery, whereas vitality had a positive effect for those people. In contrast, emotion-focused coping has a positive effect on the recovery of participants in an advanced state of recovery, whereas vitality has a negative effect on their recovery. Role limitations caused by emotional problems had a negative effect on change of self-efficacy beliefs of participants. These factors need to be taken into account by course instructors and health care professionals to promote that participants might benefit even more from the course 'recovery is up to you'.

There are some limitations of the present study that need to be addressed. First, it would be preferable to have one measure for recovery. However, no well-established Dutch instrument to measure recovery was available at the time of the study. Therefore, four proxy measures were used. These measures contributed equally to the different profiles, which suggests that these might be equally important aspects of recovery. Second, the findings of the present study cannot be extrapolated to all clients in mental health care because of the exclusion criteria. In the present study, people were included who were able to participate in a course on recovery. Therefore, people with florid psychotic problems, major addiction problems,

suicidal people, immigrants not familiar with the Dutch language and people in a 'final' stage of recovery were not included.

All in all, the conclusion is warranted that the effect of the course on participants' recovery is positive and that the peer-run course was the main explanatory factor of the recovery of its participants. This implicates that peer-run services are important for the recovery of people with major psychiatric problems.

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Chapter 7

General discussion

GENERAL DISCUSSION

During the last 30 years, the attention of mental health providers, researchers and policymakers has been drawn to the concept of recovery. In the 1980s, a new view on recovery emerged in psychiatry, based on the 'consumer's perspective' (1). Here, the focus was not on traditional (medical) outcomes, but on individually-defined and more subjective constructs, such as personal growth, hope and autonomy (2). Although interest in this type of recovery expanded rapidly in Western countries (2-5), very little research has focused on new outcome measures for recovery, or on how this type of recovery can be achieved or promoted.

This new view on recovery has been taken seriously by health care providers and policymakers. In turn, this has consequences for the organization of mental health care because a more demand-driven, recovery-oriented mental health care is required. Peer-run services are a good example of how a more recovery-oriented health care system can be arranged (6, 7). However, despite their advantages and importance for a recovery-oriented care, peer-run services are still not common as a form of mental health service provision. Moreover, studies on the effectiveness of peer-run services are scarce and poorly controlled (6, 8, 9). In order to develop a more evidence-based recovery-oriented health care, more in-depth knowledge on individually defined recovery and the effects of peer-run services is required.

In this thesis the peer-run course 'Recovery is up to you', that was developed by clients and two professionals, has been evaluated. This is a peer-run course lasting for 12 weeks with one 2-hour session each week. The groups are led by two trained course instructors who were themselves in an advanced state of their recovery process and who had previously been course participants. Each session was organised around a specific recovery-related theme, following the text of the manual and workbook.

The central aim of the present thesis was to evaluate the feasibility of the peer-run course 'Recovery is up to you' and its effects on the recovery of its participants, that is, on people with major psychiatric problems. In order to measure 'hope', a Dutch version of the Herth Hope Index was developed. The general feasibility of the peer-run course was assessed by means of interviews and checklists. To compare the peer-run intervention combined with 'care as usual' with 'care as usual' alone, a Randomised Controlled Trial (RCT) was conducted. Moreover, to gain insight into the factors related to recovery at baseline, a latent class analysis was conducted. Subsequently, four sets of sequential multiple regression

analyses were run to predict change in recovery between baseline and three months later, at the end of the course.

In this final chapter the main findings of the study are summarised, the study limitations are outlined and discussed, recommendations are made for future research, and implications for clinical practice are addressed.

MAIN FINDINGS AND REFLECTIONS

Main findings

The Dutch version of the Herth Hope Index has shown to be an instrument with adequate psychometric properties that can be used as an outcome measure when studying people with severe mental illness. The feasibility study showed that the course 'Recovery is up to you' is a promising tool because it is easy to implement and responses to the course were positive. The manual and workbook are clear and user-friendly, and no major structural problems emerged concerning adherence to the protocol. The RCT demonstrated that the course had a considerable positive effect on important domains of recovery, i.e., empowerment, hope and self-efficacy beliefs. There was also evidence for a weak positive effect on quality of life, task-oriented coping and general mental health, and a weak negative effect on emotion-focused coping. Moreover, these effects persisted (for at least) three months after the course had ended. Therefore, the conclusion that the course offers participants an opportunity to make an active start in the recovery process is justified.

At baseline, latent class analysis of empowerment, hope, self-efficacy beliefs and quality of life resulted in three classes. Characteristics of the people in the class with the lowest scores on the recovery measures appeared to correspond with the first phase of recovery, as described by Spaniol and colleagues (10), called 'being overwhelmed by the disability'. People in the middle scoring class mainly corresponded with the second phase of recovery, called 'struggling with the disability', and those in the highest class matched the third phase of recovery, called 'living with the disability' (10). The classes showed significant differences on the variables corresponding with these phases of recovery, that is, on loneliness, close social contacts, utilization of psychiatric medication, generic health status (social functioning and mental health) and task-oriented coping. Furthermore, the classes differed on health care utilization, health care needs and anxiety disorder. Multiple regression analyses showed that the course itself contributed the most to change in recovery of its participants. However, after controlling for the effect of the course and differences in classes,

other variables were shown to contribute to change in recovery on more than one key element of recovery. These variables were emotion-focused coping, anxiety disorder, and vitality.

Reflections

Hope is an important aspect of recovery and a major concern in patients with mental illness. The present study started with the development of a Dutch version of the Herth Hope Index (HHI-Dutch). Subsequently its validity (content, convergent and divergent validity) and reliability (internal consistency and test-retest reliability) were evaluated in a sample of people with severe mental illness. The Dutch version of the Herth Hope Index has proven to be an instrument with adequate psychometric properties. It is advisable to use the scale as a whole, rather than using the subscales, because studies have shown that interpretation of the subscales is difficult. Its briefness and suitability for clinical use also make the instrument an appropriate tool for research and clinical interventions investigating 'hope' in clients with severe mental illness.

The results of the RCT support the vision that peer-run services, such as the course 'Recovery is up to you', are important for a recovery-oriented mental health care, particularly because the course enhances autonomy, self-determination and self-management of participants. Internal motivation is important for recovery. The effects of the course on empowerment, hope and self-efficacy beliefs suggest that participants are activated by the course to take responsibility for their personal recovery or self-management. The course contributes to their internal motivation and enables participants to make an active start with recovery. These ideas are supported by the responses of participants in the interviews; they indicated they had gained more insight about themselves, their specific needs, social contacts, and about influences on their personal recovery. This knowledge may change their attitudes and enables them to take more responsibility for their personal recovery. About 30 % of the participants was already taking more responsibility; for example, they had learned to stand up for themselves, make choices, set goals, and take steps to achieve their aims. About 25% of the participants mentioned that their self-confidence had increased, and a smaller group was planning to improve their social contacts. Moreover, the non-hierarchical, reciprocal and collaborative relationships among peers stimulate participants to become active participants in mental health treatment.

Research on the effectiveness of, for instance, self-help groups on recovery has been limited and only a few RCTs have been conducted (6, 8, 9). In the present study, the main effects of the course on empowerment, hope and self-efficacy beliefs are comparable with

those of two recent studies (11, 12). These latter studies also assessed the effects of a 12-week peer-run intervention for people with major psychiatric problems, both based on a recovery workbook (11, 12). Although the results are comparable, the studies differ regarding the intervention, outcome measures and study design. In the Canadian study, the intervention was similar to that in the present study, but was led by one peer and one professional (12). The intervention in the American study differed from ours in that it guided users to develop a personalised recovery plan, and to explore and create goals within nine life domains (11). Outcome measures for hope and quality of life in the Canadian study (12) were comparable to those in the present study. The Canadian RCT (n=33) showed effects on hope, empowerment and recovery, but not on quality of life (12). The American study (n=47), which was not an RCT, showed improvement on self-esteem, self-efficacy, spiritual well-being, social support and psychiatric symptoms (11). Another American study (also not an RCT) investigating an 8-week peer-run intervention on recovery (called 'Wellness Recovery Action Planning') showed effects on recovery, hopefulness and self-efficacy (13). Remarkably, participants' scores on empowerment decreased after the intervention; however, this intervention contained predominantly educative illness management strategies and a highly individualized plan for recovery, which might be less empowering (13). In the present study, the weak positive effect on quality of life may be judged as significant for the practice of psychiatry, because achieving substantial improvements on subjective quality of life in a group with predominantly long-term problems is usually regarded as somewhat limited (14). The weak positive effects on general mental health and task-oriented coping after only three months are also promising. A final point is that none of the above-mentioned studies reported which elements of the intervention were responsible for the effects.

Although it is unclear exactly which components resulted in the beneficial effects of the peer-run course 'Recovery is up to you', participants mentioned the following elements as being important for their recovery: the course leaders as effective role models, the safety and openness within the group, and the course material itself. Explanations can be found in theoretical studies (6, 15-17) and in earlier studies on comparable interventions (7, 11-13, 16, 18). The majority of the participants were inspired by the course instructor and valued the social support of the other participants. These factors may promote hope, empowerment and self-efficacy beliefs (6, 15-17). Most likely a combination of these elements is responsible for the effects of the course (e.g. the course instructors create openness within the group by revealing and discussing their own experiences). The design of the present study does not allow us to conclude that peer-led groups are more effective than professional-led groups.

However, common elements in the three comparable studies (11-13) that might account for the effects in the present study were peer education, or recovery education and peer support, as well as the clear structure of the intervention. Finally, the intervention contains elements of psycho-education and illness management, both of which are well-known and evidence-based methodologies that might strengthen the effects of the course (19).

The results of the latent class analysis confirmed that peer-run services might attract people into mental health care who are not yet making use of 'standard' psychiatric care. First of all, the results showed that people in the class with the lowest scores on the recovery measures deserve special attention because they had the highest health care needs but not the highest utilization of health care. Also, the sample consisted of people with a recovery profile that best corresponds with the first phase ('being overwhelmed with the disability') or the second phase ('struggling with the disability') as described by Spaniol and colleagues (10). It is promising for mental health care that the course may attract people who are in an early phase of recovery in mental health care. Finally, it is promising that people with different recovery profiles did not differ on the use of self-help and on the use of information considering self-help. This indicates that self-help is meaningful for those in different phases of recovery and may also help to engage them into mental health care.

The effect of the course on recovery is positive for all participants and does not depend on their recovery profile. Therefore, the course is suitable for people in all phases of recovery who are motivated to work on their personal recovery. Regression analyses did not show a positive effect of the course on change in recovery with respect to quality of life, although a weak positive effect on quality of life was found in the RCT. Finally, the effect of the course also depends on other factors. One finding was that anxiety had a positive effect on recovery but only for course participants, suggesting that the course may be most beneficial for people with anxiety disorder. Some other variables only improved recovery for some people. Vitality only had a positive effect for people in an early state of recovery, whereas emotion-focused coping only had a positive effect for those in an advanced state of recovery. Therefore, course instructors and health care professionals need to take anxiety, vitality and emotion-focused coping into account to optimize participants' gains of the course.

METHODOLOGICAL CONSIDERATIONS

Client involvement in the study

Throughout the entire study, the researchers collaborated closely with a group of people who were in an advanced state of their recovery process and who were not involved in the

study as participants - these were the peer research assistants. Some were part of the advisory board of the study, others were active in the complicated data collection process which took place throughout the Netherlands, and others were trained as interviewers.

Interviews were conducted by the researchers and peer research assistants. These peer research assistants were trained in interview skills and reporting. They were supervised by the researchers by means of evaluation meetings and by regular checks and discussions about the interview reports. During the interviews a second peer research assistant was present to transcribe the interview. All interviews were transcribed verbatim by two peer research assistants and checked by the researcher. To increase the validity of the interview texts, these were sent back to the interviewees to check the content of the interview.

During the assessments, peer research assistants were also present in order to create a more comfortable atmosphere for the participants in the study. The presence of peers as researchers proved to be very reassuring for the participants and made the meetings less formal. The peer research assistants received special training on how to behave as an 'objective' researcher and how to maintain some 'distance' from the participants. Moreover, they were closely supervised by the researchers in order to guarantee the validity of the study. Although this collaboration was time consuming, client involvement was definitely of added value. For instance, peer research assistants were important for achieving participants' compliance with the study, and offered the researchers new perspectives on the interpretation of results. Working in a triad of researchers, clients and professionals, provides an opportunity to interact outside the stereotypical roles. This also offers a learning forum for working together on an equal basis whilst sharing different expertises (20).

Study limitations

The present study has a number of limitations that need to be discussed. First, the follow-up period ended three months after the course was completed. A longer follow-up would have offered more insight into the development and duration of the effects of the course. For instance, no effect was found on loneliness after three months whereas a longer time period may be needed to develop social networks (15, 21). A second limitation is that the intention-to-treat analysis could not be performed because of missing data of 24 participants (9 in the intervention group and 15 in the control condition). Due to a misunderstanding during data collection only baseline data were gathered from these 24 participants, who did not comply with the randomization. Instead, the effect of the intervention for participants who adhered to the research protocol was estimated (including those who dropped-out of the course), which

might have led to biased estimates of the effect of the intervention (22). Third, the study had only moderate statistical power to detect weak effects. The power to detect weak effects was only 0.56, which might explain why no conclusive significant effects were found for quality of life, mental health, and task-oriented and emotion-focused coping. Fourth, the cost-effectiveness of the intervention was not assessed. There is some (but not strong) evidence that peer-run services may improve symptoms, illness management and medication adherence, and reduce hospitalizations (15, 17). This indicates that the cost-effectiveness of the peer-run course may turn out to be positive. Furthermore, the intervention is easy to implement and relatively inexpensive compared with other interventions. Fifth, although the effects of the peer-run course were positive for participants in all phases of recovery, the results cannot be extrapolated to all clients in mental health care. People with florid psychotic problems and those with major addiction problems were not included in the RCT study. Finally, only a few immigrants were included in the study, although the prevalence of major psychiatric problems is high among immigrants in the Netherlands (23). Problems with the Dutch language and their lower utilization of mental health care (23) may explain the low numbers from immigrant groups.

Study strengths

To our knowledge, this is the first RCT with a large heterogeneous sample to evaluate the effects of a peer-run intervention on recovery. The RCT design, and the fact that clients were recruited at many different locations throughout the Netherlands by different people, made selection bias highly unlikely. Also, the risk of selective withdrawal is unlikely because the reasons for drop-out were similar in both the experimental and the control condition. Directly after the course more people in the control group dropped-out; this was expected because it was difficult to keep this group engaged in the study. A strength of the course is that people with different types of psychiatric problems are brought together, which results in a wide perspective on the process of recovery and not on the illness itself. The study is a further step in the quantitative evaluation of peer-run interventions, and in exploring the new recovery concept and the way this concept is operationalised. Moreover, the present study has an important emancipatory role in science due to the level of involvement of the clients.

RECOMMENDATIONS FOR FUTURE RESEARCH

Many developments worldwide aim to re-orientate research, policies and clinical practice from a traditional focus on effecting cure, to exploring ways to encourage and assist people to lead meaningful lives in the face of an enduring mental illness (3). However, in spite of this transformation of mental health care towards a more recovery-oriented care, these initiatives are not yet well supported by research. The present study shows that peer-run interventions such as 'Recovery is up to you' are important for the recovery of participants. Therefore, more research is needed on their effects and practical usefulness.

In the present study, a first quantitative orientation, steps have been taken towards identifying different classes of people with major psychiatric problems with different recovery profiles. This knowledge about the characteristics, special needs and development of people who are in different phases of recovery is important for the development of a more demand-driven mental health care.

Several issues need to be elucidated in future research. First, more studies are needed on the concept of recovery and its operationalisation in mental health care. A compact measure for recovery should be developed in the Netherlands. One short instrument will be more user-friendly for participants with limited concentration, and will certainly be preferable for clinical use. Such an instrument would also improve the comparability between different studies on recovery. Second, the successful components of peer-run services should be further explored, e.g. it is not yet established which specific elements are responsible for the effects of these services. Third, in future studies a longer follow-up is needed to assess how the effects of peer-run interventions persist or develop over a longer period of time. Fourth, the cost-effectiveness of these interventions should be assessed; this is necessary to show which costs can be saved in mental health care by the implementation of peer-run services. Fifth, research on the employability of clients in mental health care, and how they should be supervised and supported, is needed. Furthermore, the effects of being employed as a course instructor on the recovery of the course instructors themselves, should be investigated. Our practical experience with the course instructors indicates that they also benefit from their involvement with other clients, and from the 'helper-therapy' principle (24). Moreover, qualitative research has indicated a diversity of positive outcomes for peer-providers, such as personal growth, professional growth (including building job skills and moving toward a career goal), and improved quality of life (17). Finally, people with different severe (somatic) chronic illnesses may well benefit from the peer-run course and other peer-run interventions on recovery. The phases that these people go through are comparable with the phases of

mental illness as described by Spaniol and colleagues (10). Thus, people in the first phase of a chronic disease go through a very disruptive period in their life, full of turmoil and distress (25). Consequently they also make the transition toward incorporating chronic illness into their lives by an empowering process of taking responsibility for living well with the illness; this is a process of self-management (25, 26). Therefore, the peer-run course may contribute to their recovery. This is an interesting topic for further research. It is also unclear whether immigrants with major psychiatric problems will benefit from the peer-run course on recovery, or to what extent cultural differences might influence the effects of the course. Translation of the course material will probably be necessary to reach more immigrants and to reveal the effects of the course on the recovery of this specific group.

IMPLICATIONS FOR CLINICAL PRACTICE

Peer-run services can easily be implemented in mental health care settings. However, the success of such implementation depends on whether a major cultural shift in service delivery does indeed take place. First, the establishment of recovery-oriented services requires transformation of the way professionals are trained to think about their roles. Recovery-oriented training sessions for professionals will establish a new role for the professional that is facilitative, hope-inspiring and autonomy-enhancing, to help clients reach their potential, rather than being directive, pessimistic and paternalistic (4). However, not only the professionals need training in this new vision of recovery. The employability of clients as providers of mental health care requires supervision and support. Therefore, managers should also be trained to supply supervision and evaluation meetings, and to work together with clients as mental health providers in a satisfactory way. Also, new guidelines are needed that promote a collaborative relationship with the client (4). Finally, the scope of mental health services needs to become more community-oriented, with goals on different life domains, because recovery itself is related to different life domains.

Integration of peer-run services is important, because they are effective, inexpensive and might reach those persons who are not yet receiving mental health care. Moreover, peer-run services are important for a recovery-oriented care because they are complementary to 'standard care'. They supply the kind of social support that clients cannot receive from professionals, close relatives or friends, and are based on reciprocal relationships between peers. Finally, clients as mental health care providers may accelerate changing the attitudes of professionals, because they give those professionals the opportunity to see peers successfully function in their role as, for instance, a course instructor.

Implementation of peer-run services such as 'Recovery is up to you' in a community mental health care setting, such as Assertive Community Treatment (ACT) and Individual Placement and Support (IPS), may support the effects of these interventions on different life domains. These settings promote involvement and activity of the social networks of participants, which are important for their recovery. Whether or not participants take more responsibility for their personal recovery will depend on several factors. As mentioned, the effects of the 'Recovery is up to you' course on hope, empowerment and self-efficacy beliefs, promote taking responsibility for living well with the illness. However, social influences are also important. For some participants, the social support and modelling experienced in the course will stimulate their taking responsibility, whereas other participants may need more help to take this step. In that case, their health care professionals or members of their social network might stimulate this step.

In conclusion, this thesis has shown that the peer-run course 'Recovery is up to you' is an important tool for recovery-oriented care, that fulfils the health care needs of people with major psychiatric problems. People in all phases of recovery are interested in the peer-run course and it improves the recovery of participants in all phases of recovery. The course is effective, inexpensive and easy to implement. However, successful implementation needs to be promoted by a major cultural shift in service delivery, i.e. from a paternalistic, illness-oriented perspective to a collaborative, autonomy-enhancing approach. Clients as service providers are needed in a recovery-oriented care. Moreover, collaboration with professionals and researchers is important to complement the services aimed at reducing symptoms and suffering, with a focus on the process of developing self-agency for clients. This study has proven to be an example of a successful triad between researchers, clients and professionals.

7

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7

Appendix

Herth Hope Index - Dutch version

Hoop

Hieronder staan een aantal stellingen. Lees elke stelling en omcirkel het cijfer dat overeenkomt met de mate waarin u het op dit moment eens bent met die stelling.

	Sterk mee oneens	**Oneens**	**Eens**	**Sterk mee eens**
1. Ik heb een positieve kijk op het leven.	1	2	3	4
2. Ik heb doelen voor de korte en/of lange termijn.	1	2	3	4
3. Ik voel me heel erg alleen.	1	2	3	4
4. Ik kan mogelijkheden zien zelfs als ik in de problemen zit.	1	2	3	4
5. Ik heb een geloof of levensovertuiging waaraan ik troost ontleen.	1	2	3	4
6. Ik ben bang voor mijn toekomst.	1	2	3	4
7. Ik kan mij gelukkige/plezierige tijden herinneren.	1	2	3	4
8. Ik heb een diepe innerlijke kracht.	1	2	3	4
9. Ik ben in staat om zorg/liefde te geven en te ontvangen.	1	2	3	4

	Sterk mee oneens	Oneens	Eens	Sterk mee eens
10. Ik heb het gevoel dat mijn leven een richting heeft.	1	2	3	4
11. Ik geloof dat elke dag mogelijkheden biedt.	1	2	3	4
12. Ik vind dat mijn leven waardevol en nuttig is.	1	2	3	4

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Summary

SUMMARY

In the 1980s, a new view on recovery emerged in psychiatry, based on the client's perspective. Here, recovery was defined as *".... a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness"*. The new concept of recovery refers to how a person manages his or her life in the presence of an enduring illness. It focuses on individually-defined and more subjective factors, such as personal growth, hope, and autonomy and refers to an ongoing change process. The new view on recovery has consequences for the organization of mental health care, because the conventional medical definition of recovery still prevails in psychiatry. From a conventional point of view, recovery refers to cure and is primarily defined as an outcome. Current services are based mainly on this perspective. The new view of recovery, however, demands another way of working at recovery-oriented and demand-driven mental health care.

Peer-run services are an example of how recovery-oriented health care from the clients' point of view may be arranged. Peer-run services can promote recovery of people with severe mental illness, because these services enhance the autonomy of clients. Peers also supply the kind of social support that clients cannot receive from professionals and/or close relatives and friends. However, despite their advantages and importance for a recovery-oriented care, peer-run services are still not common as a form of mental health service provision. Moreover, research on the effectiveness of peer-run services has been scarce.

In order to develop a more evidence-based recovery-oriented health care, additional knowledge on individually-defined recovery and the effects of peer-run services is required. At present, most studies on recovery are qualitative and few quantitative data are available.

Central to this thesis is the evaluation of the peer-run course 'Recovery is up to you'. The central aim is to evaluate the feasibility of the peer-run course and its effects on the recovery of its participants, that is, on people with major psychiatric problems. In order to compare the recovery of participants of the peer-run intervention with the recovery of people placed on a waiting list for the peer-run course, a Randomised Controlled Trial (RCT) was conducted.

The peer-run course 'Recovery is up to you'

The course 'Recovery is up to you' was developed in 1996 by clients and two mental health professionals and was meant for people with major psychiatric problems. It consists of twelve weekly two-hour sessions. Groups are led by two trained course instructors who are prior course participants and who successfully participated in a train-the-trainer project. They have

to be in an advanced state of their recovery process, i.e.: according to Spaniol and others they should be living 'beyond their illness'. They closely follow a standardized manual, which describes the goals of every session precisely and how to reach them step by step.

Each session has the same structure and is organized around a specific, recovery-related theme, following the text of the manual and workbook. These are: the meaning of recovery to participants, personal experiences of recovery, personal desires for the future, making choices, setting up goals, participation in society, roles in daily life, personal values, how to get social support, abilities and personal resources, and empowerment and assertiveness. The participants use a standardized workbook and receive homework assignments. Important elements of the course are the presence of role models, psycho-education and illness management, learning from each other's experiences, social support, and homework assignments. In each session, themes are discussed in a group setting, individuals share experiences with each other, and skills are practiced.

Aims of the thesis

The work in the present thesis has the following aims:

1. To evaluate the psychometric properties of the Dutch version of the Herth Hope Index (HHI) in a sample of people with severe mental health problems.
2. To evaluate the feasibility of the peer-run course 'Recovery is up to you'.
3. To evaluate the effects of the peer-run course 'Recovery is up to you' by means of a randomised controlled trial.
4. To investigate whether classes of people with major psychiatric problems, with comparable profiles of individually-defined recovery, can be identified, and to relate these classes to the phases of recovery as described by Spaniol and colleagues.
5. To evaluate which factors promote individually-defined recovery.

Chapter 2 deals with the development of a Dutch version of the Herth Hope Index (HHI) and its psychometric properties. Hope is a key element of recovery and a major concern in patients with mental illness. In order to measure hope, a Dutch version of the Herth Hope Index (HHI- Dutch) was developed. Subsequently, its validity (content, convergent and divergent validity) and reliability (internal consistency and test-retest reliability) were assessed. To this end, the Dutch version of the HHI was used in three samples after a strict forward-backward translation procedure. First, a pilot study was conducted in which the content validity and comprehensibility of the HHI was tested on 25 people. Then, the

reliability and validity of the HHI were examined in a sample of 341 people participating in the peer-run course 'Recovery is up to you' (see also chapter 4). Finally, the test-retest reliability of the HHI- Dutch version was examined in a sample of 21 people with severe mental health problems working in a sheltered workplace.

Results showed that the original 3-factor structure could not be confirmed. A principal component analysis with varimax rotation was performed and two factors were identified: 'View on life and future' (α = .8) and 'Self-confidence and inner strength' (α = .69). The Cronbach's alpha for the HHI total score was .84 and a test-retest reliability of .79 was found. Convergent and divergent validity were satisfying. We advise to use the scale as a whole, rather than using the subscales, because studies showed that interpretation of the subscales is difficult (see table 1, Chapter 2). Its briefness and suitability for clinical use also make the instrument an appropriate tool for research and clinical interventions investigating 'hope' in patients with severe mental illness.

Chapter 3 describes the feasibility of the peer-run course 'Recovery is up to you'. This feasibility study was conducted to get more insight in the experiences of course instructors and participants with the peer-run course 'Recovery is up to you'. Furthermore the (dis)advantages of the course, the compliance with the course protocol, and important factors in implementing the course were evaluated.

The feasibility of the peer-run course was evaluated by semi-structured interviews and by checklists. Thirty-eight courses were evaluated. A total of 61 participants and 37 course instructors were interviewed. Checklists were assembled of 36 courses. In general, participants and course instructors reported positive experiences with the course. Participants spontaneously mentioned the course instructor, the group process and the course material as important factors for their recovery. Course instructors were reported as being important as a role model and participants felt inspired and supported by them. Concerning the group process, especially the openness and safety in the group were reported as important factors for recovery. The course material (workbook and other materials) and social support were also mentioned. Participants expressed that they learned about themselves, their specific needs, their social contacts, and their influence on their personal recovery. Course instructors noted that they had successfully stimulated and guided the group process. Checklists showed high protocol adherence and no major problems with adherence to structure, content, goals, and investment of time on each part of the sessions.

In conclusion, the results of the feasibility study suggest that the course is a promising tool to support the clients' recovery because it is easy to implement, experiences with the course were positive, the course material was clear and user-friendly, and there were no major structural problems with protocol adherence.

Chapter 4 deals with the effects of the peer-run course 'Recovery is up to you' on the recovery of people with major psychiatric problems. The effects were evaluated in a Randomised Controlled Trial (RCT) design. A total of 333 people were randomized to the experimental condition (n=168) or control condition (n=165). Participants in the experimental condition started the course within one week after randomization at T0, and completed the course after three months at T1. Participants in the control condition were placed on a waiting list and enrolled in the course after T2 (i.e.: six months after T0). Assessments for both conditions took place at baseline, after three months (i.e. at the end of the course; T1) and after six months (T2). Participants had to fill out measures on empowerment, hope, quality of life, self-efficacy beliefs, loneliness, coping and generic health status. Additional data for the control condition were gathered three (T3) and six months (T4) after the start of their course. This way, the effect of the intervention could be evaluated by (a) comparing recovery in the experimental and control condition at T1, (b) assessing whether a potential difference in recovery between the two conditions would persist three months after the course at T2, and (c) assessing recovery longitudinally in the control condition from T0 to T4. Data were analyzed using multilevel analysis.

The results of the RCT demonstrated that participants in the experimental condition had significantly higher scores on important elements of recovery after three months: empowerment, hope and self-efficacy beliefs. There was evidence for a weak positive effect on quality of life, task-oriented coping and general mental health and a weak negative effect on emotion-focused coping. There were no effects on physical health, loneliness and avoidant coping. The effects of the intervention persisted three months after finishing the course. Similar results were found for those initially placed on a waiting list (control condition) when they had participated in the course nine months later.

The effects of the peer-run course on empowerment, hope and self-efficacy beliefs confirm that peer-run services, such as 'Recovery is up to you', are of added value for recovery-oriented mental health care. The peer-run course offers participants an opportunity to make an active start with their recovery.

Although chapter 4 showed that the peer-run course contributes to the improvement of important domains of recovery, it is unclear which factors or elements of the course are responsible for these effects. Moreover, research on the factors associated with recovery is limited. **Chapter 5** describes the investigation whether classes of people with major psychiatric problems with comparable profiles of individually-defined recovery can be identified by latent class analysis. The study also evaluates whether these classes are comparable to the phases of recovery, as described by Spaniol and colleagues. Spaniol and colleagues described four phases of recovery, respectively: 'being overwhelmed by the disability', 'struggling with the disability', 'living with the disability' and 'living beyond the disability'. Based on this description, it was hypothesized that the classes would differ on loneliness, close social contacts, utilization of psychiatric medication, generic health status (social functioning, mental health) and task-oriented coping. The study also assessed whether these classes were related to other variables, i.e.: demographic and psychiatric characteristics and health-related variables.

A latent class analysis was conducted on four proxy measures of recovery, i.e.: hope, quality of life, self-efficacy beliefs and empowerment, assessed before the start of the course. The classes of people were based on participants that were either about to follow the peer-run course on recovery, or were placed in the control condition. Three classes were found, showing characteristics that are in line with phases of recovery as described by Spaniol. The classes differed significantly on the four proxy measures of recovery, but also on loneliness, close social contacts, utilization of psychiatric medication, generic health status (social functioning, mental health) and task-oriented coping. Characteristics of people in the lowest scoring class seemed to correspond with the first phase of Spaniol and colleagues: 'being overwhelmed by the disability', whereas characteristics of people in the middle class corresponded best with the second phase: 'struggling with the disability'. The characteristics of people in the highest scoring class matched especially with the third phase of Spaniol and colleagues: 'living with the disability'. Finally classes differed also on health care utilization, health care needs and anxiety disorders, but not on demographic variables.

In conclusion, different classes of people with major psychiatric problems having comparable profiles of individually-defined recovery were identified, corresponding with Spaniol's phases of recovery. Future research may focus on the characteristics and special needs of people who are in different phases of recovery. This knowledge will contribute to a more fine-tuned and recovery-oriented health care.

Chapter 6 is based upon the classes identified in Chapter 5. The aim of the study was to evaluate which factors promote change in recovery. More specifically, the study aimed to discover whether there was a positive effect of the course on change in recovery from baseline to the end of the course, for all classes of people with different profiles of individually-defined recovery. Furthermore the study aimed to discover which other variables than the recovery profiles contributed to change in recovery over time, and for which persons the peer-run course was most beneficial. Change in recovery was assessed by computing the difference in recovery at T1 and T0.

The results of sequential regression analyses showed that the course had a positive effect on change in recovery for hope, self-efficacy beliefs and empowerment, but not for quality of life. The course had a positive effect in all classes, which suggests that all individuals, whether scoring low, medium or high on recovery measures at baseline, benefit from the course. Therefore, the course is suitable for people in all phases of recovery who are motivated to work on their personal recovery.

Most other variables did not affect change in recovery. If an effect was present, the effect was small or small to medium. Sometimes the effect differed across classes. For example, the effect of emotion-focused coping on change in hope, quality of life and self-efficacy beliefs was negative for people in an early state of recovery (the class low on recovery at T0), and positive for people in an advanced state of recovery (those in the two other classes). The effect of the course was affected by few other variables. One finding was that people with anxiety disorder recovered more after the course than other participants.

The overall conclusion is warranted that the effect of the course on participants' recovery is positive and that the peer-run course was the main explanatory factor of the recovery of its participants. This implies that the peer-run course 'Recovery is up to you' is important for the recovery of people with major psychiatric problems.

Chapter 7, the general discussion, closes with recommendations for future research and implications for clinical practice. Future research should focus on successful components of peer-run services, on the cost-effectiveness of these services and on the persistence of their effects. Research on the employability of clients in mental health care is also needed, and how they should be supervised and supported. Finally, future research should focus on the suitability and effects of the peer-run course 'Recovery is up to you' for people with different severe (somatic) chronic illnesses or immigrants with major psychiatric problems.

Client involvement in practice and research is definitely of added value. In the present study, peer research assistants were important for achieving participants' compliance with the study, and they offered researchers new perspectives on the interpretation of results. This promotes interaction and exchange of knowledge in a triad of researchers, clients and mental health care professionals.

Peer-run services have an important role in a recovery-oriented care, because they may accelerate changing the attitudes of professionals, they offer a special kind of social support and they may reach persons who are not yet receiving mental health care. Implementation of peer-run services such as 'Recovery is up to you' in a community mental health care setting, may support the effects of these interventions. These settings promote involvement and activity of the social networks of participants, which are able to support them in their personal recovery continuously. Successful implementation of peer-run services needs to be promoted by a major cultural shift in service delivery, which can be achieved by training sessions for mental health care professionals and managers and by new guidelines, in order to promote a collaborative relationship with the client.

Samenvatting

SAMENVATTING

In de jaren tachtig is een nieuwe visie op herstel ontstaan in de psychiatrie, die gebaseerd is op het perspectief van de cliënt. Herstel wordt hier gedefinieerd als "…het ervaren van een bevredigend, hoopvol en betekenisvol leven, ondanks de beperkingen van je ziekte". Binnen dit nieuwe concept van herstel gaat het er dus om hoe iemand zijn leven weer onder controle kan krijgen terwijl de ziekte toch aanwezig is. Herstel is een aanhoudend proces van verandering, waarbij allerlei subjectieve factoren een rol spelen, zoals persoonlijke groei, hoop en autonomie. Deze nieuwe visie op herstel heeft gevolgen voor de organisatie van de Geestelijke Gezondheidszorg (GGz). De conventionele, medische definitie van herstel overheerst nog steeds in de psychiatrie; hier betekent herstel 'genezing' en gaat het om een eindstadium van het genezingsproces. Een groot deel van de huidige zorg is gebaseerd op dit perspectief. De nieuwe definitie van herstel vraagt echter om een meer herstelgeoriënteerde en vraaggerichte GGz.

Cliëntgestuurde interventies zijn een voorbeeld van hoe een meer herstelgeoriënteerde gezondheidszorg georganiseerd zou kunnen worden. Cliëntgestuurde interventies kunnen herstel van mensen met ernstige psychiatrische aandoeningen bevorderen, omdat ze de autonomie van cliënten vergroten. Lotgenoten verlenen echter ook een speciale soort sociale steun, die cliënten niet kunnen ontvangen van GGz professionals of van nabije vrienden of kennissen. Ondanks de voordelen die cliëntgestuurde interventies bieden en hun belang voor een herstelgeoriënteerde zorg, zijn ze nog steeds niet gangbaar binnen de GGz. Bovendien is er nog niet veel onderzoek naar de effectiviteit van deze interventies gedaan.

De ontwikkeling van een meer evidence-based, herstelgeoriënteerde gezondheidszorg, vraagt om meer kennis van subjectief gedefinieerd herstel en van de effecten van cliëntgestuurde interventies. De meeste studies over herstel zijn kwalitatief en er zijn maar weinig kwantitatieve data ten aanzien van herstel beschikbaar. Daarom is meer kwantitatief onderzoek nodig.

Centraal in deze thesis staat de evaluatie van de cliëntgestuurde cursus 'Herstellen doe je zelf.' Het centrale doel is de evaluatie van de uitvoerbaarheid van de cursus, en van de effecten van de cursus op het herstel van de deelnemers; mensen met ernstige psychische beperkingen. Om het herstel van de deelnemers aan de cursus te kunnen vergelijken met het herstel van mensen die op de wachtlijst stonden, is een gerandomiseerd gecontroleerd onderzoek (RCT) uitgevoerd.

De cliëntgestuurde cursus 'Herstellen doe je zelf'

De cursus 'Herstellen doe je zelf' is ontwikkeld in 1996 door drie ervaringsdeskundigen en twee professionals en is bedoeld voor mensen met ernstige psychiatrische problematiek. De cursus bestaat uit twaalf wekelijkse bijeenkomsten van twee uur. De groepen worden geleid door twee getrainde cursusleiders, die zelf ook de cursus gevolgd hebben en daarna succesvol een train-de-trainer project hebben afgesloten. De cursusleiders dienen zover te zijn in hun herstel dat hun beperkingen in hun leven op de achtergrond staan. Ze volgen een gestandaardiseerde handleiding waarin de doelen van elke sessie nauwkeurig staan beschreven en hoe deze doelen stap voor stap kunnen worden bereikt.

Elke sessie heeft dezelfde structuur en gaat over een thema dat met herstel te maken heeft. Hierbij worden de handleiding en het werkboek steeds nauwkeurig gevolgd. Thema's, die in de sessies aan bod komen, zijn: de betekenis van herstel voor deelnemers, persoonlijke ervaringen met herstel, persoonlijke wensen voor de toekomst, keuzes maken, doelen opstellen, deelnemen in de maatschappij, rollen in het dagelijkse leven, persoonlijke waarden, ontvangen van sociale steun, mogelijkheden en persoonlijke hulpbronnen en tenslotte empowerment en assertiviteit. In elke sessie wordt het thema besproken in de groep en worden ervaringen uitgewisseld met elkaar en vaardigheden getraind. De deelnemers gebruiken, net als de trainers, een gestandaardiseerd werkboek en krijgen huiswerkopdrachten. Belangrijke elementen van de cursus zijn de aanwezigheid van rolmodellen, psycho-educatie en het leren hanteren van de ziekte, het leren van ervaringen van anderen, sociale steun en huiswerkopdrachten.

Doelen van de thesis

Dit proefschrift heeft de volgende doelen:

1. Evalueren van de psychometrische eigenschappen van de Nederlandse versie van de Herth Hope Index (HHI) in een steekproef van mensen met ernstige psychiatrische problemen.

2. Evalueren van de uitvoerbaarheid van de cliëntgestuurde cursus 'Herstellen doe je zelf.'

3. Evalueren van de effecten van de cliëntgestuurde cursus 'Herstellen doe je zelf.' door middel van een gerandomiseerd gecontroleerd onderzoek.

4. Onderzoeken of klassen van mensen met psychiatrische problemen kunnen worden onderscheiden met vergelijkbare profielen van subjectief gedefinieerd herstel, en te evalueren of deze klassen vergelijkbaar zijn met verschillende fasen van herstel.

5. Onderzoeken welke factoren subjectief gedefinieerd herstel bevorderen.

Hoofdstuk 2 gaat over de ontwikkeling van de Nederlandse versie van de Herth Hope Index (HHI) en over de psychometrische eigenschappen van dit instrument. Hoop is een belangrijk element van herstel en belangrijk voor mensen met ernstige psychiatrische problemen. Om hoop te kunnen meten, is de van oorsprong Engelstalige Herth Hope Index in het Nederlands vertaald en zijn daarna de validiteit en betrouwbaarheid van de vertaalde versie onderzocht. Hierbij is gebruik gemaakt van drie onderzoekspopulaties. Na een strikte vertaalprocedure (forward-backward) is allereerst een pilot uitgevoerd bij 25 cliënten om de inhoudsvaliditeit en begrijpelijkheid van de HHI te testen. Daarna zijn de validiteit en betrouwbaarheid onderzocht bij 341 mensen die deel zouden gaan nemen aan de cursus 'Herstellen doe je zelf' (zie ook hoofdstuk 4). Tenslotte is de test-hertest betrouwbaarheid van de HHI onderzocht bij 21 mensen met ernstige psychiatrische problematiek die in een beschermde werkplaats werkten.

Uit de resultaten bleek dat de originele 3-factoren structuur niet kon worden bevestigd. Een principale componentenanalyse met varimaxrotatie werd uitgevoerd, waarbij twee factoren werden onderscheiden: 'Kijk op leven & toekomst' (α = .8) en 'Zelfvertrouwen & innerlijke kracht' (α = .69). De Cronbach's alpha voor de HHI-totaal score was .84 en de test-hertest betrouwbaarheid was .79. Convergente en divergente validiteit waren bevredigend. Gebruik van de totale schaal in plaats van de subschalen is aan te raden, omdat eerdere studies (zie tabel 1, hoofdstuk 2) aantoonden dat de subschalen moeilijk te interpreteren zijn. De HHI is compact en geschikt voor klinisch gebruik. De vragenlijst kan zowel gebruikt worden voor klinische interventies als voor onderzoek, met als doel kennis over hoop bij mensen met ernstige psychiatrische beperkingen te vergroten.

Hoofdstuk 3 beschrijft de uitvoerbaarheid van de cliëntgestuurde cursus 'Herstellen doe je zelf.' De studie naar de uitvoerbaarheid is gedaan om meer inzicht te krijgen in de ervaringen van cursusleiders en deelnemers met de cursus 'Herstellen doe je zelf.' Tevens is geëvalueerd of de cursusleiders zich aan de handleiding hielden, wat de voor- en nadelen van de cursus zijn en wat belangrijke factoren zijn bij de implementatie van de cursus.

De uitvoerbaarheid van de cursus is geëvalueerd aan de hand van semi-gestructureerde interviews en checklisten. In totaal zijn er 38 cursussen geëvalueerd en zijn er 61 deelnemers en 37 cursusleiders geïnterviewd. Van 36 cursussen zijn ook checklisten verzameld. Over het algemeen hadden deelnemers en cursusleiders positieve ervaringen met de cursus. Deelnemers gaven spontaan aan dat de cursusleider, het groepsproces en het cursusmateriaal belangrijk waren voor hun herstel. Cursusleiders waren volgens de geïnterviewden belangrijk

als rolmodel en deelnemers voelden zich door hen geïnspireerd en gesteund. Ten aanzien van het groepsproces werden vooral de openheid en veiligheid in de groep genoemd als belangrijke factoren voor herstel. Het cursusmateriaal (werkboek en handleiding) en de sociale steun werden ook genoemd. Deelnemers vertelden dat ze meer kennis hadden gekregen van zichzelf, hun behoeften, hun sociale contacten en de invloed die ze zelf hadden op hun persoonlijk herstelproces. Cursusleiders merkten op dat ze naar hun idee het groepsproces succesvol hadden geleid en gestimuleerd. De checklisten lieten zien dat men zich goed aan de handleiding hield en dat er geen grote problemen waren met het vasthouden aan de structuur, inhoud, doelen en tijdsinvestering per onderdeel van elke sessie.

Samenvattend lijkt 'Herstellen doe je zelf' een veelbelovende cursus te zijn, omdat deze gemakkelijk te implementeren is, de ervaringen met de cursus positief waren, het cursusmateriaal helder en gebruiksvriendelijk blijkt te zijn en er geen grote structurele problemen waren met het vasthouden aan de handleiding.

Hoofdstuk 4 gaat over de effecten van de cliëntgestuurde cursus 'Herstellen doe je zelf' op het herstel van mensen met ernstige psychiatrische problemen. De effecten werden gemeten aan de hand van een gerandomiseerd gecontroleerd onderzoek (RCT). In totaal zijn 333 mensen gerandomiseerd. Ze kwamen ofwel in de experimentele groep (n=168) ofwel in de controlegroep (n=165). Deelnemers in de experimentele groep begonnen binnen één week na de randomisatie met de cursus op T0 en beëindigden de cursus na drie maanden op T1. Deelnemers in de controlegroep werden op een wachtlijst geplaatst en startten met de cursus na T2 (6 maanden na T0). De vragenlijstafnames bij beide groepen vonden plaats op T0, na drie maanden (na het einde van de cursus; T1) en na zes maanden (T2). Deelnemers vulden vragenlijsten in over empowerment, hoop, kwaliteit van leven, (zelf)vertrouwen ofwel vertrouwen in eigen mogelijkheden, eenzaamheid, coping en algehele gezondheidssituatie. Bij de controlegroep werden extra gegevens verzameld, drie maanden (T3) en zes maanden (T4) na de start van hun cursus. Op deze manier kon het effect van de interventie worden bepaald door (a) herstel te vergelijken in de experimentele en controle groep op T1 (b) door te meten of er een verschil bleef bestaan in herstel tussen beide groepen op het tijdstip van 3 maanden na het einde van de cursus (T2), en (c) herstel longitudinaal te meten in de controlegroep tussen T0 en T4. De data zijn geanalyseerd met behulp van multilevel analyse.

De resultaten van de RCT lieten zien dat de deelnemers in de experimentele groep na drie maanden significant hogere scores hadden op belangrijke elementen van herstel, namelijk op empowerment, hoop en (zelf)vertrouwen. Verder was er een zwak positief effect op kwaliteit

van leven, taakgerichte coping en algehele mentale gezondheid, en een zwak negatief effect op emotiegerichte coping. Er waren geen effecten op fysieke gezondheid, eenzaamheid en vermijdingsgerichte coping. De effecten van de interventie bleven nog aanhouden tot drie maanden na het einde van de cursus. Vergelijkbare resultaten zijn gevonden bij degenen die op de wachtlijst waren geplaatst (de controlegroep) nadat zij aan de cursus hadden deelgenomen.

De effecten van de cursus op empowerment, hoop en (zelf)vertrouwen suggereren dat cliëntgestuurde interventies, zoals 'Herstellen doe je zelf,' van toegevoegde waarde zijn voor de herstelgeoriënteerde GGz. De cliëntgestuurde cursus biedt deelnemers de mogelijkheid om een actieve start met hun herstel te maken.

Hoewel hoofdstuk 4 liet zien dat de cliëntgestuurde cursus bijdraagt aan de verbetering van belangrijke elementen van herstel, is het onduidelijk welke factoren of elementen van de cursus nu precies verantwoordelijk zijn voor deze effecten. Daarnaast is tot nu toe weinig onderzoek gedaan naar factoren die geassocieerd zijn met subjectief gedefinieerd herstel. **Hoofdstuk 5** beschrijft of met behulp van latente klassenanalyse klassen onderscheiden kunnen worden van mensen met ernstige psychiatrische problemen, die vergelijkbare profielen van subjectief gedefinieerd herstel hebben. De studie evalueert ook of deze klassen vergelijkbaar zijn met de fasen van herstel, zoals beschreven door Spaniol en anderen. Spaniol en anderen beschreven vier fasen van herstel, respectievelijk: 'overweldigd worden door de beperking', 'worstelen met de beperking', 'leven met de beperking' en 'leven met de beperking op de achtergrond'. Uitgaande van deze beschrijving was de hypothese dat de klassen zouden verschillen op eenzaamheid, hechte sociale contacten, gebruik van psychiatrische medicatie, algehele gezondheidstoestand (t.a.v. sociaal functioneren en mentale gezondheid) en taakgerichte coping. Daarnaast richtte de studie zich op andere variabelen die een relatie met de klassen zouden kunnen hebben: demografische en psychiatrische eigenschappen en gezondheidsgerelateerde variabelen.

De latente klassenanalyse is uitgevoerd op de vier concepten die gebruikt werden om herstel te meten, namelijk: hoop, kwaliteit van leven, (zelf)vertrouwen en empowerment. De klassen waren gebaseerd op deelnemers die ofwel de cursus volgden, ofwel waren geplaatst in de controlegroep en dus geen cursus volgden. Drie klassen werden gevonden, die vergelijkbaar waren met de fasen van herstel zoals beschreven door Spaniol en anderen. De klassen verschilden significant op de vier herstelmaten en ook op: eenzaamheid, hechte sociale contacten, gebruik van psychiatrische medicatie, algehele gezondheidstoestand (t.a.v.

sociaal functioneren en mentale gezondheid) en taakgerichte coping. De eigenschappen van mensen in de laagst scorende klasse leken overeen te komen met de eerste fase van Spaniol en anderen: 'overweldigd worden door de beperking', terwijl de eigenschappen van mensen in de klasse met de middelste scores het meest correspondeerden met de tweede fase: 'worstelen met de beperking.' De eigenschappen van mensen in de hoogst scorende klasse kwamen vooral overeen met de derde fase van Spaniol en anderen: 'leven met de beperking.' Tenslotte verschilden de klassen op het gebruik van gezondheidszorgvoorzieningen, de behoefte aan zorg en op angststoornissen, maar niet op demografische variabelen.

Concluderend zijn er verschillende klassen van mensen met ernstige psychiatrische problemen te onderscheiden die vergelijkbare profielen van subjectief gedefinieerd herstel hebben. Bovendien corresponderen deze klassen met de fasen van herstel van Spaniol en anderen. Toekomstig onderzoek zou meer aandacht moeten besteden aan de eigenschappen en speciale behoeften van mensen die zich bevinden in verschillende fasen van herstel. Deze kennis zal bijdragen aan een nauwkeuriger op de cliënt afgestemde en herstelgeoriënteerde gezondheidszorg.

Hoofdstuk 6 bouwt voort op de latente klassenanalyse van hoofdstuk 5. Het doel van deze studie was om te onderzoeken welke factoren verandering in herstel bevorderen. Hierbij werd gekeken naar de verandering in herstel vanaf de nulmeting (T0) tot het einde van de cursus (T1). Dit werd allereerst onderzocht door na te gaan of er een positief effect was van de cursus voor alle klassen (ofwel: voor mensen met verschillende herstelprofielen). Daarnaast werd onderzocht welke variabelen (naast de herstelprofielen) bijdragen aan de verandering in herstel over de tijd en voor welke personen de cursus het meest effectief was.

De resultaten van de multiple regressie analyses toonden aan dat de cursus een positief effect had op de verandering in herstel voor hoop, (zelf)vertrouwen en empowerment, maar niet voor kwaliteit van leven. De cursus had een positief effect voor alle klassen, wat impliceert dat alle deelnemers, ongeacht of ze laag, gemiddeld of hoog scoren op de herstelmaten bij de nulmeting, profiteren van de cursus. Daarom is de cursus geschikt voor mensen in alle fasen van herstel, tenzij ze gemotiveerd zijn om aan hun herstel te werken.

De meeste andere variabelen hadden geen effect op de verandering in herstel. Als er een effect was, dan was het klein of klein tot gemiddeld. Soms verschilde dit effect voor de verschillende klassen. Bijvoorbeeld het effect van emotiegerichte coping op de verandering van hoop, kwaliteit van leven en (zelf)vertrouwen was negatief voor mensen in een vroeg stadium van herstel (mensen in de laagste klasse op T0) en positief voor mensen in een later

stadium van herstel (de andere klassen). Het effect van de cursus werd beïnvloed door enkele variabelen. Een bevinding was bijvoorbeeld dat mensen met angststoornissen meer herstelden na afloop van de cursus dan andere deelnemers.

De conclusie is gerechtvaardigd dat het effect van de cursus op het herstel van de deelnemers positief is en dat de cliëntgestuurde cursus zelf de belangrijkste verklarende factor is voor het herstel van de deelnemers. Dit impliceert dat de cliëntgestuurde cursus 'Herstellen doe je zelf' belangrijk is voor het herstel van mensen met ernstige psychiatrische problemen.

Hoofdstuk 7, de algehele discussie, eindigt met aanbevelingen voor toekomstig onderzoek en implicaties voor de klinische praktijk. Toekomstig onderzoek zou meer gericht moeten zijn op wat precies de succesvolle ingrediënten van cliëntgestuurde interventies zijn. Daarnaast moeten de kosten-effectiviteit en effectduur van dit type interventies nader onderzocht worden. Tevens is meer onderzoek nodig naar de inzetbaarheid van cliënten in de GGz en hoe zij daartoe het beste ondersteund en gesuperviseerd kunnen worden. Tenslotte zou nader moeten worden onderzocht of de cliëntgestuurde cursus 'Herstellen doe je zelf' ook geschikt is voor immigranten met psychiatrische problematiek en voor mensen met ernstige (somatische) chronische ziekten en wat dan de effecten zouden zijn.

Betrokkenheid van cliënten in praktijk en onderzoek is zeker van toegevoegde waarde. In deze studie waren cliënten als onderzoeksassistent van belang om mensen te binden aan het onderzoek en daarnaast gaven ze de onderzoekers nieuwe inzichten, o.a. ten aanzien van de interpretatie van de onderzoeksresultaten. Zo worden de interactie en de uitwisseling van kennis in de triade van onderzoekers, cliënten en professionals in de zorg bevorderd.

Cliëntgestuurde interventies hebben een belangrijke rol in een herstelgeoriënteerde zorg omdat ze een attitudeverandering van professionals op gang zouden kunnen brengen. Daarnaast bieden ze een speciaal soort sociale steun en zouden ze mensen kunnen bereiken die nog geen gebruik maken van de reguliere zorg. Implementatie van cliëntgestuurde interventies, zoals 'Herstellen doe je zelf' in een (GGz-)setting die zich ook richt op de sociale omgeving van de cliënt (zoals ACT of IPS), kan de effecten van deze interventies verder ondersteunen. Deze setting bevordert namelijk de betrokkenheid en invloed van de sociale netwerken van de deelnemers, die continu ondersteuning kunnen bieden bij hun persoonlijk herstel. Succesvolle implementatie van cliëntgestuurde interventies kan worden bevorderd door een cultuurverandering binnen de GGz tot stand te brengen. Deze cultuurverandering kan worden bereikt door middel van trainingen van professionals en het

management en door nieuwe richtlijnen in te voeren, met als doel de samenwerkingsrelatie tussen cliënt en hulpverlener te bevorderen.

Dankwoord

DANKWOORD

Herstellen doe je zelf. Het kán. Maar om te herstellen heb je een warm nest nodig. De cursus 'Herstellen doe je zelf' kan dat bieden. Deelnemers vinden daar de persoonlijke warmte, verbondenheid, en de rolmodellen die ze nodig hebben om goed te kunnen gedijen. Diezelfde elementen zijn onontbeerlijk bij het schrijven van een proefschrift. Zowel bij Tranzo als bij het KZE waren die elementen aanwezig.

Aan dit proefschrift hebben vele mensen bijgedragen. Het zou nooit tot stand gekomen zijn zonder Joop van den Bogaard. Joop heeft het onderzoeksvoorstel geschreven, maar mocht slechts twee jaar als projectleider hierbij betrokken zijn. Het is bijzonder spijtig dat hij niet getuige kan zijn van het resultaat van het onderzoek. Joop wilde ervaringsdeskundigheid in Nederland op de kaart zetten. Dit onderzoek draagt daar zeker aan bij. Ik voel me bevoorrecht dat ik met Joop mocht samenwerken en ben hem dankbaar voor zijn vertrouwen en steun in een bijzonder hectische periode van het onderzoek. Graag draag ik dit proefschrift op aan Joop en zijn gezin.

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Hanneke van Gestel
Riel, maart 2011.

Curriculum vitae

CURRICULUM VITAE

Hanneke van Gestel-Timmermans was born on July 30th 1962 in Tilburg, the Netherlands. She attended secondary school in Tilburg (Gymnasium B, St Pauluslyceum) where she passed her exam in 1980.

From 1980 to 1985 she studied physiotherapy in Breda. After her study she worked in different health care settings.

From 2001 to 2005 she studied Health Sciences at the Maastricht University. In 2006 she started her PhD study 'Recovery is up to you.'

At the moment she works at Tilburg University, department Tranzo on the research project 'Individual Placement and Support and Multi System Therapy'. Furthermore she is working for the Knowledge Centre for Self-help and Consumer Expertise on a pilot at Novadic Kentron Centre for Addiction Treatment in order to implement the peer-run course 'Recovery is up to you'. She is married and mother of two sons in the age of 17 and 20.

Hanneke van Gestel-Timmermans werd op 30 juli 1962 geboren in Tilburg. Na het behalen van haar Gymnasium B diploma, ging zij in 1980 fysiotherapie studeren in Breda. In 1985 studeerde zij af. Daarna is zij werkzaam geweest als fysiotherapeute in allerlei sectoren van de gezondheidszorg, o.a. bij het Albert Schweitzer Ziekenhuis in Dordrecht, Cello in Haaren (instelling voor mensen met een verstandelijke beperking), een particuliere praktijk in Tilburg en als docente pre- en postnatale educatie bij Thebe.

In 2001 is zij Gezondheidswetenschappen gaan studeren in Maastricht en in 2005 afgestudeerd richting Arbeid en gezondheid. In 2006 startte zij vervolgens met het promotie-onderzoek 'Herstellen doe je zelf.'

Momenteel is zij werkzaam bij Tranzo als onderzoeker binnen het project 'Trajectbegeleiding verbinden met Multi Systeem Therapie'. Daarnaast werkt ze samen met het Kenniscentrum Zelfhulp en Ervaringsdeskundigheid aan een pilot binnen Novadic Kentron met als doel de cursus 'Herstellen doe je zelf' te implementeren binnen de verslavingszorg. Zij is gehuwd en moeder van twee zonen van 17 en 20 jaar.