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Chapter 1

General introduction

Personal Recovery

Research in psychosis has brought several mental health care developments in the past decades with new treatment options becoming available [1,2]. Although these advances in mental health care are promising, a substantial proportion of the population with psychosis still experiences persistent symptoms, causing a profound impact in their day-to-day life [3]. Tangible problems, resulting from psychosis are high levels of loneliness, unemployment, stigma or living an involuntary single life [4-6]. These persistent problems call for a patient perspective on mental health care for people with severe mental illness (SMI). A new aim in mental health care, driven by the consumer movement, provides such a perspective. This aim, called personal recovery, started gaining momentum around three decades ago [7]. Personal recovery is focused on psychosocial outcomes such as developing an identity beyond being a psychiatric patient, being imbedded in a social network or experiencing hope for the future. The most cited definition is from Anthony [8]: "personal recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness". The Substance Abuse and Mental Health Service Administration (SAMSHA) defined personal recovery as following: mental health recovery is a journey of healing and transformation that enables a person with a mental health disability to live a meaningful life in communities of his or her choice while striving to achieve full human potential or "personhood" [9].

Although the recovery movement first started gaining momentum in the 1990's, its roots go back to the mid 1930's with the start of the Alcoholic Anonymous [10]. This was documented as the first mutual-support self-help group. The first self-help groups for mentally ill people started in the 1950's [10]. After WWII deinstitutionalization started around 1950's in the United States [10] and in Europe around 1970's [11,12]. Beds in psychiatric hospitals were reduced and many people with mental disorders were expected to life outside the protection of hospital walls and in the community. This transition exposed the impact of psychiatric illness on the difficulties in living independently in the community. The emerging of the concept of personal recovery was partly driven by the psychiatric rehabilitation method, starting in the 1980's, which is a mental health professional approach encompassing interventions that help people with mental health disabilities with their lives in the community [13-15]. Nowadays rehabilitation services are considered a type of personal recovery interventions [16].

The personal recovery construct provides new opportunities in treatment and research of mental health care, that might improve the lives of people living with a proneness to psychosis. In this thesis, treatment and research of (personal) recovery are investigated in people with psychotic disorders. First, an overview of the subject is presented.

Psychotic disorder as a severe mental illness

In the heterogenetic field of psychopathology, psychosis is considered the most severe mental state [17]. Schizophrenia is a mental disorder that is mostly characterized by psychotic episodes. Due to the debilitating and lifelong effects of schizophrenia on functioning and mental and physical comorbidity, schizophrenia is considered a severe mental illness (SMI) [18]. Living with schizophrenia can cause problems in all facets of life. In the Global Burden of Disease (GBD) 2016 study, it is ranked 12th among 310 diseases (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators, 2016). The GBD study reports the burden of living with schizophrenia measured in Disability Adjusted Life Years (DALY's). The early age of onset resulting in high numbers of years living with disability, the premature mortality due to comorbid medical conditions and the risk for suicide all contribute to the high rank in the GBD [19,20]. Furthermore, people with psychosis experience psychological difficulties such as loneliness, stigma and low self-esteem [21,22] This high disease burden warrants comprehensive research to improve the lives of people living with schizophrenia.

Recovery in mental health care

Recovery in mental health care encompasses several domains: clinical, societal and personal recovery [23]. Recovery outcomes in the clinical domain in schizophrenia stem from a health perspective with broad symptom domains: positive symptoms (i.e., delusions and hallucinations); negative symptoms (i.e., demotivation and flattened affect); and cognitive symptoms. Recovery from clinical symptoms imply a state of health in which symptoms are eliminated to subclinical levels [24]. On the societal level, recovery outcomes involve being able to fulfil social roles such as being a partner, neighbor or employee. In their study on functioning of people with schizophrenia, measured with the WHO International Classification of Functioning, Disability and Health classification (ICF), Barrios et al. [25] found that people with schizophrenia are limited in a large number of activities and in their participation in society. Problems arise, for example, in the ability to keep relationships, in taking care of one's health, in employment or in domestic life [25]. A large proportion of people living with schizophrenia experience a continuation of these problems throughout their life. Only a small proportion of 13.5% of people with schizophrenia meet criteria for 'full' recovery on clinical (symptomatic) and societal recovery [26]. These impairments in functioning impede people with schizophrenia in pursuing goals in life that are usually well-attainable for people from the general population.

The personal recovery construct has a focus beyond clinical and societal recovery. This construct evolved from the addiction services, where consumers were involved in the health systems since the nineteen thirties in the last century. Before the 1990's the general view of schizophrenia was one of a progressive deterioration. However, longitudinal research showed that not all people diagnosed with schizophrenia showed cognitive decline, and some showed improvements over time [27,28]. Furthermore, the consumer movement emphasized the role of experiential knowledge that could contribute to living a meaningful or productive life without, or even in spite of mental health treatment [29], thereby transforming the traditional role of the one-directional mode of knowledge from professional to patient. The dominant role of pharmacological treatment was also questioned due to research on long-term antipsychotics use, showing that people with first episode psychosis (FEP) had better outcomes on functioning with a dose reduction or discontinuation of antipsychotics compared to maintenance treatment [30]. Besides the direct effects of mental illness, the consumer movement also raised awareness on stigma and discrimination, which have negative effects on personal identity and limits opportunities to fulfil meaningful roles in the community [29]. In summary, the consumer movement criticized traditional mental health care for its focus on the chronic course of the disease and on the hopelessness, dependency and stigma on which it was contributing to [24].

The concerns raised by the consumer movement, and supported by scientific research, led to a view on health care with a focus on hope and strengths and the benefits of using the experiential knowledge from people living with mental health problems [29]. In this personal recovery view, the emphasis was not on merely a reduction of symptoms, but on living a satisfying life in spite of psychiatric symptoms.

Although this description portrays the personal recovery view, it is not exhaustive, as personal recovery can also be viewed with wider implications varying from a shift in philosophical underpinnings of mental health care or its organizational restructuring [31].

Facilitating personal recovery

In the past decades an increasingly number of clinicians and researchers responded to the call of the consumer movement by developing personal recovery-oriented interventions and measures. An important example of this is the development of the CHIME framework [32]. This framework was developed based on extensive literature research of studies on personal recovery. The CHIME acronym stands for Connectedness (the support people experience from others and being involved in the community), Hope (having a positive outlook on the future and being motivated to change), Identity (managing to build a positive identity and overcome internal and/or public stigma), Meaning (engaging in meaningful roles and activities, gaining quality of life and finding spirituality) and Empowerment (focusing on strengths and improve self-agency [32].

Mental health professionals can promote recovery by developing interventions based upon the five recovery processes as identified by CHIME. Single elements, such as connectedness can be the target of an intervention. However, all processes of CHIME can be mutual beneficial, thus an integrated approach could result in a greater impact than offering separate interventions by focusing on the individual elements [33]. The CHIME elements are also reflected in the results of an unrelated systematic scoping review by Jaiswal (2020) [34]. With a systematic search, key elements of personal recovery were identified. Based on 60 sources, three aspects should be the focus of personal recovery interventions. The first aspect is relationships which includes therapeutic relationships, relationships with significant others and with the wider community (i.e., feeling socially included). The second aspect involves a sense of meaning that is constituted of a positive sense of self, experiencing hope and finding purpose. The third aspect is participation, which is subdivided into participating in the community and participating in one's life decisions (self-agency). These aspects show great overlap with the CHIME framework and could be used for the development of interventions.

Several new personal recovery interventions were developed over the last few years, among others the Wellness Recovery Action Plan (WRAP) [35], REFOCUS [36], Guided Peer Support Groups (GPSG) [37], recovery colleges [38], Individual Placements and Support (IPS) [39] or individual rehabilitation [40]. All of these interventions contain elements of CHIME. The WRAP makes use of experiential knowledge as it is delivered by people with a lived experience of mental health illness. In generally ten sessions, participants develop a wellness plan that helps them to attain self-agency over wellbeing and symptoms with identifying self-help methods and the use of support from others [41]. The REFOCUS intervention is designed for mental health care teams, aiming to change mental health care delivery and changing relationships between consumers and professional by targeting all five of the CHIME processes [36]. The GPSG method was developed to support people with schizophrenia in engaging in peer support with minimal guidance from a nurse. In the CHIME framework peer support was identified as a process that could foster connectedness [42]. Recovery colleges are run by clinicians together with service-users and use an educational model to facilitate wellbeing and social inclusion [38], with impact on all aspects of CHIME. IPS is aimed at helping people towards working in a competitive job regardless of competencies [39]. If necessary, training on the job is provided. Working in a competitive job brings many positive effects such as social inclusion, having a positive identity or financial independence which could benefit all aspects of CHIME [43]. Individual rehabilitation is developed for people who are unable or unwilling to start a paid employment. The aim of individual rehabilitation is to increase functioning and satisfaction on life areas which can be related to aspects of CHIME such as housing, work, education, and social contacts [40].

Winsper et al. [16] provided a classification of four typologies of personal recovery interventions in their systematic review: Psychoeducational (individual or group) (e.g., recovery colleges); peer-support and peer-led program (e.g., GPSG); social inclusion (e.g., IPS); and pro-recovery & mental health literacy training (e.g., REFOCUS). The later type is not focused on patient but on mental health professionals and the broader public.

The HospitalitY (HY) intervention

Building further on these developments, this thesis presents the HospitalitY (HY) intervention, an eating club for people with psychosis. With focus groups, input from consumers, mental health professionals, researchers and literature research, an intervention protocol was developed and tested in a feasibility study. The intervention was developed for people with psychotic disorders who are interested in connecting to peers and in developing skills in domains of their choice, e.g., domestic tasks, preparing a dinner or social skills. Participants received individual skill training and practical support from a trained nurse. The skill training was tailored to the individual by formulating personal goals. Furthermore, nurses were trained to guide the groups in accordance with the Guided Peer Support Group (GPSG) method [42]. With the GPSG method the nurse provides structure and a sense of safety in the group, while minimally interfering in the conversations. The HY intervention is unique as it integrates two typologies of interventions according the classification of Winsper et al. [16]: peer-based interventions and interventions that focus on social inclusion. This integrated approach is expected to be more effective than its separate parts as the separate parts can strengthen each other [44,45].

Furthermore, the HY intervention is delivered at home, in the natural environment of the patient. The GPSG method that is used in the HY-intervention was initially developed for use in ambulatory settings in groups of eight or more people. Within the HY-intervention, the GPSG method was used in a home-based context and tailored to the separate courses of a dinner. Furthermore, also skills training was delivered in the participants' home environment, because homebased skill training is expected to be more effective than clinic-based skills training [46,47].

The HY project integrates several important processes of the CHIME framework into one intervention. The most important process is Connectedness, through having dinner combined with peer support. The challenging task of organizing a dinner at home is a means to induce Hope trough hope-inspiring communication by the nurses and individual skills training with a focus on valuing success. Furthermore, similar to having a job as with IPS, participating in an eating club is as method to engage in community life, cultivating meaningful social roles and social goals which are part of the process of finding Meaning in life. The peer support that the HY intervention facilitates, is focused on the impact of psychosis on participant's daily lives. Peer support is suggested as method that reduces self-stigma. Exchanging experiences about the consequences of a psychiatric diagnosis helps to find an identity beyond being a psychiatric patient. This contributes to positive Identity forming. Last but not least, the individual skill training is a way to improve self-agency, which can foster the process of Empowerment.

To our knowledge, the HY intervention is the first intervention that combined elements of peer support and home-based skill training in an eating club. Eating clubs consisting of people with mental health problems already exist but have never been described in research. The HY project is the first attempt to research the effect of eating clubs on personal and societal recovery outcomes. The HY intervention was first tested in a feasibility study with nine participants. The results inspired further development and was followed by a randomized controlled trial (RCT) to test the effectiveness of the HY intervention on personal recovery (e.g., social contact, loneliness, self-stigma) and societal recovery. In chapter two, the results of a feasibility of the HY-intervention are presented, in chapter three the HY-intervention is investigated in a RCT.

Measuring personal recovery

The development of standardized measures is key to researching phenomena in psychiatry. Measures exist for clinical, societal and personal recovery outcomes. The most commonly used scales for clinical outcomes are clinician rated positive and negative symptoms scales [48]. Although there is ongoing debate on the validity of these measures, there is also considerable consensus on the measures that are used. Less consensus is found on measures of societal recovery [49]. Clinician rated measures and crude measures, such as rates of employment or the size of social networks, are used to evaluate societal recovery. The personal recovery construct is even less tangible than the societal construct. Personal recovery is concerned with overcoming the effects of mental health disease and involves many aspects such as dealing with symptoms, stigma or gaining hope. The CHIME framework is an example of how personal recovery can be conceptualized. However, many studies have been conducted on the elements that constitute personal recovery, displaying an ongoing search for consensus of the concept [50]. This is further reflected in the differences in measures of personal recovery containing divergent domains [51].

To determine effectiveness of personal recovery interventions, questionnaires were developed that measure personal recovery as an outcome in psychiatry. In recent decades, at least 35 instruments were developed to measure personal recovery in mental health [51], at present no consensus on a standard measure for personal recovery has been established. The Recovery Assessment Scale (RAS) is the most widely used scale in research, and is one of the eight instruments that meets criteria for reliability, convergent and construct validity and able to measure change in mental health consumers [51]. Although these statistical criteria are important, it is also important to evaluate how personal recovery measures are conceptualized. The CHIME framework could serve to evaluate the domains that should be included in personal recovery measures [52].

This thesis contributes to the evaluation of measures used for evaluating personal recovery in people with psychosis. In chapter four we evaluate three personal recovery instruments, using the CHIME framework as well as psychometric parameters to classify the three measures according to their performance.

How different outcomes of recovery are related

Clinical, societal and personal recovery are distinct but related constructs [53,54]. Research in traditional mental health care was mostly focused on reducing positive and negative symptoms in psychosis. Pharmaceutical treatments for positive symptoms (i.e., hallucinations and delusions) of schizophrenia have shown to be effective [55]. However, even if positive symptoms decrease, impairments in functioning are often still present [56] due to unsatisfactory treatments for negative symptoms and cognitive symptoms. In 40% to 80% of people with schizophrenia negative symptoms and cognitive impairment are present [57]. Negative symptoms as an outcome in schizophrenia are a good example of how outcomes of recovery are interconnected.

Negative symptoms comprise of blunted affect, alogia, anhedonia, asociality and avolition [58]. In short, these symptoms involve a diminished affect and amotivation [59]. The functional impairments from negative symptoms, such as social or vocational skills, result in lower prospects on a satisfying social network [60,61] or a competitive job [62]. As a consequence, this can result in subjective experiences of feeling disconnected to others, an unsatisfying identity, reduced meaning in life and the lack of empowerment of having agency over one’s own interests. In the long run this might lead to hopelessness in achieving progress on the beforementioned areas.

This example shows how negative symptoms, affects societal and personal recovery domains. Correlational research of negative symptoms with personal recovery confirms this dependency [63]. The relationship between different outcomes stresses the importance on researching interventions on clinical, societal as well as personal recovery. Although a breadth of interventions - pharmaceutical and non-pharmaceutical - for negative symptoms have been researched, only small (glutamatergic medications, SMD= -0.289) to medium (second-generation antipsychotics, SMD= −0.579) effects were found [64]. The correlation between negative symptoms and negative outcomes on societal [57] and personal recovery warrant further research in treatments for negative symptoms. In a meta-analysis, social skills training evidence was found for the effect on negative symptoms [65]. Other interventions, such as physical exercise, might also contribute to the treatment of negative symptoms.

A contribution to the research on interventions for negative symptoms is presented in chapter five. In a meta-analysis mind-body exercise and aerobic exercise interventions were evaluated on the effects on negative symptoms.

Social connectedness

A key element in the HY project and in personal recovery is social connectedness [32,66,67]. Social relationships define a large part of who we are as human beings [68]. Three levels of social connectedness can be distinguished: 1) intimate connection through close and personal connections; 2) relational connection through a broader group of friends and family; 3) collective connection through being part of wider cultural groups such as workplace environments, belonging to a nationality or being a member of an association [69]. Many people with psychosis experience the impact of their illness on all three levels of social connectedness. In people with psychosis, intimate connections often disappear, resulting in high levels of loneliness [4]. Furthermore, social networks are small [70] and connection to the wider community, for example trough paid employment, is low [71-73].

This general social disconnectedness is a complex problem with multiple causes. Four aspects that contribute to this problem should be mentioned: cognitive impairment [74] negative symptoms [59], social anxiety [75] and public stigma [22,76]. Cognitive impairments can, for example, reduce speed of cognitive processing, affect social skills and can subsequently form a great barrier in engaging in social contact. Negative symptoms can be divided into diminished affect and social amotivation [59]. In other words, negative symptoms denote a decreased expression of emotion (diminished affect) and less goal directed behavior (amotivation). This might limit people with psychosis in reciprocal social contact and in initiating social contact [77]. Furthermore, social anxiety is highly prevalent in people with schizophrenia [75]. It can cause people with schizophrenia to refrain from contact in order not to receive negative evaluations from others. Where these first three aspects are factors related to the individual, the fourth aspect of stigma stems from societal factors [78]. Social exclusion as a result from discrimination through public stigma excludes people with mental illness from opportunities in social contact. A secondary effect is the internalizing of the stigmatizing views (i.e., self-stigma) which could lead to impaired social relationships in people with mental health problems [79]. In summary, several causes can add to the poor social outcomes for people with psychosis.

In chapter six a longitudinal study is presented on the association between social connectedness and positive and negative symptoms of psychosis. We aimed to predict one- and two-year levels of positive and negative symptoms with levels of social satisfaction.

Outline of the thesis

This thesis is a contribution to the research in psychosis on personal, societal and clinical recovery outcomes, both through experimental research and within the natural environment. Furthermore, this thesis contributes to the research on how to measure personal recovery.

The work for this thesis started with the development of a personal recovery intervention in the form of an eating club for people with psychosis. In chapter two the results of the feasibility study on eating clubs for people with psychosis is described. The feasibility study served to evaluate the method and intervention for a multicenter RCT, which is presented in chapter three. Furthermore, an evaluation of three personal recovery measures was conducted to inform the choice of a measure for research. In chapter four the result of a comparison between three personal recovery instruments is presented. In chapter five a meta-analysis on negative symptoms is evaluated on mind-body and aerobic exercise interventions. Furthermore, with the use of cohort data from the PHAMOUS database [80], we researched the two-year longitudinal relationship between social connectedness and positive and negative symptoms in people with psychosis. The results of this study can be found in chapter six.

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Chapter 2

Peer support and skills training through an eating club for people with psychotic disorders: A feasibility study

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Abstract

Objective

The HospitalitY (HY) intervention is a novel recovery oriented intervention for people with psychotic disorders in which peer support and home-based skill training are combined in an eating club. A feasibility study was conducted to inform a subsequent randomised trial.

Methods

This study evaluated three eating clubs consisting of nine participants and three nurses. Semi-structured interviews and pre- and post-intervention measures (18 weeks) of personal recovery, quality of life and functioning were used to evaluate the intervention. Participants received individual skills training, guided by self-identified goals, while organising a dinner at their home. During each dinner, participants engaged in peer support, led by a nurse.

Results

In personal interviews participants reported positive effects on social support, loneliness, and self-esteem. Nurses reported that participants became more independent during the intervention. Participants were satisfied with the HY-intervention (attendance rate = 93%). All were able to organise a dinner for their peers with practical support from a nurse. Pre- and post -intervention measures did not show important improvements.

Limitations

Outcome measures were not sensitive to change, likely due to a short intervention period (5 months) and a limited number of participants (N=9). Using Goal Attainment Scaling to evaluate personal goals turned out to be unfeasible.

Conclusions

The HY-intervention is feasible for participants with psychotic disorders. This study refined intervention and research design for the upcoming multicentre randomised controlled trial. We expect that the Experience Sampling Method will be more sensitive to changes in recovery outcomes than regular pre- post intervention measures.

Introduction

People with a psychotic disorder, such as schizophrenia, often have to cope with severe limitations in functioning related to their illness [1,2]. These can lead to a loss of self-management [3] and social and community functioning [4] and in turn to loneliness, social isolation, and internalised stigma [2,5]. During the last decades, personal recovery has gained more attention in the mental health field [6,7]. Personal recovery focuses on living a satisfying, hopeful and contributing life in spite of illness-related limitations [8]. A systematic review identified five processes involved in personal recovery: Connectedness, Hope and optimism, Identity, Meaning in life and Empowerment (CHIME) [9]. Many of these processes emerge in relationships with others. This conceptual framework therefore highlights the need for interventions that target loneliness and social isolation as well as social and community skills, which facilitate social contact.

Improving skills for people with psychotic disorders has been an important subject of research in mental health during the last decades. Skills training in a clinical setting has a limited generalisation to real life situations [10]. Home-based interventions are expected to be more effective, because skills are learned in the same context as needed in daily life [11,12] Previous studies indeed showed that home-based interventions in schizophrenia led to more improvement in social and community functioning compared to traditional clinic-based interventions [13]. Severe neuropsychological impairments in episodic memory and executive control processes are present in schizophrenia [14]. Evidence shows that these cognitive deficits result in poor functioning [15]. Recent research shows that compensating interventions for cognitive deficits lead to improvements in functioning [16].

Peer contact and support groups are widely used interventions to foster social connectedness as stated in the CHIME framework [17]. This is confirmed by research demonstrating the effect of peer support on social networks and social support [18,19]. Peer support is based on mutual recognition through similar experiences. Therefore, peers can offer authentic empathy and validation [20]. Also, Identity forming is one of the pathways in which social connectedness is positively influenced by peer support [21]. Furthermore, peer support effectively improves recovery, empowerment and feelings of hope [22,23]. Barriers in peer contact are deficits in social cognitive domains, known to be present in people with schizophrenia [24]. A more proximal mechanism is found in defeatist believes that contribute to the avoidance of social activities [25]. Therefore, in group activities a safe atmosphere should be facilitated for peers to engage in social contact.

In light of promising results in both home-based skills training and peer support, we developed a synergistic approach that is expected to improve patients' functional and personal recovery. This paper presents a feasibility study of the HospitalitY intervention: a recovery-oriented intervention combining peer-support and home-based skills training for people with psychotic disorders. This creates an integrated approach that combines functional and personal recovery domains [26,27]. The intervention is structured around an eating club. Having dinner together creates a peer support setting and organising a dinner offers many naturally occurring opportunities to work on social and community living skills in the participant's personal environment. An appointed nurse provides a safe atmosphere by being present [28] and providing encouragement and positive reinforcement [10], as a prevention to defeatist beliefs [25]. Furthermore, based on social learning principles, motivation to work on personal goals is leveraged by participating in a meaningful group activity [29,30].

We developed a personal recovery focused intervention with input from a service user. Subsequently, we conducted a feasibility study to evaluate the suitability of this intervention for people with psychotic disorders and nurses. Furthermore, this study aimed to calculate a sample size for our primary outcome and to explore several potential outcome measures for a subsequent randomised trial.

Materials and Methods

Intervention

The intervention comprises three phases. In the first phase, participants have an individual meeting with the allocated nurse for an introduction, preferably at the participants' home. During this meeting, the intervention is explained and goals and wishes of the participant are explored in a semi-structured interview (e.g., What are your wishes and goals for the eating club?).

In the second phase, the peer group members (n=3) and the nurse meet at a hospital or community centre to get acquainted with each other. In this meeting, participants make agreements about the planning of the biweekly dinners and other practicalities (e.g., dates, diets, finances) and brainstorm about topics that can be discussed during the future peer group sessions (i.e., dinners). The eating club is expected to be self-supporting where possible. Therefore, financial costs of the dinners are shared between the members and participants learn how to organise such dinners within their own financial situation.

The third phase is a period of 18 weeks in which participants take turns in organising a total of nine dinners (three per participant) at home and with support from a nurse. Participants receive individual home-based skills training while organising a dinner for their peers and the nurse three different times. By hosting a dinner, participants will work on several skills such as planning, cooking and social skills to increase their functional recovery. The skills training is focused on the self-identified goals and is counselled by the nurse. The frequency and mode (e.g., in person or by telephone) of counselling varies per participant depending on the patients' needs and progress throughout the intervention period. Skills training consist of practical support in organising a dinner for peers [17] and techniques to adapt the environment to the participants needs. Adaptation techniques are utilized to compensate for cognitive deficits, known to be present in people with psychotic disorders [31]. Applying these simple and straightforward adaptations can increase functional independence in participants who experience cognitive difficulties. Examples of adaptation techniques are: structuring kitchen cabinets with the use of labels or make use of calendars. Furthermore, standardised nursing interventions were used as described in the Nursing Interventions Classification (NIC) [32], such as behaviour modification, social skills, self-esteem enhancement or self-responsibility facilitation.

During dinner, the nurse offers support according to the Guided Peer Support Groups (GPSG) method [19] (i.e., offering structure without interfering in conversations between participants). Peer support is structured around a two-course dinner. During the main course, participants exchange positive experiences they had during the past two weeks. During the second course an illness-related topic of conversation is chosen and afterwards discussed in a twenty-minute session. An outline of the intervention is presented in Table 1.

Table 1. Outline of the HospitalitY Project

Phase	Description	Time	Goal
Recruitment of participants	The nurse and participant meet for the first time, preferably at the participant's home. The intervention is explained. Goals and wishes of the participant are explored with a semi structured interview.	30 minutes per participant.	Determining the suitability of the participant for this intervention and inclusion in the study.
Start-up meeting	The peer group, including the appointed nurse, will meet at a hospital or community center. The participants will make agreements about practicalities. The participants brainstorm about topics that can be discussed during the peer group sessions.	60 minutes per session.	Participants will meet to get to know each other.
Intervention	Home-based skill training: In turn, participants will organise dinners at home for their peers and the nurse.	Varying from 30 to 120 minutes.	Facilitating participants in obtaining functional recovery.
	Peer support: During dinner, peer support is carried out using the Guided Peer Support Groups methodology for nurses.	120 minutes per session.	Fostering social contact and peer support.

Measurements

The intervention was evaluated on five different aspects. First, attendance of participants to the dinners was registered by the mean number of attended dinners during the intervention period for each participant (maximum is 9). Second, experiences from participants and nurses were collected with semi-structured interviews conducted by the first author and research assistants. Participants were prompted to talk about their thoughts regarding the skills training, goals, peer support, nurse support, and organising the dinners. Interviews were interpreted with an inductive strategy: repeatedly reported themes where clustered and matching opinions were summed. Third, goal attainment of participants was measured with the Goal Attainment Scaling (GAS) method [33]. This method enables the achievement of personal SMART formulated goals (Specific, Measurable, Achievable, Relevant, Time bounded) to be used as an intervention outcome. The nurse and participant determine attainment on a 5-point scale (1= much less than expected outcome and 5= much more than expected outcome). Goals were considered achieved with scores ≥3. Fourth, treatment fidelity of the nurses was assessed with an open interview and a protocol adherence questionnaire (27 items), which was completed by the nurse after each meeting of the eating club. The questionnaire comprised four topics: self-identified goals (4 items), organising a dinner (6 items), peer support (9 items) and group process (8 items). Items were scored on a 5-point Likert scale (1= completely disagree and 5= completely agree), where higher scores equal more adherence. Protocol adherence was analysed by calculating the mean scores on the protocol adherence questionnaire, where a mean score of ≥88 (range 27-135) was considered sufficient. Fifth, standardised measures were used to determine their sensitivity and feasibility for this intervention. We calculated a Reliable Change Index (RCI) for each measure if the Cronbach's alpha for the questionnaire was available [34]. The outcome of the RCI shows the minimal change needed for a reliable improvement. Measurements of personal recovery, quality of life, functional recovery and psychopathology were administered within a range of one to three weeks pre- and post-intervention. All measures were self-rated, except for the Personal and Social Performance (PSP) scale [35]. Questionnaires were analysed on responsiveness by comparing pre- and post-intervention scores. Missing values were imputed by using the means of the total score or by Last Observation Carried Forward when questionnaires were smaller than 20 items. The results of a questionnaire were not included in the analysis if >50% of the values on a measure were missing.

Personal recovery domains were measured with the:

- Recovery Assessment Scale (RAS) (range: 41-205, Chronbachs' α=0.76 - 0.97. Test-retest reliability: r=0.65 - 0.88 [36]. Higher scores indicate more personal recovery.
- Netherlands Empowerment List (NEL) (range: 40-200, Chronbachs' α= 0.94, test-retest reliability= 0.79) [37]. Higher scores indicate more personal recovery.
- Lubben Social Network Scale, six item version (LSNS-6) (range: 0-30, Chronbachs' α= 0.83) [38]. Higher scores indicate a greater social network.
- Personal Network Questionnaire (PNQ) (range: 0-18). The PNQ was developed in a previous study [19] and measures the satisfaction of the amount of contact the patient has with important "others" in his/her life. Psychometric properties are not available. Lower scores indicate a higher satisfaction.

Quality of Life (QoL) was measured with the:

- Manchester Short Assessment of Quality of Life (ManSA) (range: 0-72, Chronbachs' α= 0.74) [39]. Higher scores indicate more quality of life.
- Short Form Health Survey 12 item version (SF-12) (range: 0-100, Chronbachs' α= 0.69 – 0.70 test-retest reliability= 0.60 - 0.71 [40]. Higher scores indicate more quality of life.

Functional recovery was measured with the:

- Personal and Social Performance scale (PSP) (range: 0-100, intraclass correlation coefficient = 0.98) [35]. Higher scores indicate a better personal and social functioning.

- Daily Task List (DTL). The DTL measures basic functional living skills and was developed specifically for this project, broadly based on the following subscales of the Independent Living Skills Survey (ILSS) [41]: Appearance and Clothing, Personal Hygiene, Care of Personal Possessions and Food Preparation/Storage. The DTL was developed for this intervention as standard questionnaires were not deemed suitable for this intervention. Psychometric properties are not available. Higher scores indicate better functioning.

Psychopathology with the:

- Community Assessment of Psychic Experiences (CAPE), which measures frequency and distress of symptoms on three dimensions: positive (range: 40-160, Chronbachs' α= 0.84), negative (Chronbachs' α= 0.81) and depressive (Chronbachs' α= 0.76) [42]. The CAPE is an accessible questionnaire that is used as a self-report questionnaire for this population in previous research [19]. This psychopathology measure was included to evaluate adverse effects. Higher scores indicate a higher frequency and more distress of symptoms.

Procedures

A blueprint of the HospitalitY intervention was developed based on scientific literature and the expert knowledge of a panel, consisting of a person with lived experience, a researcher and several mental health care professionals. The first author developed a detailed treatment protocol. Study procedures were in accordance with local and international ethical standards and the Declaration of Helsinki [43], as confirmed by the review board of the University Medical Centre Groningen (UMCG), The Netherlands (file number: 2014.479).

The intervention was delivered by mental health nurses or health care workers with similar professional profiles (e.g., social workers) based on the best fit with their job descriptions and on comparable interventions in previous research [19]. Nurses received a manual, a full day of training and supervision from a nurse consultant specialised in psychotic disorders and in facilitating peer support groups for this group. During the project, a two-hour interprofessional coaching session was organised to reinforce the methodology. Participants who were interested in the HospitalitY intervention were recruited from a Flexible Assertive Community Team (F-ACT) of Lentis Psychiatric Institute between April 2014 and March 2015. Follow-up ended in September 2015. Participants were enrolled in an eating club, in order of entry to study. All participants provided written informed consent. Participants had a DSM IV chart diagnosis of schizophrenia, schizoaffective disorder, or psychotic mood disorder [44]. Inclusion criteria were: 18 - 65 years of age and sufficient fluency in Dutch language. The exclusion criteria were: severe psychotic symptoms or group disturbing behaviour, substance dependence on alcohol or other drugs; frequent existing participation in dinners with peers and personal contribution (i.e., cooking).

Results

Sample

Nine participants were included in the study. The median age was 38 (range: 27-62). Gender was evenly distributed (n=5 male, n=4 female). Participants received income from welfare assistance (n=8) or employment (n=1). One participant received higher education and the other eight received secondary education. Participants were single (n=7), divorced (n=1) or had a partner (n=1) and were diagnosed with schizophrenia (n=7), bipolar disorder (n=1) or schizoaffective disorder (n=1).

Attendance

The mean attendance for all participants during the nine dinners was 93%. Per eating club, the full attendance rate was seven out of nine dinners (range: 6-8). Eight participants completed the project and one dropped out before the final session due to an exacerbation of symptoms. No clear relationship between the project and the exacerbation of symptoms was found after interviewing the participant and case manager.

Interview reports

Overall, seven out of nine participants were interviewed. Participants described their participation in the HospitalitY intervention as a positive experience. They either expressed a desire to continue (n=3) or initiated a new dinner group with members from other eating clubs (n=3). They reported being nervous to invite people into their home at first and that the HospitalitY intervention was demanding. However, in retrospect they were pleased they joined the project and would recommend it to their peers. All participants were able to properly organise a dinner according to nurses' and participants' judgements. Participants reported that three participants per group is comfortable in terms of interpersonal contact as well as practical in modest housing space and preparing a dinner.

Peer support: approximately half of the participants reported that the twenty-minute peer support sessions gave them insight in their illness or a feeling of freedom to share psychiatry-related experiences they could not share with others (n=4). Others had mixed views: some reported this was a forced way of talking about difficult matters and not really worthwhile, because having social contact and being in a group was more important (n=4). Most participants reported they valued social contact during the dinners, felt less lonely and experienced a sense of community participation (n=6).

Skills: participants enjoyed preparing dinner for their peers (n=4), which increased their self-confidence despite concerns prior to the start of the project. Increased insight in functioning and social contexts (e.g., how one is viewed by others) was also reported (n=6). Participants stipulated that the group was used as a mirror to gain insight in how to deal with life in general and living with a psychiatric diagnosis. Furthermore, participants talked about how they gained insight in their personal tendencies through the group process and mediation from the nurse. Nurses evaluated the process of the organisation and the course of the dinner with the individual participant after the other participants had left.

Nurse support: nurse-support was perceived as useful and gave participants a sense of security (n=5). Some participants stated they would not have partaken the project without the nurse. Important features of the nurse were described as being present, creating a sense of safety and structuring the sessions.

Reports from nurses: nurses highlighted that they experienced a contrast between the routine care, that is problem-focused, and the recovery oriented care offered during the HospitalitY intervention. They emphasised that it was energising to focus on strengths rather than deficits and that working in a group increased participants' motivation to work on skills. Participation was initially demanding for nurses as the counselling was time-consuming. However, participants became more independent, which led to less involvement from the nurse during the preparation of the dinner.

Goal attainment

Participants formulated a mean of 2.5 goals per person (range: 1-4). Most self-identified goals focused on gaining skills in organising and preparing group meals (n=9) and varied from cooking and hosting a group of people to cooking healthy, dealing with budget or grocery shopping. Other goals focused on having more social contact with others (n=6), social skills or gaining self-confidence in social situations (n=5) and having peer contact specifically about diagnosis-related subjects (n=3). The mean number of achieved goals was 1.9 (range: 1-3) (NB. this could not be rigorously measured using GAS as explained in the strengths and limitation section of the discussion).

Treatment fidelity

Completion scores on the protocol adherence questionnaire were less than 20%. Therefore, only the personal interviews could be used to assess treatment fidelity of the nurse. In personal interviews, nurses reported they rarely used environmental adaption techniques, which were the primary techniques as instructed in the manual and training. Instead, nurses relied more on nursing interventions as described in the NIC [32]. The NIC approach was applicable on a wide range of the participants' goals. Exercising the GPSG methodology was found difficult at the start, because nurses as well as participants needed a few sessions to get used to the role of the nurse. Nurses reported that using GAS to form and evaluate goals turned out to be unfeasible. Although participants did formulate goals, these goals did not adhere to the SMART standards. To use GAS, defining SMART formulated goals is paramount.

Measurements

The measured constructs were congruent with the topics that participants and nurses described as important in the semi structured interviews. All participants were able to complete the questionnaires and the interview (PSP). Pre-and post-measures did not show to be sensitive for change during the intervention period of 18 weeks. Personal recovery and quality of life measures showed small contradicting changes (i.e., both positive and negative changes were found). On personal recovery measures mean scores improved on the NEL and the SNA, but not on the RAS and LSNS. On QoL measures, the mean score of both SF12 components improved whereas the mean score of the ManSA decreased. Measures of functioning showed small positive changes (PSP, DTL). The CAPE showed a slight decrease in symptoms on all dimensions. The RCI of the questionnaires showed that participants did not improve on most measures. On both the SF12 physical component and the CAPE-negative three participants improved. On the NEL and CAPE-positive one participant improved. The mean scores of the measurements and the RCI are reported in table 2.

Table 2. Outcome measurement of HospitalitY intervention (N=9): pre and post treatment at 18 weeks

	Pre-treatment: Mean (SD)	Post-treatment: Mean (SD)	RCI (N)
Recovery Assessment Scale (RAS) total score*	159.0 ±23.4	154.4 ±26.8	0
Netherlands Empowerment List (NEL) total score*	154.6 ±21.7	155.6 ±22.2	1
Personal Network Questionnaire (PNQ)#	4.3 ±4.2	3.8 ±3.2	N/A
Lubben Social Network Scale (LSNS)*	12.3 ±5.5	11.4 ±4.5	0
Manchester Short Assessment of Quality of Life (ManSA)*	44.6 ±7.3	40.9 ±13.2	0
Short Form Health Survey -12 (SF12) physical component*	49.1 ±11.9	51.1 ±10.7	3
Short Form Health Survey -12 (SF12) mental component*	42.4 ±7.7	44.8 ±11.4	0
Personal and Social Performance (PSP) scale total score*	64.4 ±9.4	65.7 ±15.9	N/A
Daily Task List (DTL)*	41.8 ±8.4	42.0 ±7.2	N/A
Community Assessment of Psychic Experiences (CAPE)- Positive dimension#	50.8 ±10.6	48.3 ±8.0	1
Community Assessment of Psychic Experiences (CAPE)- Negative dimension#	49.7 ±9.9	48.1 ±10.9	3
Community Assessment of Psychic Experiences (CAPE)- depressive dimension#	29.2 ±6.7	28.2 ±8.5	0

* higher scores indicate better outcome; #higher scores indicate worse outcome; RCI= Reliable Change Index (N= number of participants with a reliable improvement).

Discussion

In this study we examined the feasibility of the HospitalitY intervention, an eating club combining peer support with skills training for people with psychotic disorders. The intervention seemed to be feasible according to participants and nurses: Participants showed high motivation to work on personal goals; all participants were able to organise a dinner for their peers with practical support from a nurse; high satisfaction rates were found; and positive effects were reported on social support, loneliness, and self-esteem. The results on measurements showed small contradicting changes. In addition, the number of participants that reliably improved on measures is low. Therefore, outcome measures did not show responsiveness to this short intervention period.

Strengths

This is the first study that evaluated peer support and home-based skills training combined in an eating club. The strength of this intervention is providing psychosocial interventions in the context of a meaningful activity. The HospitalitY intervention was well received by participants and nurses and the attendance rate was high. Participants showed high motivation to work on personal goals and the vast majority of personal goals were achieved. Personal goals in a meaningful and social context might explain this high motivation [30,45]. The presence of a nurse was pivotal for participants to feel safe in exposing themselves to socially challenging interventions, consistent with previous research [46] (Castelein et al., 2008). Furthermore, no adverse effects on psychopathology as assessed with the CAPE, resulted from this intervention. Therefore, this novel nurse led intervention was considered to be suitable for people with psychotic disorders.

Limitations

The limited sample size (N=9) impedes final conclusions on the sensitivity for change of the questionnaires used for this intervention. However, patients reported to have experienced positive changes in social support, loneliness and self-esteem in personal interviews. The discrepancy of the measurements not reflecting the reported improvements in recovery outcomes and skills may be due to the short intervention period (9 sessions in 18 weeks) and the limited sample size (N=9). Positive effects of group-interventions might require more time to develop, as previous research on peer support groups showed that high attenders to sessions (≥ 9) improved significantly on psychosocial outcomes compared to low attenders (<9) [46]. Furthermore, our primary interest personal recovery, is a highly individual and subjective process [4,47,48], which is broadly defined construct and therefore not easily measured. This is reflected in the divergent subjects that participants brought up in their report. While some participants put a lot emphasis on social support, others experienced a change in loneliness or empowerment. Therefore, measuring personal recovery with standard questionnaires was found to be insufficient for this intervention. Similarly, no golden standard is available for measuring functioning, validity and reliability of functioning measures are highly depending on context [4]. We therefore developed the DTL based on the ILSS. The DTL, however, demonstrated insufficient sensitivity for the HospitalitY intervention in this feasibility study. Furthermore, our design (pre-post measurement) did not allow us to anticipate on participants' willingness to be randomised for the upcoming RCT.

A rigorous evaluation of the methodology was not possible due to the low number of treatment adherence forms that were completed by nurses. However, personal interviews with nurses did result in specific recommendations (for example: goal formulation and skills training) to improve the HospitalitY intervention.

With regard to intervention implementation, we found that defining SMART goals, as part of the GAS method, is a time-consuming activity that is demanding for participants with cognitive problems, similar to a previous study [49]. Therefore, using GAS was found to be unfeasible. Furthermore, adapting patients' environment to compensate for cognitive deficits was not an appropriate approach in skill training. We found this approach was too narrow for the wide variety of participants' goals.

Modifications

Based on this feasibility study, four aspects were modified with regard to the intervention as well as to the measurements. First, the intervention will be extended from 18 to 30 weeks (15 dinners). This will allow for several proposed processes (e.g., group forming and skills competence), which are expected to lead to more momentum in gaining social contact, empowerment, community functioning and a decline in self-stigma. Second, less emphasis will be put on adapting patients' environment to cognitive deficits during the skills training. Instead, nurses are instructed to use a broad range of interventions as described in the NIC [32]. Additionally, nurses are instructed to look for learning opportunities, encourage participants to use their skills, and to reinforce skills when used [50]. Third, GAS will not be used as a method for measuring individual progression on goals, so that participants' goals do not need to comply with the SMART approach. However, individual goal formulation will be used to enable nurses and participants to personalise skills training. Finally, due to the small pre-post changes in the measurements we decided to shift to Experience Sampling Method (ESM) as our primary outcome for the upcoming RCT. Therefore, with regard to the primary outcome, this feasibility study was not informative anymore for a power analysis. We found that using a recovery questionnaire such as the RAS is not sensitive enough to find differences in the divergent recovery themes that patients stipulated in the interviews [51]. Therefore, in the upcoming RCT (See for study protocol: www.isrctn.com/ISRCTN14282228) [52] our primary outcome will be connectedness (CHIME) as a part of the recovery process [9]. This will be operationalised by measuring social contact in everyday life with the ESM. Participants will answer questions about the amount of contact, the quality and the persons they had social interactions with. The questionnaire is based on previous research [30]. ESM measures real world phenomena and is therefore considered a suitable method to evaluate the efficacy of interventions that focus on experiences and functioning in everyday life [53]. In a multicentre RCT the effects of the modified HospitalitY intervention will be evaluated.

Conclusions

The HospitalitY intervention was well received by participants and nurses. Participants were motivated to work on personal goals. Also, positive changes in personal recovery topics were reported by participants. The feasibility study led to refinement of the intervention. A multicentre RCT will be organised to evaluate the effects of the

HospitalitY intervention on social contact and recovery outcomes.

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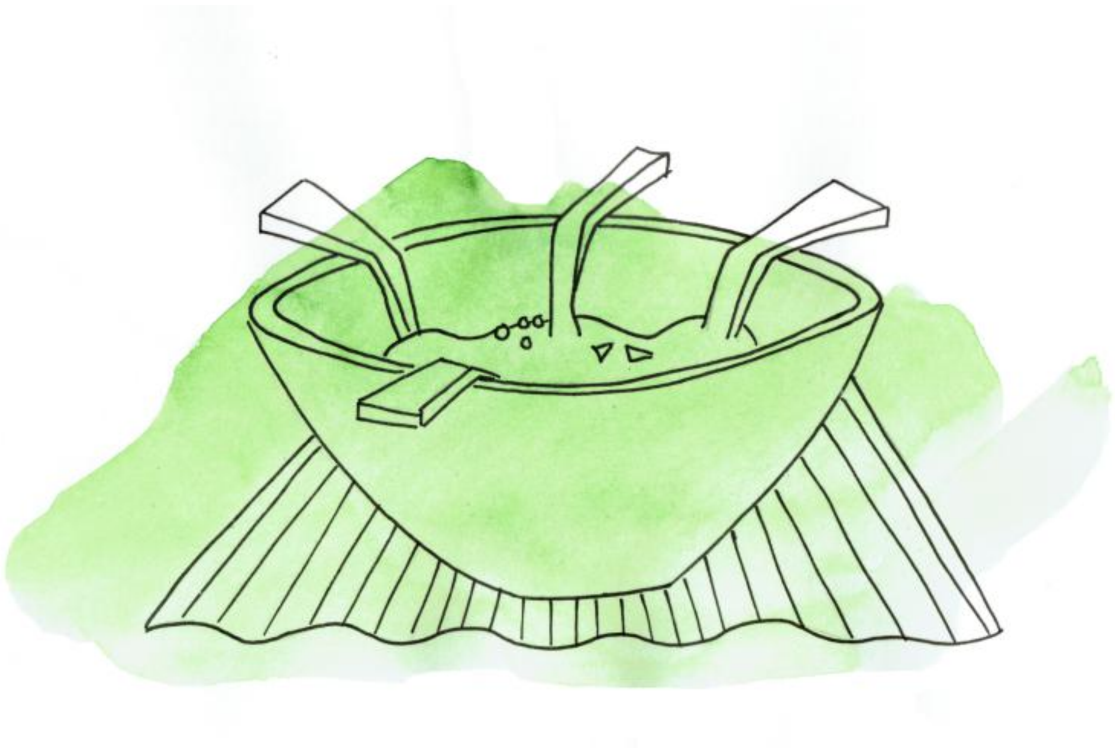

Chapter 3

Effects of an eating club for people with a psychotic disorder on personal recovery: results of a randomized controlled Trial

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Abstract

Background and objectives

Many people with a psychotic disorder are coping with severe psychosocial limitations related to their illness. The current randomized controlled trial (RCT) investigates the effects of an eating club intervention (HospitalitY (HY)) aimed to improve personal and societal recovery.

Methods

In 15 biweekly sessions participants received individual home-based skill training and guided peer support sessions in groups of three participants from a trained nurse. A multi-center RCT was conducted (intended sample size: n=84; n=7 per block) in patients with a diagnosis of schizophrenia spectrum receiving community treatment. HospitalitY was compared to a Waiting List Control (WLC) condition at three time points (baseline, end-of-treatment (8 months) and follow-up (12 months)) using personal recovery as primary outcome and loneliness, social support, self-stigma, self-esteem, social skills, (social) functioning, independency competence, and psychopathology as secondary outcomes. Outcomes were evaluated with a mixed modeling statistical procedure.

Results

The HY-intervention had no significant effects on personal recovery or secondary outcomes. More attendance was associated with higher scores on social functioning.

Limitations

With N=43 participants included, power was insufficient. Seven HY-groups were started from which three discontinued before the sixth meeting, one HY group stopped due the start of the COVID-19 pandemic.

Conclusions

Despite a promising pilot study on feasibility, the current RCT did not show any effects of the HY intervention. A mixed qualitative-quantitative research methods might be more appropriate for researching the HospitalitY-intervention to investigate what social and cognitive processes are at play in this peer guided social intervention.

Introduction

A large proportion of people with a psychotic disorder has to cope long-term with their symptoms. Despite high rates of symptomatic recovery (i.e., 50%) [1], patients experience severe psychosocial impairments related to their illness, which causes limitations in their everyday activities [2-4]. The onset of illness during adolescence, the symptoms of schizophrenia and its generally chronic character all contribute to a loss of social skills and life skills [5]. Living with a psychotic disorder might therefore lead to experiences of loneliness [6], low social support [7], self-stigma [8] and low self-esteem [9]. Many people with a psychotic disorder feel socially and emotionally isolated, and have a limited social network with few close persons with whom they can share their experiences [10,11]. Interventions that address these issues are therefore highly needed.

Early studies in psychotic disorders focused primarily on clinical recovery (i.e., reducing positive and negative symptoms), or societal recovery (i.e., regaining roles in society). However, more recent perspectives on recovery also emphasize the importance of personal recovery [12-15] or focusing on all three domains and their interaction [15]. Personal recovery outcomes are identified in the CHIME framework as Connectedness, Hope, Identity, Meaning and Empowerment [16], and can be integrated in mental health care interventions that improve functioning [17]. Integrated interventions on aspects of personal and societal and recovery might lead to better outcomes [17,18], and should thus be researched.

Peer-to-peer contact is an important element in the process of fostering personal recovery [19]. Peer groups act as a safe place where social support is provided, self-stigma is challenged and positive identity forming is promoted. Peer support interventions for personal recovery have been researched in previous studies, but results are inconclusive [20-22]. A review on various peer support interventions in people with severe mental illness found no effects on self-rated recovery [21], whereas a recent meta-analysis about one-to-one peer support did show a modest effect on self-rated recovery [20]. More research on peer support is needed to establish its effects on personal recovery.

It has been shown that clinic based (social) skill training tends not to generalize to real life situations [23]. Interventions for skill training on the spot (e.g., at home or at work) might be more effective, because skills are learned in the same context as they are needed [23-26]. Previous research on home-based skill training showed mixed results on societal recovery. One study found that clinic-based skill training had significantly less effect on social functioning in psychosis than training on the spot [25], while a recent RCT found no effect of community-based skill training on functioning in people with a psychotic disorder [27]. In this study we evaluate a novel intervention for people with a schizophrenia spectrum disorder. The HospitalitY (HY) intervention combines peer support and skill training in the home environment of participants. In essence, the HY intervention is an eating club with support from a trained nurse. HY has been developed based on previous experiences with nurse guided peer support groups (GPSG) for people with psychotic disorders [28,29]. In the former publications, the GPSG method was applied on peer groups in a clinical setting [28,29]. In the current study a variation of the GPSG method was developed for a home-based setting with three participants per group.

Furthermore, a peer support group facilitates the opportunity to work on social skills in a safe environment. Social skills have been shown to develop when appealed to during interactions (i.e., peer-to-peer contact) [19,23].

The integrated approach of the HY intervention is expected to provide opportunities to learn and practice strategies and skills relevant for personal and societal recovery [30].

Our pilot study showed that the HY project was a feasible intervention for people with a psychotic disorder [31]. In this study we investigate whether the HY-intervention increases personal recovery in a multicenter randomized controlled trial.

Materials and methods

Participants

Participants and nurses were recruited from Flexible Assertive Community Teams (F-ACT) of six mental health care organizations in the Netherlands. Patients (aged 18-65) diagnosed with a schizophrenia spectrum disorder (DSM IV or 5: 295.xx, 297.1, 298.8, 298.9) [32,33] were eligible to take part in the trial. Exclusion criteria were: substance dependence (not substance use) that prohibits participation in peer groups; frequent participation in dinners at home with peers and with personal contribution (i.e., cooking) prior to the start of the trial; insufficient understanding of the Dutch language or objection of the patients' clinician (for example due to a (current) psychotic episode). All participants provided written informed consent. The recruitment started in February 2017 and the data collection ended in October 2020.

Trial design

A multi-center randomized controlled trial was conducted with two conditions: the HospitalitY-intervention (HY) and a Waiting List Control (WLC) condition (See for study protocol: www.isrctn.com/ISRCTN14282228). The study did not require ethical approval on decision of the ethical board of the University Medical Centre Groningen (UMCG) (reference METc2014.479). Participants were randomized to one of the two treatment conditions by a list of randomly generated numbers from an online randomizer [34]. The research team was blinded for the randomization process and the allocation of treatment. The computerized randomization procedure was conducted by a person not affiliated with the research team and concealed until the data collection was finished. Block randomization [35] based on area code was applied, because traveling for a long distance was difficult for (some) participants. To safeguard a minimum of three participants per HY group, an unbalanced block randomization was used with a 3:4 ratio (HY:WLC) per block. If a participant would drop out of the HY condition, a replacement from the randomly generated list in the WLC condition would be included in the respective HY group. Participants were randomized at once (i.e., not sequential), which also included a predefined order of replacement from the WLC to the HY group in case of drop-out. Replacements were analysed as part of the HY condition in the statistical analysis.

A power analyses with G-power [36] based on the Recovery Assessment Scale (RAS) [37] as primary outcome resulted in a sample of 84 participants, including an attrition rate of 15%.

Intervention

The eight-month HY-intervention involved 15 biweekly sessions. Prior to the start of the HY-intervention, an individual assessment was planned by the nurse to explore goals [38] with a focus on daily living skills or social skills (e.g., cooking, planning, cleaning, self-care, budgeting). Furthermore, a group introduction meeting was organized to explore topics for peer support and to discuss the group rules, such as finances and dietary restrictions.

Next, participants organized a dinner in turns at their home with support from a nurse. Individual home-based skill training was provided concurrently with organizing a dinner. Per session 30 to 120 minutes were planned with the participant in charge of preparing the dinner for that evening, either face-to-face or by telephone contact, depending on the needs of the participant. During dinners the nurse offered support according to the Guided Peer Support Groups (GPSG) methodology [28]. Nurses received a one-day training, provided by a GPSG expert and the first author and six individual supervision meetings of one hour with a trained psychologist throughout the course of the intervention to increase treatment fidelity (see section 2.5 'process evaluation' for more details). An elaborate description of the intervention was previously published [31]. Participants in the WLC condition received their regular care consisting of pharmacological and psychological treatments, psycho-education, family support and vocational and rehabilitation interventions.

Outcomes

Personal recovery was measured as the primary outcome. Furthermore, secondary outcomes related to the personal recovery dimensions connectedness and identity of the CHIME framework [16] and to societal recovery and clinical recovery were measured.

Primary outcome

Personal recovery was measured with the Recovery Assessment Scale (RAS) [37] consisting of 24 items. Scores range from 1 (strongly disagree) to 5 (strongly agree) where higher scores indicated more personal recovery. Mean item scores were calculated [39]. The RAS was translated in Dutch using forward-backward translation and this translation was previously used in other studies [31,40].

Secondary outcomes

Connectedness (CHIME, [16])

- Loneliness was measured with the De Jong Gierveld Loneliness Scale (DJGLS) [41]. Sum scores were calculated with a range from 0 to 11. Higher scores indicate more loneliness. A previously established cut-off score of 3 was used to determine the presence of loneliness [42].

- Social support was measured with the Functional and Social Support Questionnaire (FSSQ) [43], with a mean item range from 1 to 5, were higher scores mean more satisfaction with social support.

Identity (CHIME, [16])

- Self-esteem was measured with the Self Esteem Rating Scale – Short Form (SERS-SF) [44]. The SERS- SF contains a positive and negative subscale with a range from 10 to 70 per subscale. Higher scores mean respectively more positive or negative self-esteem.

- Self-stigma was measured with the brief version of the Internalized Stigma of Mental Illness (ISMI) [45] with a mean item range from 1 to 4 where higher scores represent more self-stigma.

Societal recovery

- Social skills were measured with the Communication Skills Questionnaire (CSQ) [46].

- All scores were recoded from 0 to 2 for interpretation reasons. Mean scores were calculated (range of 0-2) where higher scores mean higher communication skills. The CSQ was translated in Dutch for the purpose of this study using forward-backward translation with a native English speaker.

- Social functioning was measured with the Personal and Social Performance scale (PSP) [47], with a range from 1-100, where higher scores mean better performance.

- Functioning was measured with the WHO Assessment of Disability (WHODAS) [48], with a range from 0-100 where higher scores mean a higher self-reported disability.

- Independency competence was measured with the Social Functioning Scale, independency competence subscale (SFS) [49]. This subscale ranges from 0 to 39 where higher scores mean more independency.

Clinical recovery

- Psychopathology was measured with the Community Assessment of Psychic Experiences (CAPE) [50]. Frequency scores of the positive subscale (range 14-56) and the negative subscale (20-80) were analyzed. Higher scores mean a higher frequency of symptoms.

The following demographic and illness characteristics were collected at baseline: gender, age, living situation, education, employment, the Global Assessment of Functioning (GAF) and a medical chart diagnosis according to DSM-IV or 5 [32,33].

All questionnaires show acceptable scores on reliability and validity measures. Measures were computer assisted administered by a research assistant. Measures were administered prior to the intervention (baseline), after the intervention (at 8 months) and at follow-up (at 12 months). All questionnaires were self-report measures, except for the PSP, which is an interview-based measure. The PSP interviews were conducted by two trained research assistants.

Process evaluation

Guiding nurses

Treatment fidelity of the nurses who guided the intervention was evaluated with two self-developed Likert scale questionnaires (range 1-5, score ≥3 means sufficient fidelity) on individual skill training and group guidance (see supplementary file A). The questionnaires were completed by the guiding nurses after each session and the duration of each session was registered.

Participants

Participants were asked to rate the efficacy of the peer support sessions (13 items, range: 1-3) to evaluate their perceived helpfulness on experiencing recognition, receiving support and opportunities to share experiences among others. Furthermore, participants completed a comparable questionnaire on the skill training (14 items, range 1-5) on which they rated to what extent they believed the eating club helped them with independent selfcare, cooking and confidence in inviting people at home among others. See supplementary file B.

Statistical methods

Baseline measures in the HY and WLC conditions were compared with Mann Whitney U and Pearson's Chi-square tests. The primary and secondary outcomes were evaluated with intention to treat (ITT) with linear mixed models analysis at end of treatment and at 12-months follow-up. All participants who received the HY treatment, including replacements from the WLC condition, were analysed in the HY-condition. The linear mixed models were based on model 2c of Twisk et al. (2018) [51], with participants included as level 1 predictor and with time and time*treatment allocation as level 2 predictors. Random effects were included for the intercept which allowed variance in intercepts per participant. Furthermore, a dichotomous variable was created to distinguish high attenders from low attenders with ≥ 9 sessions as cut-off score (i.e., ≥50% of the meetings) for a sensitivity analysis to correct for the effect of treatment engagement. All statistical analyses were conducted with the Statistical Package of the Social Sciences (SPSS), version 26 [52].

Results

The study included 43 participants (Figure 1), with 20 participants allocated to the HY group and 23 allocated to WLC. Loneliness was present in 72% of the total sample and 65.9% of the sample had GAF scores <60. During the trial seven participants moved from the WLC group to replace a drop-out from the HY group, resulting in 27 participants allocated to HY and 16 to WLC. Six out of seven of the replaced participants entered the HY group before the second dinner and one at the ninth dinner. No differences between the two conditions were found on baseline and clinical characteristics indicating comparable groups (Table 1). Within the HY treatment condition 10 out of 27 participants attended ≥9 meetings. Three out of seven HY groups discontinued in an early stage (i.e., <6 meetings) due to drop-out of the majority of its members. Individual participants reported the following reasons for discontinuation: not feeling comfortable with other group members, worsening of psychiatric symptoms or difficulties with traveling to other peer group members in rural areas. One HY group stopped after 11 meetings due to the start of the COVID-19 pandemic.

Figure 1. Flow chart of the HY RCT

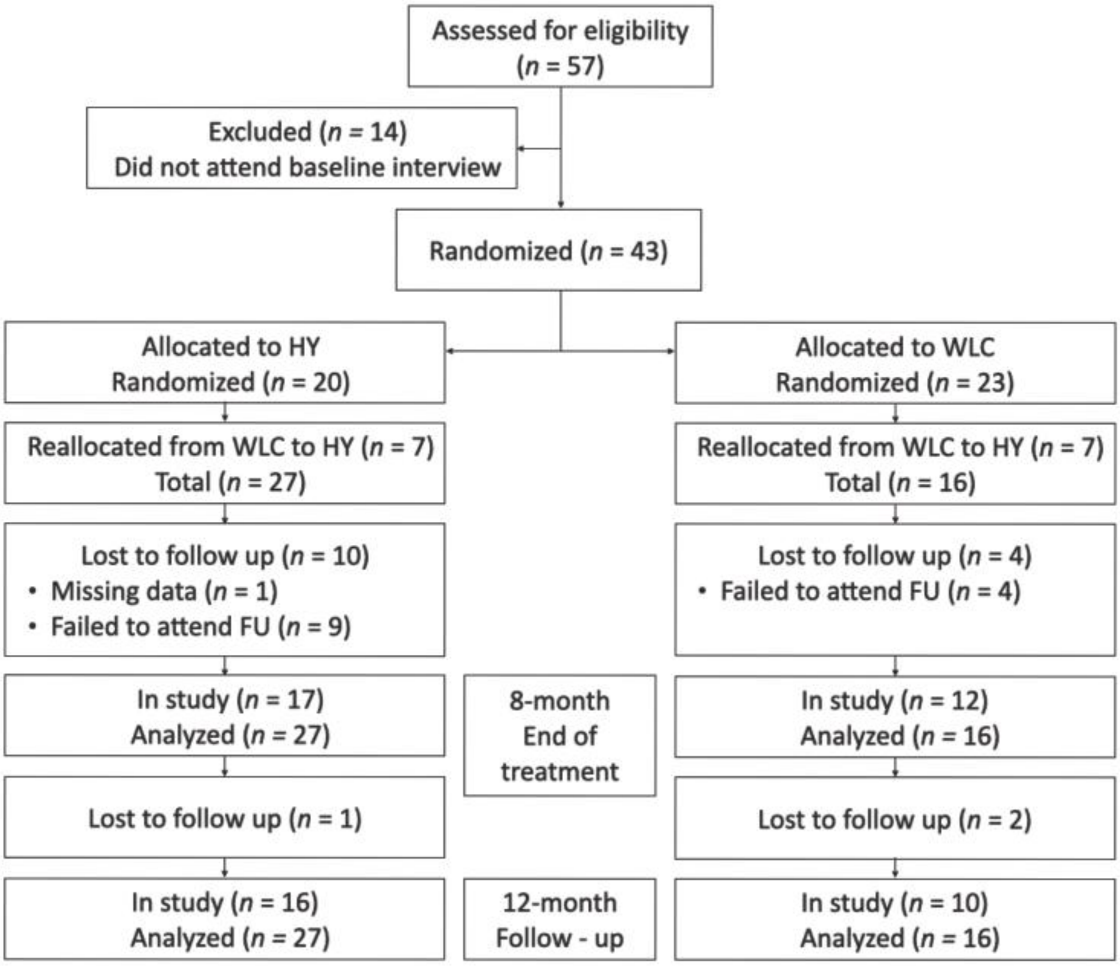

Table 1. Baseline and clinical characteristics of the study population

	HY group n=27	WLC n=16	Pearson's X^2 (df)/ Mann Whitney U test	p-value
Male, N (%)	19 (70.4)	16 (68.8)	X^2 (1) = 0.013	0.91
Age, Median (IQR)	42.0 (18.0)	42.5 (6.6)	U= 166, z= −1.258	0.21
Living situation, N (%)				
Independent alone	16 (59.3)	13 (81.3)	X^2 (4) = 2.593	0.63
Independent with partner	2 (7.4)	1 (6.3)		
With family or others	2 (7.4)	0 (0.0)		
Sheltered living	4 (14.8)	1 (6.3)		
Long-term mental health care	1 (3.7)	1 (6.3)		
Unknown	2 (7.4)			
Education (ISCED), N (%)				
Primary education (level 1)	1 (3.7)	4 (25.0)	X^2 (2) = 4.435	0.11
Secondary education (level 2-4)	15 (55.6)	7 (43.8)		
Tertiary education (level 5 - 9)	11 (40.7)	5 (31.3)		
Paid employment, N (%)	3 (11.1)	1 (6.3)	X^2 (1) = 0.281	0.60
Lonely (DJG Loneliness scale), N (%)	21 (77.8)	10 (62.5)	X^2 (1) = 1.116	0.28
GAF score, Median (IQR)	50 (13)	56.5 (12)	U= 153, z= −1.283	0.20
Diagnosis, N (%)				
Schizophrenia	19 (70.4)	8 (50.0)	X^2 (4) = 1.569	0.81
Schizophreniform disorder	0 (0.0)	1 (6.3)		
Schizoaffective disorder	5 (18.5)	5 (31.3)		
Brief psychotic disorder	1 (3.7)	2 (12.5)		
Other psychotic disorder	2 (7.4)	0 (0.0)		

IQR= Inter Quartile Range; ISCED= the International Standard Classification of Education (ISCED); DJG Loneliness scale= De Jong Gierveld Loneliness scale; GAF= Global Assessment of Functioning

Treatment outcomes

The linear mixed effect model showed no significant differences between the HY and WLC group at T8, neither on the primary nor the secondary outcomes. At T12, the HY group scored slightly lower on the RAS compared to the WLC group ($p<0.05$). Including high attenders (N=10) as a co-variable in a sensitivity analyses did not change the results. Table 2 shows the results of the linear mixed models at T8 and T12.

Table 2. Mixed Model effects of the HY intervention, Intention to Treat (ITT) analysis

	Baseline		Post intervention (8 months)				
	HY (N= 27)	WLC (N=16)	HY (N=17)	WLC (N= 12)	B (SE)	95% CI	p–value
Personal recovery							
RAS	3.70 (0.47)	3.64 (0.55)	3.86 (0.52)	3.60 (0.34)	0.08 (0.11)	–0.14, 0.29	0.481
Connectedness							
DJGLS	6.51 (3.04)	4.75 (3.36)	5.47 (3.04)	4.08 (3.42)	0.51 (0.95)	–1.38, 2.10	0.594
FSSQ	3.72 (0.74)	4.00 (0.92)	3.83 (0.49)	4.08 (0.78)	–0.30 (0.23)	–0.48, 0.42	0.896
Identity							
SERS–SF Pos.	50.11 (8.93)	47.56 (7.92)	53.94 (8.52)	46.67 (6.08)	3.43 (2.20)	–0.95, 7.82	0.123
SERS–SF Neg.	33.67 (9.48)	27.50 (12.97)	32.47 (9.21)	26.08 (8.38)	1.83 (2.68)	–3.52, 7.18	0.498
ISMI	2.07 (0.42)	1.94 (0.43)	2.08 (0.38)	1.87 (0.40)	0.15 (0.11)	–0.06. 0.36	0.160
Societal recovery							
CSQ	1.31 (0.32)	1.30 (0.27)	1.44 (0.21)	1.28 (0.40)	0.14 (0.09)	–0.03, 0,32	0.107
PSP	54.88 (13.59)	60.50 (15.96)	59.13 (13.71)	56.36 (16.69)	3.94 (4.72)	–5.45, 13.34	0.406
WHODAS	24.29 (16.11)	24.33 (15.28)	24.38 (16.57)	19.07 (8.83)	5.76 (3.79)	–1.79, 13.32	0.133
SFS – Ind. Comp.	34.00 (4.99)	38.88 (3.14)	34.76 (5.23)	35.25 (3.91)	0.60 (1.00)	–1.41, 2.60	0.555

	Baseline		Post intervention (8 months)			
	HY (N= 27)	WLC (N=16)	HY (N=17)	WLC (N= 12)	B (SE)	95% CI
Clinical recovery						
CAPE Pos. scale	28.96 (9.46)	26.31 (5.87)	27.53 (7.61)	26.75 (3.95)	−1.23 (1.94)	−5.12, 2.64
CAPE Neg. scale	24.59 (6.19)	24.06 (6.79)	23.82 (6.12)	21.85 (4.96)	2.72 (1.59)	−0.45, 5.88

* Significant at $\alpha=0.05$ level. RAS = Recovery Assessment Scale; SERS-SF = Self Esteem Rating Scale – Short Form (Positive and Negative subscale); DJGLS = De Jong-Gierveld Loneliness Scale; ISMI= Internalized Stigma in Mental Illness; FSSQ = Functional Social Support Questionnaire; CSQ= Communication Skill Questionnaire; PSP= Personal and Social Performance Scale; SFS= Social Functioning Scale – independency competence; WHODAS: WHO Disability Assessment Scale; CAPE= Community Assessment of Psychic Experiences – frequency of positive and negative subscale.

Process evaluation

Average duration was 91 minutes (SD=38) for the group sessions. For the individual skill training an average of 75 minutes (SD=62) on face-to-face and 9 minutes (SD=6) on telephone contact was spent.

Average adherence scores (maximum score was 5.0 per item) of the guiding nurses were 3.12 (SD= 0.28) on the peer support group sessions and 3.03 (SD= 0.30) on individual skill training, indicating a moderate treatment adherence (see S1).

The peer support sessions were rated by 12 participants (maximum score was 3.0 per item). Participants scored high on experiencing contact with others with similar difficulties in life (mean= 2.62, SD=0.65); having the possibility of sharing their own story (mean= 2.54, SD= 0.66); finding clarity for their situation through stories of others (mean= 2.46, SD= 0.66); and receiving acknowledgement for their problems (mean= 2.46, SD= 0.78).

Home-based skill training was evaluated by 13 participants. Participants scored moderately high (maximum score was 5.0 per item) on feeling more confidence in inviting people at home (mean= 3.42, SD= 1.08), having more pleasure in cooking (mean= 3.33, SD= 0.88) and doing more activities with other people (mean= 3.17, SD= 0.84). See supplementary file B for the full overview.

Post-hoc analysis

PSP scores at baseline were positively correlated to treatment adherence (i.e., ≥9 meetings): higher PSP scores coincided with better treatment adherence (r= 0.437, p=0.026).

Discussion

The HY intervention, an eating club for people with a psychotic disorder, is a novel approach to foster personal and societal recovery. To the best of our knowledge, no previous studies have evaluated the effects of eating clubs in an RCT. The intervention did not lead to significant changes on the primary and secondary outcome measures. Due to the small sample size of 43 participants, the study was underpowered. However, the results on the outcome measures showed such small changes, that even sufficient statistical power may not have resulted in statistically significant effects. The small significant effect on the RAS at T12 was considered a random finding due to an opposite fluctuation pattern between end and follow-up measurement. Participants in our study rated identification with others and receiving acknowledgement as key elements within the peer support sessions. These elements were also identified in other studies on peer support [29]. Based on the current study no encouraging recommendations can be made in favor of the HY intervention for people with a psychotic disorder.

Another recent RCT studied a combination of peer support combined with individual home-based skill training in people with schizophrenia and found no statistically significant effects on measures of personal recovery or societal recovery (e.g., functioning and community engagement) compared to treatment as usual (TAU) either [53]. This is in line with our own findings. However, a recent meta-analysis did find small to moderate effects of peer support interventions on empowerment [54]. The majority of these studies used the Rogers' Empowerment Scale (RES) [55].

At baseline, a high proportion of our study sample was lonely [42], indicating a need for social contact which was addressed with the HY-intervention. Furthermore, our sample was representative for a broader population of people with psychotic disorders, with similar personal and clinical characteristics and RAS scores of other large studies in the same region [15,56]. The HY-intervention was evaluated with an RCT. The rigor of this method can provide high quality evidence to inform health care policy makers. However, compared to the feasibility study [31], implementation of this RCT was more challenging with less study engagement, as indicated by not reaching the required sample size and the high dropout rate. This is a major limitation to this study and we will elaborate on the low recruitment rate, to which several aspects may have contributed.

Firstly, our block randomization protocol meant that patients sometimes had to wait up to three months before a block was completed and were no longer interested by then (some blocks were closed before reaching seven participants to avoid drop-out of the first recruited participants due to the long waiting time). Secondly, some eligible participants were not willing to be randomized or had a desire to seek social network improvements outside mental health care structures (especially the first episode population). A qualitative review on 35 studies regarding health care interventions confirms that the willingness to be randomized is often a barrier for inclusion [57]. Although randomization is standard practice in good clinical research, it might not be the best approach in this type of social interventions.

Secondly, participants and nurses reported that group members did not always form a bond, as a result of differences in interests and personal characteristics (e.g., age and gender). In contrast with the current RCT, nurses in the feasibility study were asked to select participants for the HY-intervention at their own discretion, possibly resulting in a better connectedness between participants.

Thirdly, the participants reported other barriers, such as longer traveling distance, symptom exacerbations, and difficulties in complying with the research protocol that required filling in many questionnaires).

Fourthly, the small group sizes of exactly three participants per group was a fragile balance between achieving a sufficient group-feeling for the peer support, while still being able to practically organize a group dinner. The small group size may have increased levels of social distress, as individual group members might have experienced a higher appeal to offer social contributions. On the other hand, participants and nurses mentioned that preparing dinner for others at home was a stressful challenge, but the HY feasibility study [31] showed that preparing a dinner for three peers and the nurse was still feasible for participants. Limited living space was another reason for a maximum group size of three. Dropout of a participant needed immediate replacement, since two participants no longer form a group and these changes in group members may have contributed to lower group cohesion.

This study had an unconventional randomization procedure with an option to replace participants from the WLC to the HY group. Randomization procedures were used as optimal as possible, tailored to the conditions of the current research project. The seven participants per block were randomized at once to prevent selection bias (i.e., not sequential). Participants that were reallocated received only part of the treatment. However, the majority of the reallocated participants (85,7%) entered the HY-intervention before the second meeting. Therefore, the impact of reallocation on the results was considered minimal.

In the current study, treatment fidelity was evaluated with self-report questionnaires for nurses. This approach is considered sub-optimal as bias can result from self-assessment. However, the alternative of objective measures such as video or sound recording was considered too invasive for both participants and trainers within the context of this home-based social intervention.

Combined interventions with multiple outcomes such as HY might benefit from a mixed design with qualitative and quantitative measures. Qualitatively evaluating the interaction between intervention, process and context can be informative on the barriers and facilitators for change [58]. This might inform theory on social and cognitive processes in small home-based group interventions. The HY-intervention was developed with a focus group including a service user to tailor the intervention to the needs of participants [31]. Qualitative research on motivations and expectations of participants could add to the development of home-based peer support group interventions such as an eating club.

For a home-based group intervention, such as the HY-intervention, study engagement might be improved by forming groups prior to inclusion based on geography, mutual interests, preferences and/or personal characteristics. Subsequently, groups of three participants can be cluster randomized to treatment or control condition based on these social factors. This method mimics the group forming that was applied in the feasibility study and might result in a higher inclusion rate and limited drop outs. However, this method also requires a larger sample size because group forming before randomization requires an extra level in the analysis.

In conclusion, we state that this home-based skill training combined with peer support through eating clubs did not improve personal recovery and other ways of functioning in patients with a schizophrenia spectrum disorder.

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Supplementary file S1
Treatment fidelity ratings of the Guided Peer Support Method and home-based skill training

Results of treatment fidelity on the Guided Peer Support Method

	N	Mean	SD
The participants recognized each other in their stories	60	2.92	0.98
The participants felt at ease	59	3.10	0.82
The participants listened to each other	61	3.34	0.73
The participants acknowledged each other's difficulties	60	2.97	0.88
During the dinner the conversation was positive and future-oriented	61	2.84	1.11
A subject related to psychosis was chosen to discuss	55	2.55	1.18
The nurse did not actively participate in the conversation	60	2.75	0.99
Pauses in the conversations were not interrupted by the nurse	61	2.64	1.11
Nurses did not interfere with advice or concern	61	3.31	0.85
The nurse provided compliments at closure of the dinner	61	3.61	0.49
Group process:			
The group process was disturbed due to dysfunctional group dynamics*	61	4.36	0.91
The group process was disturbed due to causes outside the group*	58	4.55	0.80

Range 1-5
*Scores were inverted.

Results of treatment fidelity on home-based skill training

	N	Mean	SD
The participant was motivated to work on goals	62	3.26	0.82
During preparations of the dinner the participant was in the lead	61	3.62	0.58
The nurse employed capabilities of the participant	61	3.57	0.69
The participants succeeded in preparing a dinner	62	3.77	0.53
The participant made use of recourses (friends, family, etc.)	62	2.50	1.18
The nurse encouraged the participant to engage in social activities	60	2.20	0.90
The nurse had a clear picture of the support that the participant needed	59	3.15	0.69
The nurse had a clear picture of the goals of the participant	58	2.79	0.833
There were sufficient opportunities to work skills/goals	61	2.69	0.923
The nurse encouraged the participant	62	3.03	0.940
The nurse provided compliments to the participant	60	3.75	0.508
The nurse provided feedback at the end of the session	57	3.37	0.919

Range 1-5

Supplementary file S2
Participants ratings on peer support sessions and home-based skill training

Results of experienced efficacy of the peer support sessions

The HY project was helping because	N	Mean	SD
I had the possibility to share my story	13	2.54	0.66
I experienced recognition from my peers	13	2.31	0.86
My peers were an example	13	2.08	0.86
I recognized myself in others	13	2.38	0.77
I experienced that supporting others was also helping for myself	13	2.38	0.65
I experienced that I was not the only one with this problem	13	2.65	0.65
I could express my emotions	13	2.23	0.73
I received practical advice	13	2.23	0.83
I saw peers who were recovered	13	2.31	0.75
Stories of others helped me in clarifying my own situation	13	2.46	0.66
I got acknowledgement for my problems	13	2.46	0.78
I came out of my social isolation	13	1.92	0.64
I got social support from my peers	13	2.31	0.75

Range: 1–3

Results of experienced efficacy of the home-based skill training

By participating in an eating club	N	Mean	SD
I increased my cooking skills	12	2.92	1.31
I feel more confidence in inviting people at home	12	3.42	1.08
I feel more control on domestic tasks	12	2.83	1.19
I purchase more healthy products	12	2.75	0.87
I spend more time on my appearance	12	2.33	0.78
I invite more often people at home	12	2.83	0.72
I cook more often for others	12	3.00	0.85
I cook more often for myself	12	2.75	0.97
I have more often a dinner at o	12	2.83	0.72
I find it less stressful to invite others	12	3.00	0.74
I have more pleasure in cooking	12	3.33	0.88
I have more order in my household	12	2.83	0.84
I have a better grip on my finances	12	2.50	0.67
I do more activities with other people	12	3.17	0.84

Range: 1–5


2 KG
1 KG

Chapter 4

Measuring personal recovery in people with a psychotic disorder based on CHIME: a comparison of three validated measures

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Abstract

Objective

Living well in spite of residual symptoms of mental illness is measured with the construct of personal recovery. The CHIME framework might be suitable to evaluate personal recovery measures and guide instrument choice.

Methods

Three validated measures were evaluated in Dutch patients with a psychotic disorder (N=52). We compared the Recovery Assessment Scale [RAS], the Mental Health Recovery Measure [MHRM] and the Netherlands Empowerment List [NEL]. The measures were assessed on six criteria: content validity (based on CHIME), convergent validity with a social support measure, internal consistency, floor and ceiling effects, item interpretability and ease of administration.

Results

The MHRM scored high on content validity with a balanced distribution of items covering the CHIME framework. The MHRM and the NEL showed moderate convergent validity with social support. In all three measures internal consistency was moderate and floor and ceiling effects were absent. The NEL scores demonstrated a high degree of item interpretability. Ease of administration was moderate for all three measures. Finally, the CHIME framework demonstrated good utility as a framework in guiding instrument choice and evaluation of personal recovery measures.

Discussion

The MHRM showed the best overall result. However, differences between measures were minimal. Generalization of the results is limited by cultural and linguistic factors in the assessment for the subjective measures (i.e., content validity and item interpretability). The broad and multidimensional construct of personal recovery might lead to ambiguous interpretations. Scientific consensus on a well-defined personal recovery construct is needed.

Introduction

In recent years the patient movement raised awareness on the importance of personal recovery [1-3]. Personal recovery is defined by Anthony as a "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" [4]. Several studies advocate for the implementation of personal recovery in nursing care [5,6]. The growing amount of research on personal recovery-focused interventions emphasizes the increasing need for the evaluation of personal recovery measures.

Recently, the CHIME framework for recovery has received increased attention as a way to operationalize recovery [7]. This framework is based on a qualitative review of 115 studies. A narrative approach resulted in the five themes of the CHIME framework: Connectedness (support from others and being part of the community), Hope (a positive view on the future and motivation to change), Identity (building a positive identity and overcoming stigma), Meaning (developing meaningful roles and activities, quality of life and spirituality), and Empowerment (gaining control over life and focus upon strengths) [7]. The importance of CHIME is widely endorsed in the literature [8] which makes the framework suitable for evaluating personal recovery measures.

Self-report instruments for personal recovery, with straightforward interpretation such as those used in depression (e.g., Inventory of Depressive Symptomatology (IDS)), could serve evaluation of clinical care as well as research. However, personal recovery is characterized by its subjective nature and unique experiences [9]. Therefore, personal recovery measures contain broadly interpretable items so that a measure can cover a large variety of personal recovery experiences for patients with divergent levels of (cognitive) functioning [10]. These aspects make personal recovery measures prone to the bandwidth-fidelity problem. This problem refers to the trade-off between obtaining a score with high fidelity and narrow bandwidth on a specific trait versus obtaining a score that covers a broad bandwidth with less fidelity [11]. Therefore, developing a generic measure with a broad bandwidth comes at the expense of specificity: mean scores on studies that use a personal recovery measure as the primary outcome can generate multiple interpretations. As an alternative approach, the dimensions of the CHIME framework could serve as single constructs resulting in more specificity compared to the multidimensional construct of personal recovery.

Furthermore, subscales in measures are commonly identified with factor analyses. However, in heterogeneous constructs, factor analyses do not always produce subscales with sufficient content validity as they rely on internal consistency of subscales. In other words: while factor analysis retains items, which correlate highly with one another and thus improves internal consistency, it may also cause items to be dropped which have a lower correlation but are important for content validity [11]. Given how CHIME was developed based on a qualitative review of the literature, the dimensions of the CHIME framework may produce subscales based on content validity rather than factor analysis.

In this study we evaluate the Recovery Assessment Scale (RAS) [12], the Mental

Health Recovery Measure (MHRM) [13] and the Netherlands Empowerment List (NEL) [14]. The choice of measures was based on different qualities of the measures. The RAS was included because it is one of the earliest developed measures and is currently the most widely used scale for measuring personal recovery [15]. However, the RAS was not validated for the Dutch speaking population. Therefore, the MHRM was included as it was the first validated scale for measuring personal recovery in the Dutch mental health care population [16]. However, both the RAS and MHRM are developed in Anglo-Saxon countries and later translated in other languages. Translated measures may have limited generalizability to their targeted population and reliability measures, such as Cronbach's alpha, or floor and ceiling parameters might perform different in their country of development [11]. Validation of the reliability of measures in a specific language is therefore needed. We therefore included the NEL, as it was originally developed in Dutch and validated in the Netherlands.

Personal recovery is a highly subjective construct in which language and cultural elements likely play an important role [17]. Consequently, we expect the NEL to perform better on measures of applicability as this measure will be evaluated in the same country as it was developed. Based on prior research, we expect all three measures to perform adequately on construct validity, reliability, and applicability [14-16,18-21].

Aims

In this study we hypothesize that a recovery measure shows higher applicability scores when applied in the country of origin, compared to recovery measures from foreign countries. Therefore, we compare the RAS, the MHRM and the NEL for measuring personal recovery in a Dutch population of patients with a psychotic disorder. Measures will be exploratory assessed on aspects of construct validity (content and convergent validity) and reliability (Cronbach's alpha and floor and ceiling effects) and explanatory on applicability for patients with psychosis (interpretability and ease of administration). Furthermore, we explore the CHIME as framework for analyzing content validity.

Methods

Sample

A convenience sample was recruited within Lentis Psychiatric Institute (Groningen, The Netherlands) from October 2015 to February 2017. Patients with a psychotic disorder (schizophrenia spectrum: 295.xx, 297.1, 298,80, 298.90) (DSM IV, [22]), age ≥ 18, were eligible for inclusion. In total 53 patients were recruited for this study. One patient was excluded due to missing data. Therefore, 52 patients were included in the analysis. A description of the sample is presented in table 1.

Table 1: Description of the sample (N=52)

Item	Mean (SD)
Age	42.3 (12.69)
Illness duration (years)	15.1 (11.05)
	N (%)
Female/Male	12 (23.1)/ 40 (77.9)
Primary diagnosis	
Schizophrenia	34 (65.4)
Psychotic disorder NOS	8 (15.4)
Schizoaffective disorder	7 (13.5)
Other	2 (3.8)
Unknown (missing data)	1 (1.9)
Type of care	
Functional Assertive Community Treatment	28 (53.8)
Functional Assertive Community Treatment + sheltered housing	10 (19.2)
Hospital admitted	4 (7.7)
Rehabilitation care	10 (19.2)
Self-reported psychosis	
1	10 (19.2)
2	10 (19.2)
3	8 (15.4)
> 3	11 (21.2)
Unknown	13 (25)
Occupation	
Paid work	8 (15.1)
Voluntary work	21 (39.6)
Study	3 (5.7)
Other (e.g., occupational therapy, domestic work)	21 (39.6)
Education[1]	
Primary education	6 (11.6)
Lower secondary education	14 (26.9)
Upper secondary education	24 (46.2)
Bachelor or Master	8 (15.3)

[1] International Standard Classification of Education

Procedures and materials

All included personal recovery measures are self-report questionnaires and use a Likert scale (range: 1= strongly disagree to 5=strongly agree) with higher scores representing more personal recovery.

Recovery Assessment Scale

The RAS consists of 24 items (range 24-120). Corrigan et al. [12] conducted a factor analysis resulting in 5 factors: Personal confidence and hope, Willingness to ask for help, Goal and success orientation, Reliance on others and No domination by symptoms (Data S1). Good psychometric properties were found in the original English measure, with Cronbach's alpha ranging between α=0.76 and α=0.97 [15]. Test-retest reliability ranged from r=0.65 to r=0.88. Three out of six RCT's found the RAS to be sensitive to change in different psychiatric disorders [15]. In four reviews the RAS received good evaluations for convergent validity and ease of administration [18-21]. For this study the RAS was translated to Dutch using forward-backward translation with a native English speaker (Data S2).

Mental Health Recovery Measure

The MHRM was developed based on a recovery model by Young and Ensing [13]. It consists of 30 items with a scoring range between 30 and 150. In two reviews the MHRM received good evaluations for internal consistency and ease of administration. Convergent validity was measured with constructs of empowerment, resilience and community living. The correlations varied from 0.57 to 0.75 [19,21]. The Dutch version of the MHRM was used for this study. Exploratory factor analyses conducted on the Dutch MHRM reduced the original seven subscales to three [16]: Self-empowerment, Learning and new potentials and Spirituality (Data S1). Cronbach's alphas for the three factors in the Dutch MHRM ranged from α=.0.86 to α=0.94 [16].

Netherlands Empowerment List

The NEL was developed in the Netherlands and based on the results of a conceptual study of empowerment. In this study, concept mapping was used with participation of 56 patients with severe mental illness [23]. The 40-item measure has a scoring range from 40 to 200. The NEL consists of six subscales: Social support, Professional help, Connectedness, Confidence and purpose, Self-management and Caring community (Supplementary file S1). Good psychometric properties were found with a Cronbach's alpha of α= 0.94 and a test-retest reliability of 0.79 (ICC). The NEL showed sensitivity to change in a two-year randomized controlled trial that evaluated a personal recovery intervention for people with severe mental illness [14].

Social Support List 12 – Interactions

Social support is recognized as a construct closely related to personal recovery [24,25]. Social support is embedded in the CHIME framework through the Connectedness dimension. Moreover, support from peers, friends or family benefits all aspects of the framework to a certain extent (as noted in subdimensions of CHIME such as Hope inspiring relationships or Meaningful life and social roles). The importance of social support is also reflected in studies of personal recovery-focused interventions, which

aim to strengthen the social network [26,27]. Therefore, correlation of a personal recovery measure with a social support measure could serve to strengthen theoretical support for the construct validity.
To assess convergent validity with social support we used the Social Support List 12-Interactions (SSL12-I) [28]. The SSL12-I was validated for use in the geriatric population [29]. The 12-item measure (range: 12-48) contains three subscales: Everyday support, Esteem support and Support in problem situations. The SSL12-I showed satisfactory psychometric properties with all subscales demonstrating an internal reliability coefficient of $r \geq 0.70$. The mean interitem correlations were $r=.029$ for the complete measure and $r \geq 0.37$ for the subscales.

Administration

Each personal recovery measure was completed along with an item on 'ease of administration' using the same 5-point Likert scale as the questionnaires. Furthermore, participants provided information about demographic variables, such as highest level of completed education and diagnosis.

Ethical considerations

This study is completed in accordance with the declaration of Helsinki [30], and all participants provided written informed consent. Participation was on voluntary basis with no compensation.

Analyses

Measures were analyzed on six criteria: content validity, convergent validity, internal consistency, floor and ceiling effects, interpretability and ease of administration. Each criterion was scored on a scale from 0 to 2 (0= inadequate performance, 1= moderate performance, and 2= adequate performance). All criteria and their scoring are further specified below.

Power analysis

The number of participants needed for this study was based on the formula that is described in Streiner & Norman [11]. Based on earlier research we expected to estimate values of Cronbach's alpha close to $\alpha=0.90$ in the current study [14-16]. With $\alpha=0.90$ (95% CI= 0.85 and 0.95) and >25 items per scale the power analysis resulted in 50 persons.

Content validity

We operationalized content validity by matching each item of each questionnaire to one of the five dimensions of the CHIME framework. The individual items were mapped to the CHIME framework by three criteria. First, an item was considered valid when it reflected at least one of the five dimensions of the framework. Second, items that did not reflect any of the CHIME dimensions were considered superfluous. Content validity was based on the premise that all aspects of CHIME were considered equally important. A measure was therefore considered an adequate representation of personal recovery when all five dimensions of the CHIME framework were represented and the items of the questionnaire were evenly distributed across all dimensions [31]. The mean number of valid items and their deviation from the mean (variance (σ)) across the different dimensions of CHIME was used as a measure for the total fit of the questionnaire to the framework. If the percentage of redundant items was ≤10% with a total variance of σ≤ 30, content validity was considered adequate (i.e., two points). Furthermore, content validity was considered moderate with >10% and ≤15% redundant items and σ> 30 and σ≤ 60 and inadequate with > 15% redundant items and σ> 60. Content validity was assessed by three authors (JSV, JB and RJL). The inter-rater agreement was analyzed with ICC estimates (two-way mixed) and their 95% CI based on the mean and absolute agreement, resulting in a fair, good or excellent agreement [32]. A fourth author (SC) could be consulted in case discrepancies could not be solved in a consensus meeting. Having allocated each item to one of the CHIME domains resulted in an alternative subscale division for each instrument, with each of the CHIME domains serving as a subscale. Significant correlations between these new subscales and acceptable values of Cronbach's alpha (α> .70) would strengthen the validity of using CHIME as a basis for content validity analysis.

Convergent validity

Convergent validity for social support was operationalized by calculating a Pearson product-moment correlation coefficient between the recovery measures and the related construct 'social support', as measured with the SSL12-I. Correlations were considered small if r= .10, medium if r= .30 or high if r= .50 [33]. Convergent validity was considered adequate if r≥.50 with p< .05, moderate if r≥.30 and <.50 with p< .05 or inadequate if p>0.05. Additional analyses were performed on subscales that primarily focused on connectedness (i.e., Reliance on others (RAS) and Social support (NEL)). Furthermore, Pearson correlations between the three measures were calculated to evaluate whether the same construct was measured between the measures.

Internal consistency

Cronbach's alpha was used to analyze internal consistency on total measures and on original subscales as well as the alternative CHIME subscales that were created in this study. Values of α< 0.70 reflect poor internal consistency and values α> 0.90 reflect redundancy of items (i.e., items have too much similarity) [11]. Measures with ≥14 items produce acceptable alphas (i.e., more items result in a higher alpha; [34]. Therefore, we also examined the mean inter-item correlation of the total measures. Total measures and subscales with an alpha below α< .70 were further evaluated on item level by calculating alpha if the respective item was deleted. A mean interitem correlation between r= 0.15 and r=0.20 was considered adequate [35]. Internal consistency was considered adequate if all of the following criteria were met: α≥ 0.70 and ≤0.90 with a mean interitem correlation between r= 0.15 and r=0.20 on total- and subscales. Internal consistency was considered moderate if one these criteria were met and inadequate if none of these criteria were met.

Floor and ceiling effects

Floor and ceiling effects occur when >15% of the respondents attain the lowest or the highest possible score respectively [36]. This is often the result in items which measure the extreme ends of the scales, that is which measure performance at the highest or lowest ends of the spectrum. This results in a negative impact on content validity, as participants at either extreme end cannot be distinguished from one another. The absence of floor and ceiling effects was considered adequate if ≤15% of the sample had either the highest or the lowest possible score respectively (moderate >15% and ≤17.5%, inadequate >17,5%).

Item interpretability

All items of the measures were screened on interpretability. Each item was independently assessed by three authors (JSV, JB and RJL). Item interpretability was assessed on seven aspects: ambiguous wording; double barreled questioning; jargon; negative wording; lengthiness; complex sentence construction; abstract terms; and face validity [11]. An item was considered adequate if no weak properties applied, moderate if only one weak property applied, and inadequate if ≥2 weak properties applied. Agreement on scores was then reached in a consensus meeting. This criterion was considered adequate if ≤25% of the items on a measure had weak properties, moderate if >25% and ≤50 % of the items had weak properties, and inadequate if >50% of the items had weak properties.

Ease of administration

The ease of administration was measured with a single Likert-scale item at the end of each measure ("this questionnaire was easy to complete") ranging from 1= strongly disagree to 5=strongly agree. The result is presented with descriptive statistics (means and SD's). A Friedman test was conducted to evaluate significant differences between the three measures. Ease of administration was considered adequate with a mean score of ≥4, moderate with a mean score of ≥3 and <4 and inadequate with a mean score of <3. Patients with higher recovery scores might find it easier to complete the measure. To assess an association between ease of administration and personal recovery, a Pearson correlation was conducted on ease of administration with all three personal recovery measures.

All statistical analyses were performed using SPSS Statistics Version 22 [37]. In case of missing values pairwise deletion was applied.

Results

Content validity

A good agreement was found between the raters (ICC= .783, 95%CI: .667-.857). Table 2 shows the outcomes of the content validity analysis. The MHRM showed the most optimal item distribution across CHIME (σ= 25.6). The RAS scored high on Empowerment with 25% of the items on this dimension. Most items of the NEL were assigned to Connectedness (27.5%). Hope and Optimism was underrepresented in the NEL (7.5%).

With the content validity analysis, items of measures were mapped to the CHIME framework. This resulted in an alternative subscale division of the measures in which each domain of CHIME could serve as a subscale. Significant correlations were found between the measures mapped by their respective CHIME dimension. Only the RAS and MHRM did not correlate on Connectedness. Other correlations ranged from r (50) = .335, p<.05 to r (50) = .717, p<.05. See Table S1 for the subscales based on CHIME that resulted from the content validity analysis. Cronbach's alpha was applied to measure the internal consistency of the alternative CHIME-subscales, and ranged from α= 0.442 to α= 0.836. Acceptable Cronbach's alphas (>0.70) were found for Connectedness on all three measures, for Identity on the MHRM and the NEL and for Hope and Empowerment on the NEL. See Table S2 for the internal consistency of all total and subscale measures.

Table 2: Content validity rating of the RAS, MHRM and NEL items as measured with the CHIME framework

CHIME categories	RAS (24 items) items (%)	MHRM (30 items) items (%)	NEL (40 items) items (%)
Connectedness	4 (16.7)	4 (13.3)	11 (27.5)
Hope and optimism	3 (12.5)	4 (13.3)	3 (7.5)
Identity	3 (12.5)	7 (23.3)	4 (10.0)
Meaning and purpose	5 (20.8)	7 (23.3)	7 (17,5)
Empowerment	6 (25.0)	5 (17.7)	8 (20.0)
Item does not map	6 (12.5)	3 (10.0)	6 (17.5)
Variance	29.5	25.6	64.4

RAS= Recovery AssessmentScale; MHRM= Mental Health Recovery Measure; NEL= Netherlands Empowerment List

Convergent validity

A significant medium correlation was found between the SSL12-I and both the MHRM (r(50) = 0.414, p<0.01) and NEL (r(50) = 0.418, p<0.01). The correlation between the SSL12-I and the RAS did not reach significance. Two subscales of the RAS and the NEL with a focus on connectedness were relevant for individual analyses. These subscales significantly correlated with the SSL12-I, with respectively a medium correlation of r(50) = 0.406, p<0.01 (Reliance on others (RAS)) and a high correlation of r(50) = 0.607, p<0.01 (Social support (NEL)). All recovery measures correlated significantly with each other (RAS and MHRM r(50) = 0.697, p<0.01, RAS and NEL r(50) = 0.692, p<0.01, MHRM and NEL r(50) = 0.821, p<0.01).

Internal consistency

All three measures showed acceptable homogeneity (α≥ 0.70) on total scores. The total score on the RAS (α=0.838), as well as four out of five subscales of the RAS, showed an adequate internal consistency. The mean interitem correlation of the RAS was sufficient with r=0.192. The subscales No domination by symptoms did not reach the lower boundary (α=0.671). An analysis on alpha if item deleted showed that by deleting the item My symptoms seem to be a problem for shorter periods of time each time they occur alpha reached an adequate score (α=0.771). The MHRM marginally exceeded the threshold for adequate internal consistency (α=0.903) as well as for the mean interitem correlation of r=0.245. The subscales Self-empowerment and Learning and new potentials showed an adequate alpha. The subscales Spirituality consists of only two items and showed an alpha of α=0.921. The NEL total score exceeded the upper threshold for both the Cronbach's alpha (α=0.920) and the mean interitem correlation (r=0.223). Five out of six subscales of the NEL have an adequate internal consistency. The subscale Self-management scored just under the threshold (α=0.628). An analysis on alpha if item deleted did not result in α> 0.70 on a single item deletion. See Table S2 for the internal consistency of all measures.

Floor and ceiling effects

None of the measures exceeded the 15% threshold for floor- and ceiling effects. Floor-effects were absent in total mean scores and subscale mean scores in all three measures. Also, ceiling-effects were absent in total mean scores, but not in subscales. Ceiling-effects on subscales ranged between 0% and 7.7% for the RAS, between 1.9% and 11.5% for the MHRM, and between 0% and 9.6% for the NEL.

Item interpretability

A little more than half (57.5%) of the items of the NEL was scored as straightforward to interpret by participants. Both the RAS and the MHRM scored low on item interpretability scores with >60% of items containing weak properties. For example: "I feel at peace with myself" (MHRM) was considered an ambiguous item. Table 3 shows the number and percentage of properties with respectively a good, fair or poor rating.

Table 3. Item interpretability scores of RAS, MHRM and NEL

	RAS (24 items)	MHRM (30 items)	NEL (40 items)
	Items (%)	Items (%)	Items (%)
Good	9 (37.5)	7 (23.3)	23 (57.5)
Fair	11 (45.8)	16 (53.3)	11 (27.5)
Poor	4 (16.7)	7 (23.3)	6 (15.0)

Good: no weak properties; Fair: one weak property; Poor: ^{3}2 weak properties; RAS= Recovery Assessment Scale; MHRM= Mental Health Recovery Measure; NEL= Netherlands Empowerment List

Ease of administration

All three measures received a positive evaluation on ease of administration by the participants, with similar scores for the RAS (m=3.71 ±0.87), the MHRM (m= 3.51 ±1.05) and the NEL (m= 3.67 ±0.96). There were no significant differences (χ2 = 2.346, p = 0.309) between the measures. The RAS showed a significant positive correlation between the total recovery score and the ease of administration (r=0.339, p= 0.014). Table 4 shows the summary of the six aspects that were measured.

Table 4. Summary of the evaluation of three personal recovery measures

	RAS	MHRM	NEL
Content validity	1	2	0
Convergent validity	0	1	1
Internal consistency	1	1	1
Floor and ceiling effects	2	2	2
Item interpretability	0	0	1
Ease of administration	1	1	1
Overall scoring	5	7	6

0= inadequate, 1 = moderate, 2 = adequate; RAS= Recovery Assessment Scale; MHRM= Mental Health Recovery Measure; NEL= Netherlands Empowerment List

Discussion

Main findings

Of the three included personal recovery measures (RAS, MHRM and NEL), only the MHRM showed good content validity with a balanced distribution of the items covering the complete CHIME framework. Unlike the NEL and MHRM, the RAS did not show convergent validity with the SSL12-I, despite the content validity analysis showing a reasonable number of items allocated to Connectedness. However, on subscale level, a medium significant correlation between the SSL12-I and the Connectedness subscale of the RAS (Reliance on others) was found. On interpretability, only the NEL achieved adequate scores on more than half of the items (57.5%). The MHRM showed the best result across all six criteria included in this evaluation due to the higher rating on content validity. This minimal difference does not suggest that the MHRM is convincingly better than the other measures. As noted in the introduction, the evaluation of measures resulted in an overall adequate score. Each instrument demonstrates a similar number of strengths and weaknesses, and as such, specific application may be the most useful guide in determining which instrument to use. If a greater focus on Connectedness is desired, the NEL offers the strongest properties. If Empowerment is of more interest, then we suggest using the RAS.

In our introduction we hypothesized better performance on the NEL on measures of applicability. Although the NEL scored better on interpretability, it did not perform better on ease of administration compared to the other measures, thus rejecting our hypothesis.

Interpretation of the results

The CHIME framework was used in this study for analyzing content validity. Items were allocated to one of the CHIME dimensions. For each measure this resulted in alternative subscales based on the CHIME framework. Significant correlations were found between subscales of the same CHIME dimension. This outcome suggests that CHIME could be used for evaluation of personal recovery measures. Additionally, CHIME could also be used for the development of new scales based on its singular dimensions.

Similar to previous studies, we found evidence for internal consistency in all three measures [15,16,23]. However, the MHRM and the NEL showed a Cronbach’s alpha >0.90, indicating redundant items in the measure. Our finding of a Cronbach’s alpha of >0.90 on the subscale spirituality of the MHRM is in line with the study of van Nieuwenhuizen et al. [16]. Also, in line with our study, the study of Boevink et al. [23] found an alpha of >.90 on the total measure on the NEL. In the current study acceptable alphas were found for all but one subscale of the NEL (Self-management, α=.628). This difference might be due to differences in sample characteristics: unlike the current study, the study of Boevink et al. [23] was not limited to patients with psychosis. Furthermore, in the current study we found a possibility for a slight improvement on alpha in the RAS by deleting the item My symptoms seem to be a problem for shorter periods of time each time they occur. This will increase the internal consistency from α=0.671 to α=0.771 in the subscale No domination by symptoms. This finding is consistent with the theory on personal recovery, placing less emphasis on clinical symptoms.

The criteria for item interpretability were only partly met by the NEL and not by the RAS and the MHRM. Different populations might have a different understanding of the concept of personal recovery [38] or the items or wording of a measure [11]. For example, aspects of spirituality are differently conceptualized in diverse cultures [17]. As a possible result, interpretation of the items of the NEL was more straightforward for a Dutch team of researchers. This shows the importance of language in personal recovery measures. Furthermore, it reaffirms the influence of culture in the personal recovery construct [17].

All measures showed moderate scores on ease of administration. In line with previous research no differences were found in ease of administration [19,21]. Only the RAS showed a significant correlation with personal recovery scores, indicating that people with higher recovery scores finding it easier to complete this questionnaire.

Measuring personal recovery

The complexity and manifold dimensions of the construct of personal recovery are shown in this study and are discussed in several previous studies [39]. For example, Liberman [40] comments on the personal recovery construct by comparing it with self-efficacy measures that often leave 'much ambiguity about what is being measured' [41]. Furthermore, Liberman [40] argues that personal recovery is not a scientific construct and should therefore not be measured as an outcome in research. In an opinion paper, Bellack [10] observed that the validity of self-assessment of personal experiences can be argued in patients with psychosis because of impaired reasoning and reality distortion [10].

A large part of the complexity and ambiguity can be attributed to the wide variety of views on personal recovery. The lack of consensus on the personal recovery construct leads to many measures with different accents. Concrete examples are the subscale Caring community in the NEL, which is not seen in other personal recovery measures [23]. Furthermore, there is debate if personal recovery should be viewed as a process or an outcome [40,42,43]. A recent scoping review of van Weeghel et al. [8] supports the viewing of recovery as a process rather than an outcome. Also, Davidson [44] argues that supporting patients who want to have a good life is at best a process with intermediate outcomes. The view of recovery as a process is reflected in measures that include stages of personal recovery. The Self-Identified Stages of Recovery (SISR) [45] and the Stages of Recovery Instrument [46]are examples of questionnaires that measure stages in the process of recovery. Other questions are to what extent personal recovery is influenced by culture [17,38], and which themes are most important in the personal recovery construct (e.g., social relationships and social activity, self-agency or hope) [43,47]. The CHIME framework offers a good starting point for consensus on these themes. However, even using the same framework can lead to different interpretations: in analyzing content validity, based on CHIME, we came to different results than Shanks et al. [20], who used the same framework. This review had much higher rates for the representation of the dimension Hope and Optimism (RAS: 17%, MHRM: 30%) and more items that did not match the CHIME framework in both the RAS (RAS: 29%, MHRM: 17%) compared to our evaluation.

Limitations

Several limitations should be considered. First, in this review, content validity and item interpretability were only evaluated by researchers and a researcher/clinician. The absence of other stakeholders (e.g., patients, family) limits the validity of these analyses.

Second, the use of the CHIME framework for analyzing content validity was confirmed by high correlations of items across measures mapped by the CHIME dimensions. However, a confirmatory factor analysis would show a more definite answer on the question whether CHIME is a suitable framework for analyzing content validity. This was, however, not possible in this study due to a limited sample size. Furthermore, there are other frameworks available [39,42] as well as adaptations on the CHIME framework [48,49]. This study only tested one framework for personal recovery and was therefore not able to analyze dimensions that are not part of CHIME such as Difficulties [48]. Although CHIME was shown to be a suitable framework for personal recovery in the current study, and several others, it is important to note that it was developed based on Western scientific literature [7].

Third, all measures were administered to the participants in the same order. This might have biased the outcome on ease of administration as systematic differences could appear from a primacy or recency effect. A counterbalanced design, in which measures are administered in a random sequence, would therefore have been preferable.

Fourth, the evaluation of convergent validity was limited by only assessing it with social support. This was shown by measuring convergent validity in personal recovery on subscale level (i.e., subscales on Connectedness), which resulted in higher correlations compared to correlations on total measures. Due to the multidimensional nature of the personal recovery construct, evaluating convergent validity with other (CHIME-related) constructs such as empowerment, self-esteem and hope, as well as divergent validity with self-stigma, loneliness and depression, would provide additional insight.

Future research

Personal recovery as defined by consumer views is still in need to transform vague, politically correct concepts into empirically reliable and valid scientific concepts (Liberman 2012). Critical evaluation of the construct, especially on the dimensions to be included in the construct, is therefore needed. An important aspect in reaching this consensus is social validation [2]. With this form of validation, different stakeholders (patients, family, clinicians, researchers and the broader public) are able to give input on the criteria for recovery. Furthermore, comprehensive construct validation could support the evidence for the personal recovery construct. However, it will not unambiguously prove the existence of such a construct [11].

The construct of personal recovery has gained much influence in mental health care. The call for the personal recovery model originated from a mental health care system with a primary focus on symptom reduction [4]. The consequences of a psychiatric disorder such as loneliness or loss of identity were underexposed in this medical paradigm. As a consequence, the patient movement advocated for a more holistic approach, considering the personal needs of patients with a psychiatric disorder. This raises the question whether the personal recovery construct should be used to guide mental health policy and practice rather than be used for evaluating mental health outcomes [10].

However, the emphasis placed on it by the patient movement demonstrates its great meaning to the clients themselves. As such, it is important that efforts are continued to further operationalize the construct. However, currently the idiosyncratic [50] and culturally sensitive [17] aspects of the construct impede the development of broad generic measures. In addition, models of recovery are primarily based on concepts of the Western world, which limits generalization to and international use of these measures in Non-Western cultures (Slade et al 2012). Until more clarity is established on the construct of personal recovery, an option might be to disentangle the personal recovery construct to the CHIME dimensions or other common constructs (i.e., social support, hope and goal orientation) and measure them as separate constructs [43]. Often these constructs have a longer history in scientific literature and have shown psychometric validity [51] as well as the before suggested social validity.

Conclusions

A comparison of three personal recovery measures (RAS, MHRM, NEL) on six criteria showed the MHRM to have the best rest results. However, there are several concerns with all personal recovery measures. The review process showed that measuring personal recovery is complex as there is little scientific agreement on the construct. In this regard it should be considered that "not everything that can be counted counts, and not everything that counts can be counted" [52]. However, as an alternative to broad generic measures, unidimensional measures that are part of the personal recovery construct (e.g., hope, connectedness, etc.) could be used to measure specific aspects of personal recovery.

Relevance for clinical practice

Personal recovery has gained an important role in mental health nursing care. In recent decades many personal recovery measures were developed. This study evaluated three recovery measures (RAS, MHRM and NEL). The MHRM showed the best result across all six criteria. However, the multidimensional and idiosyncratic nature of the personal recovery construct impedes a strong conclusion of a preferred measure. For use in mental health nursing practice, CHIME guided specific use of the NEL for a focus on Connectedness and the RAS for a focus on Empowerment.

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S1 Original Subscales

Recovery Assessment Scale – original subscales

Corrigan, P.W., Giffort, D., Rashid, F., Leary, M., Okeke, I., 1999. Recovery as a psychological construct. Community Ment. Health J. 35 (3) 231-239.

Subscale: Personal confidence and hope

11. Fear doesn't stop me from living the way I want to
14. I can handle what happens in my life
15. I like myself
16. If people really knew me, they would like me
20. I have an idea of who I want to become
22. Something good will eventually happen
24. I am hopeful about my future
25. I continue to have new interests
36. I can handle stress

Subscale: Willingness to ask for help

30. I know when to ask for help
31. I am willing to ask for help
32. I ask for help when I need it

Subscale: Goal and success oriented

1. I have a desire to succeed
2. I have my own plan for how to stay or become well
3. I have goals in life that I want to reach
4. I believe I can meet my current personal goals
5. I have a purpose in life

Subscale: Reliance on others

6. Even when I don't care about myself, other people do
37. I have people I can count on
39. Even when I don't believe in myself, other people do
40. It is important to have a variety of friends

Subscale: Not dominated by symptoms

27. Coping with mental illness is no longer the main focus of my life
28. My symptoms interfere less and less with my life
29. My symptoms seem to be a problem for shorter periods of time each time they occur

Mental Health Recovery Measure -original subscales

Young S.L., Bullock W.A., 2005. Mental health recovery measure (MHRM), in: Campbell-Orde, T., Chamberlin, J., Carpenter, J., Leff, H.S. (Eds.), Measuring the Promise: A Compendium of Recovery Measures. Human Services Research Institute, Cambridge, MA, pp. 36–41.

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Subscale: Self-empowerment

5. I believe in myself
6. I have control over my mental health problems
7. I am in control of my life
8. I socialize and make friends
11. Even though I may still have problems, I value myself as a person of worth
12. I understand myself and have a good sense of who I am
13. I eat nutritious meals every day
17. I feel good about myself
19. My life is pretty normal
20. I feel at peace with myself
21. I maintain a positive attitude for weeks at a time
29. I cope effectively with stigma associated with having a mental health problem
30. I have enough money to spend on extra things or activities that enrich my life

Subscale: Learning and new potentials

1. I work hard towards my mental health recovery
2. Even though there are hard days, things are improving for me
3. I ask for help when I am not feeling well
4. I take risks to move forward with my recovery
9. Every day is a new opportunity for learning
10. I still grow and change in positive ways despite my mental health problems
14. I go out and participate in enjoyable activities every week
15. I make the effort to get to know other people
16. I am comfortable with my use of prescribed medications
18. The way I think about things helps me to achieve my goals
22. My quality of life will get better in the future
23. Every day that I get up, I do something productive
24. I am making progress towards my goals
27. I advocate for the rights of myself and others with mental health problems
28. I engage in work or other activities that enrich myself and the world around me

Subscale: Spirituality

25. When I am feeling low, my religious faith or spirituality helps me feel better
26. My religious faith or spirituality supports my recovery

Netherlands Empowerment List – original subscales

Boevink, W., Kroon, H., Delespaul, P., Van Os, J., 2017. Empowerment according to Persons with Severe Mental Illness: Development of the Netherlands Empowerment List and its Psychometric Properties. Open Journal of Psychiatry. 7 18-30.

Subscale: confidence and purpose

33. I think of myself as a person worth something
34. I turn negative thoughts into positive ones

43. I am not afraid to rely on myself
19. I am determined to go on
13. I derive satisfaction from the things that go well
4. I have a purpose in my life
41. I can deal with my vulnerabilities
22. The role of patient is no longer central in my life
14. I am able to deal with the problems that come my way
3. I have the feeling that I can mean something for someone else
16. I decide how I control my life
36. I can see how my life has made me who I am today

Subscale: Social support
10. The people around me take me as I am
42. I can fall back on the people around me
17. The people I love support me
28. I have a good relationship with the people around me
6. The people around me accept me
9. Those around me offer me a listening ear
18. I can obtain adequate support when I need it

Subscale: Caring community
39. This society does not discriminate against people with a mental disability
12. In our society, people with a mental disability are considered full citizens
24. This society offers social security to people with a mental disability
29. This society creates opportunities that fit my level of participation
2. This society makes allowance for people with a psychiatric disability
20. Society respects my rights as a citizen

Subscale: connectedness
25. I regularly meet people outside my home
40. I do the things that I think are important
26. I can share my experiences with others with similar experiences
38. I have enough to do each day
32. I have a sense of belonging.
37. I find peace and safety in my home

Subscale: Self-management
8. I am able to set my boundaries
11. I know what is good and what is not good for me
27. I know what I am good at

21. I have structure in my life
23. I am not afraid to ask for help

Subscale: Professional help
15. My caregiver is there for me when I need him/her
1. My caregiver and I have a good collaborative relationship
7. My caregiver takes my abilities as a starting point, not my limitations
30. The care I receive fits in well with my life

S2 Recovery Assessment Scale (Dutch version)

1. Ik wil graag slagen.
2. Ik heb mijn eigen plan om me goed te gaan voelen of te blijven voelen
3. Ik heb doelen in het leven die ik wil bereiken.
4. Ik geloof dat ik mijn huidige persoonlijke doelen kan bereiken.
5. Ik heb een doel in het leven.
6. Zelfs wanneer ik niet om mezelf geef, zijn er anderen die dat wel doen.
7. Angst weerhoudt me niet te leven zoals ik wil.
8. Ik kan omgaan met wat er in mijn leven gebeurt.
9. Ik mag mezelf.
10. Als mensen me echt zouden kennen, zouden ze me mogen
11. Ik heb een idee van wie ik wil worden.
12. Iets goeds zal uiteindelijk gebeuren.
13. Ik ben hoopvol over de toekomst.
14. Ik blijf nieuwe interesses hebben.
15. Omgaan met mijn psychische aandoening is niet langer de belangrijkste focus in mijn leven.
16. Mijn symptomen hebben steeds minder invloed op mijn leven.
17. Als mijn symptomen optreden, lijken ze voor een steeds kortere periode problemen op te leveren.
18. Ik weet wanneer ik om hulp moet vragen.
19. Ik ben bereid om hulp te vragen.
20. Wanneer ik het nodig heb, vraag ik om hulp.
21. Ik kan omgaan met stress.
22. Ik heb mensen waar ik op kan rekenen.
23. Zelfs als ik niet in mijzelf geloof, zijn er anderen die dat wel doen.
24. Het is belangrijk om verschillende vrienden te hebben.

S3 CHIME Subscales

	Recovery Assessment Scale	Mental Health Recovery Measure	Netherlands Empowerment List
Connectedness	Even when I don't care about myself, other people do	I socialize and make friends	My caregiver and I have a good collaborative relationship
	I have people I can count on	I make the effort to get to know other people.	The people around me accept me
	Even when I don't believe in myself, other people do	I advocate for the rights of myself and others with mental health problems.	Those around me offer me a listening ear
	It is important to have a variety of friends	I engage in work or other activities that enrich myself and the world around me.	The people around me take me as I am
			My caregiver is there for me when I need him/her
			The people I love support me
			This society creates opportunities that fit my level of participation
			I have a good relationship with the people around me
			I can share my experiences with others
			I have a sense of belonging
			I can fall back on the people around me
Hope	Something good will eventually happen	Even though there are hard days, things are improving for me.	I derive satisfaction from the things that go well
	I am hopeful about my future	Every day is a new opportunity for learning.	I am determined to go on

	I believe I can meet my current personal goals	I maintain a positive attitude for weeks at a time.	I turn negative thoughts into positive ones
		My quality of life will get better in the future.	
Identity	I like myself	I believe in myself	I know what I am good at
	If people really knew me, they would like me	I still grow and change in positive ways despite my mental health problems	I think of myself as a person worth something
	I have an idea of who I want to become	Even though I may still have problems, I value myself as a person of worth	I can see how my life has made me who I am today
	I continue to have new interests	I understand myself and have a good sense of who I am	I am not afraid to rely on myself
		I feel good about myself	
		I feel at peace with myself	
		I cope effectively with stigma associated with having a mental health problem	
Meaning	I have a purpose in life	I work hard towards my mental health recovery	I have the feeling that I can mean something for someone else
	I have a desire to succeed	I go out and participate in enjoyable activities every week	I have a purpose in my life
	I have goals in life that I want to reach	My life is pretty normal	I have structure in my life
	Coping with mental illness is no longer the main focus of my life	Every day that I get up, I do something productive	The role of patient is no longer central in my life
		I am making progress towards my goals	I regularly meet people outside my home
		When I am feeling low, my religious faith or spirituality helps me feel better	I have enough to do each day
		My religious faith or spirituality supports my recovery	I do the things that I think are important

Empowerment	I can handle what happens in my life	I ask for help when I am not feeling well	I am able to set my boundaries
	I can handle stress	I take risks to move forward with my recovery	I know what is good and what is not good for me
	I know when to ask for help	I have control over my mental health problems	I am able to deal with the problems that come my way
	I ask for help when I need it	I am in control of my life	I decide how I control my life
	I have my own plan for how to stay or become well	The way I think about things helps me to achieve my goals	I can obtain adequate support when I need it
	My symptoms interfere less and less with my life		I am not afraid to ask for help
			The care I receive fits in well with my life
			I can deal with my vulnerabilities
Not included	Fear doesn't stop me from living the way I want to	I eat nutritious meals every day	This society does not discriminate against people with a mental disability
	I am willing to ask for help	I am comfortable with my use of prescribed medications	In our society, people with a mental disability are considered full citizens
	My symptoms seem to be a problem for shorter periods of time each time they occur	I have enough money to spend on extra things or activities that enrich my life	This society offers social security to people with a mental disability
			This society makes allowance for people with a psychiatric disability
			Society respects my rights as a citizen with similar experiences
			I find peace and safety in my home
			My caregiver takes my abilities as a starting point, not my limitations

S4 Internal consistency of the RAS, MHRM and NEL

Scale/ original subscale	Cronbach's α	CHIME subscale	Cronbach's α
RAS-24	.838		
Personal confidence and hope	.729	Connectedness	.725
Willingness to ask for help	.777	Hope	.605
Goal and success orientation	.788	Identity	.468
Reliance on others	.725	Meaning	.684
No domination by symptoms	.671	Empowerment	.556
MHRM	.903		
Self-empowerment	.867	Connectedness	.784
Learning and new potentials	.810	Hope	.558
Spirituality	.924	Identity	.871
		Meaning	.639
		Empowerment	.442
NEL	.920		
Professional help	.728	Connectedness	.836
Social support	.825	Hope	.813
Confidence and purpose	.899	Identity	.754
Connectedness	.794	Meaning	.688
Self-management	.628	Empowerment	.787
Caring community	.877		

RAS= Recovery Assessment Scale; MHRM= The Mental Health Recovery Measure; NEL= Netherlands

Chapter 5

The effect of mind-body and aerobic exercise on negative symptoms in schizophrenia: a meta-analysis

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Abstract

Objective

This meta-analysis aims to evaluate the effects of different types of physical exercise (PE) on negative symptoms in schizophrenia patients. Mind-body exercise (MBE), aerobic exercise (AE) and resistance training (RT) will be investigated.

Method

The Cochrane Library, Medline, Embase and PsycINFO were searched from their inception until April 26, 2018. Randomized controlled trials comparing PE with any control group in patients with schizophrenia were included when negative symptoms had been assessed. This meta-analysis was conducted according to the PRISMA guidelines. The methodological quality of these studies was assessed with the Cochrane Risk of Bias assessment tool. Moderator, sensitivity, and meta regression analyses were conducted to explore causes of heterogeneity and impact of study quality.

Results

We included 22 studies (N=1249). The overall methodological quality was poor. The meta-analysis (random effects model) showed a medium significant effect in favor of any PE intervention (Hedges' g=0.434, 95% CI=0.196 to 0.671) versus any control condition. MBE and AE respectively showed a medium significant effect (Hedges' g=0.461) and a small significant effect (Hedges' g=0.341) versus any control condition. The effect of RT could not be examined. The overall heterogeneity was high (I^2=76%) and could not be reduced with moderator or sensitivity analyses.

Conclusion

This meta-analysis demonstrated that PE could be a promising intervention in the treatment of negative symptoms. However, the quality of the included studies was low and heterogeneity was high, which makes it impossible to make a clear recommendation. Therefore, results should be interpreted with care.

Introduction

Negative symptoms in patients with schizophrenia are strongly associated with increased disease burden and problematic social outcome, such as a smaller social network and lower social functioning [1-3]. Negative symptoms are present in 50-90% of the patients with a first episode psychosis (FEP) and persisting negative symptoms are found in 20-40% of the patients with schizophrenia [2]. These symptoms are associated with low psychosocial functioning, such as vocational/academic and self-care problems [4]. Negative symptoms are a predictor of poor functional recovery at 12 months [5] and 7,5 years [6] after FEP. This profound impact on patients' lives warrants the research on effective treatments of negative symptoms [7].

Several different interventions targeting negative symptoms in schizophrenia have been investigated in previous research. Psychological and pharmacological interventions did not lead to clinically relevant improvements [8] and the evidence on Cognitive Behavioral Therapy (CBT) [9-11] and Transcranial Magnetic Stimulation (TMS) is inconclusive [12-14].

Negative symptoms are associated with impairments in effort-cost computations [15],meaning that people with schizophrenia presumably overestimate costs and underestimate reward of possible pleasurable behaviors. This in turn results into clinical manifestations of negatives symptoms, such as amotivation and apathy [16]. This effort-based decision paradigm might be the putative mechanism in understanding the effect of physical exercise (PE) for negative symptoms. PE is generally perceived as a high effort activity, but with beneficial effects in neural pathways for reward [17,18]. Therefore, repetitive training in PE might have positive effects on effect-cost computations in schizophrenia and subsequently in negative symptoms. Aside from an effect on negative symptoms, previous studies have also shown beneficial effects of PE on working memory, social cognition, attention/vigilance [19,20], cardiorespiratory fitness [21] depression and PANSS scores [20,22] in schizophrenia. This accumulation of beneficial effects makes PE an exceptionally interesting intervention for people with a psychotic disorder.

Previous reviews and meta-analyses have demonstrated that different types of PE interventions, such as aerobic exercise (AE) [23], yoga [24,25], and tai chi [26], resulted in significant effects on negative symptoms in schizophrenia. In recent years, new intervention studies were published on these different types of PE that have not been included in any previous reviews [24,25,27-31]. An update of the evidence of PE on negative symptoms is therefore needed. Furthermore, most previous reviews and meta-analyses have evaluated the effects of a specific type of PE interventions on negative symptoms. To our knowledge, only one previous meta-analysis by Dauwan et al. [32] has evaluated the combined subtypes of PE in people with schizophrenia. An important difference of their meta-analysis compared to this meta-analysis is that it included uncontrolled studies, which might have weakened the strength of the evidence. The current meta-analysis will update the existing knowledge on the effects of PE on negative symptoms by including the most recent studies and will only include randomized controlled trials (RCT) to provide the strongest evidence. Furthermore, this meta-analysis will make a distinction between mind-body exercise (MBE), aerobic exercise (AE) and resistance training (RT) and aims to determine the effect of these different types of PE compared to active control and groups treatment as usual (TAU).

Aim of the study

This meta-analysis aims to investigate the overall effects of physical exercise interventions that focus on relaxation and on exertion (including mind-body exercise, aerobic exercise and resistance training) in reducing negative symptoms in schizophrenia.

Material and methods

This meta-analysis was conducted in accordance with the PRISMA guidelines for systematic reviews and meta-analyses. The protocol (accession number CRD42018073983), including the search strategy, is electronically accessible through Prospero (Centre for Reviews and Dissemination).

Study identification and inclusion

All RCTs measuring the effect of PE on negative symptoms in schizophrenia were eligible for inclusion when patients were diagnosed with schizophrenia or schizophrenia related disorders (as defined by the DSM IV and V [33,34] or ICD [35] aged 18 years or older, treated in all settings (e.g., inpatient and outpatient) as well as all clinical stages. We only included studies which used standardized measurement instruments for negative symptoms, such as the Positive and Negative Syndrome Scale (PANSS) [36] and the Scale for Negative Symptoms Assessment (SANS) [37]. PE was defined as "planned, structured, and repetitive with the purpose of improvement or maintenance of one or more components of physical fitness" [38]. We included interventions that focus on relaxation and interventions that focus on exertion. The intervention or control group consisted of MBE, AE or RT. MBE integrates physical movements combined with an inner mental focus (e.g., tai chi or yoga). AE was subdivided in light aerobic exercise (light AE) and moderate aerobic exercise (moderate AE). Interventions were classified as light AE if the largest part of the exercise consisted of low energy expenditure activities such as walking. Interventions were classified as moderate AE if interventions consisted of high energy expenditure activities such as cycling or running (>5 min). Furthermore, we labeled interventions as moderate AE if they were described as such in the original article. RT is characterized by forcing skeletal muscles to contract for example by weight lifting or using one's own weight [39]. RCT's with any control group (active and/or inactive control conditions) were eligible for inclusion. Interventions in the active control conditions are initiated within the RCT to control for non-specific intervention effects. Inactive control groups are groups that receive treatment as usual (TAU) or are assigned to a waiting list. No restrictions were held on frequency or duration of PE, nor on the utilities of the training or the therapist. Inclusion was limited to peer reviewed studies published in English.

Databases and selection process

The following databases have been searched until April 26, 2018: Cochrane's database of Controlled Clinical trials, Medline, Embase and PsycINFO. All databases were searched through OVID interface. The following search terms and their synonyms were used: schizophrenia, exercise, randomized controlled trial and therapy (for more detailed information see the supplementary file S1). Authors JSV and SC performed the selection of studies. Publications were selected independently by title and abstract. A kappa statistic was used to measure the inter-rater agreement with fair (> 0.40), good (>0.60) or excellent agreement (>0.75) [40]. Full text articles were retrieved from the selected abstracts and these were screened for the inclusion criteria by JSV. A subset of 25% of all full text articles was independently screened for inclusion by SC. Discrepancies were discussed in a consensus meeting. Recent reviews and meta-analyses were screened for additional studies, not retrieved by the search. Formal testing of publication bias was done by Eggers' regression intercept [41] and Kendalls Tau [42] (2 sided) with a significance level of $p<0.05$. A significant outcome on one or both tests was followed by applying the Duval and Tweedie's Trim and Fill procedure [43].

Data extraction

The extracted data consisted of: aim of the study, number of patients included, population characteristics (age, gender, setting, and duration of illness), comparison of intervention and control groups, number of therapeutic sessions, supervision, group or individual delivery, duration of treatment, used outcome scales and reported effects (i.e., means and standard deviations). In case of missing outcome data, the corresponding author (and/or last author) of the study was contacted by email. Data extraction was performed by author JSV and verified by author CS and a research assistant of Lentis Psychiatric Institute independent from the study.

Assessment of risk of bias

Risk of bias (RoB) was assessed using the Cochrane RoB assessment tool (Higgins and Green, 2008). This measure comprises six areas of the trial design: sequence generation, allocation concealment, blinding of assessors, incomplete outcome data, selective outcome reporting, and other sources of bias. Items were rated as high risk, low risk or unclear risk of bias. The total score ranges from 1-6, with higher scores meaning less RoB. Authors JSV and JB rated the RoB score. A kappa score examined the scores of both assessors with fair, good or excellent agreement [40]. Discrepancies were solved in a consensus meeting.

Synthesis of the results

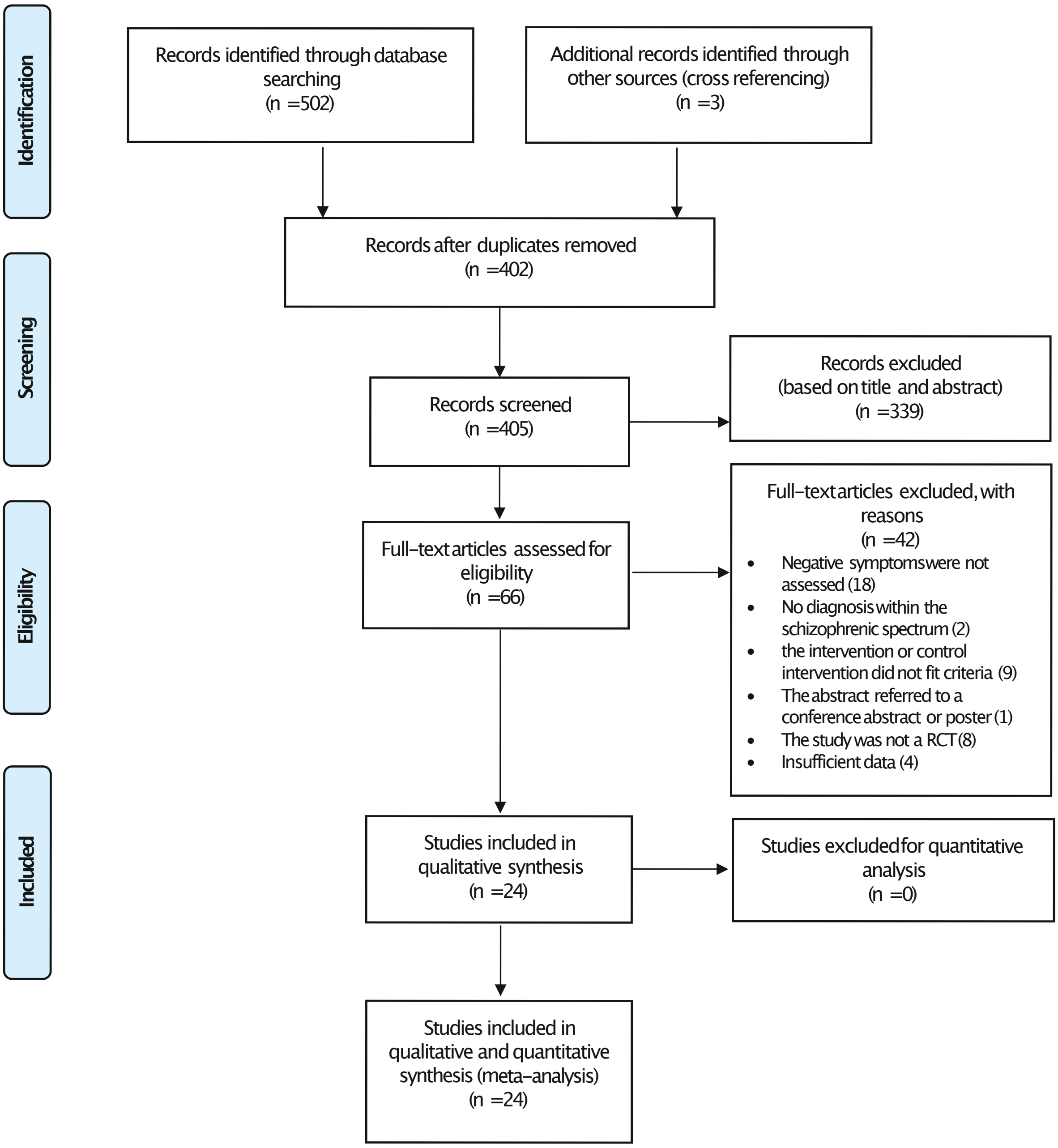
Comprehensive Meta-Analysis v3 [44] was used to examine the treatment effect of the PE interventions. Due to the heterogeneity of the offered treatments (e.g., duration, number of sessions, control conditions) and population (e.g., country of origin, disease severity) a random effects model was used. Heterogeneity was addressed with the I^2 statistic (range 1% – 100%: absent (0%), low (25%), moderate (50%) or high (75%)) and the Q statistic (substantial heterogeneity is present if $p< 0.05$) [45]. Hedges' g was used to measure the effect size as this measure corrects for small sample sizes. Intervention and control conditions in the overall analyses were pooled for studies with more than one intervention or control group in order to prevent double counting of subjects [46]. All subtypes of PE were first analyzed together. Subsequently, in subgroup analyses the separate effects for MBE and AE were computed. AE was further subdivided into moderate AE and light AE. Sensitivity analyses were conducted to explore heterogeneity and the impact of control groups (i.e., active control and TAU groups). Moderator analyses were conducted on high quality studies having a clear description of blinding and ≥ 4 points on the Cochrane RoB tool. Other moderator analyses were performed on number of sessions (>36 sessions) and duration (>12 weeks), based on recommendations in a review of Stanton and Happell [47]. Also, in a meta regression analysis we evaluated the impact of the number of sessions and duration of the intervention (in weeks) on the outcome. A post hoc analysis was conducted to explore the impact of supervision on drop-out rates with the use of Pearson's correlation coefficient.

Results

Literature search

The search and inclusion process are presented in Figure 1. The initial search resulted in 508 studies. Two studies had a second publication based on the same study sample [48-51]. Only the most recent publication was considered eligible for inclusion. A good interrater agreement was found for the inclusion process (κ = 0.60). As we found only one study that evaluated the effect of RT, a consensus decision was made to exclude this study and to focus our further analyses on MBE and AE [52]. Two more studies were excluded, because the article did not contain sufficient information about the intervention that was investigated [53] or the authors did not respond to our request for more information [54]. In total, 24 studies were included. Two studies only compared MBE to light AE [55,56]. These studies were analyzed separately, leaving 22 studies in the main analysis comparing PE to active control and TAU groups.

Figure 1. Flow diagram of included studies



Setting, participant and intervention characteristics

The majority of the patients (N=1249) was male (58%) and outpatient (12 studies). The mean number of sessions was 33 (range: 8 - 104, with one study not reporting the number of sessions [57]) with a mean duration of 12 weeks (range: 3 - 52). An overview of the setting, intervention and patient characteristics are described in Table 1.

Table 1. Description of included studies: the country, setting, outcome scale, intervention and patient characteristics, attrition and Risk of Bias

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
Acil (2008)	Turkey	Outpatient	SANS	Moderate AE	Limber up figures (10 min); aerobic exercises (25 min); cool down figures (5 min)	Group	30 (10)	15	32.1 (N/A)	10.3	0	0
				TAU	Treatment as usual			15	32.7 (N/A)		0	
Beebe (2005)	United States	Outpatient	PANSS-N	Light AE	Warm-up stretches (10 min); treadmill walking (30 min) cool down stretches (10 min)	Group	48 (16)	6	52.0 (N/A)	8.6	2	3
				TAU	Treatment as usual			6			0	
Bhatia (2017)	India	Outpatient	SANS	MBE	Yoga postures; breathing; nasal cleansing	Group	21 (3)	104	34.8 (9.6)	N/A	18	4
				Light AE	Brisk walking (10 min); jogging (5 min); exercises in standing; sitting postures (20 min)			90	35.2 (9.5)		15	
				TAU	Treatment as usual			92	35.7 (10.1)		15	
Duraiswamy (2007)	India	Inpatient and outpatient	PANSS-N	MBE	Loosening exercises (10 min); yoga postures (20 min); breathing exercises (18 min); relaxation (3 min)	Group	15 (3)	31	32.5 (7.9)	7.5	10	2

Table 1. Description of included studies: the country, setting, outcome scale, intervention and patient characteristics, attrition and Risk of Bias

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop–outs	RoB
Acil (2008)	Turkey	Outpatient	SANS	Moderate AE	Limber up figures (10 min); aerobic exercises (25 min); cool down figures (5 min)	Group	30 (10)	15	32.1 (N/A)	10.3	0	0
				TAU	Treatment as usual			15	32.7 (N/A)		0	
Beebe (2005)	United States	Outpatient	PANSS–N	Light AE	Warm–up stretches (10 min); treadmill walking (30 min) cool down stretches (10 min)	Group	48 (16)	6	52.0 (N/A)	8.6	2	3
				TAU	Treatment as usual			6			0	
Bhatia (2017)	India	Outpatient	SANS	MBE	Yoga postures; breathing; nasal cleansing	Group	21 (3)	104	34.8 (9.6)	N/A	18	4
				Light AE	Brisk walking (10 min); jogging (5 min); exercises in standing; sitting postures (20 min)			90	35.2 (9.5)		15	
				TAU	Treatment as usual			92	35.7 (10.1)		15	
Duraiswamy (2007)	India	Inpatient and outpatient	PANSS–N	MBE	Loosening exercises (10 min); yoga postures (20 min); breathing exercises (18 min); relaxation (3 min)	Group	15 (3)	31	32.5 (7.9)	7.5	10	2

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
Ikai (2014)	Japan	Outpatient	PANSS-N	MBE	Warm up and loosening up exercises (14 min); yoga postures (28 min); deep relaxation (7 min); breathing exercises (8 min)	Group	8 (8)	25	53.5 (9.9)	25.0	7	4
				AC	Regular day-care program (e.g., social skills training; and psycho-education)			25	48.2 (12.3)		7	
Ikai (2017)	Japan	Inpatient	PANSS-N	MBE	Chair yoga: warm up and loosening up exercises (4 min); yoga postures (10 min); deep relaxation (3 min); breathing exercises (3 min)	N/A	24 (12)	28	55.5 (11.4)	26.2	3	6
				TAU	Treatment as usual			28	55.0 (15.8)		2	
Jayaram (2013)	India	Inpatient and outpatient	SANS	MBE	Loosening exercises (10 min); yoga postures (20 min); breathing exercises (18 min); relaxation (3 min)	N/A	N/A (4)	15	28.3 (4.7)	6.0	0	0
				TAU	Waiting list			28	29.5 (8.2)		16	
Kaltsatou (2015)	United States	Inpatient	PANSS-N	Moderate AE	Warm up (10 min); Greek traditional dancing (40 min); cooling down (10 min)	Group	104 (35)	16	59.5 (19.6)	34.4	0	5

Table 1. Description of included studies: the country, setting, outcome scale, intervention and patient characteristics, attrition and Risk of Bias

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
Acil (2008)	Turkey	Outpatient	SANS	Moderate AE	Limber up figures (10 min); aerobic exercises (25 min); cool down figures (5 min)	Group	30 (10)	15	32.1 (N/A)	10.3	0	0
				TAU	Treatment as usual			15	32.7 (N/A)		0	
Beebe (2005)	United States	Outpatient	PANSS-N	Light AE	Warm-up stretches (10 min); treadmill walking (30 min) cool down stretches (10 min)	Group	48 (16)	6	52.0 (N/A)	8.6	2	3
				TAU	Treatment as usual			6			0	
Bhatia (2017)	India	Outpatient	SANS	MBE	Yoga postures; breathing; nasal cleansing	Group	21 (3)	104	34.8 (9.6)	N/A	18	4
				Light AE	Brisk walking (10 min); jogging (5 min); exercises in standing; sitting postures (20 min)			90	35.2 (9.5)		15	
				TAU	Treatment as usual			92	35.7 (10.1)		15	
Duraiswamy (2007)	India	Inpatient and outpatient	PANSS-N	MBE	Loosening exercises (10 min); yoga postures (20 min); breathing exercises (18 min); relaxation (3 min)	Group	15 (3)	31	32.5 (7.9)	7.5	10	2

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
Loh (2016)	Malaysia	Inpatient	PANSS-N	Light AE	Warm-up (5 min); walking exercise (20 min); cool down (5 min)	Group	39 (13)	52	21.6 (10.2)	20.3	4	3
				TAU	Treatment as usual			52			0	
Manjunath (2013)	India	Inpatient	PANSS-N	MBE	Loosening exercises (10 min); yoga postures (20 min); breathing exercises (18 min); relaxation (3 min)	Group	10 (2)	44	16.9 (8.2)	9.0	5	1
				Light AE	Brisk walking (10 min); jogging (5 min); exercises in standing and sitting postures (20 min)			44	17.1 (8.1)		1	
Oertel-Knöchel (2014)	Germany	Inpatient	PANSS-N	Moderate AE	Warm-up (10 min); boxing and circuit training (25 min); cool down (10 min)		12 (4)	8	44.6 (13.8)	10.3	N/A	3
				AC	Relaxing exercises	Group		11	34.9 (9.3)		N/A	
				TAU	Waiting list			10	38.3 (4.51)		N/A	
Paikkat (2015)	India	Inpatient	PANSS-N	MBE	Yoga: standing, lying and, sitting postures	Group	28 (4)	15	N/A	N/A	1	2
				TAU	Treatment as usual			15			1	
Pajonk (2010)	Germany	Outpatient	PANSS-N	Moderate AE	Cycling at a targeted heart rate	Group	36 (12)	13	34.8 (10.2)	10.45	0	3

	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
				TAU	Treatment as usual			15	60.4 (8.6)		0	
Kang (2016)	China	Outpatient	PANSS-N	MBE	Wu-style Cheng form Tai chi Chuan with 22 simple movements combined with social skills training	Group	26 (52)	116	49.9 (12.1)	20.5	0	4
				TAU	Treatment as usual			126			0	
Kimhy (2015)	United States	N/A	SANS	Moderate AE	Warm-up (10 min); aerobic exercise using videogames, treadmill machines, a stationary bike and an elliptical machine (45 min); cool down (5 min)	Group	36 (12)	16	36.6 (10.4)	N/A	3	4
				TAU	Treatment as usual			17	37.2 (9.9)		4	
Lin (2015)	China	Outpatient	PANSS-N	MBE	Hatha yoga: breathing control (10 min); body postures (40-45 min); relaxation (5 min)	Group	36 (12)	48	23.8 (6.8)	2.3	3	4
				Moderate AE	Included walking on a treadmill (15-20minutes); stationary cycling (25-30 minutes); cool down stretching (5 minutes)			46	24.6 (7.9)		6	
				TAU	Waiting list			46	25.3 (8.1)		7	

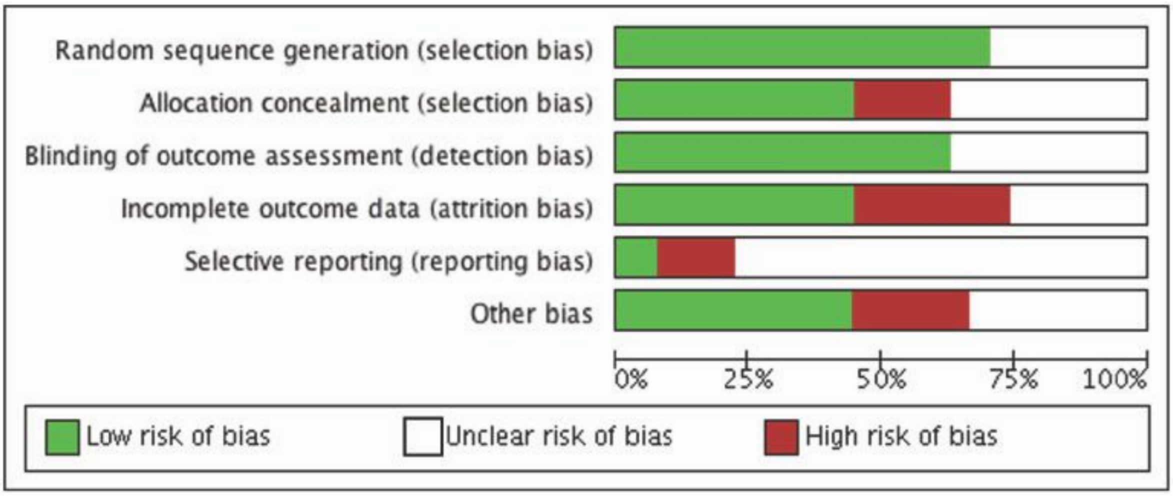
	Country	Setting	Outcome Scale	Format	Intervention descriptions	Treatment delivery	No. of sessions (duration in weeks)	N	Mean age (SD)	Duration of illness (years)	Intervention drop-outs	RoB
				Light AE	Brisk walking (10 min); jogging (5 min); exercises in standing and sitting postures (20 min)			37	16.1 (5.6)		22	
				TAU	Treatment as usual			36	15.7 (5.1)		34	
Visceglia (2011)	United States	Inpatient	PANSS-N	MBE	Yoga: breathing exercises, warm up, postures and relaxation	Group	16 (6)	10	37.4 (13.7)	N/A	0	2
				TAU	Waiting list			8	48.1 (11.2)		0	

PANSS-N= Positive And Negative Syndrome Scale- Negative subscale; SANS= Scale for the Assessment of Negative Symptoms; RoB= Risk of bias; AE= Aerobic exercise; MBE= Mind-body exercise; TAU= Treatment as usual; N/A= Not Available

Risk of bias

Across studies the RoB for random sequence generation and blinding was sufficient in >70% of the studies. Allocation concealment, incomplete outcome data and other biases were sufficient in 50% of the studies. Two studies (8%) sufficiently reported selection bias. The RoB across studies is reported in Figure 2 and summary scores of the RoB per study are reported in Table 1. Furthermore, the RoB per study at item level can be found in the supplementary file S2. The agreement between the assessors was moderate (κ = 0.44). Testing for publication bias revealed one missing study in the main analysis. The Duval and Tweedie's Trim and Fill procedure [43] showed that correction for publication bias was not needed (i.e., no unpublished negative studies were detected).

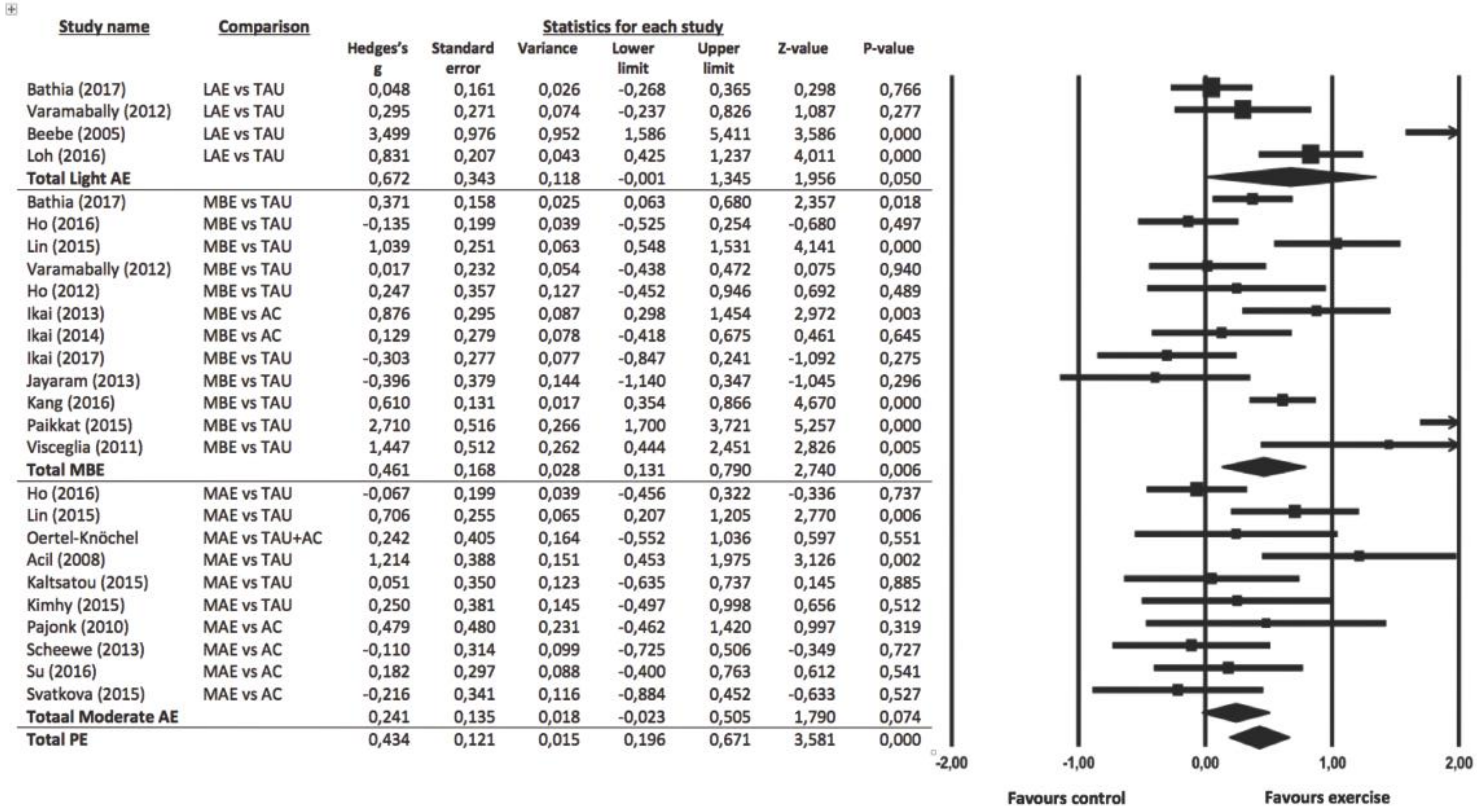
Figure 2. Risk of bias across studies



Outcomes

The overall meta-analysis (N= 22) showed a medium significant effect in favor of PE (Hedges' g= 0.434, 95% CI= 0.196, 0.671), but with high statistical heterogeneity (I^2= 76%, Q= 75.6 (df= 21), p<.000). MBE interventions showed a statistically significant effect size in a subgroup analysis (Hedges' g= 0.461, 95% CI= 0.131, 0.790), but with high heterogeneity (I^2=81%, Q= 57.9 (df=11), p< 0.000). AE showed a small significant effect of g= 0.341 (95% CI= 0.079, 0.604), with moderate to high heterogeneity (I^2=64%, Q=36.0 (df=13), p= 0.001). Forest plots of the main analysis and the subgroup analyses are demonstrated in Figure 3. Four studies evaluated the effect of MBE versus light AE. A meta-analysis on these studies did not result in a significant effect (Hedges' g= 0.266, 95% CI= -0.128, 0.659).

Figure 3. Forest plot of the main analysis and subgroupanalysis



Study name	Comparison	Statistics for each study						
		Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-value	P-value
Bathia (2017)	LAE vs TAU	0,048	0,161	0,026	-0,268	0,365	0,298	0,766
Varamabally (2012)	LAE vs TAU	0,295	0,271	0,074	-0,237	0,826	1,087	0,277
Beebe (2005)	LAE vs TAU	3,499	0,976	0,952	1,586	5,411	3,586	0,000
Loh (2016)	LAE vs TAU	0,831	0,207	0,043	0,425	1,237	4,011	0,000
Total Light AE		0,672	0,343	0,118	-0,001	1,345	1,956	0,050
Bathia (2017)	MBE vs TAU	0,371	0,158	0,025	0,063	0,680	2,357	0,018
Ho (2016)	MBE vs TAU	-0,135	0,199	0,039	-0,525	0,254	-0,680	0,497
Lin (2015)	MBE vs TAU	1,039	0,251	0,063	0,548	1,531	4,141	0,000
Varamabally (2012)	MBE vs TAU	0,017	0,232	0,054	-0,438	0,472	0,075	0,940
Ho (2012)	MBE vs TAU	0,247	0,357	0,127	-0,452	0,946	0,692	0,489
Ikai (2013)	MBE vs AC	0,876	0,295	0,087	0,298	1,454	2,972	0,003
Ikai (2014)	MBE vs AC	0,129	0,279	0,078	-0,418	0,675	0,461	0,645
Ikai (2017)	MBE vs TAU	-0,303	0,277	0,077	-0,847	0,241	-1,092	0,275
Jayaram (2013)	MBE vs TAU	-0,396	0,379	0,144	-1,140	0,347	-1,045	0,296
Kang (2016)	MBE vs TAU	0,610	0,131	0,017	0,354	0,866	4,670	0,000
Paikkat (2015)	MBE vs TAU	2,710	0,516	0,266	1,700	3,721	5,257	0,000
Visceglia (2011)	MBE vs TAU	1,447	0,512	0,262	0,444	2,451	2,826	0,005
Total MBE		0,461	0,168	0,028	0,131	0,790	2,740	0,006
Ho (2016)	MAE vs TAU	-0,067	0,199	0,039	-0,456	0,322	-0,336	0,737
Lin (2015)	MAE vs TAU	0,706	0,255	0,065	0,207	1,205	2,770	0,006
Oertel-Knöchel	MAE vs TAU+AC	0,242	0,405	0,164	-0,552	1,036	0,597	0,551
Acil (2008)	MAE vs TAU	1,214	0,388	0,151	0,453	1,975	3,126	0,002
Kaltsatou (2015)	MAE vs TAU	0,051	0,350	0,123	-0,635	0,737	0,145	0,885
Kimhy (2015)	MAE vs TAU	0,250	0,381	0,145	-0,497	0,998	0,656	0,512
Pajonk (2010)	MAE vs AC	0,479	0,480	0,231	-0,462	1,420	0,997	0,319
Scheewe (2013)	MAE vs AC	-0,110	0,314	0,099	-0,725	0,506	-0,349	0,727
Su (2016)	MAE vs AC	0,182	0,297	0,088	-0,400	0,763	0,612	0,541
Svatkova (2015)	MAE vs AC	-0,216	0,341	0,116	-0,884	0,452	-0,633	0,527
Totaal Moderate AE		0,241	0,135	0,018	-0,023	0,505	1,790	0,074
Total PE		0,434	0,121	0,015	0,196	0,671	3,581	0,000

Intervention and control conditions in the overall analyses were pooled for studies with more than one intervention or control group in order to prevent double counting of subjects.

AE= Aerobic Exercise; LAE= Light Aerobic Exercise; MBE= Mind-Body Exercise; MAE= Moderate Aerobic Exercise; PE= Physical Exercise

Sensitivity analyses

Sensitivity analyses were conducted for MBE in order to examine the origins of the high heterogeneity (see Table 2 for effect sizes and heterogeneity). Separating active control groups from TAU was not useful as only two studies compared MBE to active control groups. Also, other possible moderators such as low RoB, removing two outlier studies, number of sessions, outpatients, the use of a supervised intervention, or group versus individual treatment did not reduce heterogeneity.

Sensitivity analyses were also conducted for AE in order to examine the origins of the high heterogeneity (see Table 2 for effect sizes and heterogeneity). Heterogeneity could be removed to low by limiting the analysis to moderate AE (k=10), but this reduced the effect size to a statistically non-significant Hedges' g of 0.24. Heterogeneity was absent in moderate AE versus active control (k=5), but the effect size was then reduced to g= -0.003 (ns). With low RoB or more than 36 sessions the effect sizes reduced to statistically insignificant levels. The effect sizes remained significant with outliers removed (g= 0.28), outpatients (g= 0.40), group interventions (g= 0.43), but they are still heterogeneous. A meta regression analysis on the number of sessions and duration of the intervention (in weeks) did not show significant results. Only one moderator could remove the heterogeneity and that was the use of supervised interventions (I^2=37, Q= 33.6 (df=10), p=0.11) (Hedges' g= 0.24, 95% CI= 0.010 – 0.478).

Post hoc analyses

A post hoc analysis was conducted on the correlation between supervised interventions and drop-outs. This correlation was non-significant.

Table 2. Random effect sizes, heterogeneity and publication bias in the main, subgroup, sensitivity and, moderator analyses

Analysis		Random effect sizes					Heterogeneity			Publication bias
Intervention	Control	Number of contrasts	Hedges'g	(95% CI)	Z	p–value of Z	Q (df)	p–value of Q	I^2	(p<0.05)
1. All exercise	Any control	22	0.434	(0.196 – 0.671)	3.581	0.000	75.57	0.000	76/ HIGH	Yes
Subgroup analyses										
2. Mind–body exercise	Any control	12	0.461	(0.131 – 0.790)	2.740	0.006	57.90 (11)	0.000	81/ HIGH	Yes
3. Aerobic exercise	Any control	14	0.341	(0.079 – 0.604)	2.546	0.011	36.03 (13)	0.001	64/ MOD	No
4. Moderate AE	Any control	10	0.241	(–0.023 – 0.505)	1.790	0.074	15.55 (9)	0.077	42/ LOW	No
5. Light AE	Any control	4	0.672	(–0.001 – 1.345)	1.956	0.050	19.28 (3)	0.000	84/ HIGH	No
Sensitivity analyses										
1. All exercise	TAU	16	0.552	(0.253 – 0.850)	3.623	0.000	76.34 (15)	0.000	80/ HIGH	Yes
1. All exercise	Active control	7	0.171	(–0.138 – 0.479)	1.086	0.277	9.17 (6)	0.164	35/LOW	Yes
3. Aerobic exercise	TAU	10	0.499	(0.160 – 0.839)	2.881	0.004	25.11 (9)	0.014	52/ MOD	Yes
4. Moderate AE	TAU	6	0.433	(0.023 – 0.842)	2.072	0.038	12.72 (5)	0.026	61/ MOD	No
4. Moderate AE	Active control	5	–0.003	(–0.315 – 0.309)	–0.022	0.983	2.23 (4)	0.693	00/ NONE	Yes

Analysis		Random effect sizes					Heterogeneity			Publication bias
Intervention	Control	Number of contrasts	Hedges'g	(95% CI)	Z	p–value of Z	Q (df)	p–value of Q	I^2	(p<0.05)
Group intervention		8	0.734	(0.332 – 1.137)	3.578	0.000	41.25 (7)	0.000	83/ HIGH	No
3. Moderator analyses on aerobic exercise										
High quality studies		5	0.162	(–0.184 – 0.509)	0.918	0.359	6.586 (4)	0.159	39/ LOW	Yes
Outliers removed g>2.0		13	0.285	(0.060 – 0.511)	2.481	0.013	25.10 (12)	0.014	52/ MOD	No
≥ 36 sessions and/or ≥ 12 weeks		10	0.332	(–0.015 – 0.679)	1.877	0.060	28.07 (9)	0.001	68/ MOD	No
Outpatients		9	0.399	(0.030 – 0.768)	2.118	0.034	25.45 (8)	0.001	69/ MOD	No
Supervision		10	0.244	(0.010 – 0.478)	2.042	0.041	14.39 (9)	0.109	37/ LOW	No
Group intervention		11	0.425	(0.098 – 0.753)	2.544	0.011	33.56 (10)	0.000	70/ MOD	Yes

AE=Aerobic exercise; TAU=Treatment as usual; MOD=Moderate

Discussion

Summary of main findings

Overall, PE interventions were only effective in comparison with TAU, but not when compared to active control groups (e.g., occupational therapy or token reinforcement). The intervention effects might not be attributable to PE specifically, but are rather a general effect of interventions that appeal on activation, as is seen in the active control groups [9]. This could explain the absence of an effect in meta-analyses with PE interventions versus active control groups. The subgroup analysis of mind-body exercise (MBE) showed promising results in treating negative symptoms in schizophrenia. We found a moderate effect size for MBE, but the statistical heterogeneity was high and could not be reduced in sensitivity analyses. Therefore, we were not able to identify which active components of mind-body interventions are essential for its effectiveness on negative symptoms. This could be explained by the variety of interventions that were included. Different types of MBE (e.g., chair yoga, hatha yoga and tai chi) might have different effects on negative symptoms in schizophrenia. Similarly, there was a small to medium effect of AE on negative symptoms, with moderate heterogeneity among the studies. The heterogeneity was reduced to small including only interventions with a supervisor. Furthermore, a considerable RoB was present across studies. Analyzing only high-quality studies did not change the significant effect of MBE interventions on negative symptoms, but the effects of AE interventions became non-significant.

Agreements and disagreements with previous research

In recent years six meta-analyses on exercise have been published [9,23-26,32], but the comparability is limited as different statistical analyses were used to analyze the PANSS and SANS data. For example, the reviews of Dauwan et al. [32], Firth et al. [23] and, Lutgens et al. [9] analyzed pre-post change scores instead of post scores only. Furthermore, Broderick et al. [24,25] reported mean PANSS negative scores in contrast with the standardized effect size (Hedges' g) as used in this study.

The overall effect sizes varied across studies. Meta-analyses on negative symptoms of PE [9,32]found effect sizes of Hedges' g= 0.49 (p< .000) and pooled SMD= 0.36 (95% CI= -0.71, -0.01) respectively, compared to any control group. Despite a larger study pool and stricter inclusion criteria of studies in this meta-analysis the effect sizes are relatively similar. However, importantly different is the effect of AE versus AC. Where the meta-analysis of Dauwan et al. [32] found an effect of Hedges' g= 0.326 (p= .002), this meta-analysis could not find a significant effect. Firth et al. [23] only examined the effects of AE compared to any control group. An effect size of SMD= -0.44 (95% CI -0.78, -0.09, I^2= 0%) was found, which is slightly higher compared to our findings. Yoga compared to standard [25](Broderick et al., 2015) and non-standard care [24] was significantly more effective in reducing mean PANSS scores with respectively 1.92 and 1.15 (range 7 - 49). The meta-analysis of Zheng et al. [26] examining the effects of tai-chi, showed a large effect (SMD= .87, 95%CI= -1.15, -0.24). The difference in effect size with this meta-analysis can be explained by a larger study pool of tai chi studies available to Zheng et al. [26] which were not available for this meta-analysis due to language restrictions (only studies in English were included). With regard to the heterogeneity, almost all studies found moderate to high heterogeneity, similar to our findings. Only the meta-analysis of

Firth et al. [23] had low heterogeneity (0%), but they only included five studies in their analysis. Light AE (e.g., walking and postures) served as an intervention condition in our meta-analysis, but not in other studies [9,32]. Analyzing light AE as a control group might have negatively biased the effect of exercise in these meta-analyses. Furthermore, we excluded one of two articles [48,51] from the same study to avoid bias in the effect size, whereas Dauwan et al. [32] included both articles.

Heterogeneity and publication bias

Publication bias did not negatively influence the effect sizes. Furthermore, the heterogeneity of the offered interventions was moderate. Sensitivity and moderator analyses did not substantially lower the heterogeneity. The amount of heterogeneity warrants a careful interpretation of the results. Although our overall effect sizes suggest that PE interventions are moderately effective in reducing negative symptoms, not all included studies have found these effects and we have not been able to identify which underlying factors cause these variations in findings between different studies.

Intensity, number of sessions and duration

A systematic review [47] about program variables for AE in people with schizophrenia recommended a frequency of exercising minimally three days a week for a period of twelve weeks. A meta regression analysis in our study on PE that included both number of sessions and duration of training (in weeks) was not significant. Furthermore, former studies [47,58] recommended a moderate intensity for AE interventions. Subgroup analyses on moderate or light AE in our meta-analysis did not show significant effects. Therefore, recommendations for intensity, number of sessions or duration of PE cannot be made.

Group and supervision

Drop-out rates in some of the studies are high, likely due to motivational problems [59] and sedentary behavior [60],which is associated with negative symptomatology. It has been suggested that group interventions result in more compliance than interventions designed for individuals [61], which was also the case in our study. In addition, the presence of a supervisor was also suggested as a motivating factor [62]. However, in this study we could not find a correlation between drop-outs and the use of supervised interventions. In addition, moderator analyses on MBE and AE interventions with supervision did not result in a higher effect size. However, heterogeneity decreased in a meta-analysis on supervised AE interventions while the effect size remained significant (Hedges' g = 0.24, I^2=37, Q= 33.6 (df=10), p=0.04). Based on our findings, we recommend group delivered exercise interventions. The evidence for the use of a supervised intervention is not clear and should be further investigated in RCT's.

Strengths and limitations

A strength of this study is that it is the first meta-analysis that makes a distinction between PE interventions that focus on relaxation (MBE) and PE interventions that focus on exertion (AE). The study was conducted according to the PRISMA guidelines and was registered prior to the start of the search in accordance with the PROSPERO protocol, which is digitally accessible through the PROSPERO register. The main limitation is the high percentage of heterogeneity, which did not decrease even after several attempts with various sensitivity analyses. The heterogeneity could be explained by the high variety in treatment protocols. A second limitation is the poor methodological quality of most included studies. Furthermore, most studies on MBE interventions were conducted in Asian countries (e.g., China, India). This may limit applicability of the results in western populations. A final limitation to mention is that we were only able to make a crude difference between light and moderate AE interventions. A better distinction of exercise intensity might be based on intended metabolic effects, such as the maximum heartrate or maximal oxygen uptake [63]. However, mostly this information was not available. The overall methodological flaws and heterogeneity of the included studies impede strong conclusions on the effect of exercise to reduce negative symptoms.

Future research

The evidence of PE interventions, especially MBE interventions, showed promising effects. Furthermore, given the empirical evidence demonstrating beneficial effects of PE, it would be worthwhile to examine how PE is currently implemented in mental health care and how this could be improved. This was beyond the scope of the current review. The heterogeneity in MBE interventions necessitates the use of more standardized interventions. Also, clear descriptions of interventions increase the possibility of comparing exercise interventions in meta-analyses and may help to identify the causes of heterogeneity among different studies. We recommend the use of the Consensus on Exercise Reporting Template that is developed to standardize the reporting of exercise interventions [64]. More high quality, sufficiently powered studies with multiple treatment arms (i.e., MBE, AE and TAU) will allow for direct comparisons in future meta-analyses.

General conclusions

PE interventions showed a significant effect on negative symptoms in schizophrenia compared to any control group, with a slightly larger effect of MBE interventions versus control groups than AE interventions versus control groups. The results should be interpreted with care due to the low methodological quality and moderate to high heterogeneity of the included studies.

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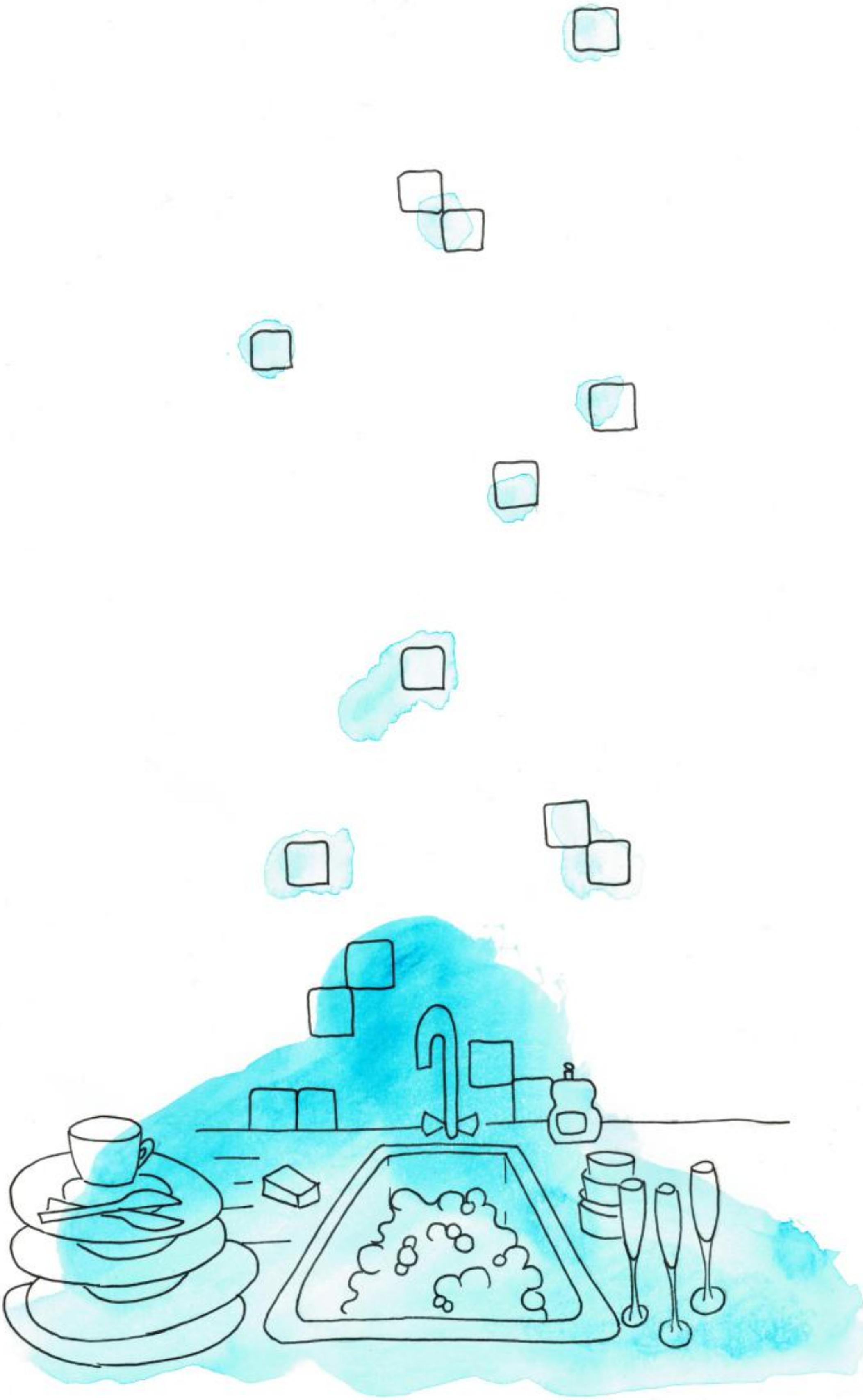

Chapter 6

Satisfaction with social connectedness as a predictor for positive and negative symptoms of psychosis: a PHAMOUS study

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Abstract

Purpose

This study examines satisfaction with social connectedness (SSC) as predictor of positive and negative symptoms in people with a psychotic disorder.

Methods

Data from the Pharmacotherapy Monitoring and Outcome Survey (PHAMOUS) was used from patients assessed between 2014 and 2019, diagnosed with a psychotic disorder (N=2109). Items about social connectedness of the Manchester short assessment of Quality of Life (ManSA) were used to measure SSC. Linear mixed models were used to estimate the association of SSC with the Positive and Negative Syndrome Scale (PANSS) after one and two years against $\alpha = 0.01$. Analyses were adjusted for symptoms, time since onset, gender and age. Additionally, fluctuation of positive and negative symptom scores over time were estimated.

Results

The mean duration of illness of the sample was 18.8 years (SD 10.7) with >65% showing only small variation in positive and negative symptoms over a two to five-year time period. After adjustment for covariates, SSC showed to be negatively associated with positive symptoms after one year ($\beta = -0.47$, $p < 0.001$, 95% CI= -0.70, -025) and two years ($\beta = -0.59$, $p < 0.001$, 95% CI= -0.88, -0.30), and for negative symptoms after one year ($\beta = -0.52$, $p < 0.001$, 95% CI= -0.77, -0.27). The prediction of negative symptoms was not significant at two years.

Conclusion

This research indicates that interventions on SSC might positively impact mental health for people with psychosis. SSC is a small and robust predictor of future levels of positive symptoms. Negative symptoms could be predicted by SSC at one year.

Introduction

Social connectedness is important for health outcomes in the general population [1]. Several aspects of social connectedness, such as loneliness, social support or network size have already been subjected to health research. It was shown that loneliness is negatively correlated with physical, mental and cognitive health [2-4]. Loneliness is also a risk factor for premature mortality, which is comparable in magnitude with obesity and physical inactivity [4,5].

In mental health, connectedness is defined as an important part of patients' personal recovery. The CHIME is a framework for personal recovery in mental health, which identifies five processes that foster personal recovery: Connectedness, Hope, Identity, Meaning and Empowerment [6]. It describes 'Connectedness' as support from others and being part of the community, which is considered an important supportive process in personal recovery [6]. In this study, we consider social connectedness a comprehensive term for subjective and objective measures of connectedness on an individual level. Subjective indicators of social connectedness can be defined as satisfaction with social support, satisfaction with the social network and experiencing unmet social needs, operationalized in the construct of loneliness. Objective indicators of social connectedness comprise network size, composition of the social network and frequency of contacts.

Despite intact hedonic experiences of social contact [7], levels of social connectedness in people with psychotic disorders are often unsatisfactory compared to people in the general population. On an objective level, they generally have smaller networks. A meta analysis showed that the average number of friends of people with a psychotic disorder was 3.4 [8]. In comparison, an average number of 10.6 friends for men and 7.6 friends for women was found in the general population (UK) [8]. On a subjective level, these patients experience higher rates of loneliness [9,10] and less satisfaction with social networks [11,12]. The frequently reported limitations in social connectedness in people with psychotic disorders impede patients in their personal [13], functional [14] and clinical recovery [15]. In this study we will focus on satisfaction with social connectedness specifically.

Poor social connectedness is associated with greater mental health risks in people with psychotic disorders [15]. A recent meta analysis concluded that network size was not associated with positive symptoms, but that a smaller social network was associated with more severe negative symptoms of psychosis [16]. Furthermore, another study showed that satisfaction with social support was protective against relapses and fewer hospital admissions in people with schizophrenia [17]. Moreover, two studies measured the relationship between social satisfaction and positive and negative symptoms in patients with First Episode Psychosis (FEP). Perceived social support predicted fewer positive symptoms in one study [18], but neither study found significant effects for negative symptoms [18,19].

The direction of causality in the relationship between social connectedness and symptoms of psychosis is not clear [20,21]. Studies on social connectedness have shown that fewer positive and negative symptoms are associated with having a larger social network, less feelings of loneliness and a greater sense of being socially supported [11,15,16,22]. Some indication for causality is found in studies with FEP in which pre morbid social adjustment is negatively associated with future levels of positive and negative symptoms [23]. However, the reversed effect was suggested in a recent study in a clinical high risk population (CHR), which showed that Persistent Negative Symptoms (PNS) were already present in the prodromal phase and were correlated with worse social functioning after two years [24]. In yet another study, onset of psychosis was followed by decreased levels of social integration [25]. In conclusion, the relation between social connectedness and clinical symptoms in people with psychotic disorders is not well understood, but may very well be bidirectional [10,26]. Some evidence was found for a self-preserving mechanism, in which loneliness makes people more sensitive to negative interpretations of social cues, leading in turn to more withdrawal [2]. These effects were found in the general population, but might also play a role in the course of psychotic disorders.

Social connectedness is the modifiable factor of our interest in the bidirectional relationship between social connectedness and symptoms of psychosis. Social network interventions for people with psychosis have shown to be effective at increasing the size of patients' social networks [27]. To provide more insight into the relationship between social connectedness and symptoms of psychosis we aim to evaluate satisfaction with social connectedness (SSC) and its longitudinal relationship with positive and negative symptoms in a broad sample of people with psychotic disorders. The results of this study might indicate a positive effect on symptoms of interventions that are focused on SSC, such as family intervention [28], social skills training [29] or peer support [30]. In the current study, time intervals of one and two years are used, as effects of social connectedness on symptoms can vary depending on the time interval [31].

Aims of the study

In this exploratory study we hypothesize that higher levels of SSC will predict less severe positive and negative symptoms after one and two year follow up. In contrast to previous longitudinal studies which have researched the relationship between SSC and positive/negative symptoms in FEP [18,19], the current study features a larger sample size and uses a multilevel approach in an SMI sample

Methods

Design

This study uses routine outcome monitoring data from the Pharmacotherapy Monitoring and Outcome Survey (PHAMOUS) [32]. PHAMOUS is an ongoing Dutch cohort study including people with a psychotic disorder in the Northern Netherlands [33,34]. This cohort, which started in 2006, involves a yearly screening on physical, mental and social domains. The screening is carried out by trained nurses at the participating psychiatric institutes. The PHAMOUS protocol was approved by the local ethical committee and conducted in accordance with the guidelines of the Declaration of Helsinki [35]. The following PHAMOUS data were used for this study: age, gender, diagnosis, year of first psychosis, symptom severity (PANSS), quality of life (ManSA) and global assessment of functioning (GAF). An elaborate description of the PHAMOUS protocol can be found in Bartels-Velthuis et al. (2018).

Sample

Patients who participated in the PHAMOUS screenings from January 2014 until December 2018 were included, meaning a maximum of five measurements per participant. Patients were included if they were diagnosed with a psychotic disorder (DSM IV/5, [33,34]) at entry of the study, were >18 years old and had participated in two or more screenings. Patients were not eligible to be included in the analysis if their psychotic disorder was induced by drugs or alcohol.

Patients in the PHAMOUS cohort receive yearly invitations to the screenings. Due to non-response and delay of screenings, the interval between two consecutive screenings varies considerably. Therefore, we allowed an interval between two consecutive measurements of minimally 9 months (39 weeks) and maximally 16 months (78 weeks) apart from each other. If two measurements occurred within 9 months, they were analysed as one measurement with the mean of the two data points (scale data) or the first observation between two data points (categorical data). We considered the measurement as missing when two measurements were more than 16 months apart.

Measures

In this study SSC was constructed from the Manchester Short Assessment of Quality of Life (ManSA) [36], which evaluates quality of life in people with a mental illness. There are 16 items on financial, employment, health and social domains. Overall social network is positively correlated to the ManSA [37]. A satisfaction scale is used in 12 items ranging from 1 (could not be worse) to 7 (could not be better). Four items are binary (yes/no). In this paper mean scores on scale items of the ManSA are reported. We selected the following items from the ManSA to operationalize SSC: satisfaction with the number and quality of your friendships (item 15), with the people you live with or with living alone (item 21), with your sex life (item 22), and with your relationship with your family (item 23). We defined SSC as the mean score of these four ManSA items (range 1-7). As the SSC measure was pragmatically constructed from an existing measure for QoL, measures of reliability were applied to evaluate internal consistency. To establish internal consistency Cronbachs' alpha, inter-item correlations and alpha if item deleted were evaluated. Positive and negative symptoms of psychosis were measured with the Positive and

Negative Syndrome Scale (PANSS) [38]. The PANSS is a 30 item structured interview on positive symptoms (7 items), negative symptoms (7 items) and general psychopathology (16 items). All items are clinician rated on a 7 point Likert scale and the total score ranges from 30 to 210. In this study we used the five-factor model from Van der Gaag et al. (2006) [39] which identifies five subscales: positive symptoms (POS; range 1 – 64); negative symptoms (NEG; range 2-69); disorganization (DIS; range 10-70); excitement (EXC; range 8-64); emotional distress (EMO; range 8-64). See supportive information S1 for the algorithm of the codes. POS and NEG were used as the outcome measures in the multilevel analyses. PANSS remission criteria were applied to describe the rate of remission in the cohort (see supportive information S1) [40]. Due to the aspired one year time interval in the PHAMOUS study, the original criterion of ≥6 months continuity of the remission could not be applied.

Statistical analyses

Descriptive data were reported for each yearly screening (range: 1-5) using mean values and standard deviations or frequencies and percentages. In order to examine SSC as an independent one and two year predictor for positive and negative symptoms, a (time lagged) linear mixed effect model with random intercept, Maximum Likelihood estimation and $\alpha = 0.01$ was used. Time was used as repeated measurement (i.e., yearly screening, range: 1-5). Predictive variables were included as one and two year lagged variables (LAG). In contrast with simple regression, multilevel models do not require independent observations. Individuals are measured repeatedly and therefore can contribute multiple times to each LAG. Due to the multilevel structure of the analysis, several time points can serve concurrently as predictor or outcome with a maximum of four time points for LAG 1 and three time points for LAG 2. For each outcome, the following covariance structures were tested for model fit: Diagonal (DIAG), Compound Symmetry (CS), First order Autoregressive (AR1) and Identity (ID). Multicollinearity was examined with the Variance Inflation Factor (VIF). A cut-off score of <4 was used to determine whether multicollinearity would bias the analysis [41]. Separate models were fit for positive and negative symptoms with a one and two year time lag. For each model, SSC was fit unadjusted as a predictor, and subsequently analyzed with adjustment for covariates to analyze the stability of SSC. Outcomes were adjusted for the PANSS subscales, illness duration [42], gender [43] and age [44]. All scale variables were standardized using z scores in order to minimalize the impact of multicollinearity. SSC and positive and negative time lag variables, respectively, were first included as fixed effects and in the final model tested as random effects using model fit parameters (deviance statistic, AIC [45] and BIC [46]). Confidence intervals were reported to measure precision of the effect.

Multiple imputation was used to deal with missing data. Linear regression was used for imputing scale data and logistic regression was used for imputing categorical variables. Fifteen imputed datasets were generated with k=10 and combined using Rubin's rule [47]. To evaluate the impact of the imputation on the results, the delta between the outcomes of the pooled and the original dataset were calculated. A sensitivity analyses on the full model was conducted on the effects of outliers (mean ±3 SD). All statistical analyses were performed using the Statistical Package of the Social Sciences (SPSS), version 26 [48].

Given the requirements of European privacy law, the dataset is encoded three times by independent institutes. A pseudonymized dataset was released by one of the PHAMOUS investigators (EV) at the Data Science Center of the Rob Giel Research center. Access to this dataset was restricted to JSV, JB and SdJ, who performed the analyses.

Results

Sample characteristics

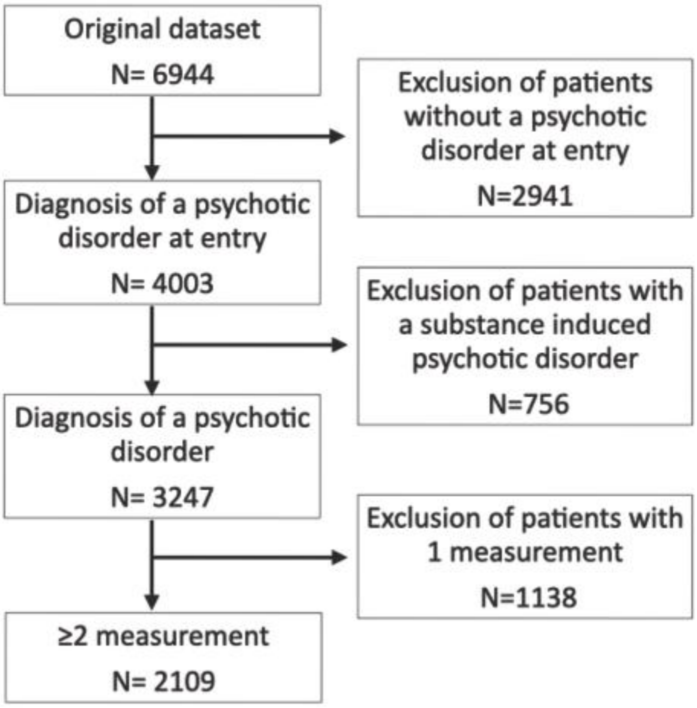
Demographic and clinical characteristics are presented in Table 1. From the PHAMOUS database population of 6944 patients, 2109 were eligible for this study. A flow diagram is presented in Figure 1. At first assessment, the mean age was 45.1 (SD= 11.2) and the mean illness duration was 18.8 (SD=10.7), signifying this is a sample with a relatively chronic illness, which is in line with an earlier report on the PHAMOUS database [32].

Table 1. Clinical Characteristics of the Study Population

Total N	2109
Male N (%)	1390 (65.9)
Age Mean (SD)	45.1 (11.2)
Diagnosis N (%)	
Schizophrenia	1532 (72.6)
Schizophreniform disorder	48 (2.3)
Schizoaffective disorder	388 (18.4)
Delusional disorder	60 (2.8)
Other psychotic disorder	81 (3.8)
Illness duration	
Mean years (SD)	18.8 (10.7)
Living situation N (%)	
Independent	913 (43.3)
Independent with partner	224 (10.6)
With family/others	140 (6.6)
Supported housing	409 (19.4)
Long term clinical	305 (14.5)
Other	44 (2.1)
Missing	74 (3.5)
GAF symptoms Mean (SD)	49.9 (13.7)

GAF= Global assessment of functioning

Fig. 1. Flow chart showing the process of applying selection criteria to participants for inclusion in the research.



Reliability of the SSC measure

Evaluation of the SSC construct showed satisfactory reliability measures. The items showed slightly below good internal consistency with Cronbach's α= 0.67 [49]. The inter-item correlations were satisfactory, ranging from 0.265 to 0.415 (p< 0.01) [50]. Furthermore, we conducted an analysis on the alpha if item deleted. This showed a range between 0.56 (item 12) to 0.64 (item 13) indicating a lower alpha if items were deleted.

Outcomes on PANSS, ManSA and SSC

Mean PANSS total scores over the five year study period ranged from 50.1 to 52.7. These PANSS total scores correspond with a Clinical Global Impression (CGI) score between 2 (borderline mentally ill) and 3 (mildly ill) [51]. At entry, 34.8% of the patients complied with all criteria for being in remission of psychosis [40]. The mean POS score was 13.4 (SD= 6.2) and the mean NEG score was 14.6 (SD= 6.3) at entry, indicating minimal symptoms. The mean SSC scores over the five year study period ranged from 4.9 to 5.0 (mostly satisfied) on item level of the ManSA. Descriptive statistics at each time point are presented in Table 2.

Table 2. Descriptive statistics of the Positive and Negative Syndrome Scale, the Manchester Assessment of Quality of Life and Satisfaction with Social Connectedness (SSC)

	Time 1	Time 2	Time 3	Time 4	Time 5
	N=2109	N=1555	N=1256	N=904	N=416
PANSS Mean total score (SD)	52.7 (16.4)	51.0 (15.3)	50.1 (15.4)	50.0 (14.6)	51.3 (15.7)
POS	13.4 (6.2)	12.9 (5.9)	12.8 (6.2)	12.8 (6.1)	13.7 (6.7)
NEG	14.6 (6.3)	14.2 (6.1)	13.6 (6.0)	13.7 (6.0)	13.8 (6.4)
DIS	16.7 (6.8)	16.0 (6.0)	16.0 (6.3)	15.7 (5.4)	15.9 (6.1)
EMO	14.6 (5.2)	14.3 (5.0)	14.1 (5.0)	14.2 (5.2)	14.8 (5.8)
EXC	11.7 (3.9)	11.4 (3.5)	11.1 (3.5)	11.1 (3.4)	11.2 (3.4)
PANSS Remission N (%)	734 (34.8)	500 (32.2)	396 (33.3)	304 (33.6)	126 (30.3)
Missing	503 (23.9)	489 (31.4)	288 (31.9)	288 (31.9)	131 (31.5)
ManSA Mean (SD)	54.2 (11.2)	55.0 (10.7)	55.0 (10.8)	56.2 (10.8)	55.3 (10.9)
SSC	4.9 (1.1)	4.9 (1.1)	4.9 (1.1)	5.0 (1.1)	5.0 (1.1)

PANSS = Positive and Negative Syndrome Scale; POS = Positive Symptoms; NEG = Negative Symptoms; DIS = Disorganization; EMO = Emotional distress; EXC = Excitement factor; ManSA = Manchester Assessment of Quality of Life; SSC = Satisfaction with Social Connectedness

Linear mixed models

With a linear mixed effect model, we estimated the associations of SSC and positive and negative symptoms with a one and two year time lag (LAG). The repeated measurement resulted in N=1686 patients with 3128 LAG one measurements and N=1431 patients with 2164 LAG two measurements. SSC was a small but significant negative predictive factor for positive and negative symptoms after one year and for positive symptoms after two years (Table 3). After adjustment for covariates the beta of SSC LAG one for positive symptoms was β= -0.47 (p < 0.001, 95% CI= -0.70, -0.25) and for LAG two β= -0.59 (p < 0.001, 95% CI= -0.88, -0.30). The adjusted beta of SSC LAG one for negative symptoms was β= -0.52 (p < 0.001, 95% CI= -0.77, -0.27) and for LAG-two β= -0.38 (p < 0.05, 95% CI= -0.72, -0.05).

There were no issues with multicollinearity given that the mean VIF was 1.95 (range: 1.73 -2.60). All independent variables were included in the analyses. Compound Symmetry was chosen as the covariance structure, based on values of the deviance statistic and the AIC [45] and BIC [46] information criteria. Inclusion of predictors as random effects rather than fixed effects did not further improve the model. Missing values in the original dataset were present in 58.01% of the cases and in 23.9% of the values. To test the impact of the imputation on the outcome, original data and pooled data were compared (Supportive Information S2). The delta between the pooled effects and the effects of the original dataset across full models varied between β= 0.02 and β=0.17 indicating an adequate imputation. Furthermore, the impact of outliers was tested in a sensitivity analyses on the full models. The β of the delta between the original analysis and the sensitivity analysis ranged between β= 0.03 and β=0.04. There was no impact on the significance levels.

Table 3. Predictive value of SSC on Positive and Negative symptoms using z scores in imputed dataset

	POS, LAG 1 β(95% CI) N=1686	POS, LAG 2 β(95% CI) N=1431	NEG, LAG 1 β(95% CI) N=1686	NEG, LAG 2 β(95% CI) N=1431
SSC	–0.75 (–1.02, –0.47)***	–1.00 (–1.31 –0.69)***	–0.74 (–1.03, –0.45)***	–0.67 (–1.02, –0.33)***
+ Symptoms	–0.50 (–0.73, –0.27)***	–0.61 (–0.90, –0.32)***	–0.52 (–0.76, –0.28)***	–0.43 (–0.76, –0.10)*
+ Time since onset	–0.48 (–0.71, –0.25)***	–0.61 (–0.90 –0.32)***	–0.54 (–0.78, –0.29)***	–0.41 (–0.74, –0.08)*
+ Gender and age	–0.47 (–0.70, –0.25)***	–0.59 (–0.88 –0.30)***	–0.52 (–0.77, –0.27)***	–0.38 (–0.72, –0.05)*

*** $p<0.001$; ** $p<0.01$; * $p<0.05$

POS= Positive Symptoms; NEG= Negative Symptoms; SSC= Satisfaction with Social Connectedness; Symptoms= Positive Symptoms, Negative Symptoms, Disorganization, Excitement, Emotional distress

Post hoc analysis: fluctuation of individual scores

The degree of individual symptom variability over time might impact the analysis. Strong individual symptom fluctuations might result in stronger associations with predictor variables compared to a stable course of symptoms. Therefore, an additional analysis was conducted to evaluate the degree of variation of individual scores on positive and negative symptoms and SSC during the study period. Mean individual fluctuations of year by year SSC scores were analysed using the Root Mean Square Deviation (RMSD). The RMSD analysis showed that in 52.6% of the patients the mean fluctuation on positive symptoms was <1 point, in 20.3% of the patients the mean fluctuation was between 1-2 points and in 27.1% of the patients the mean fluctuated >2 points. The results for negative symptoms were comparable: 51.7% of the patients had a mean fluctuation of <1 point, 18.2% had a mean fluctuation between 1-2 points and 30.1% of the patients had >2 points of mean fluctuation. In summary, >65% of the sample had only small fluctuations on both positive and negative symptoms over time. Scores for SSC (range 1-7) showed the following fluctuation levels: 42.9% of the patients showed a mean fluctuation of <0.3 point, in 39.3% of the patients the mean fluctuation was between 0.3 to 0.6 points and 17.8% of the patients showed a mean fluctuation of > 0.6 points during the study period.

Discussion

Main findings

This exploratory study partially confirmed our hypothesis that higher levels of SSC can predict a reduction of future positive and negative symptom scores. The small but significant association with positive symptoms is significant up to two years. For negative symptoms, the association is significant for one year. Notably, a post hoc analysis on positive and negative symptom subdomain scores showed that these scores did not fluctuate more than two points on the PANSS scale for more than two thirds of the sample during the five years of the study period. The limited magnitude of associations might be explained by the relatively long mean illness duration (on average 18.8 years), the mild symptoms with minimal fluctuation over five years and over a third of the patients already in remission during the first assessment (34.8%). Although the associations are small, the large sample size and the use of the multilevel statistics resulted in a robust estimated prediction. Small associations are important to consider in the ongoing development of treatments in a sample with persistent positive and negative symptoms [52].

Previous research

Previous studies have focussed on the association between SSC and a remission of symptoms in first episode psychosis (FEP). A two year longitudinal study (N=186) did not find that a remission of positive and negative symptoms was predicted by perceived social satisfaction [19]. Another FEP study analysed satisfaction with social support in a three year longitudinal study (N=113). In accordance with the two year longitudinal association found in our study, satisfaction with social support was associated with a reduction of positive symptoms (r= -0.33, p<0.01), but not of negative symptoms [18]. Our sample differs from these previous studies in the longer illness duration, the higher age and the social context (i.e., >25% in supported housing or long term clinical facilities). Furthermore, compared to the abovementioned previous studies, the current study has a larger sample size and therefore a higher ability to detect small correlations.

Besides the impact of social connectedness on symptoms of psychotic disorders, the reversed association was also found [20,21], suggesting that components are interconnected. One could reason that the complex interplay between social connectedness and positive and negative symptoms is a negative feedback loop directing towards a state of social withdrawal [53,54]. Both positive and negative symptoms are, as such, part of social connectedness in people with psychosis.

Strengths and limitations

This exploratory study used data from a naturalistic cohort (the PHAMOUS survey) and was originally not designed to quantitively measure the extent of the association between SSC and symptoms of psychosis. However, the predictive associations are a step forward in model development on the relationship between SSC and symptoms of psychosis. Next, the significance levels indicate a relationship but should be further evaluated with validated measures that are able to quantitatively estimate the extent of the association.

The protocol for PHAMOUS cohort study prescribes a yearly screening of its participants. In practice however, screenings are often conducted before or after the yearly time gap. In the current study we were able to compute a minimum and maximum time gap that restricted the time gap of subsequent measures between 39 and 78 weeks and at the same time this prevented conflicting time gaps. Furthermore, this method allowed for missed screenings and for multiple screenings within on time gap.

We constructed SSC for this research by extracting items from the ManSA, which is a frequently used measure for Quality of Life (QoL) in psychosis research. However, the SSC measure was pragmatically constructed from an existing QoL measure (ManSA) and, to our knowledge, not used before in research. Therefore, prior to evaluating the research question, the SSC was evaluated on internal consistency. This resulted in a Cronbach's alpha slightly below the optimal threshold [49]. However, the high inter-item correlations and the longitudinal relationship with symptoms of psychosis in this study might be preliminary indications of reliability and construct validity. The use of a theoretically derived measure on SSC with evaluations on validity and reliability would add to the strength of the method.

In addition, in a previous study group identification was shown to be negatively correlated to paranoid ideation [55], which is highly prevalent in people with psychosis. Group identification was not measured in this study, and therefore its association with positive and negative symptoms could not be identified. Measuring the sense of group identification would add to the strengths of the results.

The current study was conducted in the PHAMOUS cohort where patients receive yearly invitations for screening. Patients with higher scores on positive or negative symptoms are less likely to respond to the yearly PHAMOUS screening invitation. This is shown in the PANSS scores, showing a relatively mild illness profile with very few people at the severe end of the spectrum. Similarly, patients who have benefitted most from psychiatric treatment and no longer experience symptoms are likely to be discharged from specialized mental health care. Consequently, these patients are not invited for the yearly PHAMOUS screening. Results of this study can therefore not be generalized to patients in recovery or with extremely severe symptom profiles.

Measures of social connectedness show discrepancies between objective and subjective levels of connectedness [56]. In the current study, a relatively large part of the sample was living alone (43.3%) while patients were mostly satisfied with their social network SSC (mean 4.9 to 5, mostly satisfied). Possibly, both objective and subjective indicators of social connectedness should be used to predict clinical recovery [19].

Future research

The complex interplay between social connectedness and symptoms in people with a generally long term psychotic disorder could benefit from further research. Longitudinal cohorts give the opportunity to model the course of symptoms over time and adjust for bidirectional effects of symptoms and social connectedness in the more chronic stage of illness, possibly in a structural equation model (SEM). In addition, applying these models in Ultra High Risk (UHR) cohorts makes it feasible to adjust for premorbid effects of social connectedness. This will help to distinguish the impact of premorbid social connectedness on symptoms balanced against loss of social connectedness during the course of illness.

The longitudinal associations of SSC with symptoms are small, however relevant for a population with long term disabilities. Therefore, intervention research on social connectedness with long term follow up is necessary to evaluate the impact of social connectedness interventions on positive and negative symptoms. Interventions should focus on the patient level, such as social skills training [29], the network level, such as guided peer support groups [57], or as an integrated intervention on both levels [58]. Of interest is a novel intervention called Group 4 Health (G4H) [59] which was informed by the Social Identity Model of Identity Change (SIMIC) [60,61]. The G4H intervention showed a reduction in loneliness and social anxiety in people with psychological problems by developing social identity capital in group experiences. A recent review on identity change in people with psychosis presented a framework that could inform the development of new interventions for social identity [60].

Furthermore, apart from clinical recovery, chronically stable patients often have additional treatment goals on functional and personal recovery. Evidence for positive effects of social connectedness is also found on functional and personal recovery [12].

In measuring social connectedness group identification might be a promising construct for predicting mental health. Group identification showed to be a better predictor of mental health (in family and an army unit) compared to objective measures of social contact [62]. This is in line with a study indicating that negative group identity might be a risk for developing schizophrenia [63].

The current study showed that satisfaction with social connectedness is a small but robust predictor for decreased severity of positive symptoms after one and two years and for decreased severity of negative symptoms after one year in people with a psychotic disorder. The findings indicate that interventions on social connectedness might positively impact mental health for people with psychosis.

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Chapter 7

Summary and general discussion

Recovery can currently be understood from three perspectives: the clinical perspective (remission of symptoms; chapter 5 and 6), the societal perspective (functioning in society; chapter 2 and 3) and the personal perspective (personal growth in overcoming the illness; chapter 2, 3, 4 and 6). In this thesis clinical, societal and personal recovery in people with psychosis are researched, with the emphasis on personal recovery. The general discussion reflects on the studies described in this thesis: a nursing intervention for personal and societal recovery (chapter 2 and 3), an evaluation of personal recovery measures (chapter 4), exercise interventions for the treatment of negative symptoms, as part of clinical recovery (chapter 5), and the relationship between personal and clinical recovery (chapter 6).

Summary

Chapter one is an introduction to this thesis. It describes the severity of living with a psychotic disorder from a clinical, societal and personal recovery perspective. The disease burden is outlined, showing the many impairments that people with psychotic disorders experience. The three perspectives of recovery can contribute to a broader understanding of recovery and the needs of people with psychosis. Recovery rates are still low. Therefore, research on all three forms of recovery is needed.

In **chapter two** the feasibility study of the HospitalitY (HY) intervention is described: an eating club for people with psychotic disorders, which combines skill training and peer support to improve personal and societal recovery. Participants reported positive effects on personal recovery domains and were motivated to work on skills. The results showed that the combined interventions, i.e., peer support and skill training in an eating club, are promising in fostering recovery.

The results of the feasibility study indicated that the HY-intervention was suitable for a subsequent randomized controlled trial (RCT). A multicenter RCT on the HY-intervention is presented in **chapter 3** with personal recovery as the primary outcome. Secondary outcomes related to personal recovery (self-esteem, loneliness, self-stigma, social support), societal recovery ((social) functioning, social skills, independency competence) and clinical recovery (symptoms of a psychotic disorder) were evaluated as well. The RCT did not yield significant effects. In the general discussion we reflect on environments that foster personal recovery and the balance between safety and risk in personal recovery interventions.

Chapter 4 is a study on the comparison of three personal recovery measures: the Recovery Assessment Scale (RAS), the Mental Health Recovery Measure (MHRM) and the Netherlands Empowerment Scale (NEL). The three measures were compared on six different aspects of validity and reliability. The CHIME framework (Connectedness, Hope, Identity, Meaning and Empowerment) was used to measure content validity [1]. The MHRM showed the highest score on content validity with a balanced distribution of the items covering the complete CHIME framework. However, the overall differences between measures were minimal, impeding final conclusions on the choice of measure. Notions of recovery have changed over the past century, with shifting emphasis on what recovery is. Personal recovery is the latest view that impacted the notion of recovery. The general discussion reflects on the value of personal recovery as an outcome for scientific research.

An important clinical outcome in psychosis is the severity of negative symptoms. Negative symptoms greatly impact functioning in people with psychosis [2], as they are limiting people with psychosis in their societal recovery as well as their personal recovery. In chapter 5 the effects of physical exercise (PE) interventions on negative symptoms in schizophrenia are researched in a meta-analysis. The results showed a moderate effect on negative symptoms of PE versus control conditions. However, a subgroup analysis showed that PE was more effective if added to standard care, but not more effective than active control groups.

Connectedness is a key element in personal recovery [1]. A study on the relationship between connectedness and symptoms of psychosis is presented in chapter 6. In this study satisfaction with social connectedness (SSC) is used to evaluate levels of positive and negative symptoms in psychosis at one- and two-years follow-up. This study showed that satisfaction with social connectedness is a small, but robust predictor of lower levels of positive symptoms up to two years and of negative symptoms up to one year.

General Discussion

Clinical recovery

Definitions of recovery have undergone many changes in the past 120 years [3]. The primary focus stems from a medical perspective on mental health disorders. Diagnostic descriptions were first presented by Morel, with the term dementia praecox [4], and later by Bleuler, who described the term schizophrenia, or group of schizophrenia's [5,6]. Consensus on the diagnosis criteria of schizophrenia were established in 1952 in the Diagnostic and Statistical Manual of Mental Disorders (DSM) [7]. Consensus on these diagnostic criteria is important for epidemiological research. However, recovery of schizophrenia is not solely defined by the absence of symptoms (i.e., diagnostic criteria). Returning to a premorbid state is often not possible due to ongoing symptoms and lifelong disability. Substantial remission of symptoms that allows for satisfactory levels of functioning (i.e., societal recovery) and personal growth (i.e., personal recovery) should be aimed for in research and treatment.

In the past decades many different criteria for clinical recovery were used [8,9]. The first consensus definition for clinical recovery in schizophrenia were developed by the Remission in Schizophrenia Working Group (RSWG) [10]. The RSGW criteria comprise the three main dimensions of clinical recovery: psychotic symptoms, negative symptoms and cognitive symptoms. A rating of mild symptoms or less on standard rating scales such as the Positive and Negative Syndrome Scale (PANSS) [11] for 6 months or longer is defined as remission. The research in chapter 6 is an example of the applications of the RSWG criteria. The RSWG criteria are a result of close collaboration between researchers and its use is now widespread. Furthermore, the RSWG criteria for recovery are a valuable step in researching clinical recovery of schizophrenia.

Interventions for clinical recovery

In line with the RSGW criteria, three domains of clinical recovery can be distinguished: psychotic symptoms, negative symptoms and cognitive symptoms. The introduction of antipsychotic medication in 1953 contributed significantly to the remission of positive symptoms and prevention of relapses [12,13]. Positive symptoms are the most notable symptoms, and can result in behavior that is difficult to cope with by relatives as well the wider community. This might explain why most attention in research and treatment was aimed at reducing positive symptoms. However, 40% of the patients experience negative symptoms and 80% experience cognitive symptoms [14]. In contrast with positive symptoms, satisfactory treatments with similar effects for negative and cognitive symptoms are not yet available [15].

Interventions for negative symptoms, such as pharmacological interventions [16], Transcranial Magnetic Stimulation [17], Social Skill Training (SST) [18] or physical exercise (**chapter 5**) show small to moderate effects. The most robust evidence for negative symptoms up till now is found for SST [19]. Effects in magnitude comparable to negative symptoms were found for cognitive symptoms on compensatory treatments and cognitive remediation therapy [20,21].

The lack of treatments that robustly improve negative and cognitive symptoms is problematic. These symptoms are contributing significantly to the disease burden and impairment in daily life [14]. Furthermore, negative and cognitive symptoms are predictors of social disadvantage in schizophrenia [22,23]. A better understanding of the mechanisms behind these symptoms is necessary to inform research on new intervention options.

Outcomes of clinical recovery

Schizophrenia has long been viewed as a disorder with mostly poor outcomes and a deteriorating course. In 1899 Kraepelin [24] described schizophrenia with the term dementia praecox, an intellectual disorder with a positive prognosis in 10%, remission of symptoms in 20%, and ongoing symptoms in 70% of the patients. However, in the 1970's and 1980's, epidemiological studies found a wide variety of disease courses, from severe deterioration to complete recovery. Several studies showed that more than 50% of the patients had favorable outcomes, which means a mild end state or complete recovery [25-27], thus indicating more positive results on recovery. A recent systematic review on outcomes of the 21st century found a mean recovery rate of 57% for first episode psychosis (FEP) and 38% for multiple episode psychosis (MEP) [3]. A more optimistic view on recovery today is warranted compared to the earlier views in Kraepelin's time, although recovery rates are still relatively low.

Aside from achieving recovery, persistence of recovery is also an issue. Today, most FEP patients show a good response to treatment of positive symptoms, but recurrence is 78% in 24 months and 84% at more than 36 months [28]. Also, meta-analyses show that the rates of recovery had not changed throughout the past century [9,29]. The most recent meta-analysis on clinical recovery in schizophrenia found a median clinical recovery rate of 13.0% [29]. In this study the RSGW criteria were applied with a two-year persistency criterion. Persistency of clinical recovery is still a challenge and needs to be addressed in research. Preferably, follow-up periods of intervention studies should be two or more years to evaluate the persistency of effects.

Research on prevention and treatment of psychotic disorders is still paramount in order to accomplish higher rates of recovery. In the meantime, secondary effects of schizophrenia that impact functioning in daily life (i.e., societal recovery) and living a worthwhile life (i.e., personal recovery) should be addressed more prominently in mental health care policy.

Societal recovery

Despite an initial focus on clinical symptoms in treatment, the concept of societal recovery in spite of recurrent symptoms was already mentioned by Bleuler in 1908 [6], who pointed out the significance of social loss due to schizophrenia. Attention for societal recovery gained momentum with the development of psychiatric rehabilitation. The emphasis of psychiatric rehabilitation is treating the consequences of mental illness instead of the illness itself [30] and thereby focusing on skills for independent living and roles in society. One of the drivers for psychiatric rehabilitation was deinstitutionalization, starting around the 1980's [30]. As hospitals were closed, patients were expected to live in the community. However, negative and cognitive symptoms in particular are often limiting patients in their independent living skills and integration in the community [31], leading to social disconnection. Social disconnection is associated with negative effects on health [31] and high rates of loneliness [32], showing the importance of interventions that promote societal recovery.

Unlike the RSGW criteria for clinical recovery, no consensus criteria exist for societal recovery [3,29,33]. Societal recovery broadly comprises three domains: vocational functioning, independent living and social relationships [34]. Scientific literature does show consensus on the importance of societal recovery as an outcome [3]. Criteria for societal recovery similar to the RSGW criteria would be a great advance in research and should be established in a consensus meeting.

Several researchers proposed criteria for societal recovery [34-36], however, criteria for societal recovery are difficult to standardize. Not all patients with serious mental illness value the same outcomes regarding work, independent living or relationships. These values can change over time and might differ per culture. To increase validity, outcomes could be measured with respect to their context (i.e., culturally and stage of life). Furthermore, patients might show mixed patterns of outcomes. Performing well on independent living does not mean that the same level is achieved for social relationships. Different profiles of functioning should be taken into account when measuring societal recovery.

In this thesis the Personal and Social Performance (PSP) scale [37] was used to measure societal recovery (chapter 3). The PSP is an interview-based measure. Interviews allow for inclusion of context variables, which is not possible in standardized questionnaires. Furthermore, the PSP has some strong aspects: it is easily applicable, covers all three domains (i.e., vocational functioning, independent living and social relationships), it allows for varying outcome profiles, and it shows good psychometric properties [38]. Furthermore, later research also showed that the PSP is responsive to change in intervention research [39].

Recently the Functional Remission tool (FR-tool) was developed for Routine Outcome Monitoring (ROM) [34]. Similar to the PSP, this tool is interview-based. In contrast with the PSP, the FR-tool contains broad categories, resulting in less precise

ROM evaluations, that generally consist of multiple measurements. The PSP and FR-tool could be considered as a standard for measuring societal recovery in respectively intervention research and ROM.

Interventions for societal recovery

A wide variety of interventions for societal recovery have been developed. These interventions are aimed at independent living, vocational and social skills. The Boston Psychiatric Rehabilitation (BPR) is such an intervention, using real-world settings to increase recovery [40]. Up till now, divergent results of BPR on outcomes of societal recovery were found [41]. A promising element in BPR, which was also part of the HY-intervention (**chapter 2 and 3**), is goal setting [42,43]. People with schizophrenia show impairments in goal directed behavior [44,45], although hedonic experiences are intact [46]. Supporting patients with goal setting might be an effective strategy to increase motivation to work on skills (**chapter 2**).

Furthermore, motivation to work on skills can be positively impacted by meaningful contexts. Meaningful contexts are real-world settings, such as work or relationships, in contrast to clinic-based settings. The importance of real-world settings was shown in a study on motivational deficits, reporting that people with schizophrenia formulated goals that were more driven by the need for relatedness than by the need for autonomy and independence [44]. Also, the results in **chapter 2** indicated that participants in the HY-intervention were motivated to work on skills due to the context of a meaningful social activity. People with severe mental illness (SMI) value meaningful activities [47] and pursuits such as work, school or social relations [48]. Therefore, training skills in the context of meaningful activities such as an eating club, or work can be used to increase motivation to work on skills.

Outcomes of societal recovery

Rates of societal recovery are higher than of clinical recovery [3,29]. A median rate of societal recovery of 19% was found in a meta-analysis that applied a two-year persistence criterion [29]. However, this outcome was only based on three studies. Recent longitudinal studies found societal recovery rates of 13.7% [34] and 15.5% [49]. Furthermore, no real improvement on societal recovery was found in a systematic review that compared studies from 20th to the 21st century [3]. Despite increased attention for treatments, rates of societal recovery are still low and might not improve in the near future. However, societal recovery is also dependent on the broader social, political and economic context [3]. For example, on a political level, allocating recourses to increase opportunities for social contact or job opportunities positively impacts outcomes of societal recovery.

Personal recovery

Personal recovery is the latest notion of recovery and derives from the recovery movement, which advocates for the rights of mental health consumers [50]. The recovery movement evolved from a dissatisfaction with mental health care services. Patients felt disempowered due to involuntary confinement or paternalistic treatment [51].

The emergence of personal recovery resulted in policy changes, such as the implementation of shared decision making [52] and the inclusion of peer workers in the mental health workforce. Some of these policy changes were implemented regardless of initial evidence of effect, signifying that the primary driver of personal recovery was the need for mental health care reform [53]. As a scientific construct, personal recovery has its limitations as it is based on individual experiences and meaning [1]. This idiosyncratic basis conflicts with epidemiological sciences that rely on the assumption that outcomes in research can be standardized and generalized to comparable groups of people.

Exact criteria for personal recovery do not exist. It is a broad concept [53] with different themes, without a clear scientific consensus [1,54-56]. Personal recovery as a scientific construct is best understood by the models that are developed based on personal recovery experiences. The research in this thesis was mostly informed by the CHIME framework (**chapter 2, 3, 4**). Although the CHIME framework gained much attention in the literature, later research also pointed out the limitations of this model and argues that a broader framework might be more suitable to capture the construct of personal recovery [57,58]. Recently, three new models of personal recovery were developed [54-56]. These models show that the personal recovery construct is very broad with divergent themes. The model of Ellison et al. (2018) is based on the definitions of personal recovery by the USA based Substance Abuse and Mental Health Services Administration (SAMHSA) [56]. Therefore, the model of Ellison et al. (2018) might be more appropriate for the USA context. Jaiswal et al. (2020) presented a model with only three major themes (relationships, meaning and participation) that represent means to promote personal recovery as well as endpoints [55]. The model of Dell et al. (2021) appears to be the broadest model of recovery and also includes aspects of clinical recovery, physical wellbeing and context related factors [54]. This model might therefore be regarded as an integrated model for all domains of recovery. Although these news studies, as well as the CHIME model, present different themes and clustering of subthemes, there is also considerable overlap on the themes that were selected. Across the models there is an emphasis on personal growth and development of the individual in the context of current or past psychiatric symptoms. The development of new models based on more recent research leads to a broader understanding of personal recovery as a construct for research and intervention development.

The CHIME model has shown much value for informing research and interventions of personal recovery, including the research in this thesis. Several studies used CHIME to develop [59,60] or evaluate [61-63] measures of personal recovery (**chapter 4**). Compared to other models [54-56], the CHIME model has the advantage that it is concise in the number of themes. Furthermore, the CHIME themes cover a large part of the literature on personal recovery [1], making this model suitable for evaluating measures.

Despite a lack of exact criteria to define personal recovery, attempts have been made to capture the construct of personal recovery, either by proxy (e.g., the happiness index, [49]) or in specific recovery questionnaires. Several personal recovery measures have been developed and reviewed in people with psychosis or other mental health issues during the last decade (Table 1). However, as shown in **chapter 4**, different personal recovery scales emphasize different aspects of personal recovery. Subsequently, depending on the included themes the suitability of a measure may vary per situation.

Table 1. Overview of reviews on personal recovery measures

Review	Population	Number of measures identified	Preferred measure(s)
Burgess 2011	Mental health	22	RAS, IMR, STORI, RPI
Cavelti 2012	Schizophrenia	13	RAS
Law 2012	Psychosis	25	RAS, QPR
Sklar 2013	Mental Health	21	RAS, MHRM, IMR
Shanks 2013	Mental Health	13	RAS, QPR
Penas 2019	Mental Health	35	RAS, MHRM, IMR, STORI, SRS, QPR, MHRS, RPI

RAS= Recovery Assessment Scale; IMR= Illness Management and Recovery Scales; STORI= Stages of Recovery Instrument; RPI= Recovery Process Inventory; QPR= Questionnaire about the Process of Recovery; MHRM= Mental Health Recovery Measure; SRS= Stages of Recovery Scale; MHRS= Mental Health Recovery Star

The variation of emphasis on themes within recovery measures (including the evaluated measures in **chapter 4**) were developed with the help of consumer perspectives (e.g., consumer focus groups). In line with recovery views, the purpose of this approach is to ensure that the final questionnaire is close to how consumers understand personal recovery. However, this method might merely reflect the personal recovery views of the consumers included in the studies, which may not necessarily generalize to the perspective of all consumers.

A standard measure for personal recovery

Reviews of personal recovery measures (Table 1) consistently reported the Recovery Assessment Scale (RAS) [64,65] as a preferred measure, which is the reason why the RAS was chosen as the primary recovery measure for the main study of this thesis: the HY-intervention (**chapter 2 and 3**).

Because the RAS was one of the first validated measures for personal recovery its use became widespread, resulting in an accumulation of psychometric evidence for the RAS. Positive evaluations of the RAS in reviews [62,66] partly resulted from the overrepresentation of available evidence for the RAS, which stands in contrast to the absence of evidence for later developed measures, such as the Recovering Quality of Life (ReQoL) scale [67] or the INSPIRE measure [60]. This creates a self-reinforcing effect, because more use of a measure results in more evidence and subsequently in higher ratings in reviews, and thus more use of the instrument. Similar effects are shown in information technology, where being the first in a type of service often results in becoming the most used service (i.e., Facebook, Google). The absence of evidence for many recovery measures does not prove their inferiority compared to the RAS. Results of chapter 4 showed that other measures of personal recovery (i.e., MHRM, NEL) were at least equal to the RAS. More evidence is needed on separate measures to inform the choice on a standard for measuring personal recovery.

In fact, an international consensus working group identified the Recovering Quality of Life (ReQol-20) scale as the preferred measure for personal recovery for routine outcome monitoring [59]. The ReQoL was extensively researched on reliability and validity measures [67]. Due to its limited number of items (20) and its ability for use in cost-effectiveness analysis the ReQol-20 is an appealing measure for clinical research. However, the broad range of items, including also Quality of Life (QoL), implies that the ReQoL may measure multiple concepts and not just personal recovery per se. Combining multiple concepts in to one measure might result in nonspecific outcomes, which makes it difficult to interpret these outcomes. Therefore, the ReQol might not be suited to serve as a standard for measuring personal recovery. Content validity evaluation of the ReQoL with models of personal recovery [54-56] could increase evidence for its validity. However, a first step is finding consensus on a model of personal recovery which can be used for content validity evaluations.

Interventions for personal recovery

A recent meta-analysis on RCT's of personal recovery interventions showed a small, but significant effect on personal recovery, empowerment, and hope in people with SMI [68]. Interventions in this meta-analysis comprised educational (self-help) programs [69-71], the Wellness Recovery Action Plan (WRAP) [72,73], shared decision making [74,75], and an anti-stigma photo intervention [76]. The meta-analysis showed that personal recovery interventions can be effective. However, there were only seven articles included in the meta-analysis, which demonstrates that RCT's for interventions on personal recovery are still scarce [68]. Randomized controlled trials provide the highest level of evidence, as they are a powerful method for excluding selection bias [77]. However, RCT's prescribe a large degree of standardization. This empirical method might not always correspond with the notion of personal recovery which is viewed as a process and idiosyncratic, implying a need variability instead of standardization.

Social interventions

People with psychotic disorders have many unfulfilled care needs [78]. Socially-useful activities and personal and social relationships are a prominent lifetime disability in people with schizophrenia [79]. This is reflected in high levels of loneliness that many people with psychosis experience [80,81].

Social interventions such as the HY-intervention might be an answer to these needs. However, motivation for the type of social activities is highly dependent on identity and personal interests. The main social activity in the HY intervention is dining together, which may not necessarily be the most desired social context for each individual participant. The most optimal effects are likely reached when specific activities are offered tailored to personal preferences, such as exercising (**chapter 5**), photography

[82], being part of a choir or, in the case of the HY intervention, an eating club (**chapter 2 and 3**).

If possible, community-based services (e.g., community providers of social or sports activities) can be employed for social activities [83]. This method allows for wider variation in activities that are in line with personal interests of participants. Furthermore, a behavioral assessment could indicate how symptoms might impede participation in an activity [83].

Although employing community services can be an attractive method, not all people with schizophrenia are able to participate in such activities due to recurring symptoms or ongoing impairments in functioning. For this group, social interventions within mental health care settings are preferred as these settings are more adapted to the needs of people with schizophrenia.

Group interventions

Group interventions such as the HY-intervention (**chapter 2 and 3**) rely heavily on the contributions of its members, as they are expected to share personal experiences. Commitment to the group and the willingness to actively participate are important to achieve a positive outcome. Group identification is therefore essential. A study on group identification within therapy on psychiatric outpatients showed that group identification was positively predicted by members who experienced themselves as similar to one another [84]. This is confirmed in a study on social identity, which showed that how one relates to others is closely related to identity (i.e., how one sees themselves in relation others) [85]. Group identification is in particular important for small group interventions such as the HY-intervention (**chapter 2 and 3**), and could possibly be increased by matching participants on identity traits such as age or personal interests. Group identification might not have been sufficient in the HY-RCT (**chapter 3**). Due to the randomization process, it was not possible to match participants. Low group identification might therefore have contributed to drop outs in the study.

The high drop-out and the lower functioning levels of participants indicates that the balance between safety and risks may not have been optimal for all participants included in the RCT. On the other hand, the positive feedback of patients and nurses in the feasibility study, and partly in the RCT, indicated that the HY-intervention did have an appropriate balance between safety and risk taking for that particular sample. More attention on group identification might increase this balance. Differences in functioning should be used as an indicator for this balance. Safety and responsible risk taking in personal recovery might be an interesting topic in future research on personal recovery.

Outcomes of personal recovery

The first epidemiological study in people with psychosis that included personal recovery reported a personal recovery rate of 14.5%, measured with the Questionnaire about the Process of Recovery (QPR) [87]. A second study found recovery rates of 67.0%, measured with the Stages of Recovery Instrument (STORI) [88]. Furthermore, in other studies recovery is measured as subjective wellbeing, with recovery rates of 42.2% [89] and 44.3% [90], or as quality of life, with a recovery rate of 27.0% [91]. Most studies show that personal recovery rates do not exceed 50%, showing the need for health care interventions that increase personal recovery.

Outcome or process

In research, personal recovery is mostly evaluated as an outcome. Examples of this can be found in **chapter 2, 3 and 4**. However, there has been much debate about whether the construct of personal recovery should indeed be considered as an outcome, or if it would be better described as a process [54]. Deegan [92] provided one of the earliest accounts of personal recovery and described it as a unique non-linear journey with periods of development, stability and relapse [93]. From this point of view there is no real endpoint in the process of personal recovery; a person can only be in the process of recovery, i.e., the ongoing process of finding a positive sense of self [54]. Improvements in personal recovery might be measured in terms of longer periods of stability or a faster return to a positive sense of self after periods of despair.

Measuring personal recovery as a process instead of an outcome involves defining the varying stages of personal recovery. A high number of items need to be formulated that correspond with the number of stages multiplied by the themes that are evaluated (e.g., CHIME). A large number of items makes a questionnaire less suitable for clinical research, as shorter questionnaires are generally preferred. However, viewing personal recovery as a process is in line with consumer definitions, which argues for the use of process measures.

Furthermore, personal recovery is a largely idiosyncratic process that is difficult to capture in standardized questionnaires. Possibly, qualitative evaluations of personal recovery might be more informative than standardized questionnaires. Interviews can identify small changes in personal recovery and might include context related variables. With subsequent interviews, a process of personal recovery can be monitored based on themes of recovery that were selected at baseline as important to the individual. In conclusion, measuring personal recovery as an outcome with standardized questionnaires is conflicting with the initial view of recovery as a process. Preferably context and process should be taken into account, which can be established with semi-structured interviews.

Overlap between separate modalities of recovery

Recovery on all domains concurrently has not been studied much. However, some studies report the combination of clinical, societal and personal recovery, with the use of proxies for personal recovery. Four longitudinal studies found combined recovery rates (i.e., clinical, societal and personal recovery) of 12.8% [89] 17.1% [90], 4% [91] and 38% [49]. The large differences in findings might result from differences in sample characteristics or from the different measurements that are used. Standardization in measuring personal recovery is highly needed as the broad concept of personal recovery results in measures with different emphasis on themes of personal recovery (**chapter 3**).

Separate modalities of recovery show considerate overlap of and mutual influence between clinical, societal and personal recovery [88,94-96]. An example of the relationship between social connectedness and future positive and negative symptoms is shown in chapter 6. Furthermore, clinical outcomes such as negative symptoms [2] and neurocognition [97] are related to outcomes of societal recovery as predictors of real-life functioning. This overlap between domains of recovery is also found in intervention research. For example, a systematic review on Individual Placement and Support (IPS), which is aimed at societal recovery, found an association between employment and a reduction of negative symptoms [98]. Separate domains of recovery impact one another. Therefore, evaluation of separate forms of recovery should be combined in research [49,96] as gains in one domain might positively impact other domains [99].

Furthermore, real-world settings might be more suitable for integrating the separate domains of recovery than clinic-based settings (e.g., clinic-based skill training). The HY-intervention (chapter 2 and 3) as well as other in vivo- or home-based interventions [100-102], psychiatric rehabilitation [41,103] and supported employment [104], all use real-world settings to improve outcomes on societal recovery. In addition, these interventions also appeal on aspects of personal recovery, such as connectedness or meaning. Furthermore, effort allocation (i.e., the amount of effort someone is willing to put into activity), which is related to negative symptoms, is positively affected by these rewarding settings [105]. Integrating interventions in real-world settings might be more effective. The interaction between separate domains of recovery in the context of real-world interventions should be investigated in future intervention studies.

Methodological considerations

Inclusion of the HY-intervention

The RCT of the HY-intervention (chapter 3) was confronted with several inclusion problems. Although the initial inclusion period was prolonged with several months, we only managed to include half of the required sample size. Implementing the HY-intervention in the teams that were participating in the RCT showed to be challenging, which is consistent with other studies that have also shown that personal recovery interventions can be challenging to implement [42,57,99]. Implementation was planned in six regional mental health care institutes covering the northern parts of the Netherlands. However, only three out of six regional psychiatric institutes that approved the protocol ultimately participated in the HY-intervention. Several reasons were identified that contributed to the inadequate implementation of HY, on an organizational, professional and participant level.

On an organizational level, two mental health care centers initiated a reorganization during the trial period and subsequently reported that participating in the HY research project was not possible anymore. One of those two mental health care centers had already started the inclusion phase, but could not reach the required block of seven participants as described in the protocol. Their rural area might have contributed to this, resulting in a lower prevalence of eligible patients compared to urban areas. Furthermore, one center approved the protocol but was not able to find a community mental health care team that was willing or able to conduct the intervention.

On a professional level, mental health care workers reported several barriers in contributing to the HY project. All community teams that received information of the HY-intervention confirmed their support for the HY intervention. However, community teams that were interested often reported that combining the HY-intervention with their workload was not feasible. The participating nurses also reported that the HY-intervention was time consuming and that it was often not feasible to finish the work within their contracted hours. The feasibility study (chapter 2) showed that patients became more independent during the HY-intervention, suggesting that the workload of the participating nurses decreases with progression of the HY-intervention. However, this stage was not reached by some HY groups due to their early termination. Furthermore, the willingness for nurses to re-allocate working hours from office hours to early evening was lower than expected, which contributed to fewer nurses willing to participate. Some community teams expressed wishes to alter the intervention protocol, e.g., changing the location from home-based to clinic-based or changing from dinner to lunch or on the inclusion criteria (e.g., including people without psychotic disorders). Furthermore, some teams were inspired by the idea of the HY-intervention and organized similar projects on their own, outside of the research project.

On a participant level, there were also several barriers. The randomization protocol of seven participants per block often led to long waiting times: it could take up to several months before a block was finalized. This resulted in early drop-out of included participants before they were even randomized into the study, because they did not want to wait any longer for the intervention to start. Furthermore, community teams reported that consumers were reluctant to participate because they only wanted to join the eating club and were not willing to be randomized to the waitlist condition. The willingness to be randomized was not tested in the feasibility study. Another barrier for consumers to join the HY-intervention was that they could not choose their peers for the eating club. Of note, community teams who treated people with first episode psychosis (FEP) noted that consumers were reluctant to take part in an eating club with peers. They preferred to focus on meeting people outside a context of psychiatry instead. This finding is in line with research on identity change in psychosis reporting that people try to distance themselves from their diagnosis [85]. Furthermore, since the FEP population shows better prognosis on recovery compared to multiple episodes of psychosis (MEP) [3], they might feel less need for support on societal recovery such as offered in the HY-intervention (e.g., improving social network). We had not anticipated this, because other research showed that people with FEP do value peer contact by alleviating self-stigma [106]. However, this indicates that HY might be more appropriate for people with MEP.

Delivery of personal recovery interventions

The HY-intervention (**chapter 2 and 3**) was designed to be delivered by a nurse. The nursing profession is aimed at supporting people with psychosis with the consequences of their illness and in regaining societal and personal recovery [107]. Furthermore, the HY-intervention was partly based on the GPSG method [108]. The research on this method showed that participants preferred a nurse to guide the group sessions over guidance of a peer or other health care workers [108]. In the GPSG-method the role of the nurse is being present in the group without actively engaging in the conversations between the participants [108]. Based on these arguments and to standardize the delivery by one profession, HY was designed as a nurse-led intervention.

However, today much scientific literature argues for the employment of peer workers to deliver personal recovery interventions [99]. With their experiential knowledge, peer workers have the opportunity to relate to consumers with shared experiences, which is important in the process of personal recovery [1]. This would suggest that the HY-intervention might also be a suitable intervention to be led by peer support workers. The potential benefits of a peer support worker, such as sharing experiences and acting as role model for consumers, could positively affect aspects of identity (e.g., self-stigma or self-esteem) [65]. Both peer-workers as non-peer-workers should be able to support eating clubs. However, an explicit role description is necessary, as a peer support worker might take up a more active role in the group dynamics, as opposed to the passive role of a nurse (in accordance with the original GPSG method).

Measures of social connectedness

In **chapter 6**, social connectedness was measured with a satisfactory measure which was derived from the Manchester assessment for Quality of Life (ManSA) [109]. Measures of social connectedness show discrepancies between objective and subjective levels of connectedness. This discrepancy is shown in several studies. One study found that despite having fewer social contacts, people with psychotic disorders did not necessarily feel lonelier than people with mood disorders [110]. Another example is the study by Bjornestad et al. (2016) [111], which showed an effect of contact frequency, but not of social satisfaction, on clinical recovery in FEP [111]. It is possible that objective measures of social connectedness might result in stronger relationships with positive and negative symptoms than subjective measures. Since we only included a subjective measure of social connectedness, the results of chapter 6 might be underestimated. Because of the discrepancy, it is important to include both objective and subjective indicators of social connectedness.

Lessons learned on personal recovery interventions

Personal recovery interventions often come with implementation difficulties [42,57], which was also a major obstacle in the HY-intervention trial. Although the HY-intervention was aimed at increasing levels of functioning, for some participants their limited level of functioning at baseline may have created too big of a challenge to participate. It might therefore be argued that a baseline level of functioning is needed for the intervention to be effective. Otherwise, adaptations to the HY-intervention are necessary to make sure it is also feasible for people with more functional impairments.

Randomized trials provide the highest level of evidence, as they are a powerful method for excluding selection bias, and are therefore considered the gold standard for the evaluation of interventions [77]. However, personal recovery interventions are complex to evaluate as shown in this thesis. Possibly, qualitative research might be of added value to map the processes of personal recovery and provide context for the research findings. Suggestions for qualitative research are given in the paragraph future research.

The research in this thesis showed that in principle, an eating club for people with psychosis is a feasible endeavor. However, in organizing an eating club several aspects should be considered. First, people with psychosis often have difficulties with traveling. Therefore, geographical distances between participants should be minimized where possible, or participants should be offered training in employing means of transportation as part of their skill training. Secondly, the eating club is a demanding activity for participants with higher functional impairments. Lower scores on the PSP scale [37] could be used as an indication to increase support, for example in traveling, social skills or independent living skills. Third, participants should not be randomly allocated to groups. Instead, groups should be formed based on matching profiles. The input from nurses, who in general have long term relationships with their patients, might increase the chances on a match between participants. Matching participants could lead to more engagement in the intervention and prevent premature discontinuation of the eating clubs (chapter 2), thus improving its effectiveness.

Instead of organizing eating clubs in mental health care, the HY-intervention could be delivered within social district teams. In the Netherlands, these teams started in 2015 with the goal to support citizens with their personal health and wellbeing in the broadest sense. Delivery of the HY-intervention in social district teams might provide a means to facilitate integration of the participants in their community, which is in line with personal recovery aims.

A caveat in this approach is that community workers in general are not trained in working with people with psychotic disorders as opposed to mental health nurses. Specific knowledge about psychotic disorders is necessary on positive, negative and cognitive symptoms in order to support the participants with the eating club and to observe a relapse in an early stage. Collaboration between mental health care and social district teams is therefore needed. Furthermore, this collaboration could include the employment of peer workers for guiding the groups.

Possibly a stepped care intervention could be considered, in which participants start with dinners in an open group, not at home but in a community center, in which the organization of the dinners is supported by professionals. Starting in a community center with larger groups instead of starting at home might be suitable for people with higher functional impairments. This will lower barriers to participate, as the challenges of organizing a dinner at home (i.e., organizing a dinner, inviting people at home) will happen in a later stage, when participants are equipped with sufficient skills. In a second stage, participants who match with each other could form a group that organizes dinners at home, such as described in the HY-intervention.

Future research

The HY intervention was researched in an RCT. However, qualitative research on personal recovery interventions such as eating clubs might be a valuable addition to quantitative research as evidence on how exactly interventions promote recovery is still scarce [112]. Interventions should be evaluated on the interaction between the process of personal recovery, the intervention itself and context variables [113].

Personal recovery is largely a value driven concept. The availability of interventions for personal recovery should therefore not only be justified by scientific evidence but also by their intrinsic value. This corresponds with notion of personal recovery as a process as oppose to recovery as an outcome. *"Being in the process of recovery"* can be facilitated by offering recovery-oriented interventions without measuring its effects on personal recovery measures. For example, many patients expressed that participating in the HY-intervention was a valuable experience for them. Not due to expected long-term effects on personal or societal recovery, but due to the momentary experience of being part of a group and contributing to a meaningful activity (i.e., being in the process of recovery). This is in line with the view of personal recovery as illustrated by Patricia Deegan, one of the earliest advocates for personal recovery who described personal recovery as creating the right opportunities: *"essential aspects of the recovery process are a matter of grace and, therefore, cannot be willed. However, we can create environments in which the recovery process can be nurtured like a tender and precious seedling* [92]". Research should therefore not only be conducted on outcomes, but also on how interventions are oriented towards personal recovery values [63].

Concluding remarks

The aim of the research in this thesis is to improve the lives of people with psychotic disorders by informing Evidence Based Practice (EBP). In EBP, quality health care is based on the triangle of clinical expertise, the best current scientific evidence and patient values. Strong scientific evidence for personal recovery interventions is still lacking, but patient values are an established driver. Although personal recovery can be debated as a scientific construct, its value for patients has repeatedly been shown by the mental health care reform in many countries [114].

To conclude this thesis, we propose that the reader views our research in light of the 'McNamara fallacy'. Robert McNamara stated that *"the challenge is to make the important measurable, not to make the measurable important"* [115]. The importance of personal recovery is established by the patient movement, but the validity of personal recovery in scientific research is less well established due to its broad meaning and idiosyncratic aspects. However, the completion of the RSWG criteria for clinical recovery also comprised many years. With the advance of research, clear criteria for personal recovery will hopefully be established within the next decades as well.

Today, evidence for personal recovery as a well-defined outcome measure in scientific research is not yet convincing. Its value for people living with a psychotic disorder is indisputable.

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Nederlandse samenvatting

Mensen met een psychotische aandoening zoals schizofrenie kunnen veel klachten ervaren die het dagelijks leven negatief beïnvloeden. Dit uit zich onder andere in uitsluiting, eenzaamheid, werkloosheid en het ervaren van (zelf)stigma. De patiëntenbeweging van mensen met psychische aandoeningen heeft zich in de afgelopen 30 jaar ingezet om dit soort gevolgen onder de aandacht te brengen. Dit resulteerde in een drietal perspectieven op herstel van psychische aandoeningen. Een recent perspectief is persoonlijk herstel. Persoonlijk herstel onderscheidt zich van klinisch en maatschappelijk herstel op de doelen die het nastreeft. Klinisch herstel richt zich op het verminderen van symptomen (zoals stemmen horen, verlies van concentratie en geheugen of initiatief), maatschappelijk herstel op het hervinden van rollen in de maatschappij (zoals een werknemer zijn, een sociaal netwerk hebben of een intieme relatie aangaan) en persoonlijk herstel richt zich op persoonlijke groei die kan plaatsvinden ondanks belemmeringen die de psychische aandoening met zich meebrengt. Belangrijke thema's in persoonlijk herstel zijn samengevat in het CHIME-model: Connectedness (verbondenheid met anderen), Hope (hervinden van hoop), Identity (een positieve identiteit), Meaning (betekenisvolle activiteiten) en Empowerment (grip krijgen op de situatie). Het doel van deze thesis is een bijdrage te leveren aan de interventies en het onderzoek naar herstel bij psychotische aandoeningen (**hoofdstuk 1**). In de onderzoeken komen de drie vormen van herstel aan bod: klinisch, maatschappelijk en persoonlijk herstel, met de nadruk op de laatste vorm. In dit proefschrift wordt gekeken naar de haalbaarheid en effectiviteit van een eetclub voor mensen met een psychotische aandoening op persoonlijk en maatschappelijk herstel (**hoofdstuk 2 en 3**), een evaluatie van drie meetinstrumenten voor persoonlijk herstel (**hoofdstuk 4**), de effectiviteit van beweeginterventies op klinisch herstel (negatieve symptomen) (**hoofdstuk 5**) en het verband tussen sociale verbondenheid en psychotische symptomen (**hoofdstuk 6**). In **hoofdstuk 7** worden de belangrijkste bevindingen besproken, evenals de implicaties ervan voor de praktijk.

Hoofdstuk 1 is een inleiding op deze thesis. Dit hoofdstuk beschrijft de ernstige gevolgen van het leven met een psychotische aandoening. Vanuit het klinisch, maatschappelijk en persoonlijk perspectief op herstel worden de beperkingen die mensen met psychotische aandoening ervaren uiteengezet. De drie perspectieven op herstel zijn ondersteunend in een breder begrip van herstel en de behoeften van mensen met een psychotische aandoening. De mate van herstel bij psychotische aandoeningen is vandaag de dag nog laag. Het is van belang dat er onderzoek gedaan wordt naar alle drie vormen van herstel.

Hoofdstuk 2 is een haalbaarheidsonderzoek naar de HospitalitY (HY) interventie: een eetclub voor mensen met een psychotische aandoening. De HY-interventie combineert vaardigheidstraining in de thuissituatie met lotgenotencontact middels een eetclub gericht op persoonlijk en maatschappelijk herstel. Drie eetclubs werden gevormd met elk drie deelnemers en een begeleidende verpleegkundige. Gedurende vijf maanden gingen deelnemers om de twee weken beurtelings bij elkaar eten (in totaal 9 keer). De gastvrouw of gastheer kreeg vooraf vaardigheidstraining van een verpleegkundige bij het organiseren van een etentje. Hierbij stelden de deelnemers doelen op, gericht op bijvoorbeeld het bevorderen van zelfredzaamheid of sociale vaardigheden. De resultaten lieten zien dat het project positief werd ontvangen door zowel deelnemers als verpleegkundigen. In interviews rapporteerden deelnemers positieve effecten op thema's van persoonlijk herstel. Deelnemers waren gemotiveerd om aan doelen te werken. De resultaten hebben geleid tot enkele aanpassingen voor de vervolgstudie: een uitbreiding van 9 naar 15 bijeenkomsten (met mogelijk meer effect op uitkomsten van herstel), het aanpassen van de vaardigheidstraining naar generieke interventies in plaats van cognitieve adaptatie interventies, het loslaten van Goal Attainment Scaling (GAS) methode voor het evalueren van doelen in de vaardigheidstraining en het introduceren van een dagboekmeting voor het meten van sociaal contact. Deze studie liet zien dat de HY-interventie haalbaar is.

Hoofdstuk 3 rapporteert de bevindingen van een gerandomiseerd en gecontroleerd onderzoek (RCT) in meerdere GGZ-instellingen naar de effecten van de HY-interventie op persoonlijk en maatschappelijk herstel. De deelnemers werden gerandomiseerd naar de HY-eetclub of een wachtlijstcontrolegroep. De doelstelling in dit onderzoek was om 84 mensen te includeren met een blokrandomisatie van 7 personen per blok. Patiënten met een psychotische aandoening die ambulante zorg ontvingen konden worden geïncludeerd. De verschillen op persoonlijk en maatschappelijk herstel tussen de groepen werden gemeten met gevalideerde vragenlijsten op drie tijdpunten (voormeting, na afronding van de interventie na acht maanden en na 12 maanden). Zes GGZ-instellingen in het noorden van Nederland participeerden in het project. In de RCT konden geen effecten op persoonlijk en maatschappelijk herstel worden aangetoond van de HY-interventie. Procesmaten lieten zien dat de volgende aspecten van de eetclub hoog werden gewaardeerd door deelnemers: het contact met lotgenoten, de mogelijkheid om je verhaal te vertellen en het ontvangen van steun en erkenning. De meest gewaardeerde aspecten van de vaardigheidstraining waren: meer zelfvertrouwen krijgen in het uitnodigen van anderen, meer plezier hebben in koken en meer activiteiten doen met anderen. Het organiseren en implementeren van deze RCT bleek een uitdaging. Van de beoogde 84 deelnemers werden 43 deelnemers geïncludeerd en van de zeven eetclubs die zijn gestart zijn er drie vroegtijdig gestopt. In de RCT werden problemen ondervonden met het includeren en de therapietrouw van deelnemers, die niet naar voren waren gekomen tijdens het haalbaarheidsonderzoek zoals beschreven in hoofdstuk 2. Verschillende oorzaken werden geïdentificeerd: de lage bereidheid tot randomisatie, de lange wachttijd voor deelnemers na aanmelding tot de start van de eetclub, een onvoldoende match tussen sommige deelnemers en beperkingen in het reizen tussen deelnemers uit dezelfde eetclub. Geconcludeerd wordt dat een gerandomiseerde studie naar eetclubs die bestaan uit slechts drie deelnemers uitdagingen in de implementatie met zich meebrengen. De gestandaardiseerde procedures van een gerandomiseerde trial zijn mogelijk te beperkend bij het onderzoek naar eetclubs. Dit maakt dat in eerste instantie meer kwalitatieve vormen van onderzoek toegepast zouden moeten worden bij een dergelijke kleine groepsinterventie. Toekomstig onderzoek zou zich kunnen richten op een gemengd design met kwantitatief en kwalitatief onderzoek van eetclubs op uitkomsten van persoonlijk en maatschappelijk herstel.

Hoofdstuk 4 beschrijft een onderzoek naar het meten van persoonlijk herstel bij mensen met psychose. Persoonlijk herstel is in de wetenschap een jong concept waarin taal en cultuur een belangrijke rol spelen. Verschillende vragenlijsten voor persoonlijk herstel zijn in de afgelopen decennia ontwikkeld. In deze studie werd het CHIME-model voor persoonlijk herstel gebruikt om verschillende 'persoonlijk herstel vragenlijsten' op inhoud te evalueren. Het CHIME-model is ontwikkeld op basis van ervaringsonderzoek bij mensen met een ernstig psychiatrische aandoening. CHIME staat voor: Connectedness, Hope, Identity, Meaning en Empowerment. In dit onderzoek werden drie vragenlijsten bij N=52 deelnemers over persoonlijk herstel met elkaar vergeleken: de Recovery Assessment Scale (RAS; de meest gebruikte wereldwijd), de Mental Health Recovery Measure (MHRM: het eerste in het Nederlands gevalideerde instrument) en de Nederlandse Empowerment Schaal (NEL: de eerste in Nederland ontwikkelde herstelvragenlijst). De vragenlijsten werden vergeleken op zes criteria van betrouwbaarheid en validiteit, namelijk: inhoudsvaliditeit, convergente validiteit, interne consistentie, vloer- en plafondeffecten, interpretatie van de items en de ervaring van de testafname. Op deze zes criteria werden slechts kleine verschillen gevonden tussen de vragenlijsten, waardoor er geen duidelijke voorkeur voor één van de vragenlijsten kon worden bepaald. De MHRM liet de beste resultaten zien op inhoudsvaliditeit met een gebalanceerde verdeling van de items over de vijf aspecten van CHIME. De nadruk op herstelthema's verschilde per vragenlijst. De keuze voor een vragenlijst zou daarom gemaakt kunnen worden op basis van herstelthema's die belangrijk worden geacht per specifieke situatie. Zo kan de NEL - op basis van het aantal items dat zich daarop richtte - het beste gebruikt worden als een grotere nadruk wordt gelegd op Connectedness. De RAS kan worden gebruikt wanneer Empowerment van belang wordt geacht.

Negatieve symptomen hebben een grote impact op het functioneren en kunnen daardoor een belemmering vormen voor sociaal en persoonlijk herstel. Negatieve symptomen zijn onderdeel van klinisch herstel en betekent onder andere meer last van apathie. In een meta-analyse (**hoofdstuk 5**) werden bewegingsinterventies vergeleken met zowel actieve controlegroepen (zoals token therapie) als controlegroepen met standaardzorg voor het behandelen van negatieve symptomen bij schizofrenie. De bewegingsinterventies betroffen: mind-body oefeningen (zoals yoga of tai chi), duurtraining (zoals hardlopen of fietsen) en krachtoefeningen. In vier databases (Cochrane Library, Medline, Embase and PsycINFO) werd gezocht naar gerandomiseerde en gecontroleerde onderzoeken, waarbij bewegen werd vergeleken met een controlegroep in mensen met schizofrenie. De PRISMA-richtlijnen voor meta-analyses werden toegepast. Om de kwaliteit van de studies te meten, is de Cochrane Risk of Bias-evaluatie gebruikt. Moderator- en sensitiviteitsanalyses en een metaregressie werden gedaan om oorzaken van heterogeniteit tussen studies te onderzoeken. De resultaten van 22 studies (met in totaal 1249 deelnemers) werden samengenomen en geanalyseerd op het effect op negatieve symptomen. De meta-analyse liet een gemiddeld effect zien van alle bewegingsinterventies gezamenlijk vergeleken met de controlegroepen (Hedges' g=0.434). Op subgroep-niveau lieten mind-body interventies een gemiddeld effect zien (Hedges' g=0.46) en interventies gericht op duurtraining een klein effect (Hedges' g=0.341). Bewegingsinterventies waren effectief vergeleken met standaardzorg, er was echter geen effect wanneer een vergelijking werd gemaakt met actieve controlegroepen. Voor krachttraining waren te weinig studies voorhanden om een analyse te kunnen doen. Deze studie laat zien dat bewegingsinterventies toegevoegd aan de standaardzorg effectief kunnen zijn op negatieve symptomen. De lage kwaliteit en de grote verschillen tussen de geïncludeerde studies maakt dat de resultaten van deze studie voorzichtig moeten worden geïnterpreteerd.

Sociale verbondenheid is een belangrijk onderdeel van persoonlijk herstel. In het CHIME-model staat de C voor Connectedness. Dit benadrukt het belang van sociale steun en sociale relaties. Een lage sociale verbondenheid wordt geassocieerd met grotere risico's voor het mentaal welzijn bij mensen met psychose. In **hoofdstuk 6** wordt gekeken naar de invloed van tevredenheid met sociale verbondenheid op psychotische symptomen één en twee jaar later. Voor deze studie werd data geanalyseerd van 2109 patiënten die deelnamen aan de Pharmacotherapy Monitoring and Outcome Survey (PHAMOUS) studie tussen 2014 en 2019. De resultaten werden geanalyseerd met een mixed model analyse. De gemiddelde score van vier items van de Manchester short assessment of Quality of Life (ManSA) werd gebruikt om tevredenheid met sociaal contact te meten. Deze maat had een voldoende interne consistentie (inter-item correlaties $r=0.265-0.415$, $p<0.01$) en acceptabele betrouwbaarheid (Cronbach's alpha=0.67). De Positieve en Negatieve Symptomen Schaal (PANSS) werd gebruikt om symptomen van psychose te meten. De resultaten lieten zien dat positieve symptomen tot één ($\beta = -0.47$, $p < 0.001$) en twee jaar voorspeld ($\beta = -0.59$, $p < 0.001$) konden worden en negatieve symptomen tot één jaar ($\beta = -0.52$, $p < 0.001$). Deze studie laat zien dat tevredenheid met sociale verbondenheid een kleine, maar robuuste voorspeller is van psychotische symptomen. Mogelijk kunnen interventies gericht op sociale verbondenheid een bijdrage leveren aan het klinisch herstel bij psychose, naast persoonlijk en maatschappelijk herstel.

Hoofdstuk 7 reflecteert op de bevindingen uit de onderzoeken. Klinisch, maatschappelijk en persoonlijk herstel worden achtereenvolgens behandeld. De bevindingen richten zich op de constructen, de evaluatie, de behandeling van de drie vormen van herstel, maar ook op de relatie tussen deze vormen.

Klinisch herstel is het oudste construct in de behandeling en het onderzoek naar psychotische aandoeningen. Een belangrijke stap in het onderzoek naar schizofrenie gerelateerde aandoeningen was de consensus over de criteria voor klinisch herstel. Deze zogenaamde RSWG-criteria bepalen wanneer er sprake is van remissie van positieve, negatieve en cognitieve symptomen. Hoewel het onderzoek naar de behandeling van positieve symptomen bij schizofrenie veel effectieve behandelingen heeft opgeleverd, blijven afdoende resultaten voor het behandelen van negatieve en cognitieve symptomen uit. Hoofdstuk 6 laat zien dat bewegen bij negatieve symptomen een middelmatig effect heeft. De grote van dit effect is vergelijkbaar met andere behandelingen voor negatieve en cognitieve symptomen.

Maatschappelijk herstel werd sinds lange tijd in de literatuur genoemd als belangrijke uitkomst in het onderzoek en de behandeling van psychotische aandoeningen. Na de sluiting van grote psychiatrische instituten vanaf de jaren '80 kwam er veel aandacht voor maatschappelijk herstel. Een consensus over de criteria voor maatschappelijk herstel is nog niet beschikbaar, hoewel het belang hiervoor in de literatuur wordt onderstreept. Interventies voor maatschappelijk herstel laten wisselende resultaten zien. Mogelijk kan het stellen van persoonlijke doelen in een betekenisvolle context, zoals een eetclub (hoofdstuk 2 en 3) bijdragen aan de motivatie voor het werken aan vaardigheden. Uitkomsten op maatschappelijk herstel zijn nog altijd laag, en verbeteren mogelijk niet zo snel als beoogd in de nabije toekomst. Aandacht voor persoonlijk herstel is daarom belangrijk.

Het bevorderen van persoonlijk herstel wordt als belangrijk benoemd door patiënten met ernstige psychiatrische aandoeningen. Persoonlijk herstel is een breed begrip, waardoor het zich moeilijk laat afbakenen voor wetenschappelijk onderzoek. Modellen die zijn ontwikkeld op basis van wetenschappelijke literatuur kunnen het begrip van persoonlijk herstel verbreden. Het CHIME-model stond aan de basis voor het onderzoek in deze thesis. Hoewel eensluidende criteria voor persoonlijk herstel ontbreken, kan het construct gemeten worden met vragenlijsten. De nadruk op de subthema's van persoonlijk herstel verschilt per vragenlijst (hoofdstuk 4). Daarom wordt geadviseerd om per situatie de meest passende vragenlijst toe te passende.

Er zijn enkele gerandomiseerde onderzoeken gedaan naar persoonlijk herstel met kleine, maar significante effecten. Mogelijk zijn vormen van kwalitatief onderzoek meer geschikt, vooral bij groepsinterventies met kleine aantallen, waarbij de interactie tussen het proces van persoonlijk herstel, de interventie en de context beter geëvalueerd kunnen worden.

Op het gebied van sociale activiteiten en relaties hebben mensen met psychotische aandoeningen vaak een levenslange zorgbehoefte. Hoewel de HY-interventie hieraan tegemoet komt, hebben mensen verschillende voorkeuren en behoeften qua sociale activiteiten. Individuele voorkeuren zouden meegenomen moeten worden bij het ontwikkelen van interventies om mogelijke effecten te vergroten.

Voor groepsinterventies is het belangrijk dat de deelnemers zich identificeren met de groep. Vooral bij kleinere groepen, zoals de HY-interventie, is dit belangrijk omdat uitval van deelnemers een grotere impact heeft. Daarnaast is persoonlijk herstel een proces van vallen en opstaan. Voor deelnemers is het daarom van belang om de vrijheid te hebben om eigen keuzes te kunnen maken, ook al brengt dit persoonlijke risico's mee, zoals bijvoorbeeld de blootstelling aan sociale stress in de HY-interventie. Een juiste balans tussen het aangaan van persoonlijke uitdagingen en het waarborgen van veiligheid, is een belangrijk aspect bij interventies voor persoonlijk herstel. Mogelijk zou een screening van het functioneren vooraf een indicatie kunnen geven voor een juiste balans tussen risico's en veiligheid.

Uitkomsten op persoonlijk herstel in epidemiologische studies worden op verschillende wijze gemeten. De herstelpercentages zijn daarom ook uiteenlopend van 14.5% tot 67.0%, maar zijn over het algemeen lager dan 50%. Dit laat zien dat meer zorg op het gebied van persoonlijk herstel nodig is. In de wetenschappelijke literatuur wordt gedebatteerd of persoonlijk herstel een uitkomst is of een proces. Persoonlijk herstel als proces komt meer overeen met de visie van de herstelbeweging. Het meten van persoonlijk herstel zou bij voorkeur gedaan moeten worden als proces met interviews in plaats van vragenlijsten, waardoor rekening gehouden kan worden met de persoonlijke context.

Tussen de verschillende vormen van herstel is veel overlap en wederzijdse afhankelijkheid (hoofdstuk 6). Verbetering op één vorm van herstel heeft mogelijk een positieve impact op andere vormen van herstel. Onderzoek zou zich daarom kunnen richten op geïntegreerde interventies, waarbij verschillende vormen van herstel gelijktijdig worden geëvalueerd. De interactie van verschillende vormen zou onderzocht kunnen worden in in-vivo interventies zoals de Individuele Rehabilitatie Benadering (IRB), begeleiding bij het toewerken naar werk of zoals bij de HY-interventie (hoofdstuk 2 en 3).

Het doel van deze thesis was een bijdrage te leveren aan de levens van mensen met psychotische aandoeningen met behulp van het ontwikkelen van een nieuwe herstelgerichte interventie, de HY-interventie, en het verder bestuderen van het construct in meerdere studies. Hoewel de interventie geen significante effecten liet zien op persoonlijk en maatschappelijk herstel, is de waarde van het construct 'persoonlijk herstel' voor mensen met een psychotische aandoening onomstotelijk aangetoond in studies binnen en buiten dit proefschrift.

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Curriculum Vitae

Jelle Sjoerd Vogel was born in 1984 in Hoogkerk, the Netherlands. He obtained his Bachelor degree in Nursing at: NHL University of Applied Sciences in 2009. In 2010, he finalized his graduate diploma in Mental Health Nursing at Flinders University of Adelaide, Australia. Subsequently, he graduated at the Master of Evidence Based Practice at the University of Amsterdam in 2013. He then pursued his research interests by starting a PhD programme at the University of Groningen in 2014 on the HospitalitY (HY) project: an eating club for people with psychotic disorders. The efforts on this project resulted in the research work presented in this thesis. Parallel to his studies and research, he worked as a nurse with several patient groups, including people with intellectual disabilities, psychosis care, elderly psychiatry and substance abuse.