Better together

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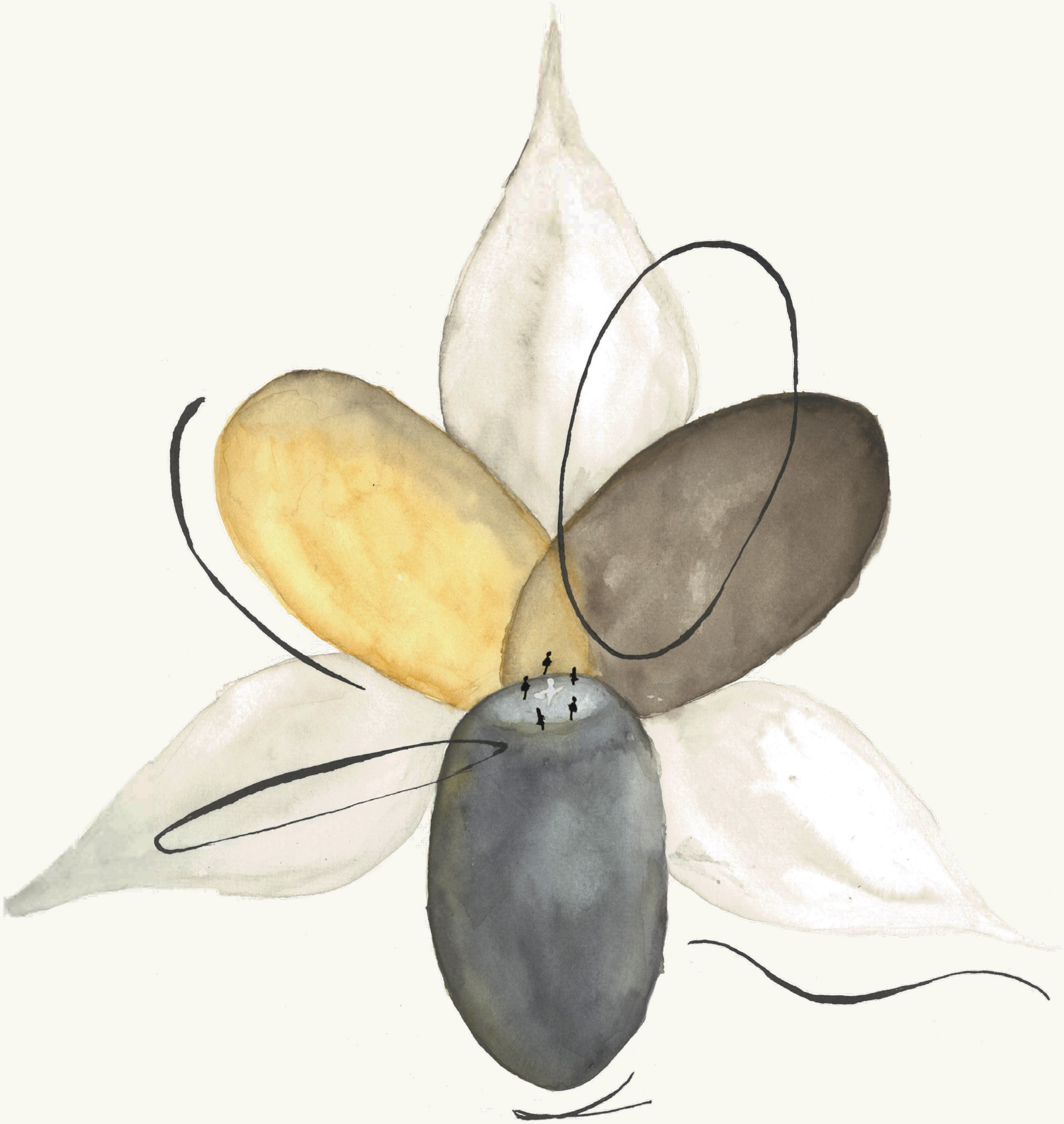

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On Meaning, Effectiveness and Costs of Resource Groups for People with Severe Mental Illness

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Chapter 1.

General Introduction

Introduction

Building on traditions of family intervention and integrated care, the resource group (RG) method might provide a structure to encourage patients to take ownership in their path to recovery, to systematically engage the patients' social network and to foster collaboration of different sources of support. By combining clinical-effectiveness data with an economic evaluation and an in-depth qualitative multiple-case study, this thesis aims to thoroughly investigate the RG method and to examine whether it leads to improvements of treatment and care for people with a severe mental illness (SMI).

This chapter provides a description of the background of the method and discusses its main principles. The chapter ends with the aims and outline of the thesis.

Severe mental illness

Many of us experience psychological problems at some point in our lives. Most of the time people overcome these struggles, sometimes with the support of their loved ones or with help from a mental healthcare professional. For some people, their problems become so severe that they seriously impair social life and the ability to function in the community. When the limitations in social and societal functioning are both cause and effect of the psychological problems; they last for at least two years; and coordinated care and treatment is needed, we speak of a severe mental illness (SMI) (1,2).

In the Netherlands, an estimated 1.7% of the population suffers from a SMI (2). Approximately two thirds of these patients are diagnosed with schizophrenia or a related psychotic disorder (2), characterized by a fluctuating presentation of positive symptoms (such as hallucinations and delusions), negative symptoms (such as amotivation and social withdrawal) and cognitive deficits (such as planning, memory and attention issues) (3). The remaining group consists of patients suffering from a severe depression, bipolar disorder, personality disorder, developmental disorder, addiction or any mental illness that causes severe functional impairment (2). Moreover, it is common for people with SMI to have co-morbid disorders, both psychiatric and somatic (4,5).

People with SMI describe that overcoming psychological symptoms represent only part of their difficulties (6,7). Their search for help involves at least as often universal themes such as being accepted as a person, having good relationships with family and friends and participating in society by work or education (8,9). As Jules Tielens describes it, when relating to their problems, people with mental illnesses do not so much think about pathology but instead about failed careers, loneliness and loss of friends (Tielens, 2012). Hence, coordinated care that meets the needs on these several domains is recognized to be best care for people with SMI.

History and development community-based treatment and care for people with SMI

De-institutionalization

Traditionally, SMIs were considered chronic diseases with persisting, relapsing or deteriorating symptoms (10,11). The mental health system reflected this belief and people with mental illness were kept in large asylums or nursing homes, far away from family and society. Patients were discouraged from engaging in normative activities, such as employment, education, childrearing, and independent living (12).

Goffman, in his landmark publication from 1961 'Asylums, Essays on the Social Situation of Mental Patients and other Inmates' (13) questioned the need to keep people in institutions and disputed the use of power and coercion in these institutions. This book reflected a change in thinking about the role of institutions in providing mental healthcare. Together with the introduction of antipsychotic drugs that significantly reduced symptoms, this was a cornerstone for the process of downsizing and closing of asylums. Eventually labeled "deinstitutionalization", this process aimed to minimize the amount of care provided in isolated mental hospitals and to increase care in the community (14). Implicit in the concept of deinstitutionalization was therefore the development of community-based mental healthcare to support people with SMI in building a social and community life. Family, community, and society were hereby brought into the treatment process.

In 1975, Stein and Test started the 'Training in Community Living' program in the United States. They argued that helping patients in their own environment (outreach) was an essential criterion for good care. In addition, the help had to be assertive: the care professionals had to actively look for the patients and insist in helping to find solutions. From this program Stein and Test developed the Assertive Community Treatment (ACT) model (15), in which the delivery of care was not only focused on medical aspects but also involved support in a wide range of social and community activities, such as housing, finances, maintaining their support system and family contacts.

Despite the development of ACT and other community-based initiatives, communities were often not adequately prepared or equipped to meet the patients' needs. As a consequence many patients were poorly integrated in their community, as Bevilacqua (1995) described it: "the quality of life for people with SMI continues to be marginal and unsatisfactory. Too many consumers struggle with the demons of inadequate income, lack of meaningful and fulfilling activities, and an illness that isolates them even when they live in the community" (p. 27). Deinstitutionalization also promoted a new wave of stigma toward people with mental illness, as fear and hostility grew in the general public now people with mental illness became more visible in the community (16,17).

Recovery-oriented mental healthcare

In response to the dehumanizing effects of treatment in psychiatric hospitals and the failure to adequately support community inclusion, groups critical of psychiatry began to unite in the 1970s. Members often called themselves mental health consumers, psychiatric survivors, or ex-patients; collectively they are mostly referred to as the Consumer/Survivor movement. The movement was predicated on the desire for personal freedom and it claimed their personal and collective human rights, as they were suffering from stigma, discrimination and exclusion.

The movement challenged the view of the chronicity of a mental illness and criticized the mental health system with its emphasis on pathology, deficits and dependency. They argued to move beyond the narrowness of the biomedical approach to mental health that emphasizes clinical recovery, indicated by the remission of mental health symptoms. Instead, they advocated for a new concept of recovery, defined by Anthony (18) as "…a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (p.527).

In this sense, recovery does not mean cure as it is seen as an ongoing journey rather than a final destination (Farkas, 2004). Most importantly, each individual's journey of recovery is unique and people will make this journey in their own time and at their own pace (19). Nevertheless, several studies have identified common phases in the process of recovery (e.g. (20,21)). In the Netherlands the four phases model of Gagne (22) is widely adapted:

1. Feeling overwhelmed by the condition. The person is likely to experience confusion and disorientation as the result of the overwhelming nature of the symptoms. This phase is marked by feelings of despair, hopelessness and isolation from the self,

others and the environment.
2. Struggling with the condition. The person starts to question how to live with the condition and develops coping strategies to deal with the symptoms. Struggles are characterized by a lack of self-confidence and the search for one's identity.
3. Living with the condition. The person gains confidence in one's ability to cope with the condition and learns to recognize one's strengths and limitations. Contacts with significant others are (re)stored.
4. Living beyond the condition. The person regains a sense of connection with others and starts to explore new capacities and talents. There is room for new goals in one's life.

In the conceptualization of recovery is thus embedded that disabilities and limitations caused by the illness will have a place in life. This means that individuals will have to integrate new lifestyles or behaviors into their everyday life. As described by the four phases, a fundamental transition takes place in which individuals realize that they are not subjected to the illness but that they can, despite the limitations, regain control over their lives. Hence, overcoming a feeling of powerlessness is an essential component in recovery. Indeed, the concept of 'empowerment' is identified as a key aspect of recovery-oriented mental healthcare (23–25). Below the concept of empowerment is further explored.

Empowerment

Empowerment has been argued to embody a key component in drawing attention to the capacities of individuals rather than their deficits and needs, and to promote power and participation (26,27). The increased focus on empowerment is described as representing a shift from a paternalistic to a participatory and collaborative way of thinking about health and healthcare (27–29). Since then, research has shown the benefits of empowerment and it has been suggested that empowerment should be considered as one of the main goals within recovery-oriented community-based services (30,31). In a frequently cited narrative synthesis of personal recovery, Leamy and colleagues (7) defined Empowerment as a core component of the CHIME recovery framework, together with Connectedness, Hope and Optimism about the future, Identity and Meaning in life.

Many definitions of the construct have been proposed throughout the years. Most of these describe empowerment as a multifaceted and layered process that entails vision, process and outcome, on an individual, collective, organizational and political level. This implies that empowerment is not only about people changing, but also about environmental, organizational and system change. Hence, it is important to make clear that individual empowerment, which is defined below, is embedded within a broader process of gaining power. Empowerment in its broadest meaning therefore not only concerns individuals gaining skills for themselves but is also about communities overcoming structural barriers, such as poverty and employment (32). Within this thesis the term empowerment refers to individual empowerment, and does not involve the broader meaning of empowerment.

Boevink and colleagues (33) define empowerment as processes in which someone rediscovers his identity and "takes his life in his own hands". This definition includes and/or implies the most common elements of many other definitions that have emerged: assuming control or influence over one's life (27,34–37); the importance of renewing hope and meaning (37–41) and overcoming stigma and other sources of trauma associated with serious mental illnesses (38,40).

Empowerment is recognized both as an outcome in itself and as an intermediate step towards an individual's improved long-term health (32). Empowered patients report feeling involved, motivated and satisfied with medical care (42,43), and can hereby improve their own health outcomes in terms of self-esteem, social and community functioning, and their abilities to manage their illness (29,44,45). Studies also suggest that empowerment plays a mediating role in improving quality of life and decreasing hopelessness and depression among individuals with mental illness (46–48).

Although in this thesis empowerment is seen as a desirable outcome, it is important to also acknowledge criticisms of the construct. By its increased use in multiple sectors, empowerment has evolved from an emancipatory movement into public policy and mainstream thinking. Some authors warn that empowerment is instrumentally used as new forms of social control. Achieving self-sufficiency, resiliency and ongoing self-improvement have become new norms (49–51). However, empowerment as an obligation goes against the principles of empowerment (27,52–59). Some also associate empowerment with the transition from welfare to workfare, using empowerment as legitimization for budget cuts in the support of people in vulnerable positions (60).

Empowerment suggests a distinct approach for developing mental health services. Several studies refer to the necessity of opportunities for choices and involvement in treatment planning, by setting goals and determining treatment activities which meets their needs, and with which they are happy to co-operate with (37,61,62). Providing information on the options available, encouraging active involvement of the person with mental illness at all stages of contact and checking in regularly with the individual for their views and feelings is hereby essential (63,64). Mental healthcare professionals need to be willing to collaborate and work in partnership with patients and put aside beliefs that the professional knows best (65,66).

It has been increasingly recognized that processes of empowerment take place within the context of the network of the individual's family and other personal relationships (67,68). That is, empowerment for the patient involves taking responsibility for their behavior and learning to manage their distress. From the perspective of the caregiving relationship, empowerment introduces a new set of requirements, such as the need for family members to balance their attempts to maintain control with efforts to hand back control and allow the individual to take risks. This promotes a perspective of empowerment processes embedded within an interpersonal network, rather than residing only within an individual. However, as explored below, families and the social context have occupied an ambiguous and complicated space in mental health research and practice.

Role of the family and the social network in community-based mental healthcare

In the 1950s – 1970s, the dominant idea was that families were to blame for the development of illness (69,70). Patient pathology was assumed to be located within disturbed family structure and dynamics, and to be directly caused by neglect, abuse or conflict. In this context, patients were seen as victims, families as persecutors, and treatment staff as rescuers. As a consequence, families were kept away from the care of their loved ones (15,71).

The closure of the institutions (de-institutionalization), however, resulted in individuals with mental illnesses returning to live in the community. Mental healthcare became more dependent on the support and cooperation of the social network around the person with SMI (72). Together with the rise of the family advocacy movement an alternative view of family emerged, stressing the impact of illness on the family and the role of families as a predictor of successful resettlement in the community. Awareness grew that living with an SMI is demoralizing, frustrating, and confusing for patients and families alike. In a reciprocal process, the resulting stresses on families can lead to persisting patterns of interaction that have devastating effects on the patient and the course of the disorder.

The notion of "expressed emotions" (EE) was used to describe these patterns of interaction and family factors. The value of the negative EE of hostility, criticism and overinvolvement was demonstrated (73) and research showed they should be viewed as important psychosocial environmental stressors during the course of the illness (74). Following their meta-analysis of 26 studies, Butzlaff & Hooley (75) concluded that EE was a robust predictor of schizophrenic relapse (High-EE relapse rate = 65%; Low-EE = 35%). Studies have confirmed that EE is significantly associated with relapse in a range of other health and mental health problems (see (76)).

Although the EE research has contributed to the widespread recognition of the benefits of working with relatives of people with psychosis, the emphasis on communication patterns associated with the relapse and re-admission of psychosis resulted in resistance of family organizations who felt that therapists were blaming them for having caused the psychosis (77). In addition, few family-intervention studies have investigated outcomes beyond the traditional relapse, hereby discarding the potential benefits in terms of other symptoms (e.g., anxiety, depression) or functional outcomes such as occupation, social networks or quality of life. In addition, family member's needs were addressed in terms of family burden as a result of the patient's illness, hereby discarding the importance of reciprocity and equality within relations. Taken together, most family research and practice was mainly directed towards relatives' attitudes that negatively impact the person with psychosis. The effect of positive EE, described as supportive comments and emotional warmth, has received much less attention, both in research and in clinical practice (78–80). The importance of including family in working towards recovery or resilience was hereby neglected. As a result, family interventions were prone to illness-thinking, rather than a recovery-orientation in which the role and needs of the social environment would be part of developing a rewarding life in spite of the struggles (81).

Nowadays, it is increasingly recognized that families can be both a source of trauma and a source of resilience, which led to research investigating the interpersonal environment in working towards recovery. In the section below, four initiatives that are aimed to support involvement of the social network are discussed. It is beyond the scope of this thesis to present a comprehensive overview. Instead, those that were deemed most relevant were selected: Family Group Conferencing; Open Dialogue; Coordination of Care Dialogue and Systemic Family Therapy.

Family Group Conferencing

The roots of the family group conference (FGC) lie in the culture of New Zealand's Maori people. When a child or family experienced problems, the authorities placed the child in care. The Maori people challenged this and demanded that the child's community would be consulted first, as they traditionally were responsible for the welfare of their children. They used a family meeting, involving the child's entire network and developed a family plan on how the child was to be supported (82).

The use of FGCs has spread to more than 20 countries, such as Australia, Canada, UK, France, Israel, the US, Sweden and the Netherlands, where the model has been adapted and developed in various contexts. Although it was originally applied in child welfare and youth justice, FGC is nowadays used in cases of social isolation, child abuse, debts, learning disabilities and domestic violence (83–88). The FGC philosophy has also moved into adult mental healthcare and offers an opportunity to engage both professionals, family and other support networks to help patients to manage their condition (89,90).

An FGC is a meeting between a person who needs help and support—the patient—and his social network (including family members, friends, acquaintances, colleagues, neighbors, etc.), in which they discuss the situation, possible solutions, and set up a support plan. Mental health professionals can be involved to give information or facilitate the social network's decisions. However, the plan is made by those who know the person and his situation best: the person himself and those closest to him. It is therefore a decision-making model which keeps a person and his social network responsible for the existing situation and for finding solutions. The FGC is organized by an independent coordinator who works for the national foundation. The coordinator should not be seen as a professional, but as a citizen who is willing to support fellow citizens (91).

Open Dialogue

The open dialogue (OD) family and network approach was developed during the 1980s in Western Lapland, Finland. Since then, the OD approach has been implemented across mental health services globally, with established sites in the United States, Australia and across Europe, including the United Kingdom, Italy, Scandinavia and the Netherlands. The idea behind OD is the provision of psychotherapeutic treatment for all patients within their own personal support systems during a mental health crisis. This is done by generating dialogical communication within the treatment system, and mobilizing resources as mobile crisis intervention teams, patients, and their social networks are brough together in joint meetings (92–96). OD favors working with service users in the community over admission to hospital and aims to redress power imbalances between the service user and clinician by facilitating autonomy and transparent decision-making. Other therapeutic modalities can be added, depending on the needs of the person and family, as part of an unfolding and flexible "treatment web" (97–104).

There are seven key elements in the OD approach (105–107). These can be understood as related to both the organization of services and a way of being with people. Relevant to the organization of care are (i) the provision of immediate help as the first meeting is arranged within 24 hours from referral; (ii) a social network perspective, (iii) flexibility and mobility: duration, place and content of treatment is adapted to the specific and changing needs (iv) responsibility: whoever among the staff is first contacted becomes and remains responsible; and (v) psychological continuity, the responsibility for the entire treatment process rests with the same team in both inpatient and outpatient settings.

A way of being with people includes the elements of tolerating uncertainty and dialogism. Tolerating uncertainty describes how clinicians try to avoid premature decisions and treatment plans as a reflexive desire to remove the uncertainty. Instead, connection to the distress being experienced is key, and this means not acting too rapidly to bring about change. Dialogism is defined as a focus on creating dialogue, where a new understanding is constructed in the area between the participants, while promoting a sense of agency and change for the service users and their families (95,98,108).

Coordination of Care Dialogue

The purpose of a Coordination of Care Dialogue (CCD) is to improve coordination and cooperation during transition of care between patients, significant others, the outpatient team, the inpatient team, and any other involved professionals. In the Netherlands, a CCD [Zorgafstemmingsgesprek – ZAG] (109) is mostly used in case of an episode of acute illness, thus in the transition of outpatient care to inpatient care, and aims to improve the quality of inpatient care and shortening its duration. The first CCD will take place within 24 hours of clinical admission. A follow-up CCD will take place both at regular intervals and additionally at important transitional moments, depending on the duration of stay.

During the CCD the parties involved come together to discuss relevant tasks related to the treatment plan. The outpatient treatment plan shapes the service, meaning that the inpatient interventions have to fit within the treatment plan set out by the outpatient community mental health team. The patient is explicitly invited and supported to share care requests, questions, wishes, needs and goals. It is important that patients can share their story, indicate what may help, what they need in the recovery process, and how they want to work on recovery during the stay the clinic. The wishes and goals of significant others are also discussed during the CCD. Care delivery approaches to improve care transitions are also investigated and used outside the Netherlands (e.g. (110–114)).

Systemic Family Therapy

At the core of family systems approaches is the assumption that families and their patterns of communication and interaction profoundly affect human beings. Functioning of individuals is not so much determined by intrapsychic factors but merely by the place in their system(s). That is, people are subject to the pushes and pulls of a system, including competing emotional demands, role definitions and expectations, boundary and hierarchy issues, loyalty conflicts and family culture and belief systems (115,116). Any change in one individual within a family is likely to influence the entire system and may lead to change in other members. Hence, psychopathology does not reside in the individual, but rather in a disturbed system of family relations (117).

The theory principle has three important implications: 1) the emotional functioning of every family member plays a part in the occurrence of medical, psychiatric or social illness in one family member; 2) treatment should not be directed at the symptomatic person only but also at the structure and behavior of the broader relationship system; and 3) treatment should not only work with the parts of the family (its individual members), but also with the interactions or relationships among family members (118).

There are different forms of family therapy that are based on a family systems perspective and the FST. Classical and widely used approaches include Bowenian, structural and strategic family therapy:

- Bowenian family therapy (119,120) focuses on the balance between togetherness and individuality. Too much togetherness creates fusion and prevents developing one's own sense of self. Too much individuality results in a distant and estranged family. The main goal is to facilitate the ability of individuals to function autonomously and making self-directed choices while remaining emotionally connected in important relationships. Techniques include the use of genograms, process questions and "I" statements.
- Structural family therapy, designed by Salvador Minuchin (121), focuses on adjusting and strengthening the family system to ensure that the parents are in control and that both children and adults set appropriate boundaries. It is referred to as a therapy of action; exploring or interpreting the past is not viewed as essential for changes in the present. To this end, the therapists joins the family and the focus is on family relationships, behaviors, and patterns as they are exhibited within the therapy session in order to evaluate the structure of the family.
- In strategic therapy, developed by Jay Haley and Cloe Madanes (122,123) , the focus is on influencing the family to move out of recurring and circular patterns of communication or interactions that are not working for them through direct and active problem solving. The objective of this therapy is for the family to initiate actions and solutions that are different to the ones previously attempted (124). The therapist orchestrates change directly and actively and decides upon therapy, goals and interventions.

Role of the family nowadays

Although the form and theoretical assumptions differ, the essence of all described approaches lies in the explicit acknowledgement of the importance of the social network in recovery, illness and health. This has become increasingly recognized in mainstream policy and nowadays practically all mental health guidelines suggest some form of family, friend or carer involvement in the treatment and care of people with SMI. Nevertheless, structural involvement of the social network is generally poorly implemented (125–128) and family approaches are not routinely available.

This problem is well documented: over decades of research, frustrations have been expressed about the difficulties of implementing family involvement into routine psychiatric care. Family members often find that access to needed resources and information is lacking, let alone being a participant in the care process. Studies investigating experiences with care, report that families feel marginalized, uninformed, distanced from the care planning process and they lack a recognized role (127,129,130). Furthermore, family carers often experience physical, psychological, social and financial problems as a consequence of caring for a relative. Stress, depression, anxiety and frustrations are common in the periods of acute care and for some they may continue for many years (68,131,132).

Next to the burden and frustrations of the social environment, the poor implementation also discards the potential of social relationships to contribute to patients' recovery. Tew and colleagues (133) argue that 'relationships are vital to recovery: they shape identity and contribute to or hinder wellbeing' (p. 451). It has been suggested that phenomena such as autonomy, self-determination and empowerment take place within the contact between individuals and the social and cultural milieus in which they are embedded (134). However, in the present mental healthcare there is limited knowledge as to how to develop, promote and implement approaches that properly acknowledge the relational nature of recovery (135,136). This justifies the ongoing search for a way for recovery-oriented mental health services to establish meaningful involvement and true collaborative partnerships between patients, significant others and professionals.

The Dutch landscape

Nowadays, the recovery model of mental health treatment has become a widely accepted approach throughout the Western world and beyond (137). Also in the Netherlands, policies aim for a mental healthcare system in which people with SMI are stimulated to be in control of their own lives and to (re)build a living based on their own abilities, needs, hopes, and goals (138). To commit to these principles, Flexible Assertive Community Treatment (Flexible ACT) (139) was established as the Dutch variant of ACT (15). FACT is the service delivery of choice for people with SMI in the Netherlands and with 400 FACT teams throughout the country it is widely used (140).

Flexible Assertive Community Treatment

FACT teams are delivering flexible multidisciplinary support for SMI patients in a particular district or region. Adapted to patients' needs, goals and preferences, this includes recovery-oriented case management, peer support, CBT for psychosis, and psychiatric medication monitoring (141). When needed, the FACT model allows staff to provide more intensive support to patients by applying the principles of ACT. After the patient has stabilised, their level of care reverts to standard individual case management within the same FACT team. On average, a FACT team monitors 200 patients and has a staff/patient ratio of 1:15/20. Although FACT was developed for the Dutch mental healthcare system, its usability in other countries has been shown, such as the UK (142); Sweden (143), Hong Kong (144) and Denmark (145).

However, an examination of model fidelity of FACT between 2009 and 2014 showed that support of recovery, rehabilitation and participation was implemented insufficiently and systematic and formal forms of support and contact with family members were seldom established (146). A nationwide survey in 2020 reported that 81% of patients with SMI experienced feelings of loneliness, that 25% did not feel that they were part of society, and that only 21% had paid employment (140). These numbers confirm that people with SMI still live in a manner inconsistent with the purpose of recovery and that implementing a recovery-orientation in mental health care is demanding and cannot be assumed

This is not unique for the Netherlands and internationally the same tendency is observed. That is, due to the complex and multidimensional nature of the concept of recovery, implementing practice guidelines that reflect the underlying philosophy has been challenging and research suggests that there is persistent confusion amongst mental health staff as to the meaning of recovery and how it is, or should be, applied to clinical practice (147). It has been argued that although many mental health services would declare themselves "recovery-oriented", it is not common that a focus on empowerment, identity, meaning and resilience is ensured in ordinary practice (148).

Hence, although the importance of recovery-oriented mental healthcare for people with SMI is widely acknowledged, essential elements of the movement such as personalization of care and structural involvement of significant others are not adequately implemented in clinical practice. In order to firmly establish a recovery-orientation in community care for people with SMI, this thesis investigates whether the current FACT teams can be enriched by using resource groups (RG): a structured method aimed towards increasing patients' empowerment, systematically involving significant others and creating a form of integrated care on the level of the patient.

Resource Groups

According to the handbook of the RG (149), an RG is defined as 'a group of people, chosen by the patient, who can provide support to achieve personal recovery goals'. These people can be part of patients' informal network (such as friends and family) and their formal network (such as mental health nurses, social workers and job coaches). See Figure 1. The RG method involves six phases (see Table 2 in Chapter 2) that are aimed towards establishing a RG that meets quarterly in order to support patient's recovery goals.

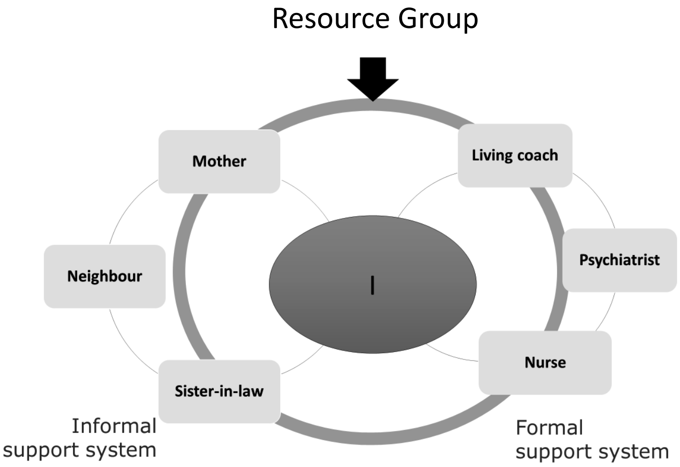

Figure 1. Example composition recource group with members from the formal support system and the informal support system.

The RG method builds on traditions of family interventions and integrated care and has three fundamental principles: (i) patients' empowerment; (ii) the systematic involvement of significant others and (iii) integrated care on the patient's level. The three principles will be further explained in detail below.

Main Principles

Principle 1: Empowerment

The method is built around (re)capturing the patient's agency and patients themselves are considered to be the directors of the group. To this end patients are encouraged to take the lead in the decisions around the RG: they nominate the members of their RG, they choose the chairman and minute-taker of the meeting, they prepare the agenda and they decide on the location. Furthermore, they draft their RG plan, in which they describe their short- and long-term recovery goals, and a plan to recognize and act on early warning signs. This change in structure and patterns of care is a crucial factor in the empowerment of the patient, as considering these decisions is thought to increase patients' sense of autonomy and of ownership over treatment.

Principle 2: Involving significant others
The second important characteristic of the RG method is that significant others are structurally engaged. Patients nominate the RG members from their network and thus the team no longer comprises solely care professionals but is augmented with the patient themselves, family members, friends, or others who are important to the patient. RG members are invited to think along with how to work on the recovery goals that patients have written in their RG plan. Decisions are jointly made in the RG meetings, based on shared decision-making principles.

By being part of an RG and attending its meetings, significant others are helped to acquire the skills they need to contribute to the recovery goals. Importantly, attention is also paid to their role, burden and need for emotional support. Through active collaboration and by creating space for sharing experiences and emotions, an empowered and supportive social environment can be built that serves as a safe basis to work on the recovery goals.

Principle 3: Integrated care
Arising from the Optimal Treatment (OT) model (see the section below), the last principle of the RG method concerns the integrated approach in treatment and care. Characteristic to suffering from a SMI is experiencing problems on multiple domains in life, for example housing, finances, medical health, employment, social relationships and parenting. To meet the needs on these different domains, care is frequently divided among professionals with specific expertise that work in different teams and service levels (e.g., mental healthcare, social services, primary care). As a result, there is a clear need for coordination between these services to prevent fragmentation of care.

The RG aims to provide a way to bridge the disconnect between the services involved. Rather than referring patients to specialists such as employment specialists, and housing staff, these specialists are invited to join the RG meetings in order to facilitate collaboration and mutual dialogue in working with the recovery goals. Hereby, the RG aims to foster continuity in the different phases of illness and recovery and to provide integrated care on the level of the patient.

Effectiveness of Resource groups for people with SMI

The origins of the RG method lay in the Optimal Treatment (OT) model. Established by Falloon in 1994, the project comprised an international study of 51 sites over 23 countries and aimed to provide integrated care by adapting a biopsychosocial approach in the treatment of schizophrenia and other non-affective psychotic disorders (150,151). To this end, a range of evidence-based pharmacological and psychosocial practices were implemented, including minimally effective doses of antipsychotic medication, education and training to maximize medication compliance; education for the consumer and their caregivers to cope more effectively with environmental stresses; assertive case management to help prevent and resolve major social needs and crises; social living skills training; and targeted strategies for persistent and/or emerging symptoms (151). At the time, evidence existed to support the efficacy and effectiveness of each of these practices separately (152–155); but the OT model integrated these different practices into routine treatment services. Within the OT model a "family unit in community" was established, in which patients and their families became part of the treatment team and decisions were made based on shared-decision making procedures.

A randomized clinical trial (RCT) (156) showed that the aggregated outcomes of 14 of the participating sites comparing the OT model (n = 146) to routine case management (RCM) (n = 114), resulted in significant improvements in patients in terms of mental health, stress and social functioning. The OT model was also found to be more effective than RCM in reducing the stress experienced by significant others. In addition, at several participating sites separate investigations were performed and reported. A meta-analysis of the OT model for patients with a psychotic disorder included the studies conducted between 2001 and 2011 (157) (N = 2263, 6 randomized studies, 11 observational studies, follow-up between 12 and 60 months). Relative to care as usual, participating in the OT model was associated with improved functioning (Cohen's d = 0.82), increased well-being (d = 0.88) and reduced symptoms (d = 0.72).

In the introduction of the meta-analysis, the researchers described that the 'family unit in the community' was regarded as a central element of the OT model in Sweden and by including not only the family but also resource persons from the social network of the patient, the concept of the "resource group" (RG) was developed. To reflect the central position of this element and integrate it into existing mental healthcare programs, the Swedish OT program was relabeled as Resource Group Assertive Community Treatment (RACT) (158,159). It is however not clear to what extent the included OT studies in the meta-analysis also implemented the characteristics of the RACT program and the use of RGs.

The efficacy of the Swedish RACT program for functioning and user satisfaction in patients with schizophrenic disorders was supported by two RCTs, one with a follow up of two years (160) and one with a follow up of five years (159). A systematic review that included both the Swedish RCTs and the meta-analysis mentioned above, concluded that the RACT program improved symptoms, functioning and well-being in patients with a psychotic disorder (161). Also here, it is not quite clear to what extent the implementation of the OT program at other sites was comparable to the Swedish RACT.

The RACT model was described in detail in a phenomenological study, performed from the professional's point of view (158). In a study theoretically comparing the RACT program with other ACT models including FACT, it was concluded that the RACT program has most radically focused on decision making and reinforcement of patients' self-confidence and abilities (162)). In a critical response van Veldhuizen and colleagues (163) argued that FACT and RACT seem to be quite compatible and that some of what Nordén and colleagues claim as being unique features of RACT have been intentions and practice in FACT for years. Instead of contrasting the programs they propose that RACT provides a specific contribution to working with others to achieve the patient's treatment and social inclusion goals and could be used to enrich FACT.

Taken together, when reviewing the existing literature, some gaps in knowledge are observed. First, in the studies included in the meta-analysis and review referred to above, integrated care models were assessed and later relabelled as RACT. However, the effectiveness of the RG method as an isolated element in community-based mental healthcare has not been investigated. Second, as FACT and RACT have been developed around the same time but at different places, it could be that the promising research of the Swedish RACT program can be attributed to elements that are already present within FACT. Third, although it has been proposed that the RG method might be suitable for patients suffering from non-psychotic diagnoses (157), previous studies focused on patients with diagnoses only within the psychotic spectrum. Fourth, the qualitative study on RACT was performed from the case-managers' point of view (158). Hereby, the meaning, experiences and perspectives of patients, RG members and other professionals when working with the RG method have been omitted. Fifth, the working-mechanisms of the method have not yet been investigated and no studies are known that contribute to a deeper understanding of how the RG method takes place in clinical practice. Sixth, to our knowledge there are no studies available that evaluate the cost-effectiveness of the RG method. To inform policy makers and health care providers more information is needed on the health impact and economic cost. Seventh, the effectiveness of involvement of significant others has been typically operationalized in terms of relapse, hospital stays and medication adherence (see (76)) but recovery-oriented outcomes are scarce. As a result, the influence of the social environment in recovery and recovery-related outcomes is not well understood.

To address the above-mentioned gaps in the literature, this dissertation has the following aims:

- To explore the concept of empowerment by means of the association between empowerment and attachment patterns;
- To gain in-depth understanding of the meaning, experiences and interpersonal dynamics when working with RGs, including perspectives of patients, significant others and professionals;
- To investigate whether using the structure of RGs within community care has favourable effects on empowerment and recovery-related outcomes, compared to community care as usual within the context of Flexible Assertive Community Treatment;
- To evaluate the cost-effectiveness of working with RGs within FACT.

Methodology

A key scientific challenge is that the philosophy of recovery stress the unique and personal nature of the journey, whereas evidence-based practice prioritizes group-level aggregated data (35,164). The drive towards evidence-based practice has increased the necessity for recovery research to adopt other methodologies, as one of the common criticisms of the recovery movement has been the lack of a scientific evidence base (165–167). However, as Barber (168) argues, stressing personal recovery within services does not necessarily point to the abandonment of evidence-based medicine. Consistent with this view an empirical evidence base for recovery-oriented interventions is progressing. The present thesis aimed to further expand this evidence base for recovery interventions by testing the efficacy of the RG method by means of a RCT. To also gain deeper insight into the different perspectives and needs of individuals working with the RG and to give voice to their unique and deeply personal experiences, an important part of this thesis entails the results of a longitudinal, exploratory multiple case study.

Yin (169) defines a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident”. Central focus of a case study is the study of the particularity and complexity of a case, coming to understand its activity within important circumstances (170). Case-studies are thus focused on particularization not generalization. It is about coming to know a case well, not primarily as to how it is different from others but understand what it is, what it does. Case study research is used to investigate a specific phenomenon through an in-depth limited-scope study. It is useful in early phases of research where they may be no prior hypotheses or previous work for guidance (171). The multiple case study in this thesis takes place within an interpretative paradigm (172,173). In contrast to studies within a positivist paradigm, the case study is hereby intended to explore the RG as experienced by direct stakeholders, and in relation to the specific context of each individual RG. To guide the study, the grounded theory (GT) approach is used in which there is no initial preconceived framework of concepts and hypotheses (174). Reality is approached without predetermined ideas about how that should happen (171). This form of research requires trust and openness in the research relationship, high levels of ethical and critical engagement, mutual and sincere collaboration, participants having a full voice, reflexive engagement throughout, tolerance of ambiguity, and using multiple data sources.

Outline of the thesis

The outline of this dissertation is as follows. **Chapter 2** provides a description of the study protocol, explaining design, instruments, constructs and analytic strategy. **Chapter 3** is directed towards the first aim of the thesis and uses the attachment framework to explore the primary outcome of the study: empowerment. **Chapters 4** and **5** are directed towards the second aim of the thesis and include the research of the longitudinal multiple-case study. The study in **Chapter 4** aims to provide a framework of the RG method for a deeper understanding of the working mechanisms and influence on patients' recovery. In **Chapter 5,** a narrative analysis is performed to explore the interpersonal dynamics that arise within RGs and their influence on recovery. To address the third and fourth aim of the thesis, **Chapters 6** and **7** include the outcomes of the randomized clinical trial. The study in **Chapter 6** evaluates whether using the structure of a RG within FACT has favorable effects on empowerment and recovery-related outcomes after 9- and 18 months follow-up compared to FACT as usual. **Chapter 7** focuses on the cost-effectiveness of the RG method integrated in FACT and reports the outcomes of a trial-based cost-effectiveness analysis and cost-utility analysis. The thesis ends with a discussion of the findings, limitations, recommendation for future research and implications for clinical practice (**Chapter 8**).

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Chapter 2.

The Resource Group Method for People with Severe Mental Illness

Study Protocol for a Randomized Controlled Trial and a Qualitative Multiple Case Study

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Abstract

Background

The resource group method provides a structure to facilitate patients' empowerment and recovery processes, and to systematically engage significant others in treatment and care. A patient chooses members of a resource group (RG) that will work together on fulfilling patients' recovery plan. By adopting shared decision-making processes and stimulating collaboration of different support systems, a broad and continuous support of patients' chosen goals and wishes is preserved and problem solving and communication skills of the RG members are addressed.

Objective

The objectives of this study are (1) to establish the effectiveness of the RG method in increasing empowerment in patients with severe mental illnesses (SMI) in the Netherlands; (2) to investigate the cost-effectiveness and cost utility of the RG method; and (3) to qualitatively explore its dynamics and processes.

Methods/Design

This multisite randomized controlled trial will compare the effects of the RG method integrated in Flexible Assertive Community Treatment (FACT) (90 patients) with those of standard FACT (90 patients). Baseline assessments and 9-month and 18-month follow-up assessments will be conducted in face-to-face home visits. The primary outcome measure, empowerment, will be assessed using the Netherlands Empowerment List (NEL). The secondary outcomes will be quality of life (MANSA); personal, community and clinical recovery (I.ROC); general, social and community functioning (WHODAS 2.0); general psychopathological signs and symptoms (BSI-18); and societal costs (TiC-P). An economic evaluation of the cost-effectiveness and cost utility of the RG method will also be conducted. A qualitative multiple case-study will be added to collect patients', RG members' and professionals' perspectives by in-depth interviews, observations and focus groups.

Discussion

This trial will be the first to study the effects of the RG method on empowerment in patients with SMI. By combining clinical-effectiveness data with an economic evaluation and in-depth qualitative information from primary stakeholders, it will provide a detailed overview of the RG method as a mean of improving care for patients with SMI.

Introduction

Traditionally, severe mental illnesses (SMI) were seen as chronic diseases with relapsing or deteriorating symptoms and poor prognoses (1,2). Recovery was perceived as a medical outcome defined by remission of mental health symptoms (3). Due to the consumer movement, a new view emerged in psychiatry in the 1990s (4,5). Within this view, recovery is conceptualized as a unique, personal and ongoing process of growth that involves learning to live with one's disability despite the limitations of symptoms, and gradually rebuilding a sense of purpose, agency, and meaning in life (5,6).

This conceptualization of recovery was incorporated within the development of new working models for organizing mental healthcare. One of these models is Flexible Assertive Community Treatment (Flexible ACT) (7) that was established in the Netherlands as a Dutch variant of Assertive Community Treatment (ACT) (8). Flexible ACT teams deliver services for an entire group of people with SMI in a particular region by adapting a flexible switching system between standard community mental healthcare and an intensive ACT equivalent (9,10). This combination of flexibility and continuity of care provides opportunities for combining recovery-oriented care with evidence-based medicine, best practices and integrated community and hospital care.

However, an examination of the model fidelity of FACT teams between 2009 and 2014 showed that support of recovery, rehabilitation and participation was implemented insufficiently (11). Similar findings were shown by a nationwide survey in 2019, which reported that over 80% of patients with SMI experienced feelings of loneliness, that 40% did not feel that they were part of society, and that only 20% had paid or unpaid employment (12). Second, although the informal support system is perceived as an important factor in supporting recovery and participation and the effectiveness of involving significant others in SMI care is well established, it has been found that systematic and formal forms of support and contact with family members are seldom achieved (3,11,13,14). These implementation problems justify the ongoing search for a mental health service that empowers patients with SMI, by stressing their choice and autonomy and by encouraging social connectedness and participation.

A structured method for reinforcing empowerment and social connectedness in mental healthcare is represented by the resource group method. In short, to constitute a resource group (RG), patients nominate significant others from their informal network (such as friends and family) and their formal network (such as a social worker or job-coach). During the frequent RG meetings, the RG discusses patients' goals and wishes, and jointly determines a recovery plan to achieve them.

The first important characteristic of the RG method is that patients themselves take the lead in any decisions: they nominate the members of their RG, set their recovery goals and determine important aspects of how the RG meetings are designed (15). Considering these decisions is a crucial factor in patients' sense of autonomy and sense of ownership of their treatment. Patients are then encouraged to extend this to autonomy and ownership of their illness (such as their ability to cope with symptoms) and regarding other social and community aspects of life. This process of regaining control over one's life- despite the need for support- is a key concept of empowerment, and is regarded as an important driving force in recovery (16,17).

The second important characteristic of the RG method is that significant others are systematically engaged in treatment and care (18). As a patient and his or her significant others form a team together with involved professionals, support in the recovery plan is broadened. Hereby, the fulfillment of a meaningful life and everyday activities is strengthened. In other words, through collaboration – joint discussion of patients' wishes and needs, and creating space for sharing experiences and emotions – an empowered and supportive social environment can be built to supplement professional care. Having such environment in turn, is assumed to foster resilience and continuity in social and community integration. Improved integration and a feeling of connectedness are seen as facilitators and indicators of recovery (2,19–21).

Also, it is increasingly recognized that significant others need social support to break isolation and reduce stigma (22,23). Moreover, studies investigating experiences with care report that families feel marginalized, uninformed, lack a recognized role and distanced from the care planning process (24–26). Therefore, a structured and more frequent contact between professionals and significant others would meet with their need to feel more part of the treatment and care. Additionally, professional support and attention to the consequences of the patients' disease for the personal wellbeing of the important people around the patient, may reduce their burden, increase their sense of security, and improve their own mental health status (13,27,28). Moreover, during the RG meetings all involved professional caregivers from different sectors (e.g., mental health, social affairs, housing and employment) can be invited. In this way, the RG method responds to the need to improve communication between all those involved, pursuing a consistent and collaborative model of integrated care.

In sum, the RG method structures the care and support that is built around patients' personal choices, wishes and aspirations. It focuses on creating a mental health system that encourages patients to be active, informed and autonomous participants who, by collaborating with their social environment, can develop the support that meets their needs and chosen lifestyle. By systematically engaging patients' significant others, continuity in support is embedded. Eventually, it is hoped, a resilient, empowered social support system can be created that functions independently of professional resources. As the RG method thus has great potential for promoting the autonomy, empowerment and recovery of patients with SMI, it may bring valuable improvements to standard FACT. The origins of the RG method lay in the Optimal Treatment (OT) model, which integrates biomedical, psychological and social strategies in the management of SMI (29,30). It was shown in a meta-analysis of the effectiveness of variations of the OT model for patients with a psychotic disorder (N = 2,263, 6 randomized studies, 11 observational studies, follow-up between 12 and 60 months) that participation in the OT model led to clinically significant improvements. Relative to care as usual, it improved functioning (Cohen's d = .82), increased well-being (d = 0.88) and reduced symptoms (d = .72) (31). Similarly, a systematic review of eight RCTs showed that the OT program improved symptoms, functioning and well-being in patients with a psychotic disorder (18). In Sweden, the "family unit in the community" was regarded as a central element of the OT model, and was further developed early as the concept of the "resource group" (32). To reflect the key role of the RG and to integrate it into the existing mental healthcare programs for patients with SMI, the Swedish OT program was relabeled as Resource Group Assertive Community Treatment (RACT) (33,34). In this way, ACT teams (8) were enriched and augmented by resource groups involving patients and their network in clinical case management by shared decision-making procedures.

This study is intended to add to the existing research in three ways. First, in the studies included in the meta-analysis and review referred to above, integrated care models related to the RACT program were assessed. However, no study has investigated the specific additional value of the RG method in a head-to-head comparison with FACT. Second, previous studies focused on patients with psychotic disorders. Knowledge is lacking about the effectiveness of the RG method for patients across the entire psychiatric spectrum. The third contribution is intended to provide in-depth understanding of the meaning of the experiences in using the RG method to those involved. Very few qualitative contributions have been conducted. As most focused mainly on the case-managers' point of view (34), they overlooked the experiences and perspectives of patients, RG members and other professionals. To better understand the RG method and its implementation, we thus intend to conduct exploratory research that analyses its dynamics and meaning from the perspectives of those involved.

To achieve these objectives, this study consists of a randomized controlled trial (RCT) to establish clinical effectiveness, an economic evaluation and a qualitative case study on the dynamics, meaning and implementation of the RG-method. The primary objective of the study is to determine whether the RG method integrated in FACT is more effective in empowering patients with SMI when compared to standard FACT. Secondary objectives consist of the assessment of the RG method in improving quality of life and enhancing social and community functioning; and, in an economic evaluation, to investigate its cost-effectiveness. An add-on qualitative study will explore the perspectives of those involved and the implementation of the RG method in Dutch mental healthcare.

Methods

This three-part study will consist of an effectiveness study, an economic evaluation and a qualitative case study. The study protocol was written in accordance with the CONSORT guidelines (35).

Part one: effectiveness study

Study design

Patients in this multisite RCT will be randomly allocated either to RG method plus FACT or to standard FACT (ratio 1:1). Randomization will be performed at individual patient level. Data for both conditions will be collected at baseline and after 9 and 18 months (follow-up assessments). For an overview of the flow of screening procedures and assessments, see Figure 1. Importantly, since FACT teams do almost all outpatient care in the Netherlands for SMI patients, it was not possible to have a second control group without FACT.

Study population

The study will be conducted within the context of community-based outpatient psychiatric care for people with SMI. In the Netherlands, FACT (8) is the used service-delivery model for the care and treatment of people with SMI (see Interventions for a description of FACT). The target population consists of patients who meet the criteria for the Dutch definition of people with SMI who receive FACT.

Inclusion criteria

The inclusion criteria for the study are consistent with the general inclusion criteria for FACT. That is, patients will be eligible if: 1) they are aged between 18-65 years, 2) are expected to have FACT for > 12 months, and 3) suffer from a SMI according to the Dutch consensus definition (36). For the latter, individuals must meet the following five criteria, in which:

a. they have a psychiatric disorder which requires care and treatment (≈ are not in symptomatic remission);
b. they have severe limitations in social and community functioning (≈ are not in functional remission);
c. these two criteria are interrelated, with the limitations being the cause and consequence of the psychopathology
d. these problems are not transient in nature (i.e., they are systematic and long-lasting)
e. the treatment plan requires coordinated care provided by integrated networks of health practitioners.

Exclusion criteria

Patients are not eligible if: 1) their knowledge of Dutch is not sufficient for them to understand and read the questionnaires; and if 2) they are unable to understand and sign the informed consent form.

Hypotheses and research questions

Hypothesizing that FACT plus RG is a helpful intervention for patients suffering from SMI by improving their empowerment and strengthening their support sources, we state the following research questions:

- Does RG plus FACT increase the empowerment of patients with SMI more effectively than standard FACT?
- Does RG plus FACT improve these patients' quality of life and satisfaction with care, and enhance their social and community functioning more effectively than standard FACT?

Study Procedures

Recruitment

Patients will be recruited at nine mental healthcare organizations throughout the Netherlands, each of which will participate with minimum two FACT teams. Care providers of the FACT team will screen patients on the basis of the inclusion and exclusion criteria (see figure 1). After informing eligible patients of the RG procedures and the study, care providers will then ask them to participate. To this end, patients will receive oral and written information about the RG model and an information letter outlining the trial procedures, explaining confidentiality, and providing the contact details of the research team. Interested patients will be given a week to consider their participation.

The above described procedure for screening and informing patients about the study will be performed on two different groups of patients: either new patients entering a FACT team (i.e., during the intake phase); or a randomly generated selection of patients who

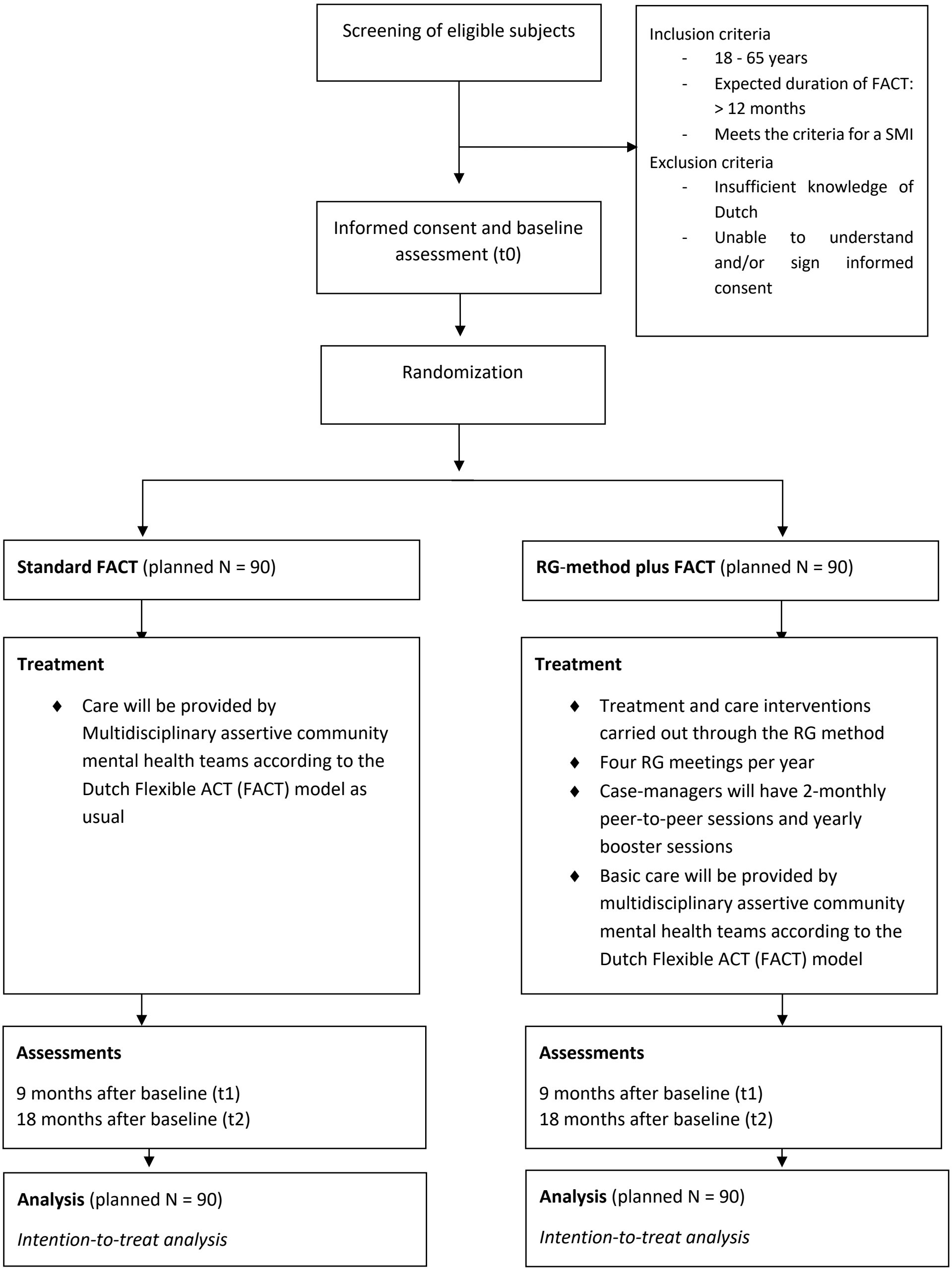

Figure 1. Flow chart of study design. FACT = Flexible Assertive Community Treatment, RG = Resource Group

have already been in FACT for no more than 24 months. For the latter, we will use an online tool (www.randomizer.org), to randomly select patients who have been recently (24 months) added to the caseload of the case-managers trained in the RG method. Importantly, these two routes are used to screen and inform a representative sample of the FACT population of the study. After patients sign informed consent, the researcher will perform an extra check on the inclusion and exclusion criteria and an independent interviewer will contact the participant to make the first appointment for the baseline assessment. After completing the assessment, participants will receive a gift voucher worth €15.

Randomization and blinding

Randomization will be performed on an individual level. A statistician from the Trimbos Institute, who will be independent from the research team, will perform the randomization using a computer-generated concealed-randomization sequence stratified on teams. To keep randomization unpredictable, the sequence will contain variable-allocation block sizes (Jensen et al., 2016), in which two sizes of allocation blocks (i.e., 2 and 4) are randomized. Assuming ten participants per team, this results in three possibilities for block size 4 (i.e., 2x4; 1x4; 0x4). To minimize the risk of imbalance between conditions, the ratio of these sequences will be stratified on respectively 1:2:2. The allocation sequence will be stored by the independent statistician and be concealed from all researchers, care providers and participants. Participants will be allocated after baseline measurement. Once they have been allocated, the researcher and local staff will be informed of the condition by email. Further matching between patient and case-manager will be performed by the local FACT team staff and will be based on condition. That is, when participants are allocated to the RG condition, care providers trained in the RG procedures will be the case-manager. Patients in the control condition can have any FACT care providers as their case-manager.
Assessments comprise self-report questionnaires, and structured and semi-structured interviews (see Table 3). They will take place at the participants' homes or any other location they prefer. An independent and blinded interviewer will guide them through the self-report questionnaires and will conduct the interviews. The interviewer will bring a laptop and- using an unique login-code- will assess the questionnaires online, then securing them on an encrypted server (Jambo). If participants are unable to use the laptop, they will fill in the questionnaires on paper.

Given the nature of our study, blinding of participants or care providers is only secured at baseline assessment when condition (e.g., RG + FACT vs. standard FACT) is not known to participants or care providers. However, after baseline assessment condition blinding of participants and care providers is not possible anymore as the condition determines the treatment. Interviewers will be blind for the allocated condition during all three assessments. To assess blinding during follow-up assessment, interviewers will fill in control questions after assessments. To optimize inter-interviewer reliability, interviewers will: 1) receive face-to-face training on the study protocol, questionnaires and interviews; 2) discuss the interviewing process with each other in regular telephone and/or face-to-face meetings; and 3) use a detailed standardized study protocol.

Interventions

See Table 1 for an overview of the differences and similarities between the two conditions: standard FACT and FACT + RG.

Standard Flexible Assertive Community Treatment (FACT) *(*for a more comprehensive description, see (10)). FACT is a rehabilitation-oriented outpatient clinical case management model for patients with severe mental illness. Integrated care and support is provided in the patients' own environment by a multidisciplinary team of professionals (e.g., psychiatrist, psychologist, nurses, social worker, job coach and peer specialist). On average, a FACT team consists of 11–12 professionals that monitor 200 patients (10). The FACT model is characterized by its flexible switching between two types of care, according to patients' needs:

1. *Individual case management for more stable patients.* The case-manager visits a patient 2–4 times a month at his/her home or elsewhere and is responsible for the individual care and treatment plan. This plan is renewed at least once a year and is formulated in a way that patients and their families can understand. Part of this plan can be a so-called crisis plan, which describes early-warning symptoms and concrete arrangements for intensifying care if necessary. Appointments with the psychiatrist (for management and evaluation of medication) and with the psychologist (for psycho-education or cognitive behavior therapy) can take place at the FACT center or at the patients' home. On indication, family interventions and supported employment may be added to the treatment plan.
2. *Shared case management and intensive assertive outreach care for unstable patients who are at risk of relapse, neglect or readmission*. The care for the individual patient is intensified but performed by the same team. That is, this group of patients is discussed daily during the team meeting using the digital FACT-board (DigiBoard); the psychiatrists sees the patient within two days; the crisis plan is updated and set in motion; and the case-manager informs the patient (and if necessary the family) that more intensive care will be organized and that colleagues from the FACT team will work together to prevent readmission and to shorten the crisis. If the crisis or risk of relapse has decreased and the situation has stabilized, the care is shifted back to individual case management.

Table 1. Overview of the differences and similarities between the two conditions: FACT and FACT + RG

Main elements	Description of FACT	Description of FACT + RG
Involvement of social network	Social network is invited during intake phase and contact can be developed during course of FACT. Actions: • A contact person is established for each patient and contact details are provided • Family or significant others can be invited as FACT proceeds • In the event of (upcoming) crisis, the contact person is informed	Social network (including family, friends, colleagues and significant others) are structurally involved and collaborate as partners in treatment and goals. Actions: • Within three months, nominated significant others from the social network meet the FACT staff for the interview • During the RG meeting, the RG members are actively involved in maintaining the goals • FACT staff and RG work together as a team (equal experts)
Treatment/ recovery plan	• Recovery goals are developed by client and caregiver (treatment plan) and are discussed during the FACT meeting. • To achieve these goals, the FACT team allocates tasks and responsibilities on the basis of expertise • The treatment plan is discussed at least once a year by the multidisciplinary FACT team • The treatment plan contains SMART formulated, concrete goals.	• Recovery goals are developed by client and caregiver (RG plan) and are discussed with the RG members (possibly including FACT team members) during the RG meeting. • The client decides together with the RG on actions to be taken to achieve the goals • The RG plan is discussed once every three months by the RG; the psychiatrist is present at least once a year • The RG plan contains two long-term goals (=future dreams and wishes) and two short-term goals (=SMART formulated, concrete goals)
Continuity of care	FACT contains two modes of operation within the same team: high-level intensity (ACT, adaption of shared caseload) and low-level intensity (Individual Case Management). The flexibility to switch between them enhances continuity of care.	Additional to the flexibility in FACT, the flexible composition of the RG incorporates various institutes and people and allows a broader range and intensity of care. Although the RG members may differ, the RG itself is the constant factor.

To date, the effects of FACT have not been studied in the context of an RCT. Uncontrolled studies have shown a pre-post effect on symptoms and admissions (9,37–39).

Resource Group plus FACT. In this condition, patients will be guided to form a Resource Group (RG) embedded within FACT. In other words, together with the case-manager, patients will prepare, attend and evaluate 3-monthly RG meetings that are integrated in standard FACT.

Director. An essential element in the RG method is the position of the patient as the director of the group (34). The patient nominates the RG members, determines his or her short- and long-term recovery goals, and decides on the location, chairman and agenda of the RG meetings. As a patient's ownership of the treatment is vitalized by explicitly thinking about and determining these aspects of care, it is also essential to the patient's empowerment – which, in turn, was shown to be the major driving force behind successful treatment (18,34).

RG members. The patient will ask his/her significant others to join the RG, a process referred to as nominating. The composition and size of the RG are flexible, and can change over time according to patients' goals and phase of recovery. The patient and the case-manager always attend the RG meetings. At least once a year, the psychiatrist of the FACT team will attend the RG to evaluate the recovery plan. Before the first RG meeting, the case-manager will invite the nominated RG members for an interview that explores working with the RG and the commitment and responsibility of being a RG member. Also, the relationship between the nominee, the patient and other RG members and previous eexperiences in good and bad times are investigated. Exploring these emotions and experiences will provide valuable information and will also provide insight into the personal wellbeing and burdening of significant others. Discussing these objectives at an early stage is also intended to reduce the so-called expressed emotions (EE) (40) during the RG meetings. Having individual contact with relatives before initiating any activity involving groups is also considered essential to structured work together (13). The aim is for all RG members to work together in an emotionally stable environment that contributes to a resilient and continuous support system. Previous experiences with the RG method showed that most of the nominated RG members agreed to participate (34). However, in some cases the network of a patient might be dysfunctional or almost invisible, or the significant other is unable or does not want to participate. In these cases, the RG will start with the minimal composition of an RG, consisting of the patient, the case manager and the psychiatrist. Together they will work on the steps that the patient or his/her significant others need to expand the RG. By means of the model-fidelity scale we will collect information on the composition of every RG.

Recovery plan. To prepare the RG meetings, the patient and case-manager will develop the recovery plan that is to be discussed during the RG meeting. This plan will comprise two long-term recovery goals, two short-term (i.e., 3-month) recovery goals, and a plan to recognize early warning signs (a “crisis plan”). The recovery goals will be formulated by the patient and can relate to all aspects of recovery, such as personal recovery (recovering identity); social rehabilitation (meaningful participation in society and social relationships); and health (improving physical and mental symptoms). In the crisis plan, patients will describe how others should recognize the personal early warning signs that indicate an approaching relapse, and how they want others to respond.

Resource-group meetings. RG meetings are usually scheduled once every three months, but the frequency may vary according to needs and wishes of the patient and the other RG members. The meetings will be structured clearly and consistently by an agenda that is determined by the recovery plan. The role of each member in accomplishing the recovery goal will be decided jointly by the RG, which will take shared responsibility for following the plan (shared decision making). The patient determines what the overall objectives of the RG meetings should be, and the group takes joint decisions on how they should be achieved (18). Between meetings, the patient, RG members and care professionals will work on the different parts of the recovery plan, using the next RG meeting to evaluate the steps they have taken. During these activities in between, the empowerment of the patient and the collaboration of the different RG members form the fundamental elements that shape the contact. Also, the crisis plan will be discussed during one of the first RG meetings. In the event of crisis or the need to prevent it, the aim is to enable RG members to provide the effective, adjusted guidance determined by the patient.

Previous experiences have shown that in some cases it might take time to organize an actual RG meeting (34). Moreover, sometimes there are unsolved issues between RG members that need to be addressed in order to have a constructive meeting with low EE. This could cause a delay in the occurrence of the RG meetings. However, the preparation in which the patient actively takes part in the planning and is involved as a key decision maker is considered to be a crucial factor in the empowerment of the patient (18,31). The increased commitment of the case managers to involving the informal support system is also starting in the preparation phase. Hereby, the shift towards empowering the patient, restoring his/her self-confidence and increased attention for the interactions in the informal support system is gradually taking place before and in between the RG meetings.

RG members’ skills. As well as the 3-monthly RG meetings, the RG method comprises several options for proving specific training sessions. The case manager and/or other professionals train the patient and the significant others to allow them to improve their skills to communicate, handle stress and solve everyday problems. No costs are involved for the RG members. The need for these training sessions can be addressed by all RG members. In this way, maladaptive patterns and potential stressors in the patient's environment can be addressed so as to create a healthy and communicational emotional climate around the patient. Alternatively, when more complex problems are evident, the RG members can decide to involve an expert—in family therapy, for example—for an extra session for the complete RG or a subgroup of it.

To set up, structure up and continue a RG in the way described above, the patient and case-manager will jointly pass through six phases. For a description of each phase, see Table 2.

Implementation

To ensure that the RG method is implemented solidly and in a similar fashion across the different centers and teams, an implementation strategy with several components was developed. This strategy involves the following components: 1) training in the RG method for participating case-managers of the FACT team; 2) regular visits by research teams (at least once every three months) to ensure good communication; 3) newsletters to keep teams and care providers informed and involved; 4) six-weekly telephonic peer-to-peer meetings among case-managers working with the RG method; and 5) questionnaires after every RG meeting (to ensure model fidelity). Three of these components require a more detailed description:

Training in the RG method. At least two members from each FACT team will participate in a 2-day training program before the start of the study, and in 2 follow-up sessions during the study itself. Additional yearly booster sessions will also be organized. Two experienced trainers, one of them being a family therapist, will lead the interactive program. The program will consist of lectures, role-play and discussions that enable case-managers to study and familiarize themselves with the vision, methodology and content of the roles within the RG method. During these days, the central theme will be ensuring that case-managers learn the reflexes necessary to transferring the guidance in treatment to patients and their RG so as to nourish patients' confidence in reaching their goals. Mental health institutions and teams are selected to participate when they expressed their motivation to be involved in the national effectiveness study and are interested in the implementation of the RG method. Within the participating teams, team members decide between themselves and the management who will be trained. An estimated number of 50 members of the different FACT teams will be trained. Most of them will be working as a case-manager or nurse, and also some peers-by-experience workers, psychiatrists and psychologists will be encouraged to participate to pursue a broad implementation.

Model fidelity. The adherence of each RG to the RG protocol will be assessed with a new instrument: the Resourcegroep Model Evaluation Tool (R-MET), which was developed on the basis of the Dutch RG handbook (41), and documents for assessing RG model fidelity developed in Sweden during previous studies. The purpose of the tool is to estimate the extent to which an individual RG operates according to the intended approach. In collaboration with experts by experience, representatives of the participating mental health centers and researchers, the tool was drafted, tested, adjusted, and will be implemented in all teams. To obtain a model-fidelity score, the patient, RG members and case-manager will fill in questions that provide an overall picture of each individual RG. By collecting the answers from the different people that are involved in an individual RG, different perspectives are integrated in the final model-fidelity score.

The R-MET has two sub-forms that together compose the RG model fidelity score. The forms are to be filled in as specified here:

1. *RG meeting form.* This form consists of 25 short questions that are filled in by the case-manager in consultation with the patient after each RG meeting. The questionnaire collects information on characteristics of the RG (e.g., its members, chairman and frequency of RG meetings), on its preparation (interviews with nominated RG members and drafting the agenda), the recovery plan and the patient's degree of ownership. The emotional environment of the group is also assessed. For this, five Visual Analogue Scales (VAS) are used to review the five domains of EE: hostility, emotional over-involvement, critical comments, warmth (reversed), and positive comments (reversed)(40). Because the questions are filled in after each RG meeting, recurring information on the individual RG is collected. This not only gives insight in the development of the RG but is also a way to keep track of the progress of all RGs.
2. *Yearly Evaluation form.* This consists of 9 questions and is completed by the patient, RG members and case-manager once every 12 months before an RG meeting. During the RG meeting itself, the RG jointly evaluates the RG meetings by discussing the questions. As well as contributing to model fidelity, filling in this yearly evaluation form thus provides input for optimizing the RG. It uses different VAS to evaluate how the different RG members experience the main features of the RG method. Its themes are the emotional environment with regard to trust, equality, and responsibility during the RG meetings. In addition, the patient fills in some questions on his or her experience of ownership of the RG. Finally, all RG members, including the patient and case-manager, rate satisfaction with the RG meetings.

Telephonic peer-to-peer sessions. All trained case-managers attend 6-weekly telephonic peer-to-peer sessions. These are one-hour group sessions that are held by telephone by a

Table 2.The six phases of the RG-method

Phase	Actions
Preparation	Patient and case-manager draft sociogram; Patient and case-manager nominate RG members; Patient and case-manager draft the RG plan (containing two long-term goals; two short-term goals; crisis plan)
Investment	Case-manager establishes contact with nominated significant others; Case-manager interviews nominated significant others, covering at minimum: • Their expectations of, commitment to and responsibility in the RG • Their relationship and previous experiences with the patient and other nominated RG members • Their contribution to the RG
Planning	Patient and case-manager set date of first RG meeting; Patient and case-manager set up & print agenda; Patient decides: • The location of the RG meeting • The chairman • The frequency of the RG meetings • The channel of communication between the different RG meetings
First RG meeting	All RG members introduce themselves or are introduced by the patient; The patient and/or case-manager give a short explanation of the RG method and confidentiality; • The RG discusses the agenda: • The RG goals • The crisis plan • The role of each RG member, concrete actions to achieve the RG goals
Follow-up RG meetings	During the follow-up RG meetings: • The RG evaluates goals, assignments and progress • The RG updates the goals and the RG plan, and decides on new actions to achieve the goals • Skills trainings are available for RG members (e.g., problem solving and emotional communication) When wished by the patient or another RG member, the composition of the RG can change if different persons are better suited to achieve the updated goals; Once a year psychiatrist attends the RG
Reorientation	Discussion on composition of the RG, depending on the phase of care: De-intensification of care: transition to GP/social domain or to only informal RG members Intensification of care (e.g., crisis plan)

fixed group of no more than 8 case-managers from different mental health organizations throughout the Netherlands. Each group has a chairman, who leads the sessions. To keep track of recurrent themes and of quality across the sessions, a researcher also attends the sessions. During the sessions, case-managers exchange their RG experiences and discuss individual cases, the aim being to learn from each other regarding RG work and to improve the quality of the individual RGs.

Outcome Measures

Several instruments (questionnaires and interviews) will be used in the clinical effect and economic evaluation studies. See Table 3 for an overview of outcomes and instruments.

1. *Baseline demographic information and clinical information (DEM_1)*
   Basic demographics (self-report) will be collected, including age, gender, education, housing, country of birth, and children. In addition, data will be collected on the duration of psychiatric illness, on alcohol/drug use, on psychiatric diagnosis and on history of psychiatric care (including the number of voluntary and compulsory admissions).
2. *Primary outcome*
   The primary outcome measure is empowerment, measured with the Netherlands Empowerment List (NEL). The NEL (40 items, self-report) contains 6 subscales: confidence and purpose (12 items); social support (7 items); connectedness (6 items); self-management (5 items); caring community (6 items); and professional help (4 items). Items are rated on 5-point Likert scales (strongly disagree – strongly agree). We will use the total score of the NEL as our primary outcome measure. The scale was defined in collaboration with patients and experts-by-experience, and has been validated (17). Sensitivity to change has been demonstrated (42,43).
3. *Secondary outcomes:*
   a. *Quality of Life.* The Manchester Short Assessment of Quality of Life (MANSA; 16 items, self-report) is a shortened version of the Lancashire Quality of Life Profile (LQLP) (44). It reliably measures quality of life in patients with psychological problems (45).
   b. *Recovery.* The Individual Recovery Outcomes Counter (I.ROC; 12 items, interview) has been found to be a valid and reliable measure of recovery in mental health (46).
   c. *Social and community functioning.* To obtain information regarding social and community functioning, several self-report questions (DEM_2) on education, work, social network and frequency and quality of social contact will be included.
   d. *Role functioning.* The World Health Organization Disability Assessment Schedule – 36 items (WHODAS 2.0 – 36, interview) produces reliable disability measures across six domains to assess general, social and community functioning (47).
   e. *Global functioning.* The global assessment of functioning scale (GAF) and the social and occupational functioning scale (SOFAS) will be derived from DSM Axis

V to assess global functioning & symptom severity (GAF) and social functioning (SOFAS) (48–50). The interviewer, who is blind for condition, will administer both scales after each measurement.

f. *Clinical symptoms.* The Brief Symptom Inventory – 18 items (BSI-18; self-report) is a validated, reliable instrument for assessing general psychopathological symptoms as an index of severity of syndromal disorders (51–53). As well as the total score, a dimensional score on somatic complaints, depression and anxiety will be obtained.

g. *Attachment.* The Revised Adult Attachment Scale (RAAS, 18 items, self-report) has moderate to good psychometric properties for assessing attachment style (54–56).

h. *Satisfaction with care.* Patients' appreciation of care will be assessed using the Client Satisfaction Questionnaire (CSQ-8) (57) supplemented with the relative's involvement dimension of the Verona Service Satisfaction Scale (VSSS-EU) (58). The CSQ-8 is a one-dimensional 8-item instrument for assessing global patient satisfaction. It has demonstrated high construct validity and internal consistency reliability (57), also in Dutch (59). The relative's involvement dimension of the VSSS-EU consists of six items that cover various aspects of the patient's satisfaction with help given to his/her closest relative. Also, four self-formulated questions were added, two covering the degree of patients' satisfaction with the role of their relatives in their treatment, and two covering patients' satisfaction with the collaboration of the various services involved.

4. *Cost data*
    a. The Trimbos and Institute of Medical Technology Assessment Cost Questionnaire for Psychiatry (TIC–P, interview) estimates use of care services, use of medication, and the amount of work loss (absenteeism and reduced efficiency) (60). The questionnaire will be adapted to fit the purpose of this study and uses a 3-month recall period.
    b. The 5-level EuroQol 5 dimensions (EQ-5D-5L) is a standardized non-disease-specific instrument that will be used to obtain utility scores on the basis of social tariffs, expressed in Dutch unit prices (61,62).

5. *Burden of significant others (filled in by significant others)*

The Involvement Evaluation Questionnaire (IEQ, 31 items, self-report) assesses the consequences of mental illness for significant others (63). It will be sent online to the significant others who are proposed by the patient.

Table 3. Outcomes and instruments

Measurement	Outcome	Instrument (type of assessment)	Time (min)
Primary	Empowerment	NEL (self-rated)	15
Secondary	Demographic information	DEM_1 (self-rated)	10
	Quality of Life	MANSA (self-rated)	5
	Recovery	I.ROC (interview)	15
	Community and social functioning	WHO-DAS 2.0 -36 (interview)	15-20
	Global functioning	GAF/SOFAS (observer-rated)	
	Social contacts	DEM_2 (self-rated)	5
	Clinical symptoms	BSI-18 (self-rated)	10
	Attachment	RAAS (self-rated)	5-10
	Satisfaction with care	CSQ, domain relatives involvement	5 -10
		VSSS-EU (self-rated)	5
Economic Evaluation	Use of healthcare services	TIC-P (interview)	10
	Quality of Life	EQ-5D-5L (self-rated)	3
Significant others	Burden of significant others	IEQ (filled in by informal support system)	10

Sample size

Power calculations of the study will be based on the earlier described meta-analysis investigating the effectiveness of RACT (31). Using the program G*power (two-sided, power = 80%, alpha = 0.05; G*power 3.1) with a medium effect size (*d* = .5), we found that a total of 126 participants would be sufficient to detect a statistically significant difference between the two conditions. If account is taken both of repeated measures within a person (assuming a within-correlation of 0.6) and of clustering of data (teams; assuming an Intraclass Correlation Coefficient (ICC) of .05, health centers; assuming an ICC of 0.1), a sample of N=133 is needed. To account for possible drop-outs (rate 35%), we aim to recruit a total sample of N=180. Eighteen teams at a total of nine Dutch mental health centers will participate, each with two teams. In principle, each team should deliver a mean of N=10 patients per team over the course of one year.

Analyses

Outcome data will be analyzed using multilevel mixed regression models with 4 levels: observations within people, people within teams, and teams within centers. Analyses will be conducted on the entire randomized sample (i.e., intention to treat). Supplementary analysis will be done on the completers sample. A completer will be defined after further inspection of the frequency of the RG meetings to define a minimum of attendance of an RG meeting during a 12-month period after the first assessment. In future publications the number of minimum RG meetings will be clearly stated within the definition of a completer and included in the consort flow chart of the RCT. To analyze potential between-condition differences in baseline characteristics (such as gender and diagnosis), we will use Student's t-tests for continuous variables and Pearson chi-squared tests for categorical variables. As a covariate, the analysis will include variables that show different distributions in the conditions (p=> .05 difference at baseline) and are correlated with the results. For categorical outcome variables we will choose counts and, if there are non-normal residuals, appropriate forms of mixed regression (such as binomial, Poisson and gamma). All analyses will be carried out using SPSS version 20+ and/or R version 3.0+. Results will be described in accordance with the CONSORT guidelines for randomized controlled trials (35).

Part Two: Economic Evaluation

The economic evaluation will involve both a cost-effectiveness analysis (CEA) and a cost-utility analysis (CUA). It will be performed from a societal perspective according to the intention-to-treat principle, using imputation to address missing data on the basis of the latest guideline for health-economic evaluation (64,65). All costs will be expressed in euro. Costs will be divided into one of three types: (1) main intervention costs in participating healthcare center; (2) mental healthcare utilization (e.g., medication, general practitioner, emergency care, outpatient visits to a general hospital, housing counseling, and admissions to a general hospital); and (3) costs stemming from productivity losses in paid work and volunteer jobs (both due to absenteeism and less efficiency while at work). Costs and outcomes will be evaluated at baseline, 9 and 18 months (parallel with the trial).

Research question

From a societal perspective, is the addition of RGs to FACT preferable to FACT alone in terms of costs, effects and utilities?

Analysis

At baseline, the homogeneity of groups will be assessed with regard to both costs and outcomes. Where necessary, we will control for baseline differences (66,67). The primary outcome parameter for the CEA will be treatment response after 18 months, which is defined as within-patient pre-post increase in empowerment (NEL). For the CUA, we will convert the health states resulting from the five dimensions of the EQ-5D-5L into utilities based on the Dutch tariffs of the EuroQol, the so-called EQ-5D value set (62). Using the area under the curve (AUC) method, the periods between the assessments will be weighted by these computed utilities. This will allow quality-adjusted life years (QALYs) to be adjusted over the entire trial period. Similarly, cumulative costs over the entire follow-up period will be obtained from the cost estimates at the various assessments (61,68). The total QALYs gained during 18 months is the primary outcome of the CUA.

Incremental Cost Effectiveness Ratios (ICERs) will be calculated for both CEA and CUA: ICER = (C1 - C2)/(E1 - E2), where C refer to costs, E to effects, and subscripts (1 and 2) to the two trial conditions (RG + FACT/ standard FACT). These ICERs express the average incremental costs associated with 1 additional unit of the measure of effect (69). For the CEA, this refers to the incremental costs per treatment responder (=increase at the NEL); for the CUA, it is the incremental costs per QALY gained. Next, confidence intervals around the ICER will be computed using a nonparametric bootstrap approach: >2500 non-parametric bootstrapped samples will be extracted from the original dataset. For each of the bootstrapped samples, the incremental costs, incremental effects, and the incremental cost-effectiveness ratio (ICER) will be calculated. The point estimates of the mean ICER and the resulting >2500 ICERs will be used for further calculation, and will be graphically displayed in a cost-effectiveness plane (69). Sensitivity analyses will be performed to assess the robustness of the findings. When conducting the analyses and describing the results, we will follow the CHEERS guideline for health-economic evaluations (70).

Part Three: Qualitative Case Study

The qualitative case study will be performed to improve our understanding of the RG method. It will focus on the dynamics of the RG, its meaning to those involved, and conditions for successful implementation. To this end, a multiple grounded case study with an interpretative, inductive analysis will be carried out (71–73). To increase validity, two people will jointly perform the case studies.

For inclusion, patients will be selected by means of the information derived from the baseline measurements taken during the quantitative study. Selected patients will then be approached for their approval for participation and to sign informed consent. Variation in inclusion will be pursued in terms of the time patients have been in care, the size and composition of the RG and the therapeutic working relationship. The case selection takes place in several steps. Based on the experiences with the first cases, new cases will be selected. We expect to include a total of approximately 6–8 patients and their RG before saturation occurs, saturation being the point at which sampling more data will not produce more information on the emerging theory and research question, or greater insight into them (71). The aim of this so-called purposive sampling is to produce a sample that can be assumed to be representative of the variety of the population.

Over the first year, the progress of all included patients and their RG will be followed closely. To this end, interviews will be held with the patient at several time points, and various parts of the process will be observed, such as goal-setting, the RG meetings and their evaluation. To complement patients’ view, interviews will be also held with different stakeholders (RG members and professionals). Participation in this part of the study will be voluntary, and will also take place independently of participation in the quantitative part. In a member check, all participants—thus patients and RG members alike—will be invited to attend a focus group session in which the main outcomes of the interviews and observations are discussed. They will be asked to verify whether their opinion has been expressed correctly.

Research questions:

- How do RG dynamics develop in practice?
- What is the significance to patients and the other RG members of participating in the RG?
- How and under what circumstances can the RG influence a patient's personal processes of recovery?
- How and under what circumstances can the RG influence the resilience of the social network?

Analysis

To provide scope for exploring any unexpected aspects of the material the analysis and data collection will be interwoven (73). The analysis will be performed according to the constant comparative method, in which, to develop the theory as it emerges, two analysts jointly collect, code and analyze the data, deciding as they go which data to collect next (73). To generate theories iteratively, we will also perform three rounds of coding: initial coding, focused coding and theoretical coding (71). To investigate unique processes within individual RGs, and the similarities and differences with other RGs, "within case" and "cross-case" analyses will be performed. To code and compare text fragments, themes, and concepts, we will use software for qualitative analysis (MAXQDA).

Discussion

This paper describes the study protocol for assessing the effectiveness, cost-effectiveness, meaning and implementation of the RG method for patients with severe mental illnesses. Our primary outcome measure is the empowerment of the patient in the RG.

This study has the potential to address two key issues in the care for patients with SMI. First, by combining clinical-effectiveness data with an economic evaluation and in-depth information from primary stakeholders, it will provide a thorough overview of the potential of the RG method to improve mental healthcare for patients with SMI. Giving patients directorship and systematically involving significant others both represent a break with more traditional forms of treatment, as they change the dynamics between patients, professionals and significant others. Using mixed methods to investigate the consequences will provide profound insights into the working mechanisms of the method, and will allow a clear prescription for the implementation of the RG method in Dutch mental healthcare. Second, even though significant others are in principle supposed to be involved within FACT, formal forms of integrating family into FACT are absent or limited in practice (11). The RG method fills this gap because it not only engages and activates resources of the informal network, it also pays attention to the subjective wellbeing, psycho-education knowledge and mutual communication- and problem-solving skills of patient's significant others. As well as having the potential to form a broad and stable social and community integration, the method hereby also contributes to a resilient emotional social environment.

Limitations

Some potential risks for bias are to be expected. First, although efforts are made to include the full range of severely mentally ill patients from the FACT population, it may still prove difficult to include patients who are not motivated to involve their social network within mental healthcare. This means that great caution will be necessary when generalizing the results to all patients in FACT-care—including those who have a difficult or non-existent relationship with their social network. In any case, generalization will be possible only after thorough inspection of the data and baseline data.

Second, in line with the RG model, patients will decide who will be nominated as RG members. This may mean that they do not select people from their informal support system (e.g., family, friends, colleagues), but only from their formal support system (e.g., professionals from within and/or outside mental healthcare). However, previous studies indicate that the variety in the RG composition and the engagement of the informal support system might be determining factors in the effectiveness of the RG method (34). It is therefore possible that potentially positive effects are missed because the informal environment is not engaged. However, as the main intention of the RG method is to develop agency over and ownership of treatment, it would conflict with the model if patients were obliged to include certain people. To deepen understanding of the effect of engaging the informal support system within the RG, the qualitative case study will seek to include cases with varying RG compositions (e.g., with and without informal support system).

Third, because the same FACT team will perform treatment and care for both conditions, it is possible that elements of the RG method will spill over into the standard FACT control condition. Although trained caregivers will be explicitly instructed not to integrate aspects of the RG method within the standard FACT condition, it cannot be ruled out that discussing and thinking about the RG method will lead to the unconscious application of principles of the RG method within standard FACT.

Fourth, the RG method has a specific structure, and identifies clear steps for putting the intended philosophy in practice. As such steps are not described so clearly within standard FACT, there is a risk of erroneous concluding that the RG philosophy leads to better effects, while any such effect could also be attributed to the differences resulting from the provision of structure for involving significant others. The use of qualitative material to interpret the quantitative findings will help to avoid this risk.

Statements

Ethics approval and consent to participate

Ethical approval has been provided by the Medical Ethical Committee at the VU Medical Center (IDS: 2017.316), which confirmed that the Medical Research Involving Human Subjects ACT (WMO) does not apply to the study. The local ethical research committees at all participating mental health centers also approved participation. The study has been registered in the Dutch Trial Register, identifier: NTR6737. All participants will sign an informed consent form prior to participating. A separate consent form is signed for participation of the add-on qualitative part of the study.

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Chapter 3.

Attachment as a Framework to Facilitate Empowerment for People with Severe Mental Illness

Associations between Attachment Anxiety, Attachment Avoidance, Social Functioning and Empowerment

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Abstract

Objectives

Recovery and empowerment have evolved into key objectives in the treatment and care of people with severe mental illness (SMI), and interest has grown in the role of social relationships in recovery. This study is the first to explore whether attachment styles are related to levels of empowerment, and secondly, whether attachment anxiety and attachment avoidance are associated with lower empowerment levels, independently of quality and frequency of social contact.

Design

We used a cross-sectional design.

Methods

In a sample of 157 participants with SMI in outpatient care, associations between attachment (Revised Adult Attachment Scale), self-reported social functioning, and empowerment (Netherlands Empowerment List) were assessed.

Results

Attachment anxiety and attachment avoidance were both associated with lower levels of empowerment. A stepwise multiple regression analysis showed that the prediction of empowerment was significantly improved by adding attachment anxiety and attachment avoidance to quality and frequency of social contact. Attachment anxiety, attachment avoidance and quality of social contact were significant predictors; frequency of social contact was not.

Conclusions

Although our design does not allow causal conclusions, our results highlight the importance of interpersonal processes and behaviours as routes to improving empowerment for people with SMI. A promising approach might thus consist of securing attachment bonds with significant others so that the self and the other are perceived as reliable resources. Our findings also feature the importance of reciprocity and equality in social relationships. Taken together, our study emphasizes the value of social, contextualized interventions in recovery work for people with SMI.

Practitioner points

- Working towards attachment safety in interpersonal relations may be important in recovery-oriented treatment and care for people with severe mental illness (SMI).
- Helping people with SMI to recognize and change how they tend to relate themselves

to others may promote engagement and effectiveness of recovery-oriented treatment and care.
- Reciprocity and equality in social relationships as vital complements to the more one-sided nature of 'standing alongside' and offering support may be important requisites for empowerment.

Introduction

Traditionally, severe mental illnesses (SMI) were considered chronic diseases with relapsing or deteriorating symptoms and poor prognoses (1). Recovery was perceived as a medical outcome defined by remission of mental-health symptoms and return to normality (2,3). However, the consumer movement has stimulated a focus on a broadened definition of recovery within the mental-health services (3). Here, recovery is conceptualized as 'a personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles', and 'a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness' (4). The evidence for recovery practices and outcomes is increasing rapidly (e.g. (3,5)), and the enhancement of recovery is evolving into a key aspect of international mental-health policies (see (6)). Recovery orientation in mental health care is now a fundamental principle of the World Health Organization's Comprehensive Action Plan for Mental Health (7).

Empowerment is a key aspect of recovery from SMI (5,8). It refers to a learning process focused on restoring a sense of self-determination in everyday life by improving individuals' levels of choice, influence and control (9,10). The mental health care culture is moving towards more equitable and collaborative approaches with the ethic of empowering patients to make informed decisions (11,12). Empowered mental health consumers have a good self-esteem, use health services more effectively, have improved abilities to manage their disease and adopt healthier behaviour (13–17). Moreover, they believe to be self-efficacious, and are optimistic about the future (18). Importantly, as well as an individual focus, empowerment entails a group dimension focused on the social and relational context of the process (19–22). Indeed, according to its working definition, empowerment does not occur in the individual alone, but includes a sense of connectedness with other people (5,23).

As a result, there is an increased interest in social relationships as a way to empower people within their own environment. In fact, social relationships and interactions have been identified as key agents of change in recovery (24–26) and it has been found that at least one relationship that provides hope and encouragement is a critical factor in the process of recovery (27). This highlights the important task of mental-health services to facilitate patient's connectedness with others in a way that contributes to a social environment within which recovery and empowerment processes can take place.

However, people with SMI often experience difficulty in developing and maintaining social relationships (28,29). Over half of them report feeling lonely (30), they have fewer close relationships (31) and not all relationships and social interactions are experienced as positive or supportive (22,32,33). Moreover, the emotional atmosphere within social relationships is found to be important: the risk of relapse can be greatly increased by a high level of expressed emotion (defined as intrusive over-involvement or consistent patterns of criticism and hostility) (34). So, although it is increasingly recognized that social factors are important to the process of empowerment, it remains unclear how individuals with SMI and their significant others can be supported in changing the characteristics of their relationship such that their interactions offer opportunities for support, engagement and empowerment.

Attachment theory might provide a promising theoretical framework to enhance understanding in how to create such empowering interactions and support the development of positive relationships. Attachment theory proposes that one's interpersonal relating styles emerge from early experiences with primary caregivers. As a child ages, internal working models about the self and others are developed, representing internalized beliefs and expectations in relationships. These models characterize attachment styles, and guide emotions, motives and goals in interpersonal situations (35–37). Attachment styles are assumed to be stable over time but recent research shows that they can change, according to context and recent experiences (e.g. (38–42)).

Attachment is conceptualized in terms of two independent dimensions that underlie internal working models: attachment anxiety and attachment avoidance (43). The dimension of attachment anxiety is also referred to as the model of self, and is associated with a negative self-perception and an excessive need to be approved by others. Attachment avoidance is referred to as the model of the other, and reflects the extent to which a person distrusts the goodwill of other people, and strives to maintain behavioral independence and emotional distance (44,45).

An individual's location at the intersection of these two dimensions yields four attachment prototypes, see Figure 1 (44). Prototypically secure individuals score low on both dimensions. They have positive images of the self as deserving love and support, and perceive the other as a source of comfort and assistance. In contrast, individuals with an insecure attachment style have high levels in one or both dimensions: they are preoccupied (high anxiety, low avoidance); dismissing-avoidant (low anxiety, high avoidance); or fearful-avoidant (high anxiety, high avoidance) (44,46). Since Bowlby's influential work, a growing body of research has linked attachment insecurity to different forms of psychopathology (47–50), including serious psychiatric disorders (51–54). However, even though research has linked attachment style with clinical outcomes, there has been little exploration of the potential link between attachment style and indicators of recovery.

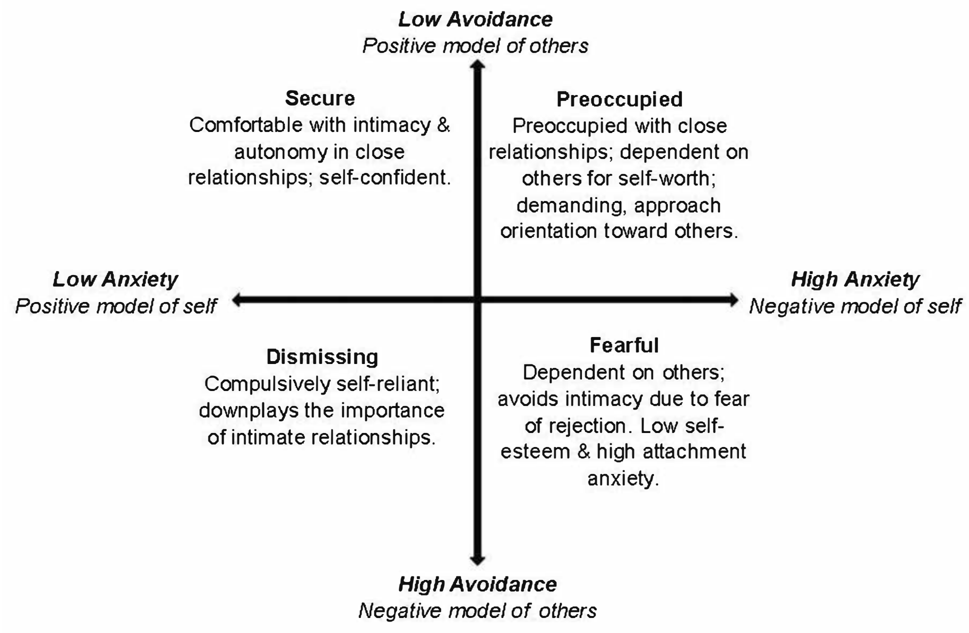

Figure 1. Bartholomew's Two Dimensional, Four-Prototype Model of Adult Attachment.

Therefore, the present study intends to explore whether attachment theory can enhance our understanding of how to create social interactions within which recovery can take place by investigating the associations between attachment patterns and empowerment for people with SMI. Because attachment patterns shape individuals' beliefs about their environment through a sense of self and others, they might support shaping beneficial environments in which people with SMI feel empowered. Greater understanding of attachment processes can then be useful for patients, family, friends and practitioners in facilitating recovery. We hypothesized that (1) prototypical insecure attachment styles are associated with lower levels of empowerment, and that (2) the dimensions of attachment anxiety and attachment avoidance are associated with lower levels of empowerment, independently of quality and frequency of social contact.

Methods

Study Design

This study has a cross-sectional design and is based on baseline data from a randomized controlled trial assessing the effectiveness of Resource Groups in Flexible Assertive Community Treatment (FACT) (55) for people with SMI in the Netherlands. Details of the protocol are described elsewhere (56). FACT is the most widely used long-term outpatient care for people with SMI in the Netherlands.

Procedures

Patients were recruited between September 2017 and February 2019 at nine mental-health centers throughout the Netherlands. The study population consisted of patients aged between 18 and 65 who met the Dutch consensus criteria for SMI (57) and were expected to be treated by the FACT team for more than 12 months. Patients entering a FACT team (i.e., during intake) and those who had already been treated by the FACT team for no more than 24 months were eligible. Patients were excluded if they were unable to understand Dutch and/or to sign for informed consent. Care providers in the FACT team informed eligible patients on the study and invited them for participation. An independent researcher checked the in- and exclusion criteria and scheduled an appointment for signing informed consent and a face-to-face assessment that lasted approximately 90 minutes. Participants received a gift voucher worth €15. Socio-demographic characteristics gathered during the interview included gender, age, marital status, education, employment status, and history of mental health and hospitalization.

Outcomes

Empowerment. The *Netherlands Empowerment List* (NEL; (58)) is a 40-item self-report questionnaire for measuring empowerment. Items were generated from a narrative, qualitative analysis of the recovery process in people with SMI. The NEL contains six subscales: 'social support' (7 items); 'professional help' (4 items); 'connectedness' (6 items); 'confidence and purpose' (12 items); 'self-management' (5 items); and 'caring community' (6 items). A sample item from the 'confidence and purpose' scale is 'I decide how I control my life'. Respondents rate their agreement on a 5-point Likert-scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The NEL displayed good internal consistency, moderate convergent validity and good discriminant validity (58). For this study, the mean of the total score was used (α =.92).

*Attachment***.** The Revised Adult Attachment Scale (RAAS; (59,60)) is a 18-item self-report questionnaire intended to assess difficulties in adult attachment. The respondents answer items such as ‘I often worry that other people don’t really love me’, on a 5-point Likert-scale ranging from 1 (*not at all characteristic of me*) to 5 (*very characteristic of me*). The scale consists of three subscales, each containing six items: ‘close’, ‘depend’ and ‘anxiety’ (Collins, 1996). The items of the ‘close’ and ‘depend’ subscales were reverse scored and averaged to form an overall index of the ‘attachment avoidance’ dimension (12 items) that reflects the degree to which individuals tend to avoid intimacy and interdependence with others (α = .78). The ‘anxiety’ subscale comprises an index of the ‘attachment anxiety’ dimension (6 items) that reflects the degree to which a person is worried about being rejected or unloved (α = .84). Participants responded in terms of their general orientation toward close relationships (61,62). The reliability of the RAAS is satisfactory to good (59,63,64).

The two dimensions generate four prototypical attachment styles: secure, dismissive, preoccupied and fearful. To this end, we z-transformed the scores so that the two dimensions cross at zero and the standard deviation equalizes the spread. See Collins and Feeney (63) for this procedure. While categorical representations are often used in a clinical setting, dimensional representations are preferred for research purposes (65). In this study we used both representations of attachment in order to both appeal to a wide, clinical audience and obtain a deeper comprehension of the results. Figure 1, presented by Allison et al. (66), shows the features and characteristics of the dimensional and categorical representations of attachment.

*Frequency and quality of social contact***.** To obtain information on social functioning, subjects self-reported the frequency and quality of social contacts over the past 3 months for five different categories: ‘family’, ‘friends’, ‘acquaintances’, ‘colleagues’ and ‘general’. Per category, the frequency of social contact was assessed on the basis of questions such as ‘In the past 3 months, how frequently did you see your friends?’. Answers were rated on a 7-point scale ranging from 1 (*daily*) to 7 (*not at all*). The perceived quality of social contact per category was assessed on the basis of items such as ‘In the past 3 months, it was pleasant to see my friends’. Answers were rated on a 5-point scale ranging from 1 (*always*) to 5 (*never*). If participants had indicated they had not seen their friends in the past 3 months, they did not fill in the questions on the quality of the contact. Participants who did not work did not fill in questions on contact with colleagues. Scores over the 5 groups were averaged to assess frequency (α = .63) and quality of social contact (α =.83).

Data analysis

The data was stored using an online encrypted server (Jambo) and all analyses were performed using SPSS, version 25 (IBM). One participant quit the assessment after finishing under 10% of the questions; the data was removed. Before the hypotheses were tested, the following analyses were conducted. First, the data was checked, using boxplots for outliers and kurtosis and skweness z-scores for normal distributions. Second, we computed frequency distributions, and mean and standard deviations for the subjects' socio-demographic characteristics, empowerment, attachment style, and the frequency and quality of social contact. Last, to explore associations, we determined correlations between empowerment, attachment dimensions (i.e. anxiety and avoidance) and measurements of social functioning (i.e. frequency and quality of social contact).

To test the first hypothesis – whether prototypical insecure attachment styles are associated with lower levels of empowerment – we performed a univariate analysis of variance (ANOVA), comparing intergroup differences in attachment styles on empowerment. We then converted the attachment styles into dummy variables, with secure attachment style as the reference category, and used a linear regression to predict the empowerment score. For the second hypothesis, we used the dimensional representation of attachment. A hierarchal regression analysis was performed to determine whether the two attachment dimensions predicted empowerment scores, independently of frequency and quality of social contact. To this end, the measurements of social functioning (frequency and quality of social contact) were entered into the model in the first step, and attachment anxiety and attachment avoidance were entered in the second step. The level of statistical significance for all analyses was set at p <.05.

Results

Sample characteristics

The definitive sample consisted of 157 participants aged 20 to 66 (M=40.17 years, *SD* = 11.2), 93 (59%) male and 65 (41%) female. Thirty-three percent of the sample had a partner and 45.6% had children. Most had been born in the Netherlands (79%). The highest completed educational level varied: 4.4% of the participants had not finished any education, 19.1% had completed primary school, 58.3% had finished secondary school, and 17.1% had finished college/university. Half of the participants (50.1%) of the participants were unemployed, 13.9% were in paid employment and 15.2% did volunteer work. Mean self-reported age at first contact with the mental-health services was 28.3 years (SD = 12.7, range = 6 - 60), and mean self-reported duration of contact with these services was 8.1 years (SD = 7.45, range = .08 – 35.00). Seventy-three percent of the sample had been hospitalized in their life, 23.3% of them more than three times.

Attachment style and empowerment

We first explored the correlation of some demographics (age, gender, education) with the mean NEL total score. As none of these were significant, we did not include these in the further analyses. To test the first hypothesis, we divided participants into one of the four categorical attachment styles (Collins & Feeney, 2004). This produced 52 (32.9%) patients with a secure attachment style, 28 (17.7%) with a preoccupied attachment style, 23 (14.6%) with a dismissive attachment style, and 54 (34.2%) with a fearful attachment style. The mean NEL total score differed significantly between attachment styles ($F_{3,\ 153}$ = 10.12, p< .001). More specifically, the dummy regression showed that the empowerment scores of patients with a secure attachment style were significantly different from those of patients with a dismissive attachment style (β = -.245 p< .05) and from those of patients with a fearful attachment style (β = -.500, p < .001). See Figure 2.

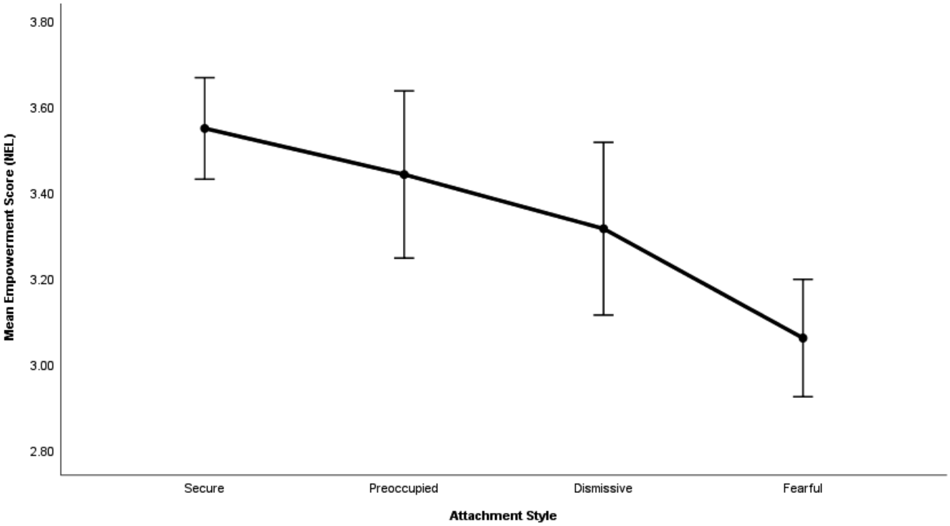

Figure 2. Mean empowerment score (NEL) for the four prototypical attachment styles. Error bars represent 95% CI.

Attachment dimensions, social functioning and empowerment

To test whether attachment anxiety and attachment avoidance would predict empowerment scores independent of the social functioning measures, we first explored correlations between the variables (Table 1). This showed that attachment anxiety and attachment avoidance were moderately correlated (r = .5), indicating related but distinct aspects of the same construct. Attachment anxiety and avoidance were both significantly correlated with the mean NEL empowerment score. Quality of social contact was also significantly correlated with the mean NEL empowerment score, but frequency of social contact was not.

Table 1. Pearson correlation coefficients between the variables.

Variable	1a	1b	1c	1d	1e	1f	1g	2	3	4a	4b	4c	4d	5	6
1 Empowerment															
1a Mean Total Score	1														
1b Confidence and purpose	.876**	1													
1c Social support	.726****	.446****	1												
1d Caring community	.665****	.435****	.472****	1											
1e Connected-ness	.788****	.604****	.553****	.405****	1										
1f Self- management	.798****	.813****	.400****	.353****	.575****	1									
1g Prof help	.376****	.133	.277****	.247****	.313****	.160**	1								
2 Attachment anxiety	-.403**	-.312****	-.372**	-.356**	-.211**	-.330**	-.126	1							
3 Attachment avoidance	-.440**	-.348****	-.436**	-.271**	-.361**	-.276**	-.171*	497***	1						
4 Attachment tyle[1] [2]		**													
4a Safe	.295**	.246**	.275**	.181*	.200*	.219**	.130	-.692****	-.633****	1					
4b Preoccupied	.098	.102	.087	.003	.128	.019	.063	.343**	-.291**	-.325**	1				
4c Dismissive	-.014	-.023	-.005	.119	-.087	.007	-.110	-.243**	.264**	-.289**	-.192*	1			
4d Fearful	-.383**	-.328**	-.353**	-.291**	-.252**	-.253**	-.103	.590**	.666**	-.505**	-.334**	-.297**	1		
5 Frequency of social contact	.128	.109	.139	-.001	.254**	.027	.026	.043	-.086	-.032	.042	-.002	-.012	1	
6 Quality of social contact	.615***	.491**	518**	.313**	.558**	.458**	.293**	-273***	.384***	.182*	.120	-.099	-.199*	.219**	1

Note. *** indicates p < .001. ** indicates p < .01.

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[1] Correlational values of the different attachment style (represented as dummy variables) and the other continuous variables are Point Biseral correlation coefficients.

[2] Correlational values between the different attachment styles (represented as dummy variables) are Phi correlation coefficients.

We next performed a hierarchal multiple linear regression to predict the mean empowerment score. Quality of social contact and frequency of social contact were entered in the first step and attachment anxiety and avoidance were entered in the second step. As Table 2 shows, addition of the two dimensions of attachment significantly improved the prediction of empowerment. The final model explained 44.1% of the variance (R^2=.455; Adjusted R^2=. .441; $F_{4,\ 151}$ = 31.51, *p* < .001). Quality of social contact was a significant predictor of empowerment (β = .50, p<.001), and attachment anxiety and attachment avoidance were negative significant predictors (β = -.19, p<.01 and β = -.16, p <.05 resp.). In neither model was frequency of social contact a significant predictor.

Table 2. Regression model for predicting empowerment scores (NEL, outcome variable) from the frequency of social contact, the reported quality of social contact and attachment (predictor variables).

		b	*SE b*	*b*
Step 1				
	Constant	1.723	.197	
	Frequency of social contact	-.004	.030	-.009
	Quality of social contact	.433	.046	.617***
Step 2				
	Constant	2.648	.287	
	Frequency of social contact	.005	.028	.011
	Quality of social contact	.352	.047	.501***
	Attachment Avoidance	-.123	.058	-.155*
	Attachment Anxiety	-.099	.037	-.189**

Note. R^2 = .38 for Step 1; R^2 = .46 for Step 2 (*ps* < .001). * indicates *p* < .05. ** indicates *p* < .01. *** indicates *p* < .001. *b* represents unstandardized regression weights, *SE b* the standard error for the unstandardized regression weights and *b* indicates the standardized regression weights.

Discussion

To the best of our knowledge, this is the first study to examine the relevance of attachment theory to facilitating empowerment in people with SMI. Our findings suggest that the incidence of insecure attachment patterns is high in people with SMI. They also showed an association between insecure attachment patterns and decreased empowerment. As expected, when entered in a regression model with quality and frequency of social contact, the two attachment dimensions– attachment anxiety and attachment avoidance – were significant predictors for empowerment scores. This indicates not only that attachment problems are highly prevalent, but that they may obstruct recovery-based social and societal interventions. To shape empowering social relationships, and to maximize engagement and the effectiveness of recovery-oriented treatment and care, people with SMI may therefore benefit from insights from attachment-oriented interventions.

Given the high predictive value of quality of contact to higher empowerment scores, our findings highlight the importance of creating social environments that facilitate empowerment processes. Rather than being a function of the frequency of social contacts and activities, such empowering environments seem to depend on their perceived quality. These findings are in line with a substantial body of research that argues for the need to include the social context in understanding, analysing, and responding to people's mental-health difficulties (20,22,67,68). They also show the key importance of positive social interactions in contributing to recovery in people with SMI (25,69). Moreover, previous evidence suggests that rather than focusing on increasing the number of social contacts and relationships, social interventions should emphasize their quality (29,70).

To build on this, our study sought to take a further step towards understanding how social relations are perceived as empowering by investigating attachment patterns. As with previous studies (71–73), our results suggest that a majority of people with SMI have an insecure attachment style and are therefore prone to difficulties in trusting and relying on others and themselves. Notably, our results suggest that this influences the degree of empowerment. Indeed, the prediction of empowerment scores was improved when the two dimensions attachment anxiety (i.e. model of self) and attachment avoidance (i.e. model of other) were added to measurements of social functioning. In the final model, attachment anxiety, attachment avoidance and quality of social contact were significant predictors, while frequency of social contact was not. With regard to empowerment, this indicates that attachment is a distinct and important component of satisfying social contact, not merely a function of it.

Our results suggest that low attachment anxiety – in other words, a person's sense of self as capable, competent and having something to offer in relation to significant others – is an important requisite for empowerment. This highlights the importance of reciprocity and equality in social relationships as a vital complement to the more one-sided nature of 'standing alongside' and offering support (22). For as long as social contacts are characterized by the latter, the working models of the fragile, unlovable self and the strong, knowing other may be confirmed – thereby verifying the characterizing tendency in attachment anxiety to depend on others for personal validation, acceptance and approval. As this might, in turn, stimulate feelings of being dependent on others, it would stand in the way of developing a sense of autonomy and agency that is essential for empowerment (74,75). Hence, a degree of mutuality and equality within relationships is important to improving one's sense of self-worth (76,77). This supports the view that a functional sense of self or identity is an important factor in recovery, and in facilitating effective coping and mobilization of support (64,78).

The negative predictive value of attachment avoidance on empowerment indicates that the process of empowerment is also interfered by a pattern in which a person downplays the importance of close relationships, has little confidence in others, and defensively denies the need for their support. If people do not trust others' goodwill and strive to maintain emotional distance, they will be unable to build safe social relationships, thus discarding potential sources of support. This reinforces the notion that empowerment is not the same as being able to do everything independently, but involves actively choosing to let others in, ask for help, and develop trust in them (79–81). Indeed, a crucial part of recovery is choosing to move towards rather than away from others (18).

Implications

In short, our results show that relational views of the self and others are substantial components in facilitating empowerment. This has several theoretical and clinical implications for working towards empowerment for people with SMI. Most importantly, rather than working with individual members, an attachment framework would emphasize the importance of increasing empowerment through a focus on relationships within social systems. Hence, by creating a secure base that facilitate connectedness within this system and exploration outside of it; treatment and care would focus on shifting the mutual attachment relationships within a social system toward greater security (82). Hereby, working with attachment relations is a way of perpetuating the role of the interpersonal world in treatment and care. Both individual treatments (e.g. (83)) as well as family attachment interventions that target the family attachment system as a framing device (e.g. (84)) describe different ways towards transforming impaired and distorted representations of self and others in order to create security within a social system. The development of bidirectional and supportive relationships is one aspect of such secure base. Moreover, working towards understanding the past from everyone's perspective, expressions of forgiveness and acceptance, and open communication are all essential parts that constitute a secure base, change the mutual relational styles and have the potential to modify internalized attachment representations (84–88).

In addition, the notion of epistemic trust might be important in the development of a secure base that is characterized by trustful mutual collaboration partnerships in order to facilitate empowerment. Epistemic trust describes the willingness to accept new information from another person as trustworthy, generalizable, and relevant and it allows individuals to benefit and learn from their (social) environment (89–91). In other words, in order to be able to develop meaningful partnerships and to turn to others in time of need to make sense of what is happening to us, individuals need a workable level of epistemic trust. To facilitate empowerment by creating attachment safety in a social system, future studies could therefore consider the three communicational systems that are maintained to restore epistemic trust (see (91)). The notion of epistemic trust constitutes a shift towards a socially oriented perspective and to interventions that target both malignant and beneficial aspects of the environment (89), and it also emphasizes the importance of a good therapeutic relation. That is, the feeling of being understood, supported and valued within the therapeutic relation is seen as an essential starting point which makes life outside treatment and care a setting in which new information about oneself and the other can be acquired and internalized (91,92).

Taken together, we argue that the facilitation of the process of empowerment of the patient should be considered in the context of the interpersonal and social world so that relations with significant others, such as family, friends and professionals, become meaningful working mechanisms in treatment and care. Importantly, a good therapeutic relation might be fundamental to engage readiness for patients to step into beneficial partnerships with their social environment. Future research can rely on these theoretical advances to further investigate how to establish a social environment that is characterized by safe attachment bonds in order to facilitate empowerment.

According to the social baseline theory (93), developed from the social neuroscience of attachment processes, the human brain evolved in a highly social environment. The presence of other people helps individuals to conserve important and metabolically costly resources. Therefore, rather than conceptualizing human beings as separate entities, it makes more sense to consider social relatedness and its mental correlates as the normal ‘baseline’ condition (93–95). Using this as a starting point helps us to understand why experiences of separation, loneliness, rejection, abuse, and neglect are so detrimental and distressing, and why restoring functional and safe social relationships is so essential to recovery and empowerment.

Limitations

The current findings have to be interpreted in light of the following limitations. First, our findings are based on cross-sectional data, which limits causal conclusions on the influence of changes in attachment for empowerment. Given various promising attempts to revise and modify attachment during treatment (e.g. (42,84,96,97)), we would recommend that future studies use longitudinal data to explore whether attachment patterns could indeed be a working mechanism for bringing about changes in empowerment. In addition, applying mediation analyses on longitudinal data would be helpful in order to further investigate whether quality of social contact is in fact a mediator between attachment and empowerment. Also, the effect sizes for attachment dimensions appear rather small, with quality of social support being much larger. This does not invalidate the role of attachment, but does suggest a nesting within a more complex set of factors. Longitudinal data and mediation analysis would be helpful to unravel the different factors that influence empowerment.

Second, psychotic episodes and levels of positive and negative symptoms have been argued to influence attachment styles (98); if the course of illness is more severe, an individual may develop more difficulties in attachment relationships and therefore a more insecure attachment style. For this reason, it is not fully understood whether attachment style is predictive of symptoms of illness, or whether it changes as a result of the illness (71,98). Our patient sample had a range of diagnoses, including affective and non-affective psychosis, bipolar disorder, and personality disorder. As we did not control for symptomatic levels of any kind, the influence of fluctuating symptoms on attachment scores cannot be ruled out, and require longitudinal studies. Related to this, we did not control for factors potentially influencing the association. Therefore, future studies should include other variables (i.e., depression, loneliness, having a partner, etc.) or apply tighter inclusion/exclusion criteria to further isolate and clarify the effect.

Third, it could be argued that empowerment and attachment – which derive from two different fields of research and practice – are essentially two sides of the same coin, both involving situations and influences that make people feel that they are important and matter to themselves and the world around them. Indeed, we found high correlational values between (the subscales of) the constructs, as reported in Table 1. However, examinations of the items in the two questionnaires made us doubt their similarities. While the RAAS mainly concerns relational distance from and trust in others, the NEL clearly assesses a broader range of areas in life. Some questions concern significant others, support and feeling accepted, while others assess hope for the future, having purpose in life, insight into autobiographical events, and being able to do things that matter. Nevertheless, future research should further investigate the overlap and distinctness of the two constructs.

Lastly, we argue that a two-dimensional method of assessing attachment should be used to include the perspectives of practitioners and significant others (i.e. involved family members and close friends). This would provide insight into the bilateralism of the attachment patterns and the subsequent approach to enhancing attachment safety of the social environment. Indeed, problematic relationship styles may reflect low self-esteem on the part of carers (99), indicating that, if the relationship is to recover, carers may need support too (22). As strengths, resources and vulnerabilities in the network become visible, insight into the interaction would facilitate system changes.

Conclusions

Empowerment is increasingly recognized as an important objective in the treatment and care for people with SMI. Our main finding – that attachment is a consistent predictor of empowerment for people with SMI – is important in the context of its clinical applications, as it indicates the significance of interpersonal processes and behaviours for improving empowerment. We show that a majority of the people with SMI have insecure attachment patterns, and therefore find it difficult to trust and rely on others and themselves. This complicates social interventions and may explain the social difficulties and loneliness that people with SMI experience. In line with attachment theory, it might be important that those in a patient's social environment all develop alternative coping strategies to adjust interpersonal attachment safety. It then follows that to achieve sustainable alterations in empowerment the focus of treatment should be broadened towards system changes. Hereby, our study emphasizes the value of social, contextualized interventions in recovery work for people with SMI.

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Chapter 4.

Embracing the Social Nature of Recovery

a Qualitative Study on the Resource Group Method for People with Severe Mental Illness

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Abstract

Objective

The resource group method for people with severe mental illness might provide a useful framework to facilitate patient's empowerment and systematically engage significant others. However, no research has explored the perspectives and experiences of patients and their significant others. This is crucial for better adjustment to the needs of the people using the method. The aim of this study was to develop a useful framework for a deeper understanding of the resource group method and its outcomes.

Method

The study used a longitudinal, qualitative multiple case-study design based on grounded theory methodology. During a period of two years, the developments and processes in eight resource groups were explored by conducting a total of 74 interviews (e.g. with patients, significant others and mental health professionals) and 26 observations of resource group meetings.

Results

Analysis showed that a well-functioning resource group set the stage for five processes to unfold: (i) experience of support; (ii) acknowledgment of significant others; (iii) activation; (iv) openness; and (v) integration. These processes facilitated recovery both in terms of an arousing curiosity within the patient as well as increasing reciprocity and equality in their social relations. In addition, the method emphasized the uniqueness of each recovery journey, thereby providing a framework to shape recovery-oriented care. The analysis also revealed three hindering factors: (i) embedding and implementation issues; (ii) predominant network; and (iii) tensions inherent in the resource group setting.

Conclusion

Working according to the resource group method involves that the person's recovery work becomes a social process that takes place in relation to the social environment and everyday life in which it is important to acknowledge and integrate the needs of significant others in treatment and care. This study provides a first step toward a multidimensional comprehension of the resource group method, the working mechanisms and its influence on recovery for people with severe mental illness.

Introduction

Flexible Assertive Community Treatment (FACT), a Dutch variant of Assertive Community Treatment (ACT; (1)), has been implemented throughout the Netherlands for patients with severe mental illness (SMI) experiencing problems in important domains in life (e.g., housing, finances, work, and social functioning). FACT is a service delivery model that combines highly intensive multidisciplinary treatment for clients at risk of relapse with moderate intensive care in times of stability (2). It has been argued that the current FACT teams can be enriched by integrating the resource group (RG) method into FACT for a more effective mobilization of patients' networks to achieve treatment and social inclusion goals (3). However, in-depth knowledge of the potential value of the RG method in the Dutch context of FACT is lacking.

According to the RG method, patients, significant others from their informal network (friends and family) and members of their formal network (social worker, nurse, case manager, psychiatrist, and peer worker) form an RG (4) (5). The RG meets quarterly to discuss the patients' recovery goals and wishes, and to jointly develop a plan to achieve them. The RG method is built around (re)capturing the patient's agency. Therefore, patients are encouraged to nominate those who will be included in the RG, define the recovery goals that determine the agenda of the meetings, and make decisions on how the meetings are designed (6). An important characteristic of the RG method is that significant others are systematically engaged in treatment and care (7). The treatment team no longer solely comprises care professionals but is augmented by the patient themselves, family members, friends, or others who are important to the patient. Mutual partnerships are developed and important treatment decisions are jointly made in the RG meetings, based on shared decision-making principles (8) (6).

The origins of the RG method lie in the Optimal Treatment (OT) model, which integrates biomedical, psychological, and social strategies in the management of SMI (9) (10). In Sweden, the model was further developed and relabeled as Resource Group Assertive Community Treatment (RACT) (11) (4) (7), in which ACT teams were enriched by resource groups. Research on RACT has focused on effectiveness and found improvements in functioning, well-being, and symptoms for people with psychosis (7) (4). However, the available studies provide little insight into the meaning for and experiences of all those involved when the RG method is implemented. Qualitative contributions to the body of knowledge of the RG method are scarce and have focused on the case managers' point of view (6). Therefore, this study used a qualitative design to explore the perspectives of patients, family, friends, and mental health care professionals when working with the RG method within FACT.

Study Aims

Based on the limited knowledge in the literature of the meaning of working according to the resource group method, the present study aimed to: (i) identify the general themes of the resource group method from the perspectives of patients, significant others and mental health professionals; and (ii) develop a useful framework for deeper understanding of the resource group method and its outcomes in terms of recovery for people with severe mental illness.

Methodology

Context of the study

This exploratory qualitative study was conducted in the context of a randomized controlled trial (RCT) on the (cost) effectiveness of RGs embedded in FACT for people with severe mental illness (SMI) in the Netherlands; for a detailed description, see Tjaden et al. (12). To start an RG in FACT, several phases are carried out. In short, patients ask their significant others and mental health professionals to join the RG; this process is referred to as nominating. Then, together with a mental health practitioner of the FACT team, patients prepare the first RG meeting by developing a recovery plan to discuss during the meeting, by setting the agenda, and by deciding on the location and chairman (preferably, the patients themselves). Before the meeting, the practitioner invites the nominated RG members for an in-depth conversation about the relationships among the nominee, the patient, and the other RG members, and the role the nominee wants to have in the RG. Follow-up RG meetings are scheduled once every three months on average. The composition of the RG is flexible and might change over time depending on patients' goals, wishes, and phase of recovery.

Design

The study used a multiple case study design, based on the grounded theory (GT) methodology, for the in-depth exploration of processes and developments in eight cases (i.e., eight patients and their RGs). GT is a method that inductively builds an interpretative theory of a social phenomenon, based on qualitative data (13) (14). By following a smaller number of cases for a longer period of time, the researchers aimed to acquire rich data (15) (16) to identify key concepts supporting the theoretical understanding of the impact of the RG method on all those involved.

Recruitment

After patients completed the baseline assessment of the aforementioned RCT, the first author asked them whether they agreed to participate in the qualitative study. Initially, a purposive sampling strategy was employed among those willing to participate, aiming to include a diversity of patients in terms of sites, diagnosis, gender, and current and past service use. The first author approached seven patients and provided more information about the study; all of them agreed to participate. Two patients dropped out after the first interview and their data was removed; one of them was referred to a different treatment setting, and the other withdrew consent after one week. A second round of sampling was conducted after the first few months of data collection and initial analysis. In this round, RGs who could shed light on preliminary categories and concepts were invited. This form of theoretical sampling was made possible because the first author had insight into all the RGs in the RCT. Three additional cases were included in the study after the second round of sampling.

The final sample included eight cases: eight patients and their RGs, comprising 10 informal RG members (i.e., family and friends) and 20 formal RG members (i.e., mental health professionals). Five cases were followed and interviewed by the first author and three by the second author. Cases were followed until within-case saturation occurred (i.e., the moment when new data collection no longer seemed to bring up major new developments in that particular case (17)); the time period ranged from six months to two years. In one case, setting up the resource group was repeatedly postponed until after the end of the study; however, we continued to monitor this case and included the data in the study because it offered insight into the impeding factors of the RG method. See Table 1 for a short description of each participant and his/her RG.

Data collection

Data collection took place between November 2017 and December 2019. All interviews and RG meetings were recorded, transcribed verbatim, and anonymized. The researchers kept memos and field notes throughout the data collection. There was no time limit set for the interviews, the duration ranged from 20 minutes to 2 hours.

In each case, the data collection started with a narrative interview with the patient (18) to get acquainted with his/her life story, most important relationships, wishes for the future, perceived obstacles in life, and expectations of the RG. In the following period, the researchers established a personal connection with the patients built on the co-construction of knowledge and the recognition that the researchers were carrying out research with their participants, not on them (19) (20) (21) (22). To this end, the researchers remained in close contact with the patients throughout the study period by means of telephone calls, app contacts, and low-key, face-to-face visits. The researchers kept notes and memos of these contact moments.

During the RG meetings, the researchers recorded the meeting and took field notes. In between the meetings, the researchers conducted repeated in-depth interviews with the patients to explore their experiences with regard to the RG meetings, the perception of their own goals and aspirations, and their relations with their social environment (23). The interview style was interactive and guided by neutral, open questions; participants were encouraged to discuss topics that they considered relevant.

The last phase of the data collection included in-depth evaluative interviews using an interview topic guide with both patients and their RG members, including informal and formal members. The topic guides were constructed by the researchers after approximately 1.5 years of data collection and were based on the collected data and the emerging themes and categories; see appendix 1. See Table 2 for an overview of the data collected per participant.

Data analysis

Data were analyzed using the constant comparative method to identify similarities and differences in the themes emerging from participant experiences. This guided the researchers into more abstract understandings of the themes and the development of more holistic interpretations of the meaning of the RG (13) (14). Data were analyzed chronologically by case, meaning that all data from one case was analyzed in chronological order, after which all data from the next case were analyzed. The MAXQDA software (version 2) for qualitative data analysis was used for coding (24). The consolidated criteria for reporting qualitative research (COREQ) checklist (25) was used to guide the analysis and report.

To conduct the analysis, the researchers first carefully read and re-read the transcripts of all data to familiarize themselves with the material, and they made notes about the content. They developed a global coding frame based on these first impressions and their observations, memos, and meeting notes during data collection. In this coding frame, a distinction was made between processes, effects, and hindering factors. Subsequently, the researchers jointly coded all 95 transcripts line-by-line, and more detailed codes were generated (“open coding”). When the analysis of the different cases was underway, they compared, combined, and clustered all labels to connect codes and categories and to find potential overarching patterns and themes (“axial coding”) (13) (26). The researchers kept notes of their discussions of the process during the analysis. They continually looked for shared understanding to check the validity of the codes as they were developed, refined, and codified. The benefits of having multiple coders rest in the “content of (coding) disagreements and the insights that discussions can provide to refine coding frames” (p.1116) (27). Emerging themes were discussed with a wider research team as a validity check.

Table 1. RG composition and short description of the background of each participant.

Participant	**RG composition**	**Short description**
Karen	4: Husband, case manager, job coach, and psychologist	Karen is married and lives together with her children and husband. She suffers from severe obsessive cleaning and ruminative thinking. She aims to be a good mother, broaden her world, and be better understood by her husband.
John	5: Brother, mother, peer worker, case manager, and job coach	John suffered his first psychotic episode during young adulthood. He lives together with his brother, works as a volunteer, and is doing a vocational study. He aims to travel, have a paid job, and meaningful social relations.
Brit	6: Partner, mother, good friend, case manager, peer worker, and psychologist	At the start of her treatment, Brit had not been out of her house for several years. She lives together with her partner. She makes art and writes. She aims to feel free, to be able to go outside without fear, and to develop her (artistic) talents.
Martin	6: Mother, stepfather, brother, sister-in-law, case manager, and mentor of volunteer work	Martin suffers from drug addiction and severe depression. He lives with his cat and does volunteer work. He aims to get clean and save money to re-engage in his hobbies.
Mandy	None: No RG related activities have taken place during the course of the study	Mandy has had manic periods alternating with severe depressive episodes since she was young. She lives with her son and has changing jobs. She aims to reconnect with herself and to complete a study.
Leon	7: Mother, (ex)partner, two friends, case manager, peer worker, and supported living supervisor	Leon experiences frequent dissociative fugue states and has a history of addiction, self-harming, and suicide attempts. During the study period, he moved in with her parents after breaking up with his partner. He aims to have a meaningful job, live independently, and have a satisfying social life.
Raoul	4: Mother, brother, case manager, and social worker	Raoul suffered his first psychotic episode during young adulthood, during a period of substance abuse. After living on the street, he now lives in a sheltered housing. He aims to stabilize on medication and to become an peer worker.
Martha	3: Case manager, psychologist, and psychiatrist; her partner is invited to participate but does not attend the meetings	Martha has experienced early childhood traumas and suffered from paranoid ideas and severe depression, leading to many hospitalizations. She has two grown children and lives together with her partner. She aims to reconnect with life and become an peer worker.

Some information (such as profession and living situation) has been modified in order to protect the identity of the participants.

Table 2. Overview of the collected data[a], sorted per participant

Parti-cipant	**Narrative interview**	**In between interviews**			**RG meeting**	**Evaluative interview**	**Interviews RG members informal**					**Interviews RG members formal**				**Total**
		visits	*phone*	*total*			*partner*	*mother*	*brother*	*friend*	*total*	*CM*	*PS*	*other*	*total*	
Karen	1	3	1	4	2	1					0	3		1	4	12
John	1	4		4	7	1		1	1		2	1			1	16
Brit	1	5	1	6	4	1	1	1		1	3	2	1	2	5	20
Martin	1	2	2	4	1						0	3			3	9
Mandy	1	1	3	4		1					0	1			1	7
Leon	1	4		4	6	1		1		2	3	1	1		2	17
Raoul		3		3	4	1		1	1		2	1		1	2	12
Martha	1	1		1	2	1					0	1		1	2	7
Total	**7**			**30**	**26**	**7**					**10**				**20**	**100**

[a] As we lost contact with one of the participants during the data collection (Martin) we could not conduct the final interview, nor ask his RG members (n=4) to participate. Moreover, as one of the participants did not start a RG (Mandy) there were no RG meetings to attend and no RG members to interview. Also, one informal RG member (partner Karen) and one formal RG member (peer-worker John) did not respond to our request to interview them despite several attempts. Lastly, one of the participants (Raoul) had invited his mother and case-manager to the narrative interview, and therefore we couldn't follow the topic-guide. We added this interview to the 'in-between' interviews.

[b] CM = casemanager; PS = peer support worker

Quality procedures

A number of techniques were incorporated in the study design to increase methodological rigor (27) (28). First, data triangulation was applied by collecting data over the course of two years, in various regions of the Netherlands, and by asking different persons to reflect on the same situation. Second, methodological triangulation was applied as we used various methods to gather the data (open interviews, semi-structured interviews, and observations of the RG meetings). In addition, different perspectives were included, covering experiences from patients, significant others, and mental health professionals (27) (29) (25). Third, the internal validity and reliability were enhanced through reflection procedures. The first and second author kept memos of their experiences and discussed these during the study to be aware of their personal frames that shape their interpretations and to be aware of any distortions caused by personal and professional background (29).

Results

Description of participants

The eight patients ranged in age from 27 to 60 (mean = 37). The duration in mental health care ranged from 5 to 19 years. There was a wide variety of diagnoses, including schizophrenia, addiction, personality disorder, obsessive-compulsive disorder, and mood disorder. The RG of the patients varied in composition and goals; see Table 1.

Qualitative results

The analysis showed that in cases in which the specific elements of the RG method were successfully implemented (i.e., the patient nominated members for his/her RG, the RG met regularly, a recovery plan was made, and the agenda of the meetings was set by the patient), five recovery-facilitating processes unfolded that, in turn, provoked effects for individual patients, social interaction, and the provision of care. Three factors emerged from the analysis that might hinder the potential of the RG method. These processes, effects, and hindering factors are reported below and are illustrated by anonymized excerpts from transcripts from patients, significant others, and mental health professionals.

Recovery-facilitating processes within resource groups

Five recovery-facilitating processes were derived from the analysis: (i) experience of support; (ii) acknowledgment of significant others; (iii) activation; (iv) openness; and (v) integration.

Experience of support. The first process concerned the way the support system is mobilized. Seeing their own RG gathered in a room made patients realize they are being loved, acknowledged, valued, and encouraged. That is, the explicit experience of people wanting to be part of the RG conveyed the message to patients that their burden is legit, that one doesn't have to do it all alone, and that there is hope for change. Importantly, the analysis showed that it was the mere presence of the RG members that seemed to provoke this, rather than practical help or actual tasks. "Being there" was the important mechanism, both for the affirmation of lived experiences and psychosocial problems, and for the establishment of a foundation from which change may arise.

> *John: "What was also nice about it, you know, is that when you join such a resource group, you actually feel that you matter and that you are working on something. Yes, you know, during those meetings you are actually gathered all together. And I think that is also very nice. That you do matter again a bit, so to say, that you don't feel that you are being abandoned, or that no one cares about you. Feeling that there are people around you who are trying to achieve something with you. I think that is also very important. Having that realization, 'Oh, we're working on something together,' at least there are people who want to do that with me. […] That you are part of something, so to speak."*

> *Leon: "In itself, it has certainly been helpful, yes, it certainly helps. Just having all those people in one room. Just the feeling of 'look at the kind of network I actually have around me.' To have that in front of you, literally, pictured, and around you, that is very valuable and very supportive."*

Acknowledgment of the significant other. The second process that unfolded in the RG has to do with the firm recognition of the role and position of the significant other in the illness and the recovery journey of the patient. This was initiated during the in-depth conversation prior to the first RG meeting between the significant other and the practitioner from FACT (i.e., one part of starting up an RG includes the practitioner from the FACT team meeting with significant others). Significant others reported that during these interviews they felt that the mental health professionals carefully listened to their side of the story about their loved ones' illness, their experienced burden in daily life, and their personal needs. Moreover, significant others experienced the RG meetings as a stage to share their own experiences, including their concerns, anxieties, and needs. This strengthened their confidence in working together with the mental health professional, who was considered a reliable partner, and softened their attitude toward the patient. The analysis showed that the process of acknowledgment of the significant others was fundamental to establishing readiness for stepping into an active, constructive role as an RG member.

> *Leon's case manager: "It is good to talk about who can do what. What can we do as mental healthcare providers, what can your network do and, well, what does your partner need to support you in this? What you need is very important, but also what your partner needs in that situation."*
> *Leon: "It is of great importance to see if we can spare her a little."*

> *Raoul's mother: "Yes on that [living independently], panic just takes over for me."*
> *Case manager: "Yes, and I did indeed notice that during the personal interview at the beginning. We then concluded that it would be good if we inform you a bit more about that and how we approach it and how it works, so that the steps become more visible. […]"*
> *Social worker: "I absolutely understand your concerns, ma'am. If you have been through all that, I can imagine that you feel very scared and nervous about taking this step again."*

Activation. The third process is that all involved in an RG were motivated to take on an active role in the recovery process. There were two ways in which the method was found to be activating for the patient: through self-reflection and through commitment toward his/her significant others. The method was also found to be activating for significant others.

Activation through self-reflection. Patients related that the RG method motivated them to actively think about their needs, wishes, vulnerabilities, relations, and future perspectives, as they were invited to design their own RG plan, decide which topics would be discussed, and take the lead during the RG meetings. In addition, the presence of their significant others in the meetings motivated the patients to find a way to describe what is wrong, what is hoped for, and what is to be done about it, in a manner that was accessible and understandable by their RG members. The self-reflective processes that emerged from this then led to patients becoming more intrinsically motivated to achieve their own recovery goals and recapture a sense of agency over the topics, actions, and challenges concerning their illness and recovery process. Patients increasingly felt that the recovery process they faced was actually *theirs*, and that they would have to take action themselves if they wanted to see things changed. These self-reflective processes also helped them to distinguish between what changes they were able to make by themselves and what they needed others for.

> *John: "I really enjoyed making the resource group plan myself. That is a new experience for me because you get to think about things that usually only your*

> *practitioner thinks about. And, you have … you actually put things on paper. And yes, that's nice. […] I have the feeling that my brain is slowly starting to work again."*
> *Brit: "Because God, you get to know yourself well! That is really very bizarre."*
> *Researcher: "Through the resource group?"*
> *Brit: "Yeah. Yes."*
> *Researcher: "Do you think that's the most important thing? That you get to know yourself?"*
> *Brit: I think that if you lose yourself or can't 'read' yourself … then you get lost. And if you learn to look at yourself from the perspective of 'what do I actually need to be happy,' then you can ask for help with that."*

Activation through commitment. The second way in which the RG method was found to be activating is because patients experienced the RG meetings as periodic evaluation moments in which their recovery goals were shared, evaluated, and further developed with the other RG members. The analysis showed that this committed patients to work on these goals in between the meetings because they felt responsibility toward others, and the presence of others served as an extra motivational impulse.

> *Brit: "Yes. Plus if you say, 'well I want to go to the petting zoo,' you say that in a group of people who all hear you say 'I want to go to the petting zoo.' And that then becomes a driving force to indeed try to go to that petting zoo. If it doesn't work, it doesn't work, but you know it gives you something to hold on to. It is difficult, but it is something that, for me, works very well."*

> *Raoul's brother: "[…] And I can imagine that if you do all this by yourself that you are more inclined to think 'I can postpone it for a while.' But now we are all together, and I think that gives him direction and focus when working on his vision for the future. I think it activates him—that might be a better word—it activates him and also us."*

> *John: "The risk for me is mainly that I feel that I am completely free again, and that I continue to live as if nothing happened. And I think the RG is really important in this. Because you have that responsibility to each other, I have the responsibility to you all, and I really can't let it go wrong."*

Activation of significant others. Finally, the RG method also activated significant others in two ways. First, the setting of the RG and the encouragement by professionals to explore the interactivity of encountered problems meant that the closest significant others reflected on their own role in these problems. They gained new knowledge and improved and adjusted their behavior and coping skills. Importantly, this did not always imply an increase in the significant other's active behaviors. In certain relations, it meant creating more distance or establishing firmer boundaries. Activation of the significant other is thus to be understood as being activated to reflect and learn about one's own role in encountered problems.

> *Researcher: "And would he involve you in certain goals?*
> *Raoul's mother: "He doesn't do that quite so quickly, and I understand that. I may have to intervene less rather than more with his issues; that would be very nice for him, I think."*

Secondly, significant others outside the circle of the main caregivers (e.g., friends) were invited to become part of the support system as well. They were present during the meetings and involved with the discussion about how to achieve the goals. Moreover, they were encouraged to share their opinions, feedback, and possible concerns. This made them active collaboration partners in the patient's process rather than passive bystanders.

> *Brit's friend: "I'm happy to be able to help. She asked me to go biking together once a week, and after that I will stick around for a while because it is just fun [...]. And I also notice that biking is becoming easier for her, because she likes to do it with me."*

Openness. The fourth process that unfolded in the context of the RG is a breakthrough of mutual communication patterns within the informal support system. The setting of an RG meeting set the stage for honesty, mutual disclosure, and candid discussions within the safety of the patients' support system. Although many patients described feeling tense to be open and talk about their vulnerabilities, the setting served as an invitation to all RG members to jointly explore a way to open up and address difficult events or feelings in their lives. This openness had to do with both the patient's recovery process and the perspective of all RG members concerning struggles from the past and the role they could play in the recovery process. This way, expectations and responsibilities were discussed, adjusted, and approved; and patients had the experience that sharing difficulties does not indicate a sign of weakness but is part of the person, who is liked and valued by others. The openness in the RG meetings about both the good and the bad internalized the message that they can be ill and well at the same time because it is part of their total self. Importantly, the analysis suggested that the previously described processes of acknowledgment and activation were both essential prerequisites for the process of openness to emerge as these induced readiness to become equal partners in the open interaction and take on a meaningful role in the dialogical process.

> *Raoul: "I think it is nice to have a set time for everyone to be honest and open so the difficult things don't interfere in the meantime. And I found out that my family is not good at discussing these things directly with each other. Now we all have a say in those meetings; yes, that's good, and I like it."*
>
> *Martin's brother: "I think it is great that you're telling us what you want [some distance from the family] but at the same time I think, 'Well, that is easily said,' because for me, I find it very difficult. And why do I find that difficult, because, and now I am going to say something very personal, but you have had suicidal tendencies. And for me it is really scary to leave you alone for a long time. […] I think it's scary if I haven't spoken to you in a week. When I am at your door, I think, 'Maybe he is lying there on the floor and I have lost my brother [tears in his voice].' Do you understand?"*
>
> *Raoul's brother: "So the vulnerability that he shows now, that is something he never dared to or could have shown before. So yes, absolutely, that's the biggest difference I've seen. The meetings really trigger that, or maybe it was already there, and give the meetings a stage for all of us to be a bit more vulnerable, I don't know."*

Integration. The final process evoked by the RG method is that a more unified support system around the patient. Characteristic of having a severe mental illness is facing difficulties in multiple domains in life. Gathering the people that belong to these different domains facilitated a better representation of the different parts of a recovery journey and encouraged the search for one's integrated narrative. Patients felt that all RG members obtained a new, improved understanding of their situation when the significant others and involved professionals met on a regular basis because it was felt to be a more complete representation of who they are. Moreover, it allowed RG members to place different parts in the context of the bigger picture and facilitated integration of both healthy and sick parts of their recovery journey toward a coherent storyline within a recovery process. In this way, the recovery journey as a whole was affirmed.

> *Raoul's social worker: "Well, now it's more of a system, it's not just him, but it's all of his system around him. And that makes you feel more ... Yes, how do you say that ... as if you now know more about his life. Normally, it was something Raoul said, and I never knew the other side, and now I get to see that his mother has a completely different view on things, which is also partially true. So now, the story has become more complete."*
>
> *Brit: "I think it is very important that as a patient you don't always feel like a patient, that you are really seen as a person and that they also try to see what her character*

> *is and what fits in there. […] And now we are really looking at 'who is Brit, what does actually work for her.'"*

Not only did the RG method ensure better integration at the level of the personal story, it also served as a platform for better integration of the professional disciplines involved. The regular meetings provided a stage for the adjustment of and more comprehensive communication about treatment and care aspects within the context of the patient's narrative and his/her social environment and everyday life.

> *Martha's case manager: "I think if the psychologist weren't part of the RG, Martha would be on higher levels of medication than she is now. Martha and the psychiatrist now dare to try to lower her medication level. I believe that the encouragement and confidence of the psychologist have been decisive in reducing the level of medication. That's why I like that we are gathering together."*

Effects of the resource group method: Where did the emerging recovery-facilitating processes lead?

The analysis produced three themes that represent effects of the RG method: (i) arousing curiosity about the world beyond illness in patients; (ii) steps toward reciprocity and equality in their social relations; and (iii) a framework for recovery-oriented mental health care. It is important to keep in mind when interpreting these results that these effects cannot be attributed unilaterally to the RG method itself. The analysis showed that other factors, such as the backgrounds, experiences, and characters of those involved, and the patient's readiness for change also play an important role in achieving these successes.

Arousing curiosity in patients. Patients with a well-functioning RG seemed to develop, after a while, an increased interest in participating in the world beyond mental health care. Although the RG method did not lead to recovery in a specific domain, an enhanced overall curiosity was identified in patients who worked with an RG. The processes initiated by the RG method seemed to establish a feeling of being worth it to participate and to enhance self-confidence, which, in turn, aroused a curiosity to (re)discover one's place in the societal world. As such, participants related that the RG awakened them, set them in motion, and motivated them to reconsider their situation and themselves.

> *Brit's case manager: "I can see that she has grown a lot in realizing that she actually is someone and that she is allowed to be. That she is allowed to be part of society even if for now only in a limited way. But that she realizes that the world is bigger than just her apartment and the internet."*

> *Leon: "That space has grown in my head."*
> *Researcher: "And why is that?"*
> *Leon: "It feels as if I have woken up a bit. I now wonder what is going on in the outside world. And I am discovering little by little what part ... yes, what is in it for me."*

> *Researcher: "And has the RG played a part in that?"*
> *Leon: "Yes, yes, I do think so. It just triggered me to do things, and I've found that when I discuss things with other people that the world kind of becomes a bit bigger."*

Steps toward reciprocity and equality in mutual social relations. In most of the RGs that were studied, a shift took place over time from a relationship of dependence to a more reciprocal interaction between patients and their relatives, in which not only the patient but also the relatives could have and show their vulnerabilities. It was observed that the processes initiated by the RG method enhanced the relatives' trust and released them from the task to be constantly alert. This, in turn, decreased tension and stress in their contact with the patient and created space wherein a more equal relationship could evolve. The RG method thus seems to have the potential to make difficulties and vulnerabilities a human feature: something that is shared and that deepens mutual relationships.

> *Leon's peer worker:"[…] if you are open to your network and your network is open to you, then, what I just told you about my own friends, then the relationship deepens. For you, but also for the other person. All people have the need for deep, meaningful friendships. You create these together in this way. And I really mean that."*

> *Raoul: "I'm finally out of that deep hole I was in, so they can count on me again. That feels nice indeed, that it is more equal now. It's not just them helping me, but also me helping them. So it's not one-way anymore."*

The analysis showed the first steps of a (re)building of mutual relationships *beyond* the illness. In many of the RGs, the processes described above created space to jointly explore how to relate to the other in a relationship that was no longer defined by the illness and in which people started doing fun activities together again. Often this was preceded by RG members mutually reinventing their shared interest and a joint search of how they could shape those together.

> *John's brother: "But when I see myself now, compared to a year ago. I feel connected with him again; we interact more normally and there is much less stress. […] And then come moments when you can do something fun together again. We went to the*

> *cinema together last week."*

Framework for recovery-oriented mental health care. The most notable outcome in terms of mental health provision is that the RG method gave mental health professionals a framework in which to work according to the recovery-oriented principles of agency of the patient and involvement of significant others. The structure of the RG ensured a shift toward the context of patients' everyday lives. Explicitly inviting significant others into treatment and care implied that the most important people that accompanied the individual in his/her recovery journey were no longer mostly professionals whose presence was warranted by the person's problems. Instead, the presence of relatives and friends emphasized the uniqueness and multiple facets of one's identity, life stories, and competencies. Mental health care was sensitized to adapt to the uniqueness of the recovery journey and to see an individual within his/her personal context. As a result, a true connection could develop between patients and the professional, comprising curiosity for a person as an individual and sincere attention to what works for them. Although professionals related that these recovery principles were also considered important in their routine services, the method anchored them as the fundamental points of departure of their work.

> *John: "I think that by means of such an RG you get to know someone much better, you know, multiple sides of someone. You can clearly see that every person is different. If you apply the RG to someone else, you will probably get very different results."*

> *Martha's case manager: "I do think that it contributes to an improved quality of treatment. As I said, you consider those close to the patient, and that is so important, and you really take time, you consistently focus on truly understanding and acknowledging the person and his/her wishes for development. Organizing the meetings, gathering together, and the cooperation actually force you to do so."*

Hindering factors in establishing an RG

The analysis revealed three factors that interfered with establishing an RG that would serve as a safe basis for unfolding the recovery-facilitating processes and effects as described above: (i) embedding and implementation issues; (ii) predominant network; and (iii) tensions inherent to the RG setting. These reflect domains of attention when working according to the RG method for people with SMI, especially in the initial phases.

Embedding and implementation. The analysis showed that mental health professionals experienced an increased workload when incorporating the RG method into the routine practice of managing patient symptoms and basic needs (such as housing, hygiene, and medication). Mental health professionals reported that the method demanded extra time, particularly in the initial phase, to thoroughly prepare the RG meetings with the patient and to establish a good working relationship with significant others. Although they felt that it contributed to what they perceived as good mental health care, and they considered the extra time to be a valuable investment, they were hindered by high caseloads, recurrent staff turnover, and organizational issues, such as reorganization and lack of management support.

> *Researcher: "And do you plan to expand this in your work?"*
> *John's case manager: "I would like that for the future, but I actually feel overloaded at the moment; it is not feasible."*
> *Researcher: "Time wise?"*
> *John's case manager: "Yes, I just don't have the time for that. [..]. So things like that … yes well, that it's just not possible. It is frustrating, though. I mean, there are more things you don't get around to. Because in essence, the concept is simply beautiful."*

> *Mandy's case manager: "In the first instance, I have to take my own share of the blame; I actually have not had room for this [implementation of the RG method]. I know from my own experience, because I've done it before on another team, that when you start, you really need to have space and time, which I just haven't had in the past period."*

Predominant network. The analysis revealed that several forms of complexity within the support system could interfere with establishing a well-functioning RG. The first is significant others that were too agitated, anxious, judgmental, or distressed during the RG meeting. The RG meeting was then no longer about the patient's issues and recovery, but was interfered with those of the significant others. Moreover, tension between the informal RG members—including feelings such as blame, disappointment, and disagreement—and unwillingness of the informal RG members were both found to be complicating factors. The data showed that thorough preparation and collaboration with significant others was fundamental to decreasing their emotions and frustrations and obtaining readiness to constructively contribute to the patient's recovery process. When overlooked, the RG method could aggravate the existing complexities, which stood in the way of an empowering and safe environment in which patients could work on their recovery process.

> *Leon's friend: "Yes, sometimes I had to bite my tongue. My frustrations … Yes, I did not really consider it to be the place to express them, but I sometimes found it difficult to deal especially with his mother. [...] And then I feel like, I should not mention it here because it is already difficult for Leon and of course you do not want to have an*

> *argument about him. But that sometimes makes you go there with a bad taste in your mouth, yes. So I sat there … well yes, more negative."*

Tensions inherent to the RG setting. Finally, the analysis showed that the setting of the RG could be stressful for patients and evoke feelings of vulnerability, insecurity, and weakness. This was especially the case when psychiatric or psychological symptoms and associated problems, such as suspicion, anxiety, low concentration, changes in medication, side effects, and abrupt alterations in goals, wishes, and motivation were not sufficiently recognized and acted upon. As a result, patients were placed in a position they were not able to live up to, which compromised the patient's agency and evoked feelings of blame, disappointment, and misunderstanding in significant others. This complicated the establishment of a well-functioning RG.

> *Excerpt from field notes about Karen: In my experience, her feelings of inferiority are very much in the way of a healthy and fertile RG trajectory. She is not (yet) at all on the track of experiencing the RG as a group of people who can support her in her process. Rather, she feels subjected to the RG structure and everything that goes with it.*

> *Leon: "Yes, the exam feeling. Just like, 'did I pass the past period or not?' I think that's a little how it feels. Yes, and every time I felt like I had taken a step back, it felt like I had to justify why I 'failed'."*

Discussion

In this paper, we aimed to gain a deeper understanding of the RG method when integrated into FACT. Based on the data obtained from observations of RG meetings and interviews with patients, their significant others, and mental health professionals, our findings indicate that a well-functioning RG sets the stage for five processes to unfold: experience of support, acknowledgment of significant others, activation, openness, and integration. These processes, in turn, facilitate patients' entrance into what can best be described as a 'pre-phase' of recovery: they develop an arousing curiosity about the world beyond illness and, together with their significant others, rediscover forms of reciprocity and equality in their social relations. Of particular relevance is the finding that the method emphasizes and reinforces the uniqueness of each person's context and recovery process, thereby providing a framework for the provision of recovery-oriented care. However, it is not self-evident that a well-functioning RG will be established. There are at least three hindering factors that should be addressed and overcome: implementation issues, a predominant network, and tensions inherent in the RG setting.

Overall, the study showed that working according to the RG method anchors the view of mental health and recovery as a contextual and relational phenomenon. This cultivates a shift of treatment and care toward the context of patients' social environment and everyday life. As a result, the person's recovery work takes place in relation to the other people in his or her surroundings. The recovery path, including both recovery and relapse, inherently becomes a social process in which all RG members are important and equal partners whose needs are acknowledged and integrated within the journey. Importantly, conceptualizing recovery as a social process doesn't imply that the patient's recovery path is necessarily related to an increase in collective or social experiences. For some, working on their recovery meant disconnecting from certain relationships, establishing firmer boundaries, and growth in autonomy and self-determination. Nevertheless, these alterations are all located in the context of community, family, and other relationships (see also (30) (31)). In this way, it was not only the individual patients going through a recovery process but also their social network. The RG method offered an opportunity to align these co-existing but interdependent processes and to construct a mutual story, in order to create space for long-lasting changes within the environment of everyday life.

In much of the literature, recovery is perceived as a process that takes place within and by the individual and in which autonomy, responsibility, and self-determination are essential elements. In what has become a classic definition, Anthony (32) described recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness" (p. 4). Here, the individual essence of recovery of SMI is emphasized. Based on our study, one should assume a deeply *social* process rather than a deeply *personal* process, in which concepts such as autonomy, responsibility, and self-determination become meaningful in the context of relationships; consequently, they cannot be regarded as isolated goals of the recovery process. As Schön et al. (33) argued, "It is through social relationships that the individual is able to redefine themselves as a person (as opposed to a patient)" (p. 345). In other words, the social world is the medium through which transformation becomes possible. Importantly, this transformation concerns not only the patient; the social network is also subject to change in order to facilitate, acknowledge, and live with the transformation.

Our findings are in line with the increased recognition of the importance of including the context of community, family, and other relationships in understanding, analyzing, and responding to mental health difficulties and recovery (30) (34) (31). Family members' emotions, behaviors, and attitudes toward mental illness are among the strongest predictors of both relapse and recovery for people with an SMI (35), and the social and contextual nature of recovery has been underlined (36) (31) (37). As such, this highlights an essential task of mental health care: to facilitate social environments within which recovery is enabled (38). Our study suggests different processes that are important in creating these enabling environments in order to develop equal partnerships between mental health service providers, service users, and significant others.

Limitations

The findings of the study should be viewed in light of some limitations. First, the uniqueness of the recovery journeys of the participants and the small sample size limits the generalizability of our findings to a wide population of people with SMI. Although we were able to identify common and shared processes and effects by participants and have thus reached a certain level of theoretical saturation, the findings of this study are rooted in time, place, and person. Hence, future studies should investigate the role of specific characteristics, such as social network size, and also different clinical diagnoses for further application of the RG method.

Second, in qualitative research, the researcher is a central figure that influences, if not actively constructs, the collection, selection, and interpretation of data (39). In addition, we were unfortunately not able to conduct a member-check meeting as we had intended, due to the COVID-19 crisis. Although we embedded a number of precautions in our study design to reduce the risk of biased interpretations, it cannot be ruled out that the data interpretation and meaning construction are contingent on the subjectivity of the researchers.

Third, as the first and second author followed patients and their significant others for a longer period of time, they became trusted partners in the development of the participants (both patients and their significant others). This was one of the main strengths of the study because we could develop confidential relationships with the participants, which enabled the disclosure of deeply personal information and vulnerabilities. At the same time, the sincere attention and interest for the participants and the repeated visits might have had a therapeutic influence and contributed to an enhanced sense of self and feelings of social connectedness. In addition, the researchers repeatedly asked to evaluate and reflect on the RG method and its influence on the recovery journey, which may have evoked reflections and attributions to the method that participants otherwise would not have interpreted that way.

Implications for clinical practice

The role of the mental health professional. The five processes identified in the study require the redefinition of roles, responsibilities, and mutual relationships in the context of care provision. That is, the dynamic between professionals, patients, and significant others is reshaped to “doing *with*, rather than doing *to* and doing *for*” ((40), p. 41). This demands a shift in attitude of the mental health professional when compared to a more individualistic, focused treatment. It requires that professionals decenter their professional expertise and instead take on the role of monitoring the processes within the RG in order to establish the conditions that enable the patient to take the lead. Although this is a very active role, this activity does not concern determining or controlling the outcomes of the process. Instead, it includes helping to reflect on decisions, recognize vulnerabilities, and incorporate different perspectives. The challenge for the mental health professional here is the simultaneity of their work at the individual patient level and at the RG level. Above all, building on a safe environment for facilitating the patient’s recovery process should be preserved as the main aim of the RG meetings, and elements that are affecting this warrant thorough preparation and attention.

Organizational issues. In addition, our study suggests that the RG method needs to be embraced by the workplace and firmly included in work routines in order to be implemented, as with other family-oriented practices (41). When the workplace does not encourage the RG-related activities, providing a training program for an individual professional is not sufficient. Thus, for sustainable implementation, there is a need to develop clear practical guidelines to obtain insight on how to integrate elements of the RG method into outreaching services as usual, including the related organizational challenges.

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Appendix 1: Topic lists interviews

1.1: Topic list narrative interview patient

Part 1: Present

How does your life look like now, what do you do, daily activities, living situation, etc

Part 2: Course of life

What have been important events in your life

Drawing of the life line

Important relations throughout your life

Part 3: Future

Future in 5 years: how does that look like, what has changed, what has remained the same

What do you need to find meaning in life

Part 4: Resourcegroup

Description of the composition and why

How are the relations with and between members

Expectations/hopes/themes to be discussed in the RG

1.2 Topic list final interview patient

Part 1: Reflections on the RG

How would you describe a resource group?

We started the RG (…) years / months ago, first the interviews with your significant others, then the planning of the meeting, and the meetings themselves. How did you experience the starting phase of the group?

Meeting structure

Gathering together

Personal relation with your casemanager

Most important developments in the RG

RG versus previous care: most important change?

What you do need to start an RG?

Part 2: Influence of the RG on your recovery process

What does having an RG offer you? What has been its influence?

Have you seen a different side of yourself?

Has something been started? (social, personal, clinical recovery process). If so, what / how / why?

More control over treatment? And life?

Could you describe your new struggles, new conflicts, new challenges
RG and moments of crisis/you are feeling severely bad
Change in interest in the social world?

Part 3: Influence RG on relationship with the people of your group
Course of the relationship with the people in your group / influence RG on it
Normalizing the relationship
Or professionalize (stigmatization? Control?)
Feelings of dependence

Part 4: Good mental health care
The aim of the research is to improve care. What do you think about the most important steps that still have to be taken?

1.3 Topic list interview significant others informal support system

Part 1: Reflections on the RG
How would you describe a resource group?
We started the RG (…) years / months ago, first the interviews with your significant others, then the planning of the meeting, and the meetings themselves. How did you experience the group?
Most important developments in the RG
RG versus previous care: most important change?
Good sides of it; improvements?
Most important role within the RG? (Do you like that/can you handle it?)
What is needed to start an RG?

Part 2: Influence of the RG on the recovery process
What does having an RG do with your significant other? What has been its influence?
Have you seen a different side of him/her?
Has something been started? (social, personal, clinical recovery process). If so, what / how/why?
More control over treatment? And life?
RG and moments of crisis/your significant other was feeling severely bad

Part 3: Influence RG on relationships
Course of the relationship with patient/influence RG on it
Normalizing the relationship
Or professionalize (stigmatization? Control?)
Feelings of dependence

Part 4: Influence RG on your personal well-being
Well-being/burden of being a caretaker
Experience of caretaking and supporting, can you handle it, is there enough space for yourself?
Acceptation
Feelings about psychological problems of your significant other

Part 5: Good mental health care
The aim of the research is to improve care. What do you think about the most important steps that still have to be taken?

1.4 Topic list interview mental health professional

Part 1: Reflections on the method
We started the RG (…) years / months ago, first the interviews with the significant others, then the planning of the meeting, and the meetings themselves. Experiences with working according to the method.
How would you describe a resource group/definition
Most important developments in the RG
RG versus previous care: most important changes in your work
Good sides of it; improvements
Most important role within the RG (Do you like that/can you handle it?)
Hindering and facilitating factors
RG and your team (implementation)
Is the RG needed within FACT?

Part 2: Influence of the RG on the recovery process
What does having an RG do with your patient? What has been its influence?
Have you seen a different side of him/her?
Has something been started? (social, personal, clinical recovery process). If so, what / how/why?
More control over treatment? And life?
RG and moments of crisis/your significant other was feeling severely bad

Part 3: Influence RG on relationships
Course of the relationship with patient/influence RG on it
Therapeutic relationship
Relationship patient and his/her sign other

Part 4: Influence RG on your profession
Changes in your work: better/less
Additions of the RG in your work

Part 5: Good mental health care
Future of the RG
The aim of the research is to improve care. What do you think about the most important steps that still have to be taken?

Chapter 5.

Interpersonal Relations Within the Context of Resource Groups for People with Severe Mental Illness

a Narrative Approach

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Abstract

Objective

The resource group method intends to promote patients’ agency and self-management and to organize meaningful partnerships between patients and their informal and formal support systems. The aim of this study was to enhance the understanding of interpersonal dynamics that arise within resource groups for people with severe mental illness. Insight into these unfolding processes would enable improved implementation of the resource group method so that it contributes to establishing a positive social environment, which can lead to more enduring recovery.

Methodology

We performed a narrative analysis of transcripts and field notes obtained in a longitudinal, qualitative study on the resource group method. The stories of four different resource groups were reconstructed and analyzed in depth. Data included a total of 36 interviews (with patients, significant others, and mental health professionals) and 18 observations of resource group meetings.

Results

The degree to which the resource group method actually contributes to recovery was based on the extent to which the existing roles of and patterns between the patient and his/her resource group members were altered. Breaking through old patterns of inequality and the joint search for a new balance in relationships proved to be crucial processes for establishing an empowering resource group. The four cases showed that it takes time, patience, and small steps back and forth to overcome the struggles and fears related to finding new ways of relating to each other. An honest and reflective atmosphere in which all participants are encouraged to participate and be curious about themselves and each other is essential for changes in interpersonal dynamics to emerge. Such changes pave the way for individuals with SMI to find their own voices and pursue their unique recovery journeys.

Conclusions

The functioning of the resource group and the ability of the involved members to respond in new ways are important when working toward the patient’s recovery goals. The resource group method should therefore not be considered an intervention to organize informal support for the patient, but a platform to expose and adjust the functioning of the patient’s social network as a whole.

Introduction

Over the past 40 years, a confluence of factors has contributed to the evolution of a renewed view of mental health recovery for people with severe mental illness (SMI). There is increased recognition that patients are surrounded by social networks that may support, undermine, substitute, or supplement professional help (1,2). Together with processes of deinstitutionalization and changing ideas about "good care," this recognition has led to an increased focus on community care in the last few decades (3,4). Simultaneously, the consumer/survivor movement has fought for patients' right to co-decide and co-create the care and support they receive, and it has aimed to achieve greater empowerment for patients, de-stigmatization, and renewed hope for the future (5,6). As a consequence, international policies and guidelines now emphasize the importance of partnerships between mental health professionals, service users, and their social networks to improve service quality and enhance the empowerment and involvement of service users and their significant others (7).

Evolving from this movement, the resource group (RG) method (8) is a promising way to combine the call for agency and self-management with the appeal to organize meaningful partnerships and establish care that is embedded within community life. The origins of the RG method lie in the Optimal Treatment (OT) model, which integrates biomedical, psychological, and social strategies in the management of SMI (9,10). In Sweden, the model was further developed and relabeled as Resource Group Assertive Community Treatment (R-ACT) (11–13), in which ACT teams were enriched by RGs. Research on R-ACT has focused on effectiveness and found improvements in functioning, well-being, and symptoms for people with psychosis (12,13). Implementation and effectiveness of RGs outside Sweden is being investigated (14).

To create an RG, patients invite significant others from their informal network (such as friends and family) and their formal network (such as mental health nurses, social workers, or job coaches). Each RG has a unique composition that is suited to the individual and their recovery wishes and needs. During RG meetings, which are held quarterly, the RG discusses the patient's goals and wishes and jointly determines a recovery plan (8).

Central to the RG method is the assumption that recovery emerges from the relationship between individuals and the social and cultural environments in which they are embedded (15–17). Extensive research indicates that the presence and involvement of significant others contributes to recovery, as they are a source of warmth, support, and encouragement. For example, family members possess a deep knowledge of the patient from years of “standing alongside the person,” and can prevent them from adopting a stigmatized, illness-related self-image (18). Also, families can encourage engagement with treatment plans and recognize early warning signs of relapse (19), and they can assist the patient in accessing services during periods of crisis (20–22). In addition, it has been reported that families can provide practical assistance, such as by offering temporary housing or cooking meals (23).

However, establishing positive social support and rebuilding beneficial social networks that enable recovery are recognized as challenging features of treatment programs. Some forms of assistance or specific behaviors or communications can unintentionally lead to aversive events or stress for the person with SMI. Thorough investigations have found that high levels of expressed emotions within the social environment—referring to close kin’s criticism, hostility, and over-involvement in relation to a relative with schizophrenia—can be a source of stress that negatively impacts the course of the psychiatric disorder (24,25). In addition, the involvement of significant others can impede the recovery process when they remain fixated on a helper role and are unable to support an individual’s movement toward autonomy and reciprocal relationships (23,26). Also, family members who do not understand how environmental cues, adverse events, or stress can increase the risk of relapse might act in ways that increase risks without realizing it (27).

Taken together, although the involvement of significant others in treatment and care has been broadly acknowledged as a source of support that leads to more positive outcomes, more knowledge about interpersonal dynamics is needed to shape social support interventions. In addition, while mental health professionals fulfill an important part of the interpersonal dynamics within a RG, beneficial and hindering aspects of their attitudes are not well understood. Hence, the aim of this paper is to provide an in-depth understanding of the interpersonal dynamics that arise within RGs and their influence on the recovery journey of the individual suffering from SMI and his/her significant others. Insight into these unfolding processes enables improved implementation of the RG method so that it contributes to establishing a positive social environment, which leads to a more enduring recovery for people with SMI.

Methodology

Resource Group method

To work according to the RG method (11–13)(14,28), the patient first asks his/her significant others and mental health professionals to join the RG. This is referred to as nominating.

Then, the patient is stimulated to take the lead in preparing the first RG meeting by deciding on the location and chairman (preferably the patient themself). In addition, together with a mental health professional, they develop an RG plan that contains the recovery goals they want to discuss during the meeting. Before the first meeting, the professional separately invites all nominated RG members to engage in an in-depth preparatory conversation to discuss the relationships among the nominee, the patient, and the other RG members as well as the role the nominee wants to have in the RG. Follow-up RG meetings are scheduled, on average, once every three months. The composition of the RG is flexible and might change over time depending on the patient's goals, wishes, and phase of recovery. In the present study, the RG method was implemented in the context of Flexible Assertive Community Treatment (FACT) (29), the most frequently used outreach service in the Netherlands. FACT involves a multidisciplinary team who provides individual care—including case management and home visits—and scales up to team care with intensive, full ACT when needed.

Design

This paper is based on a narrative phenomenological-hermeneutic analysis ((30), p.295) of transcripts and field notes that were derived as part of a larger qualitative study exploring multiple perspectives on the RG method for people with SMI. The methodology of the larger study, including the recruitment of the cases, is described in depth elsewhere (31). In short, the study used a longitudinal multiple case-study design based on grounded theory (32,33) to explore the developments and processes in eight RGs. Five of these cases were studied by the first author, and three were studied by the second author. In the current paper, the five cases studied by the first author are re-analyzed from a within-case perspective. One case was dropped because no informal network was involved in the RG and thus it contained too little information on the topic of interest: interpersonal processes within RGs. Hence, four cases were analyzed in the current paper.

Data collection

Data were collected between November 2017 and December 2019. Data collection for each case started when the RG was set up. Data was collected through four means. First, a narrative interview was conducted with the patient at the start of data collection based on a global topic list (34)(see Appendix 1). Second, the RG meetings were observed and audio-recorded. Third, between the meetings, repeated in-depth interviews were conducted with the patients about their daily life, perceptions of their goals and aspirations, relations with the social environment, and experiences with the RG. Later in the process, the initial interpretations of the data were discussed with the patients during these interviews. Fourth, by the end of data collection, all the RG members (patients, significant others, and professionals) were interviewed about their experiences with the RG. Throughout the study period, a personal connection was established between the researcher and patient via telephone calls and messages.

The interviews with the patients were interactive and guided by neutral, open questions. Participants were encouraged to discuss topics that they considered relevant. Hereby, these interviews were aimed to co-construct understanding of the meaning and unfolding of the RG (35–38). The interviews took place at the patient's home or another preferred location. There was no time limit, and the duration ranged from 20 minutes to 2 hours. The interviews with RG members were somewhat more structured. The topics of those interviews were pre-determined by a topic list (see Appendix 1), which was constructed by the first and second author based on the emerging themes and categories. Most interviews and RG meetings were recorded and transcribed verbatim. One participant ("Martin") was difficult to reach, and most contact was informal and by phone. These contacts were not recorded and transcribed; instead, the researcher wrote field notes about the topics that were discussed.

Short field notes were written after every contact, interview, or RG meeting to describe the initial associations of the researcher. Cases were followed until within-case saturation occurred (i.e., the moment when new data collection no longer seemed to bring up major new developments in that particular case (39). Within-case saturation was defined based on the general research question of the larger qualitative study exploring multiple perspectives on the RG method for people with SMI, based on grounded theory. Consistent with the grounded theory approach of saturation categories (40), data collection continued until nothing new was being heard and all areas that seemed to warrant further investigation had been pursued. Hence when the first author observed that new data tend to be redundant of data already collected, and did not lead to new themes regarding the understanding of the role RG for that case, this was discussed with the second author in a meeting. When both agreed, the case was considered to be saturated. The time period to reach saturation ranged from six months to two years. For one of the cases ("Martin"), we had to stop data collection earlier, as he no longer answered his phone or called back. The first and second author were in constant dialogue during data collection to explore developments and discuss their interpretations. In the current paper, a total of 36 interviews (with patients, significant others, and mental health professionals) and 18 observations of RG meetings are analyzed. See Table 1 for an overview of the collected data for each participant.

Table 1. Overview of the collected data[a] sorted per participant

Parti-cipant	**Narrative interview**	**In between interviews**			**RG meeting**	**Evaluative interview**	**Interviews RG members informal**				**Interviews RG members formal**				**Total**
		visits	*phone*	*total*			*mother*	*brother*	*friend*	*total*	*CM*[b]	*PS*[b]	*SW*[b]	*total*	
John	1	4		4	7	1	1	1		2	1			1	16
Martin	1	2	2	4	1					0	3			3	9
Leon	1	4		4	6	1	1		2	3	1	1		2	17
Raoul		3		3	4	1	1	1		2	1		1	2	12
Total	**3**			**15**	**18**	**3**				**7**				**8**	**54**

[a] as we lost contact with one of the participants during the data collection (Martin) we could not conduct the final interview, nor ask his RG members (n=4) to participate. Also, one formal RG member (peer-worker John) did not respond to our request to interview them despite several attempts. Lastly, one of the participants (Raoul) had invited his mother and case-manager to the narrative interview, and therefore we couldn't follow the topic-guide. We added this interview to the 'in-between' interviews.

[b] CM = case manager; PS = peer support worker; SW = social work

Data analysis

For the larger study (31), the first and second author had coded all transcripts and field notes together in an ongoing dialogue and had written memos of their discussions, so both were familiar with the data. For the present study, the first author reread the transcripts, field notes, and memos of the coding associated with a particular case several times, searching for excerpts that raised curiosity or questions related to the aim of the study. Puzzling parts of the data material could function as significant events and uncover possible plots (41,42). After identifying the possibly significant events for each case, the first author constructed initial narratives for each case and thoroughly discussed them with the second author. Then, the first and second author read parts of the transcripts and the field notes again to search for possible explanations for the raised questions and for other parts of the data material that seemed connected to important developments. These data were used to reconstruct the narrative. The analysis followed the principles of the hermeneutic circle (30), which involves an interpretation process in which the research continuously goes back and forth between pieces of a text and the preliminary understanding of the whole narrative. This procedure continued until a satisfactory, coherent interpretation was achieved. This interpretation led to a deeper level of understanding of the experiences and interactions of all involved (43).

Ethical considerations

The Medical Ethical Committee of VU Medical Centre granted approval for the study (IDS: 2017.316). Written informed consent for publication and usage of anonymized quotes was obtained from all patients and informal RG members before data collection. We changed names and details to maintain participants' confidentiality.

Reflexivity

The study is part of the PhD thesis of the first author, CT. Next to her work as a researcher, CT is a psychologist in an urban area with people facing diverse problems, both with regard to severity as well as nature. For her PhD, CT briefly followed the developments of 58 RG's throughout the country, although with an utterly different intensity compared to the four men of the present study. In addition, she was involved with the supervision of the mental health professionals implementing the method, including those involved with the four men. JB, the second author, is an experienced qualitative researcher with a focus on investigating and understanding service user's lived experiences with psychological suffering as well as the process of recovery. Before the start of the study, CT and JB took time to truly get to know each other and to share their personal stories to be able to promote each other's' reflexivity.

Results

In the following section, we share the remarkably different stories of four men and their RGs: John, Leon, Martin, and Raoul. We narratively describe how their RGs developed over time and how the interpersonal relations evolved, both from their perspectives and from the perspectives of their significant others and professionals. The stories are not merely characterized by successes or smooth transitions toward meaningful collaboration and empowerment. They also reflect the struggles, the ups and downs, and the tensions that arise during a recovery journey. Above all, the stories provide insight into the unique and different ways in which the RG method takes shape in the lives of the four men. Each story ends with a short reflection by the researchers on the emerging interpersonal processes within that RG.

Case 1: John—Agency versus dependency

At the start of data collection, John has just moved from the clinic—where he stayed after two severe psychotic episodes—to live with his brother. He sets up his RG with a peer worker and nominates his brother, mother, case manager, and social worker to be part of it. From the beginning, John is very involved in the RG method. He explains that he expects it to help him regain control and an active life now that he is out of the clinic. He enthusiastically appoints himself as chairman of the RG meetings, and he puts a lot of effort into making his RG plan and agenda. Together with living in a new city and being out of the clinic, he sees the beginning of the RG as a promising new start and aims to make some profound changes in life.

> *RG meeting.* John: "It gives me a lot of space to think about stuff and to write things down myself. And I also think that the goal of the RG is to make sure that I get certain things done in my life, and that it can serve as a big stick when I postpone things or not keep my promises. That would be very nice. Because I have stood still for a few years and have not been doing anything at all and then it is obviously not going well."

In the first few months of data collection, it becomes clear how deep John desires to get back to living a "normal life." He feels challenged by the fast-moving world around him, in which everyone seems to be able to participate and to build a meaningful existence. His RG plan illustrates what a normal life would look like to him. It is filled with long-term, ambitious plans, varying from travelling the world to having a full-time paid job. He struggles to connect this with his current situation.

> *Interview John.* John: "I have a lot of trouble to accept that I am being treated. Well….

> Wait, I [said] it wrong. I have accepted it but I have a bit of trouble that I don't function fully as I used to."

The RG increasingly becomes an audience to communicate his struggles. The researchers' field notes describe that John has a tendency to think thoroughly about everything, and that expressing himself in the RG meetings allows him to gain an overview of all the plans in his head and bring them closer to the world around him. In an in-between interview, John describes the RG meetings as a "platform" where he can share his thoughts and where he feels in control about decisions in his life. Although this is a positive experience for him, he clearly expresses that he is uncomfortable with actually asking for help from his family. During the meetings, he rejects their help and sometimes gets irritated when they try to advise him.

> *RG meeting*. Peer worker: "And what can others in the group do about this?" John: "Well, I also said that I prefer to do as much as possible myself, that is really, really important to me. […]." Mother: "But don't you think it would be easier when your brother asks you, you know, 'have you thought about this or that'. So that you keep your promises." John: "no it will work out…. *sighs deeply. Mother wants to start a sentence but John interrupts her, talking fast* […]. I will keep my promises, I just have to be a bit more adequate. Faster, better understanding. I get it, I know how it goes. It will be alright."

After about six months of data collection, John starts to drink again and is taking his medication irregularly, leading to several incidents. The nature of the RG meetings changes somewhat, and they evolve into a place where these incidents can be openly discussed. Not only the RG members but also John acknowledge the urgency of the situation, which paves the way for joint agreements. His mother and brother explain in interviews that the RG meetings provided an opportunity to make clear agreements on what to do in the case of an incident, and they appreciated the ability to quickly contact mental health professionals, especially because John has a tendency to downplay incidents. Importantly, the mutual trust is not violated, because John remains part of the conversation and gives his permission to discuss these difficult topics.

> *RG meeting.* Mother: "So we have agreed that we can have a conversation with [case manager] about you, both your brother and I, if a crisis situation arises […]." John: "Yeah, that is when, if you have a signal. So when [brother] or you have that idea, and then you think that things are not going well again, then you immediately get in contact. And I'm just going to make sure it goes well."

> *Interview brother.* Brother: “It gives him confidence, I think, that one doesn’t talk *about* him, but *with* him. Because if you don’t do that, you’ll get problems. Because in the past too much has been decided behind his back, and that made him very suspicious.”

In the period that follows, John starts to take classes and volunteers. He achieves more structure in his daily life, which he appreciates. Despite this, John doesn’t follow up on the agreements made in previous RG meetings, and several incidents happen. Thus, the relationship between John and his family remains dominated by tension. Toward the end of data collection, the researcher’s field notes state that although the RG has become a place for John to feel connected with the world around him, no actual *joint* recovery process arises. John still seems to interpret the help or involvement of others in his recovery journey as an infringement on his freedom and undermining of his agency. Most importantly, it conflicts with his idea of leading the “normal”, independent life that he desires. Both the mental health professionals and his family members look at it differently. In their final interviews, they claim that John’s conception of agency is actually hindering his recovery, and that he has to learn to accept help from others to turn his ideas into actions suitable for his daily life. However, the RG meetings were not used to jointly reflect upon these differences in perception. According to the case manager, she was hesitant to facilitate a critical, open dialogue because there was a risk that John would be placed in a vulnerable position in relation to his family.

> *Interview case manager.* Researcher: “Do you feel that he is more in control over his treatment?” *Silence.* Case manager: “No, I don’t really think so. I think in his experience he is, also because he is the chairman and during that meeting he is really in that role. But I don’t think he is more in control at this moment [in life]. In the sense that I, the mental health care professional, always have to get him to: what you are going to do now, what do you have to do, make sure that you pay attention to that, et cetera […].” Researcher: “So even though that—according to his words—the group gives him control, helps him to make decisions; that is not in line with the reality, with how it really goes?” Case manager: “Well, I’m afraid not. I think it is good that he has that feeling, but what is the value of it if I, and my colleagues, are still pretty tightly in charge of his functioning?”

Reflection

For John, the setting of the RG—in which he served as chairman and his significant others were there for him in the meetings—was encouraging, as from the very beginning it allowed him to experience agency and responsibility. The RG became a place in which John could feel socially connected with the world around him while being the one in charge. However, his own ideas about what he was able to do himself and what he needed others for did not quite match the perceptions of the people around him. John was very focused on not being a patient, and he could hardly tolerate talking about his vulnerabilities or accepting any help. In the interactions with his RG, the other members felt forced to emphasize the problems and risks in his life. As a result, John wanted even more to prove that he could be in charge and did not need others. By the end of the study, John's final goal remained doing everything independently, as he still perceived that as the ultimate form of agency. The RG members went along with this to prevent friction, although they believed that it was not in line with the current situation. Thereby, John and his RG were engaged in a vicious circle and seemed to be stuck in their roles. The difference in perceptions was not directly addressed in the RG meetings, and no openness or reflection emerged in communications. Thus, the RG as a whole was not encouraged to create a story that they all wanted to pursue, and the other members only partially believed in John and his efforts. John's experience of agency remained limited to the RG meeting and did not expand to his treatment, social relations or broader life.

5.3.2 Case 2: Leon—Urged to reshape toward reciprocity

Since early adolescence, Leon has been in contact with mental health care professionals. At the start of data collection, he has been in and out of different clinics for about three years, and he is looking for a way to find meaning in his daily life. He explains that his main struggle is regulating his emotions. In the past, he has experienced several blackouts with self-harming behaviors and overdosing on medication and drugs. During the first interview, Leon describes how insecure he feels about himself:

> *Interview Leon.* Leon: "I still find it difficult to receive compliments or to hear positive things about myself. It is easier to identify myself with failure. I basically set the bar always too high for myself, so that I fail and it is confirmed that I am not worth it. […] That is one of the greatest core beliefs of my life. Like, I'm not worth it, I'm not worth anything."

Leon is very motivated to work on himself and puts a lot of effort into fulfilling what is expected from him regarding the setup of the RG. In addition to his case manager, he nominates his partner, his mother, two friends, his music therapist, a peer worker on his FACT team, and a social worker from supported housing. Before and during the first RG meeting, Leon looks stressed. In the subsequent interview, he explains that he felt great pressure for it to be a good meeting. He found it difficult to believe that these people want to be there for him because they like him and care about him; instead, he feels like they are judging him:

> *Interview Leon.* Researcher: "How do you feel when you're the chairman at the meeting?" Leon: "Very embarrassed. Embarrassed, a bit anxious. You know, have I prepared myself well enough, that kind of things just stick in my head all the time. It's just, yes, like if you take an exam, that feeling a little bit."

The somewhat tense undertone of the first meeting persists in the following meetings. According to the researcher's field notes, although Leon easily shares his vulnerabilities and struggles, he does not talk about what he is truly thinking or feeling. He tends to inform the people around him after a difficult period but isolates himself in the moment, hesitant to ask for help because he fears putting strain on them. The members of his own network take a "wait and see" approach because—as they explain later—they don't really know what their role is and they are cautious to avoid stressing Leon even more. The professionals unintentionally reinforce this by mainly directing the conversation toward Leon and not so much toward his significant others. Thus, rather than serving as a strengthening, supportive atmosphere, the RG meetings emphasize Leon's vulnerable side and his role as the patient, and it is mostly the professionals and Leon making an effort to change the situation.

> *Interview with friend.* Friend: "[...] the group was not being asked anything at all, like what do you want to do or what do you think we should do or something. Often, Leon was talking most of the time, and then the professionals said things, we will arrange a house for you, we will do medication, et cetera. And then nobody asked me, [other friend], or mother anything."

About halfway through data collection, several important events take place that change the way the RG takes shape. After being his main source of support for many years, Leon's partner breaks up with him. In reaction, Leon is overwhelmed and feels severely depressed, not seeing any meaning in life. He experiences a blackout in which he overdoses and has to spend several nights on the intensive care. In the aftermath of this incident, frustration and difficulties arise regarding the communication between different parties (family, friends, and professionals). In the RG meeting that follows, an RG member—one of Leon's friends—asks for a joint evaluation. The RG then openly talks about the lessons learned, who can do what in case of an emerging incident, and how to improve communication in critical moments. This seems to be a first step toward the informal RG members' involvement as active and equal partners. A few weeks later, Leon again feels severely bad. The professionals actively stimulate him to get in touch with one of his friends and share how he feels in order to prevent another incident. When Leon does so, it becomes a positive and important experience for both Leon and his friend:

> *RG meeting.* Friend: “I am glad that you contacted me during that period you felt so bad, and that you really told me what was going on inside you. Not only, well yes, I am feeling bad, but also why and what it did to you. It made me feel like I could better be there for you.”

From this experience, as he later comments in an interview, Leon learns that letting other people know what he truly feels and asking for help at difficult times is not a sign of weakness or dependence, but can be strengthening and rewarding, both for him and the other person. The atmosphere and content in the following RG meetings changes. The conversation is no longer solely directed toward Leon and his challenges; the RG members start to use the meetings as a platform to openly explore how *everyone* feels, reflect on the influence of their own behaviors, and discuss their thoughts and doubts. The open and reflective atmosphere that arises seems to function as a mirror for Leon, helping him to learn to express himself and his emotions. This allows him to start searching for his own voice, and gradually, he realizes that he is capable of being in charge of his own decisions:

> *RG meeting.* Mother: “Yes, now you really choose […].” Leon: “[…] my own social contacts […]” Mother: “[…] things yourself. Just as well as deciding to grow your beard.” Leon *smiling shyly*: “Yes, that is indeed one of those choices.” Mother: “Yes. Your own choice.” *Silence*. Leon: “Little by little making my own choices. I definitely feel like I’m slowly growing in that […].” Case manager: “Yes, absolutely.”

At the time of the final interview, the researcher’s field notes indicate that the RG has undergone a transformation process; the roles of the RG members have changed, and their mutual relationships have been gradually reshaped. In addition, Leon’s use of language when speaking about his RG changes. While he first tended to use proto-professional phrases, such as “utilizing my support system” and “significant others,” he seems to have left those terms behind at the time of the final interview and replaced them with phrases such as “asking a friend to go for a beer and talk” when he is having a difficult time.

Reflection

An important development within this case was the break-up of Leon and his partner. When Leon could no longer rely on her, he was forced to find new ways to take care of himself. This new situation caused existing patterns and current relationships to come into question and be reshaped. Hence, the interaction pattern within the RG, in which Leon felt vulnerable and judged and his significant others were reserved and hesitant in order to spare his feelings, changed. The RG members slowly transformed from passive listeners into active participants. They started to reflect on themselves and the process, and they shared their needs, frustrations, and emotions. This stimulated Leon to also express himself. Thereby, the RG became reciprocal instead of unilateral in its functioning. Also, Leon started to believe that he was worth the attention of his RG and therefore could experience the RG as a source of support. He gradually moved beyond the role of patient and was able to take more charge in making decisions. As a result of these parallel and intertwined developments, the RG process became a joint effort and led to increased equality within mutual relationships. The case is a clear example of the fact that difficulties and tensions are unavoidable parts of a recovery journey, and jointly overcoming them may be key to moving in a fruitful direction.

Case 3: Martin—Distance and closeness

At the start of the first interview, Martin proudly shows a large grid drawn on the wall that represents the number of days he is clean from drugs. He is happy to finally be at a point in life where he could manage to take this step. However, being clean takes enormous strength, and he describes feeling constantly confused and tired. During the interview, Martin openly speaks about himself and the severe events that occurred in his young childhood. The past ten years of his life have mainly revolved around his substance abuse and the associated lifestyle. He states that although he has been through a lot with his family, they are really close to him and he is grateful for their support. At the same time, he feels pressured by them, and he hopes the RG meetings will help him to be better understood. In addition to his case manager, he nominated his mother, stepfather, brother, sister-in-law, and coach from his volunteer work to be part of the RG.

> *Interview Martin.* Researcher: "What do you hope [to achieve with the RG]?" Martin: "Well, uhm…. My parents and my brother have said a few months ago, yes, we now accept you the way you are, and if you relapse, well okay, you know. But now my mother tried to say the other day, why don't you try to work a bit more. And then I really said, mom, you shouldn't do that. You just have to let me do it my way, because if you are going to say that, then I immediately get more cravings, and the feeling that I am not accepted anymore. So I said, please, just let me do it at my own pace."

The search for recognition and acceptance of his fight against addiction is a very important theme for Martin. In the preparation for the first RG meeting, he decides—with the help of his case-manager—to write a letter in which he reintroduces himself to his family and asks for some distance from them in order to recover. During the first RG meeting, he reads the letter out loud:

> *RG meeting.* Martin: "Well here I am, and that is someone with an addiction and the associated lifestyle, that I am trying to get out of. That's a little bit how or who I am

> now. How it feels. My goal is to build a normal rhythm of life again, to be clean. To enjoy things again and to pick up my hobby again. […] At the moment I have mixed feelings, because despite the good feedback from everyone, I still feel that more is expected from me than is feasible at this moment, for example if I hold off the contact with you guys, from everything. But to stay clean requires so much energy, to alter the cravings to something else. […] From the inside, I feel really messed up at the moment, and that just demands all my energy now. So I need a bit of distance to be able to hang on."

The letter and the way that Martin reads it impresses the family. They appreciate that he is honest, and they tell him that they understand his request for space. The RG jointly and respectfully talks about what everyone needs in this new situation. Later on in the meeting, when Martin shares his goals and wishes for the near future, the RG responds by expressing their positive beliefs and expectations. Martin afterwards comments that, despite the positive tone, their hopes and expectations made him feel pressured:

> *Field notes.* "It had hurt him that his father had said that he actually wanted him to be like his little brother: work, girlfriend, house. He found that painful to hear, and he seemed to be annoyed about it too."

In the period following the first RG meeting, the researcher and Martin have several informal contacts in which it is revealed that Martin is struggling to find the right balance between closeness and distance in both contacts with his family and the case manager:

> *Field notes. "*Right after the RG meeting his brother stopped contacting him. Although this was what he had asked for, it made Martin feel upset, as he felt abandoned and not being part of the family. One month later, when the two brothers had talked about this and his brother had invited Martin a couple of times to come over, Martin felt pressured and unseen in how he feels because his brother was expecting too much."

Two months after the RG meeting, it is revealed that Martin has used again and that he manipulated his mother to get money and his stepfather does not know about this. Martin expresses to the researcher that he feels deeply disappointed in himself. In the same period, several interpersonal tensions between members of his RG manifest: his stepfather threatens to reveal secrets about his mother to Martin and his brother, his sister-in-law and stepfather have a dispute and refuse to talk with each other, and the family is annoyed by the mental health professionals. Martin cancels the subsequent RG meeting. He explains that although he would like to continue in the long term, the idea of an RG meeting now causes him too much stress due to all the tensions. The last time the researcher gets in contact with Martin, he considers continuing the RG with a different composition because he wants to gain some distance from his family and focus on the future.

After a few months and several attempts, the researcher is no longer able to get in touch with Martin, and to respect this, she does not interview his family. About a year later, she hears from his case manager that Martin is setting up a new RG meeting with the same members.

Reflection

The RG meeting took a first step toward overcoming the existing interactional difficulties and working to (re)build mutual trust. However, both Martin and his family were entangled in a pattern of seeking distance and closeness. Therefore, Martin alternated between feeling pressured and abandoned. This complicated the establishment of satisfying interactions in which Martin's need to be truly seen and accepted could be acknowledged. When his family sought closeness and said they wanted the best for him, Martin felt as if he is only worth something when he is absent. This interpretation of conditional love and attention made him feel pressured to behave in a certain way. Drugs—and later distance—became a way to take back control and avoid being left and hurt. The interactional patterns of Martin and the other RG members seemed to be entangled with drug use, which made it difficult to jointly work towards recovery. In addition, it became clear that there are many unspoken tensions and complexities within the family, which interfered with the establishment of a well-functioning RG. Distance seemed to be accepted when there is conflict or disagreement, which reinforced Martin's (destructive) behavioral pattern. Thus, existing interactional difficulties stood in the way of establishing an open and honest alliance within the RG.

Case 4: Raoul—The struggle of opening up

When data collection begins, Raoul lives in a sheltered housing. He has a history of severe substance abuse and psychotic episodes, and he now wishes to be more independent from mental health care. In the first interview, he states that a psycho-education course two years ago taught him that the voices he had been hearing for about twenty years are actually his own. However, distinguishing them from reality takes a lot of his energy, and he is not able to do some kinds of work or daily activities. Raoul has nominated his mother, brother, and social worker to be part of the RG. He is enthusiastic and plays an active role in the setup of his RG. He borrows the case manager's book about the RG method, appoints himself the chairman of the RG meetings, and wants to take the lead in the in-depth preparatory conversations with the invited RG members. Nevertheless, Raoul indicates that he is not looking forward to the RG meeting because he does not like to be the center of the attention:

> *Interview Raoul.* Raoul: “One hour […] That sounds so long to me, how are we going to fill one hour? […] and then I feel like, what do I have to say right now, why is it about me. Why do people find that important? So, it is difficult for me to express myself about myself.” [...] Researcher: “So talking about yourself for an hour is difficult.” Raoul: I find it really troublesome, yes. I’m pretty much dreading it.”

At the start of the first RG meeting, Raoul asks the RG members to read the report of the in-depth preparatory conversation with his mother, explaining that everyone knowing about his past is a good start. From the report, it is clear that his mother has gone through a lot with Raoul. The past ten years have been tough for her because she had to watch her son slip away while ceaselessly trying to save him. Despite the considerable improvement in their relationship since then, his mother repeatedly intervenes in the meeting with implicit references to the past. The researcher’s field notes describe her clear need to be heard and persistent urge to share her struggles and fears with the professionals. Several times, she expresses that it is hard to have confidence in the future and support Raoul’s wish to be more independent.

> *RG meeting.* Mother: “He says that he wants to live independently, well then I just flinch, I take three steps back and…that is just a bitter pill to swallow. And I heartily wish it for him, but as he is now, I just really, really not see it happening.”

In response to the first RG meeting, the case manager encourages Raoul’s mother to join a family psycho-educational program on psychosis and schizophrenia. At this program, she learns what her son’s illness actually entails and how she can better relate to it. This changes the dynamics of the second meeting, and it stimulates her to reflect on the influence of her own behavior on Raoul’s functioning:

> *RG meeting.* Mother: “I wanted to push him, you know, ‘go for a walk, go for a nice run’. Well, you should definitely not do that. Because people who are schizophrenic seem to be really, really, really tired. Completely exhausted. So, at lesson 2 I already knew I shouldn’t do that.” *Laughs*.

Despite the changed dynamics between Raoul and his mother, the second meeting has a tense atmosphere. In the period between the first and second meeting, Raoul had told the researcher that he is occasionally using drugs again. The mental health professionals know, but Raoul is terrified that his family will find out and demands that it will not be a topic during the RG meeting. The professionals respect his wish, although they struggle with the situation. In the period after the second meeting, they repeatedly confront him, expressing their own discomfort to address the subject of honesty and openness. Looking back at this period in an interview, Raoul says that although it was stressful at the time, the RG setting served as an incentive for self-reflection and confrontation of the situation. He decides to quit using drugs so that he will no longer have to lie to his family.

> *Interview Raoul.* Raoul: "The RG has definitely accelerated that; that I have come to my conclusions, this is untenable, this cannot continue, it will go wrong somewhere. And also that I became aware of it; I just lied to her [mother], and that's really not okay. I couldn't pretend any more that I wasn't."

This realization is a first step toward being honest and open with his family. After about one year of data collection, a similar event takes place. In consultation with the psychiatrist, Raoul decides to quit taking medication and involves his family in this decision. The RG meeting becomes a very honest conversation in which Raoul and his family open up and share their worries and fears with each other. After the meeting, Raoul tells the researcher that his family needs to feel that they are part of his decisions and that considering the perspectives and well-being of others gives him more gratification in the long term than making decisions by himself. In addition, he noticed that openness allows other people to come close, and that this had substantially improved his relations with both his family and the mental health professionals:

> *Interview case manager.* Case manager: "[At first] he was absolutely inscrutable; I really had no idea what was going on inside him. And look at him now; yes, really it is a huge difference."

In her interview, Raoul's mother explains that the increased openness is very important because it gives her confidence that she will not be left out again. Toward the end of data collection, Raoul, his mother, and his brother all state that the RG meetings have evolved into a place where they can be vulnerable, honest, and open with each other. Importantly, the topics of the RG meetings are no longer solely directed toward Raoul and his goals; they include the mutual relationships between Raoul and his family as well as the latter's vulnerabilities, fears, and behavior. Thus, their relationships become reciprocal, and the openness extends beyond Raoul's goals to cover broad aspects of daily life:

> *Interview Raoul.* Raoul: "The last two times were just very open conversations, everything could come to the table and that gave me peace of mind and also my mother,

> I know that for sure. Apparently, we usually don’t talk with each other so openly, and now the setting makes us ready to do just that. Yes, I found that a lot more pleasant.”

Interview brother. Brother: “I think the RG offers a stage to continue that [being vulnerable], as there is safety for everyone. And that the vulnerability does not only apply to Raoul, but also to us, as family. […] Yes, that certainly connects. Absolutely. That is, of course, what it is all about in a relationship: that you are honest with each other and that you share what is going on inside. That has been disturbed for a long time, and that it is now slowly repairing again; yes, that is really very valuable.”

Reflection

This story is characterized by increased openness in the communication between Raoul, his family, and the professionals. At the start, there was a pattern in which, based on past events, Raoul’s family closely watched him and therefore exerted control out of fear. Raoul interpreted this as a lack of trust, which led him to keep things to himself. This, in turn, enhanced his family’s fear. The RG meetings evolved into a place where this pattern was exposed and could be adjusted. The members all developed more self-reflective and vulnerable attitudes, and they gained an understanding of each other’s past experiences. Raoul learned that being open to his family made them less suspicious, and he increasingly allowed them to be part of his decisions. This, in turn, increased his family’s confidence and gave them the space to see him as a person with dreams and wishes instead of a patient they had to keep a close eye on. The mental health professionals contributed to this by not openly judging Raoul for withholding information from his family and instead repeatedly questioning the consequences and stimulating him to open up. Although it was a struggle for all members of the RG, these developments helped them jointly work toward opening up to each other and (re)building mutual trust. Remarkably, Raoul and his family indicated that they do not have these kinds of conversations in between the RG meetings; the fact that they are scheduled provided an opportunity to build equal, normalized relationships in which Raoul’s illness was *not* the central topic. Hence, the RG meetings were a place where they could discuss the past and let issues go in daily life.

Discussion

The RG method intends to promote patients’ agency and self-management and organize collaborative partnerships between patients and their informal and formal support system. The present paper aimed to enhance the understanding of the interpersonal dynamics that arise within an RG as well as their influence on the recovery journey of the individual suffering from SMI. To this end, we narratively reconstructed the stories of four men—Leon, John, Martin, and Raoul—setting up RGs. Based on our analysis, below we explore the relations and interpretations of the unfolding processes within the four RGs, and we discuss possible implications for practice.

Within the RG method, patients are encouraged to be the director of their group and to take responsibility and ownership regarding their path to recovery (11–13). In the four stories, however, most of the RG members had long histories of dependence, risk prevention, and non-reciprocity with each other, and these existing interaction patterns—which varied in rigidness—interfered with the idea of agency of the patient. Thus, being the director of the group cannot be imposed; instead, a movement in the existing interactional patterns is needed to enable ownership and responsibility to emerge. The four stories illustrate how such interactional movements go hand in hand with struggles and interpersonal tensions. For Leon and Raoul, being the director of their group led to pressure, fear of letting others down, and struggles with being fully open and vulnerable during the RG meetings. Leon tended to place himself below his significant others and thus take on the position of patient. For Raoul, his RG had trouble seeing him as a person with wishes and dreams instead of a patient on which they had to keep a close eye. For both, the process of moving beyond the role of patient and finding new balance in their relationships proved to be essential for establishing RGs that facilitate their empowerment. Importantly, this process required a shift in roles and restructuring of all RG members' perceptions of the relationships. In both stories, the RG meetings served as platforms for interpersonal patterns to be exposed and readjusted.

In the stories of John and Martin, no such shift in existing patterns was observed. John did not redefine his perception of agency and persisted in striving toward independence without help. The other RG members acted to protect him in order to reduce risks. Both John and his RG responded based on old patterns, and the RG meetings did not expose or help adjust them. The lack of change in interpersonal dynamics impeded John's recovery journey, as there was no room for him to take responsibility for both his strengths and weaknesses. Martin's RG process was too short to establish an actual group process. Martin and his family used distance and closeness to regulate their own feelings and regain control over the other. This interfered with the development of mutual trust and joint work toward recovery. Perhaps the expertise of an educated system or family therapist would have been helpful to explore the family's frustration with the mental health professional and increase their understanding of existing frictions and tensions. In this way, the first steps could have been taken toward cooperative partnerships, which could have served as a foundation for further work within the RG.

The analyses suggest that the degree to which the RG method contributes to recovery is strongly determined by the degree to which the existing roles of the patient and his/her RG members are changed. It is essential to break old, rigid patterns that are characterized by inequality and dependence. Jointly searching for a new balance in relationships is a vital process for establishing an RG that facilitates the patient's empowerment. Non-reciprocity can make individuals feel lonely, guilty, weak, incapable, indebted, and inferior, and such relationships, even when they provide much help, can be harmful to psychiatric clients in various ways (44). The stories of Leon, John, Martin, and Raoul show that breaking through old patterns is challenging. In addition, achieving social support within the involved relationships requires a delicate balance, as such support implies that a person is dependent on others, which tends to distance the helper from the person being helped ((17,44,45). To change the mutual perceptions of relationships, it is essential to investigate the underlying emotions, fears, and attitudes of patients, their significant others, and the involved mental health professionals. An open and reflective atmosphere during the RG meetings stimulates members to explore and question their own roles, so working toward recovery goals becomes a shared and honest process.

The importance of openness and reflection for adjusting existing roles and patterns raises the question of how such an atmosphere within an RG arises or be facilitated. We saw that it can arise in response to an external event, such as the break-up between Leon and his partner, and that it can be stimulated by mental health professionals. When the professionals broadened their focus from Leon to the dialogue between Leon and the other RG members, the members started to reflect on themselves and the situation, and they became more direct and open toward each other and Leon. Similarly, when the professionals gave space to the concerns and fears of Raoul's mother, Raoul became more aware of the consequences of his behavior on his family, and the communication between them became more open and honest. Thus, it is important that all RG members are invited to play an active role and to consider what they truly need to believe in the goals and participate in achieving them.

By recognizing the importance of including the social context in understanding, analyzing, and responding to mental health difficulties and recovery (17,45,46), the RG method is best be viewed as a person- and network-oriented approach. Indeed, our findings are in line with identified working mechanisms of meaningful and sustained inclusion of the social network. These have been found to be characterized by collaboration principles, which promote deep listening to the lived experience of families; a commitment to work in equal partnership with service users and family members; an openness to acknowledge, articulate and address power relations; and a commitment to change service delivery cultures (47–

50). Above all, such approaches firmly recognize that no one exists in isolation. In contrast, most people's lives are defined by their networks and relationships, and problems and solutions are socially constructed through shared language and understandings (51).

An influential example of such approach is Open Dialogue (OD) (52,53). The approach aspires to create a space where decision making is transparent and service users are able to find new words for their experiences. Studies of OD can be helpful in further developing and shaping the RG method. Mechanisms of change in OD have been identified (56,57) and seven key elements were outlined in fidelity criteria (54). These elements can be understood as related to both the organization of services and a way of being with people, the latter including the elements of tolerating uncertainty and dialogism (55). Future studies should investigate their similarities, differences and lessons to learn to establish the social and contextual nature of recovery in treatment and care for people with SMI.

Clinical implications

Mental health professionals' role is to monitor the processes within the RG by inviting RG members to share their thoughts and feelings; stimulating openness about frictions or differences in point of view; acknowledging and investigating the positions and needs of patients' significant others; and provoking curiosity of each RG member about themselves, the situation, and the group process. This stimulates members to re-think their roles, needs, and behaviors (17,50). The stories of Leon and Raoul show that this not only facilitates openness but also increases mutual understanding. If individuals feel that they are understood by someone, they will be inclined to learn from them (58). Hereby, the RG serves as a "we," and as a collaborative learning community in which new knowledge and meaning arise from mutually influencing processes (55,59). The functioning of the social network as a whole and the ability of the involved members to respond in different ways are important when working toward the patient's recovery goals.

By making space for all RG members to be heard, the RG itself and the RG meetings could evolve into a *holding environment*, a safe setting that enables individuals to explore new methods of interaction and communication (60). The holding environment can serve as a safe place in which people in recovery and their significant others feel that they can take risks, consider each other's perspectives, and explore their true feelings (61). The professional is part of this holding environment and thus is an equal partner in the process, as opposed to an expert that brings knowledge (62–65).

Cultivating such attitude and taking on a monitoring role within the RG involves a subtle but significant shift in the dynamics between mental health professionals and patients and their significant others and is reshaped to “doing *with*, rather than doing to and doing for” (66). Developing appropriate skills is not restricted to a certain professional background but training and supervision is recommended (see (8,14,31)).

Methodological considerations and limitations

First, the uniqueness of the recovery journeys of the participants and the small sample size limits the generalizability of our findings to a wide population of people with SMI. The findings of this study are rooted in time, place, and person and future studies should investigate the role of specific characteristics, such as illness acuity, ability of self-reflection, and different phases of illness on group dynamics for further application of the RG method. Above all, the paper is meant to stimulate reflection and thinking about the different ways the RG method takes shape in clinical practice. Hereby, we hope that our analysis encourages mental health professionals to embrace the uniqueness of each individual RG and adapt to the personal needs of its involved members.

Second, hermeneutical analysis is based on the idea that data cannot be regarded as purely isolated information units that can be observed separately by other researchers. Rather than trying to eliminate the effects of the researcher, researchers should try to understand and exploit them (67). Therefore, continuous reflexivity regarding our impact on the data, analysis, and interpretations was important throughout all phases of the study. To that end, the first and second author were in continuous dialogue with each other to ensure they remained open and curious about the participants’ unique situations. During data collection, they critically questioned each other to gain an understanding of the origin of certain beliefs and interpretations that could affect the course of the interviews. During data analysis, the first and second author jointly reviewed all transcripts and field notes, made memos of their discussions, and eventually achieved intersubjective agreement on their interpretations. It is thus important to take into account, when reading the paper and interpreting the analysis, that their personal and professional experience and knowledge inspired and informed the analysis and interpretations (68).

Third, the confidential relationships between the first author and the participants (both patients and significant others) were important in the interpretation process. The first author followed the four stories for a longer period of time and attended all RG meetings. Participants shared deeply personal information and vulnerabilities throughout the process, which indicates that they saw the researcher as a trusted partner. Initially derived meanings and hypotheses regarding the participant’s recovery process and the interpersonal dynamics within the RG were discussed with the participants to jointly interpret the data. This was one of the main strengths of the study as the research became an equal and joint exploration and investigation. At the same time, the attention and sincere interest for the participants and the repeated visits might have had a therapeutic influence that may have been tangled with the method. In addition, the researchers repeatedly asked to evaluate and reflect on the RG method and its influence on the recovery journey, which may have led to an attributed importance of the method for the participants, that would otherwise not have been experienced or interpreted that way.

Conclusions

Taken together, by reconstructing the four stories, we aimed to gain insight into the different ways the RG method takes shape in the four men's lives. The stories showed that the RG method should not be considered an intervention for organizing informal support for the 'designated' patient, but as a platform for changing the functioning and dynamics of the social network as a whole. For a well-functioning RG, it seems essential to break through old patterns of inequality and dependence and work toward openness and reciprocity in interpersonal dynamics. The four cases showed that it takes time, patience, and small steps back and forth to jointly overcome the struggles and fears related to finding new ways of relating to each other. An honest and reflective atmosphere in which all participants are encouraged to participate and be curious about themselves and each other is essential for changes in interpersonal dynamics to emerge. Such changes pave the way for individuals with SMI to find their own voices and pursue their unique recovery journeys.

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Chapter 6.

Effectiveness of Resource Groups for Improving Empowerment, Quality of Life and Functioning of People with Severe Mental Illness

A Randomized Clinical Trial

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Abstract

Importance

Although the importance of recovery-oriented care for people with severe mental illness (SMI) is widely acknowledged, essential elements such as personalization and involvement of significant others are not adequately implemented in practice.

Objective

To determine whether using resource groups (RGs) within flexible assertive community treatment (FACT) has favorable effects on empowerment and recovery-related outcomes in people with SMI.

Design, Settings and Participants

This assessor-blind, multisite randomized clinical trial was conducted from September 1, 2017, to September 30, 2020, with follow-up at 9 and 18 months. A total of 158 participants aged 18 to 65 years meeting the criteria for SMI were randomly allocated to FACT plus RG vs FACT as usual (1:1) in 20 FACT teams throughout the Netherlands. Data were analyzed from September 1, 2020, to January 31, 2021. The study was prespecified in the trial protocol and data from the intent-to-treat population were analyzed.

Interventions

In the FACT plus RG condition, patients chose members from their informal and formal networks to form an RG that meets quarterly to discuss self-formulated recovery goals. The RG was integrated into the multidisciplinary support provided by the FACT team. In the FACT as-usual condition, empowerment (defined as overcoming powerlessness and gaining control of one’s life) and involvement of significant others was also part of the provided care, but without the structure of the RG.

Main outcomes and measures

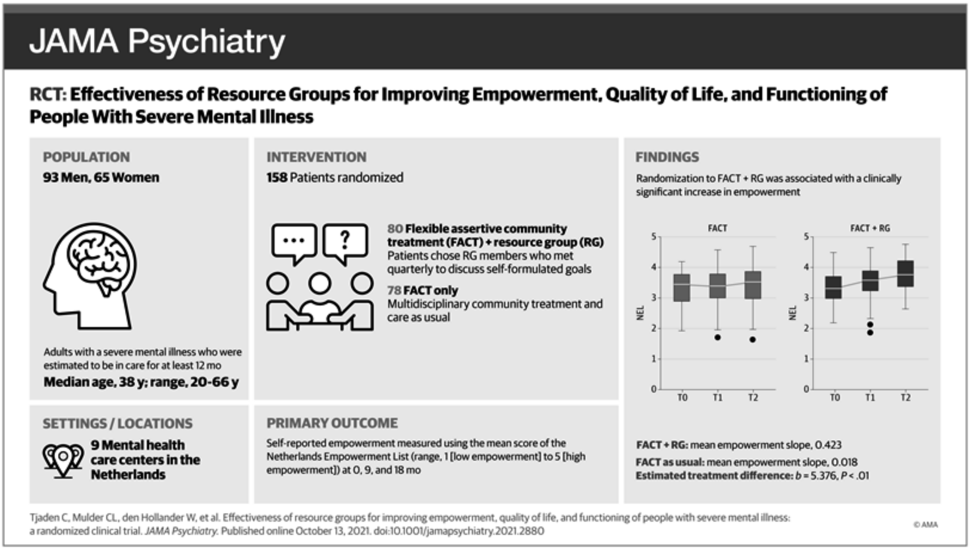
The primary outcome was self-reported empowerment, measured with the Netherlands Empowerment List.

Results

A total of 158 participants with SMI (median age, 38 [median absolute deviation, 13] years; 93 men [58.9%]) were randomized to FACT plus RG (n = 80) or FACT as usual (n = 78) care. Intention-to-treat analyses showed that randomization to the RG condition was associated with a clinically significant increase in empowerment (Cohen d, 0.54; 95% CI, 0.21-0.86) and improved outcomes with small to medium effect sizes in terms of quality of life (Cohen d, 0.25; 95% CI, −0.07 to 0.56), personal recovery (Cohen d, 0.38; 95% CI, 0.06-0.69), quality of social contact (Cohen d, 0.24; 95% CI, −0.07 to 0.56), disability (Cohen d, 0.29; 95% CI, −0.03 to 0.60), general functioning (Cohen d, 0.30; 95% CI, −0.01 to 0.62), and social functioning (Cohen d, 0.28; 95% CI, −0.04 to 0.59). No differences between conditions were found regarding psychopathological symptoms, attachment, frequency of social contact, and employment. Compared with FACT as usual, participants who stayed with the assigned treatment in the RG condition were more satisfied with treatment at 9 (Cohen d = 0.45; t135 = −2.62; P = .009) and 18 (Cohen d = 0.41; t116 = −2.22; P = .02) months.

Conclusion and relevance

These findings show that working with RGs improves empowerment and other mental health outcomes in people with SMI who receive community-based mental health services. This method of network-oriented care empowers people with SMI within their own environment.



JAMA Psychiatry

RCT: Effectiveness of Resource Groups for Improving Empowerment, Quality of Life, and Functioning of People With Severe Mental Illness

POPULATION

93 Men, 65 Women

Adults with a severe mental illness who were estimated to be in care for at least 12 mo

Median age, 38 y; range, 20-66 y

INTERVENTION

158 Patients randomized

80 **Flexible assertive community treatment (FACT) + resource group (RG)**
Patients chose RG members who met quarterly to discuss self-formulated goals

78 **FACT only**
Multidisciplinary community treatment and care as usual

FINDINGS

Randomization to FACT + RG was associated with a clinically significant increase in empowerment

FACT + RG: mean empowerment slope, 0.423

FACT as usual: mean empowerment slope, 0.018

Estimated treatment difference: *b* = 5.376, *P* < .01

SETTINGS / LOCATIONS

9 Mental health care centers in the Netherlands

PRIMARY OUTCOME

Self-reported empowerment measured using the mean score of the Netherlands Empowerment List (range, 1 [low empowerment] to 5 [high empowerment]) at 0, 9, and 18 mo

Tjaden C, Mulder CL, den Hollander W, et al. Effectiveness of resource groups for improving empowerment, quality of life, and functioning of people with severe mental illness: a randomized clinical trial. *JAMA Psychiatry*. Published online October 13, 2021. doi:10.1001/jamapsychiatry.2021.2880

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Visual Abstract. RCT: Effectiveness of Resource Groups for Improving Empowerment, Quality of Life, and Functioning of People With Severe Mental Illness

Key Points

Question

Does the structure of a resource group have favorable effects on empowerment and recovery-related outcomes of people with severe mental illness?

Findings

In this randomized clinical trial of 158 people with severe mental illness aged 18 to 65 years, self-reported empowerment improved significantly when working within a resource group method compared with well-established community-based care. Exploratory secondary outcomes such as quality of life and social functioning also indicated a broad range of benefits.

Meaning

These findings suggest that resource groups establish widely endorsed principles of empowerment and engagement of significant others as cornerstones of community-based mental health care.

Introduction

Severe mental illnesses (SMI) are psychiatric disorders that imperil lives over a long period, challenging and preoccupying mental health professions (1). Although the potential benefits of involving significant others in mental healthcare are well documented (2), poor implementation rates are often reported (3–6). The resource group (RG) method, which builds on traditions of family intervention and integrated care, is a promising initiative to overcome this problem by providing a structure to ensure that family, friends and carers maintain full involvement in routine services, thereby becoming collaborative partners in the recovery process. A patient’s RG comprises individuals from their informal (ie, friends, family) and formal (ie, social worker, psychiatrist, peer-worker) network and meets quarterly to discuss patients’ recovery goals, and jointly develop a plan for achieving them. By being part of an RG, significant others acquire skills to contribute to the goals, and attention is paid to their burden and needs as well as those of the patient.

Because the RG method designates patients as the directors of their RG, they are encouraged to take ownership in shaping the support that meets their needs and aspirations. The primary aim of the method is to facilitate patients’ empowerment (ie, processes in which someone rediscovers their identity and takes their life in their own hands (7). Empowerment is identified as a key aspect of recovery-oriented mental healthcare in itself (8–10) but it is also recognized as a mediator towards improved long-term health (13). That is, empowered patients are thought to improve their health behaviors in terms of self-esteem, social and community functioning, and abilities to manage their illness (11–15). In addition, a lack of empowerment is related to enhanced depression and hopelessness (16–19) and impaired quality of life (16,20). The importance of empowerment in disease prevention and health promotion is recognized in various international policy guidelines (21–24).

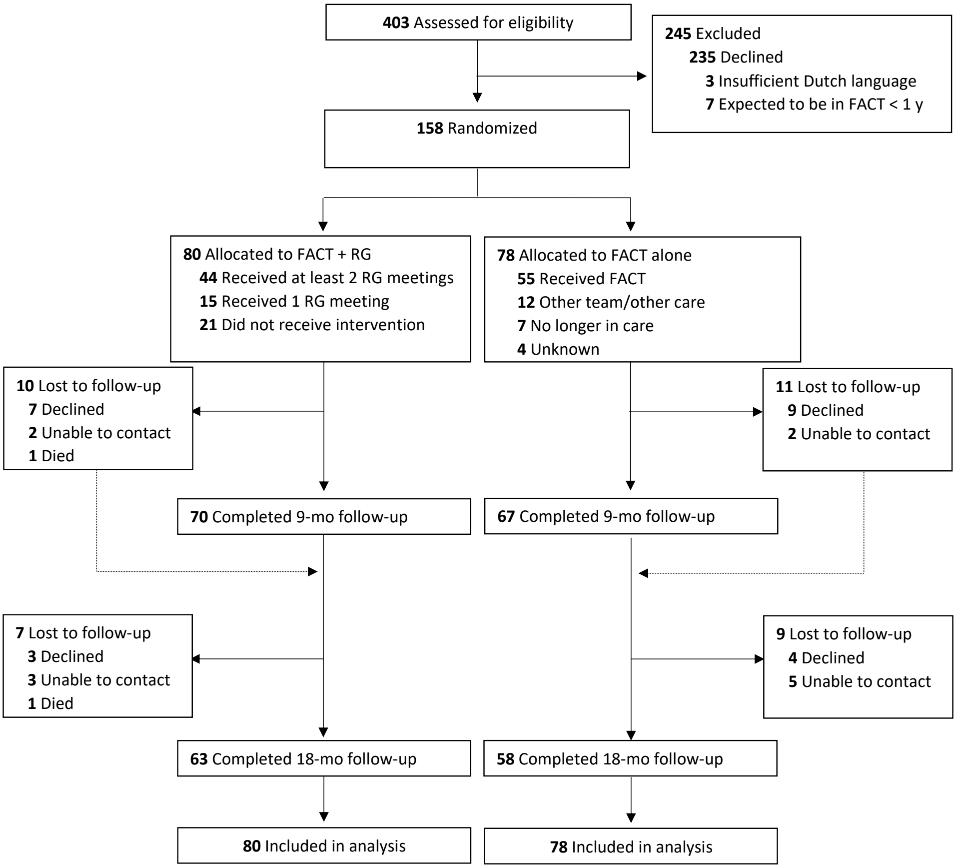

Figure 1. CONSORT Diagram of Participant Flow Through the Trial

Patients were recruited from 20 FACT teams (range: 2 – 18 patients per FACT team) at 9 mental health care centers (range: 1 -3 teams per center). FACT indicates Flexible Assertive Community Treatment; RG, resource group.

The origins of the RG method lie in the optimal treatment model, which integrates biomedical, psychological, and social strategies in the management of SMI (25,26). In Sweden, the optimal treatment model was further developed to RG Assertive Community Treatment (RACT) (27,28). A meta-analysis showed outcomes in favor of RACT for patients with psychosis in social functioning, well-being and symptoms (28). However, RACT consists of various differences with care-as-usual and the use of RGs was only one of these. The present study therefore investigated whether integrating RGs with community care has favorable effects on empowerment as well as quality of life, recovery, social and societal functioning, and symptoms compared to community care as usual.

Methods

Participants and design

This assessor-blinded,2-arm, pragmatic RCT was conducted from September 1, 2017 to September 20, 2020, within the context of flexible assertive community treatment (FACT; (29–31)) , the community-based care of choice for people with SMI in the Netherlands. The study was prespecified in the trial protocol (32), that was approved by the Medical Ethics Committee at VU University Medical Centre. No important changes were made after trial approval, and no data were analyzed before study completion and database lock. Participants provided written performed consent after receiving a complete description of the study. The study followed the Consolidated Standards of Reporting Trials (CONSORT) (33).

Participants were recruited from 20 FACT teams at 9 mental health care centers throughout the Netherlands. Eligibility screening and enrolment were conducted by FACT professionals during the intake phase for new patients. The 6 inclusion criteria consisted of age 18 years or older; an SMI according to the Dutch definition (34); estimated FACT future involvement for at least 12 months but not more than 2 years in the past; capacity to provide written informed consent; and sufficient Dutch language skills.

Randomization was performed after baseline assessment. Follow-up assessments were conducted after 9 and 18 months. Assessments took place at a participant's home or at the treatment site, and took 90–120 min to complete. Owing to the COVID-19 pandemic, 50 of 416 interviews (12.0%) took place by telephone.

Randomization and masking

Patients were randomized to FACT plus RG or FACT as usual (1:1) via an interactive web-response system based on a random-allocation sequence generated by a statistician who was not involved in the trial. The system sent an email with the randomization to the involved mental health professionals, who notified the participants. Randomization was stratified by FACT team. To conceal allocation sequence, random permuted blocks with sizes 2 and 4 were used.

Participants and mental health professionals were not blinded to allocation, whereas the research staff conducting follow-up assessments at 9 and 18 months were blinded. To assess blinding, the research staff filled in control questions about participants' allocation status after each assessment.

Interventions

Resource groups

Working with RGs within FACT involved six phases (Table 5) to establish an RG that would meet quarterly. The intervention protocol was adapted from the RACT program (27,35) and is described in detail elsewhere (32,36). Briefly, patients drafted their RG plans, which consisted of short and long-term recovery goals and early warning signs, with the support of the professional that was trained in the RG method. The patients then asked ("nominated") significant others and/or professionals who could contribute in working towards the goals to join the RG. The composition was flexible and could change according to patients' goals and phase of recovery.

Together with the mental health professional, each patient prepared for their first RG meeting by setting the agenda and by deciding on a location and chairperson. Before the first RG meeting, the professional invited the nominated members of the patient's RG for an in-depth interview to discuss their involvement and their mutual relationships among RG members. The RG met quarterly to discuss and evaluate patient's recovery goals and the plan for achieving them.

Training in the RG method for professionals involved 2 full days and 2 half days and attendance at 6-weekly telephonic supervision in small groups. There were no restrictions regarding educational background.

FACT as-usual

FACT as-usual consisted of multidisciplinary treatment and care. According to patients' needs and goals, this included case management, peer support, and psychiatric medication monitoring (29). Support and involvement of significant others could be part of treatment but not in the structured used in the RG method. Twenty of 22 participating FACT teams (90.9%) were certified to ensure similar and guaranteed quality of care.

Table 1. Baseline characteristics

Characteristic a	**All (N = 158)**	**FACT as usual (n = 78)**	**FACT plus RG (n = 80)**
Gender			
Male	93 (58.9)	46 (59.0)	47 (58.9)
Female	65 (41.1)	32 (41.0)	33 (41.3)
Age, median (MAD), y	38 (13)	41 (12)	37 (14)
Educational attainment			
None or only elementary school/GED	37 (23.4)	20 (25.6)	17 (21.3)
At least secondary education	121 (76.6)	58 (74.4)	63 (78.8)
Partnered			
Yes	53 (33.5)	24 (30.8)	29 (36.3)
No	105 (66.5)	54 (69.2)	51 (63.8)
Employment			
Employed	26 (16.5)	15 (19.2)	11 (13.8)
Voluntarily work	24 (15.2)	10 (12.8)	14 (17.5)
Unemployed	79 (50.0)	37 (47.4)	42 (52.5)
Other	29 (18.4)	16 (20.5)	13 (16.3)
Living situation			
Alone	61 (38.6)	36 (46.2)	25 (31.3)
With partner and/or children	46 (29.1)	20 (25.6)	26 (32.5)
With parents	13 (8.2)	9 (11.5)	4 (5.0)
Supported housing	30 (19.0)	11 (14.1)	19 (23.8)
Other	8 (5.1)	2 (2.6)	6 (7.5)
Ethnicity [b]			
Dutch	93 (58.9)	47 (60.3)	46 (57.5)
Western	19 (12.0)	9 (11.5)	10 (12.5)
Non-Western	45 (28.5)	22 28.2)	23 (28.8)
Unknown	1 (0.6)	0	1 (1.3)
Lifetime contact mental health service, median (MAD), y	6 (5.93)	7 (7.41)	5 (5.13)
Lifetime admissions to psychiatric hospital			
Never	41 (25.9)	22 (28.2)	19 (23.8)
1	38 (24.1)	17 (21.8)	21 (26.3)
2-4	73 (46.2)	36 (46.2)	37 (46.3)
>4	6 (3.8)	3 (3.8)	3 (3.8)
Main clinical classification			
Schizophrenia or schizoaffective disorder	36 (22.8)	18 (23.1)	18 (22.5)
Other psychosis	22 (13.9)	15 (19.2)	7 (8.8)
Bipolar affective disorder	12 (7.6)	3 (3.8)	9 (11.3)
Depressive disorder	18 (11.4)	11 (14.1)	7 (8.8)
Anxiety disorder	4 (2.5)	0 (0.0)	4 (5.0)

Characteristic a	All (N = 158)	FACT as usual (n = 78)	FACT plus RG (n = 80)
Post-traumatic stress disorder	5 (3.2)	1 (1.3)	4 (5.0)
Substance-related disorders	23 (14.6)	11 (14.1)	12 (15.0)
Personality disorder	13 (8.2)	7 (9.0)	6 (7.5)
Autism	8 (5.1)	4 (5.1)	4 (5.0)
Other	6 (3.8)	2 (2.6)	4 (5.0)
Unknown	11 (7.0)	6 (7.7)	5 (6.3)

[a] Unless otherwise indicated, data are presented as n (%) of participants.

[b] Ethnicity was classified according to national guidelines of Central Bureau of Statistics. Non-western included participants from former Dutch colony Suriname.

Model fidelity

Adherence and model-fidelity were assessed with the RG model evaluation tool (R-MET, Table 6), which was developed in parallel with the study. The R-MET consisted of 25 questions that were completed by the professional after each RG meeting from which a model-fidelity score per RG was obtained (Table 7).

Outcomes

The primary outcome was self-reported empowerment, which was measured with the Netherlands Empowerment List (NEL; 40 items, self-report (7)). The NEL contains six subscales: confidence and purpose, self-management, connectedness, social support, professional help, and caring community. Internal consistency (Cronbach α = 0.94), aspects of validity, reproducibility (Cronbach α = 0.79) and responsiveness were good (7,37). The questionnaire has been used as outcome measure in several randomized controlled trials (38–42).

Secondary self-report outcomes were: quality of life (Manchester Short Assessment of Quality of Life (43); psychopathological symptoms (Brief Symptom Inventory-18 (44)); difficulties in adult attachment (Revised Adult Attachment Scale (45)); frequency of social contact (5 Likert scales [range 1-7]); quality of social contact (5 self-report Likert scales [range 1-5]); employment (binary variable: a voluntarily or paid job [1] or no job [0]); and satisfaction with treatment (Client Satisfaction Questionnaire (46)) and with involvement of relatives in treatment (subscale of Verona Service Satisfaction Scale (47)).

Interview outcomes were personal recovery (Individual Recovery Outcomes Counter (48)) and disability (World Health Organization Disability Assessment Schedule-32 (49)). Assessor-based outcomes were global functioning (Global Assessment of Functioning (50),and social functioning (Social and Occupational Functioning Assessment Scale (51)) as scored by blinded investigators. Outcomes were assessed at 0, 9 and 18 months, except for treatment satisfaction measurements (Client Satisfaction Questionnaire and subscale of Verona Service Satisfaction Scale, assessed at 9- and 18- months follow-up).

Statistical analyses

Data were analysed from September 1, 2020 to January 31, 2021 in R, version 3.0+ (R Program for Statistical Computing) and SPSS version 27.0 (IBM Corporation). Assuming an effect size of Cohen *d* = 0.5 (52), a 2-sided α = .05, and repeated measurement analysis, a minimum sample size of 133 was required to detect significant differences between groups with a power (β) of 80%.

Outcomes were analyzed according to the intention-to-treat population using repeated-measures linear mixed modelling, using the R-package lme4 (R Package for Statistical Computing) (53). Linear mixed modelling includes incomplete cases in the analysis and uses restricted maximum likelihood estimation to calculate parameter estimates. Because LMM performs internal imputation, no other procedure of missing data was performed (54).

Although the data had a 4-level structure (repeated measures, patients, teams, and centres), adding a random intercept for centre did not offer a better model fit (χ2 (8)=0.51 [n=158], P=.91) when compared to the more parsimonious 3-level structure. Hence, intercepts for patients nested in teams were included as random effects. To determine whether outcomes significantly differed between conditions over time, linear mixed models were fitted with the respective outcomes as the dependent variables. The independent part consisted of the fixed effect log-time and the interaction effect between condition and log-time. Treatment effectiveness was determined by comparing the mean slope in the two conditions, reflected by and reported as Cohen *d* (55). Completers were defined as subjects who had attended at least 2 RG meetings, 2 being the median. In addition, we explored whether differences in improvements of secondary outcomes seen between groups are accounted for by an early change in empowerment. To this end, mediation analyses were performed (R package mediation [R Program for Statistical Computing]) with change between T0 and T1 in empowerment as the mediating variable, treatment as independent variable and slope of the respective secondary outcome between times 0 and 2 as the dependent variable.

Results

A total of 403 people with SMI were screened for eligibility, and 158 participants were randomized to FACT plus RG (n = 80) or FACT as usual (n = 78) (Figure 1). The baseline group characteristics were similar (Table 1). Participants' median age was 38 (median absolute deviation [MAD], 13) years; 93 (58.9%) were men and 65 (41.1%) were women. Primary clinical classifications varied, with a similar proportion of comorbidity in the intervention and control condition (48 of 80 [60%] vs. 42 of 78 [53.9%], respectively). During 28 of 258 assessments (10.9%), research staff were not blinded to allocation.

Follow-up data was available by September 28, 2020. Fifty-nine participants (73.8%) allocated to FACT plus RG had at least one RG meeting, and 44 (55.0%) had at least 2 RG meetings. Reasons for not starting up an RG were lack of motivation patient (n=6); lack of time or motivation professional (n=3), repeated crisis (n=8) or referral to other care (n=4). Model-fidelity scores indicated a sufficient dose of the RG method (mean [SD], 3.99 [0.46]; median, 4.00 [range, 2.71–4.71]) (Table 7). For the 21 (26.3%) participants without an RG meeting, model-fidelity was scored as 0.

Primary and Secondary Outcomes

The primary analysis showed a greater increase in empowerment over time in the FACT plus RG condition than in the FACT as usual condition; this is reflected in a significant treatment-by-time interaction effect (estimate 0.40555 [SD, 0.07543]; $P < .001$) with a moderate effect size (Cohen *d* = 0.54; 95% CI, 0.21 – 0.86), indicating significantly different slopes between treatment groups (Table 2 and 3 and Figure 2 and 3).

Exploratory secondary outcomes analyses showed that FACT plus RG was superior to FACT as usual for personal recovery (Individual Recovery Outcomes Counter; Cohen *d,* 0.38 [95% CI, 0.06 -0.69]), quality of life (Manchester Short Assessment of Quality of Life; Cohen *d,* 0.25 [95% CI, -0.07 to 0.56]), disability (World Health Organization Disability Assessments Schedule 2.0; Cohen *d*, 0.29 [95% CI, -0.03 to 0.60]), quality of social contact (Cohen *d*, 0.24 [95% CI, -0.07 to 0.56]), general functioning (Global Assessment of Functioning Scale; Cohen *d*, 0.30 [(95% CI, -0.01 to 0.62]), and social and occupational functioning (Social and Occupational Functioning Scale, Cohen *d*, 0.28 [(95% CI, -0.04 to 0.59]), as reflected by differences in slopes between conditions with a small to moderate Cohen's d (Table 2 and 3). With regard to psychopathological symptoms (Brief Symptom Inventory), attachment (Revised Adult Attachment Scale), frequency of social contacts and employment, there were no differences (Cohen *d,* <.20) in slopes between the conditions.

Subgroup analyses

Exploratory subgroup analyses, in which completers in the FACT plus RG condition (n = 59) were compared with participants in the FACT as usual condition (n = 78), yielded similar or slightly larger effect sizes (Table 8). The effect size for the primary outcome analysis increased from .54 to .61 (95% CI, 0.28-0.93).

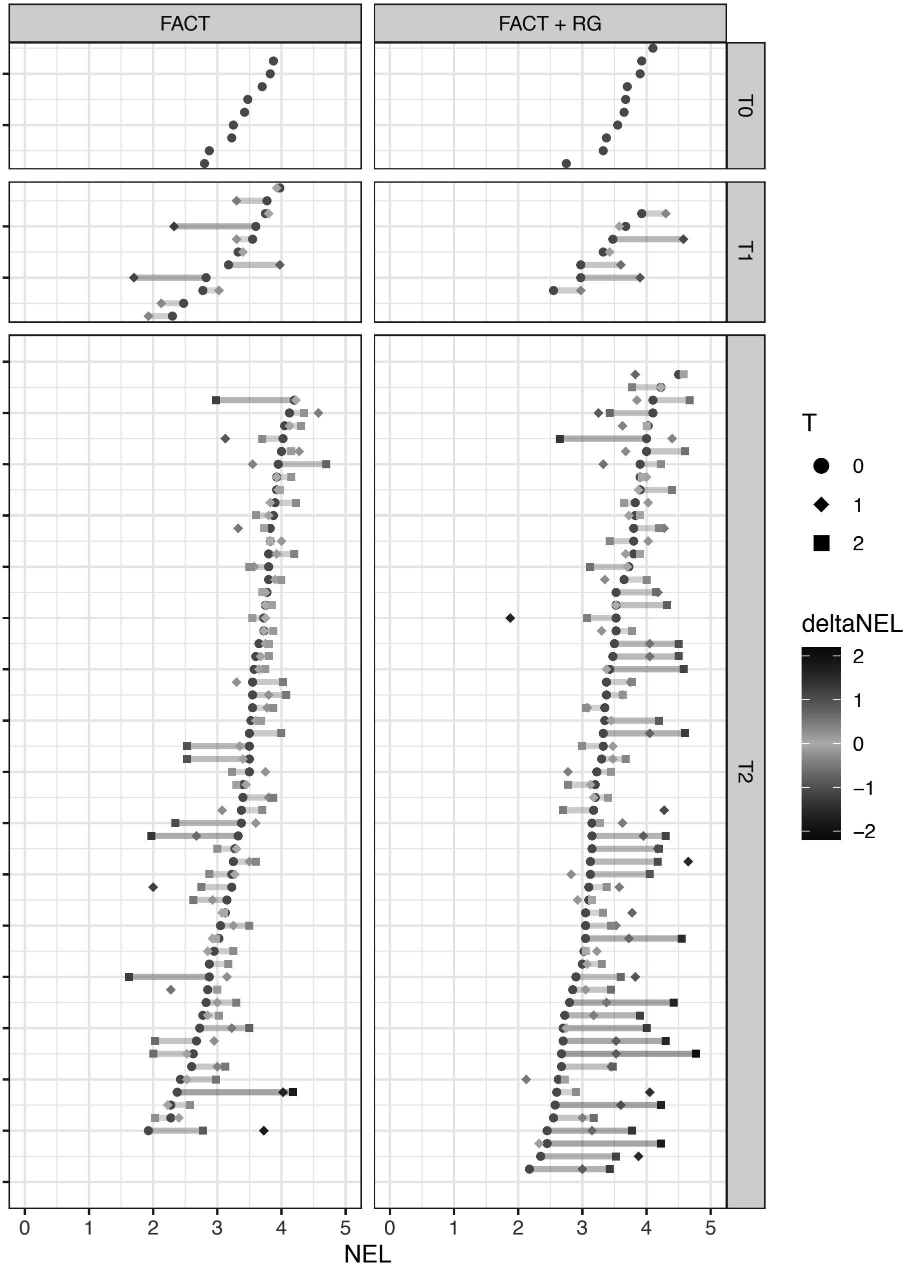

Figure 2. Absolute empowerment scores within participants across timepoints
Participants are sorted by empowerment score [Netherlands Empowerment List; NEL:] at T0 [baseline] per pane. Left panes show participants in the FACT alone [care-as-usual] condition, and right panes show participants in the FACT + RG [RGs integrated in care-as-usual]. The upper pane contains the

participants that completed only T0; the middle pane contains the participants that completed T0 and T1 [9-months follow-up] and the lower pane contains the participants that completed T0, T1 and T2 [18-months follow-up]. In the middle and lower panes coloured lines are drawn within participants from T0 to the latest measurement. Colours indicate the direction and extent of change (deltaNEL).

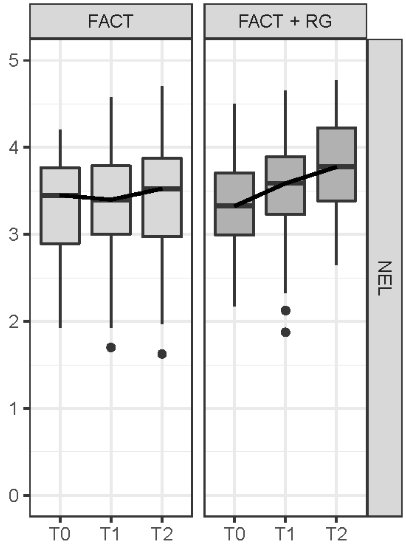

Figure 3. Trajectory of mean empowerment scores over time, based on the intention-to-treat population.

Error bars indicate the standard errors. FACT indicates care-as-usual; FACT + RG indicates resourcegroups integrated in care-as-usual. T0 represents baseline scores; T1 the 9-month follow-up and T2 the 18 month follow-up.

Mediation analyses and Treatment Satisfaction

Results from the mediation analyses, as shown in Table 9, revealed that improved empowerment after 9 months was a significant mediator for changes in personal recovery (proportion-mediated standardized mean difference, 0.32; 95% CI, 0.03 – 0.70, *P* = 0.04) and general functioning (proportion-mediated standardized mean difference, 0.13; 95% CI, 0.01-0.36; *P*= 0.04) after 18 months. Compared with the FACT as usual condition, participants in the FACT plus RG condition were more satisfied with their treatment at 9 (Cohen *d*, 0.45; t(135)=-2.62, *P* =.009) and 18 (Cohen *d*, 0.41; t(116) = -2.22; *P* = .02) months as well as the involvement of their relatives at 9 (Cohen *d*, 0.48; t(132) = -3.96; *P* < .001) and 18 (Cohen *d*, 0.59; t(115) = -4.40; *P* < .001) months (Table 4).

Table 2. Primary and Secondary Observed Outcome Measures During the 3 Time Points by Condition

	FACT plus RG			**FACT as usual**		
	Baseline (n = 80)	9-mo follow-up (n = 70)	18-mo follow-up (n = 63)	Baseline (n=78)	9-mo follow-up (n = 67)	18-mo follow-up (n = 58)
Primary outcome Mean (SD) score						
NEL[a]	3.32 (.51)	3.55 (.53)	3.77 (.57)	3.34 (.52)	3.34 (.62)	3.38 (.7)
Secondary outcomes Mean (SD) score						
MANSA[b]	4.12 (.88)	4.49 (.74)	4.67 (.74)	4.26 (.85)	4.34 (.9)	4.48 (1.04)
I.ROC[c]	3.49 (.77)	4.04 (.77)	4.21 (.73)	3.65 (.73)	3.89 (.93)	3.98 (1.04)
WHODAS 32[d]	37.73 (18.73)	30.93 (19.31)	29.90 (20.51)	36.62 (19.92)	32.87 (19.99)	32.87 (18.96)
GAF[e]	47.91 (10.22)	53.8 (10.16)	58.33 (11.76)	51.45 (10.58)	54.03 (11.26)	54.84 (13.43)
SOFAS[f]	51.55 (9.49)	55.8 (9.44)	59.13 (10.81)	53.71 (11.46)	54.82 (11.05)	56 (13.96)
BSI[g]	2.11 (.72)	1.98 (.86)	1.92 (.82)	2.15 (.85)	1.98 (.81)	1.91 (.76)
RAAS[h]	2.92 (.61)	2.84 (.66)	2.78 (.68)	2.99 (.7)	2.85 (.74)	2.9 (.74)
Frequency social contact[i]	4.51 (1.15)	4.5 (1.1)	4.5 (.89)	4.58 (1.11)	4.5 (1.25)	4.24 (1.25)
Quality social contact[j]	3.76 (.76)	3.98 (.58)	3.99 (.55)	3.76 (.7)	3.84 (.68)	3.86 (.66)
Employment[k]	0.4 (.49)	0.47 (.5)	0.52 (.5)	0.49 (.5)	0.49 (.5)	0.52 (.5)

Abbreviations: NEL, Netherlands Empowerment List; MANSA, Manchester Short Assessment of Quality of Life; I.ROC, Individual Recovery Outcomes Counter; WHODAS, World Health Organization Disability Assessment Schedule 2.0; GAF, Global Assessment of Functioning Scale; SOFAS, Social and Occupational Functioning Scale; BSI, Brief Symptom Inventory; RAAS, Revised Adult Attachment Scale.

a. Scores range from 1 to 5, with higher scores indicating better empowerment
b. Scores range from 1 to 7, with higher scores indicating better quality of life
c. Scores range from 1 to 6, with higher scores indicating better recovery
d. Scores range from 1 to 5, with higher scores indicating more disability
e. Scores range from 0 to 100, with higher scores indicating better functioning
f. Scores range from 0 to 100, with higher scores indicating better social functioning
g. Scores range from 1 to 5, with higher scores indicating more symptoms
h. Scores range from 1 to 5, with higher scores indicating more attachment unsafety
i. Scores range from 1 to 7, with higher scores indicating higher frequency
j. Scores range from 1 to 7, with higher scores indicating better quality of social contact
k. Zero indicates no job; 1, having a volunteer or paid job.

Table 3. Outcomes Linear Mixed Model analyses of Primary and Secondary Outcomes

Outcome and Effect	Slope (SD)	Cohen *d* effect size [95%CI][a]
PRIMARY OUTCOME		
Empowerment (NEL) score [a]		0.54 [0.21 to 0.86]
Control Group	0.018 (0.004)	
Treatment Group	0.423 (0.003)	
SECONDARY OUTCOMES		
Quality of Life (MANSA) score [b]		0.25 [-0.07 to 0.56]
Control Group	0.192 (.007)	
Treatment Group	0.461 (.007)	
Personal recovery (I.ROC) score [c]		0.38 [0.06 to 0.69]*
Control Group	0.276 (0.007)	
Treatment Group	0.675 (0.006)	
Disability (WHODAS 32) score [d]		0.29 [-0.03 to 0.6]
Control Group	-0.079 (0.003)	
Treatment Group	-0.273 (0.003)	
General functioning (GAF) score [e]		0.30 [-0.01 to 0.62]
Control Group	3.682 (1.54)	
Treatment Group	8.394 (1.465)	
Social and occupational functioning (SOFAS) score [f]		0.28 [-0.04 to 0.59]
Control Group	2.008 (1.466)	
Treatment Group	6.166 (1.396)	
Symptoms (BSI) score [g]		0.07 [-0.24 to 0.38]
Control Group	-0.164 (0.005)	
Treatment Group	-0.228 (0.005)	
Attachment (RAAS) score [h]		0.10 [-0.21 to 0.41]
Control Group	-0.068 (0.004)	
Treatment Group	-0.148 (0.004)	
Frequency social contact score [i]		0.15 [-0.16 to 0.46]
Control Group	-0.243 (0.014)	
Treatment Group	-0.012 (0.014)	
Quality social contact score [j]		0.24 [-0.07 to 0.56]
Control Group	0.033 (0.004)	
Treatment Group	0.24 (0.004)	
Employment score [k]		0.10 [-0.21 to 0.42]
Control Group	0.123 (0.132)	
Treatment Group	0.565 (0.128)	

Abbreviations: NEL, Netherlands Empowerment List; MANSA, Manchester Short Assessment of Quality of Life; I.ROC, Individual Recovery Outcomes Counter; WHODAS, World Health Organization Disability Assessment Schedule 2.0; GAF, Global Assessment of Functioning Scale; SOFAS, Social and Occupational Functioning Scale; BSI, Brief Symptom Inventory; RAAS, Revised Adult Attachment Scale.

* p<.05

a. Scores range from 1 to 5, with higher scores indicating better empowerment
b. Scores range from 1 to 7, with higher scores indicating better quality of life
c. Scores range from 1 to 6, with higher scores indicating better recovery
d. Scores range from 1 to 5, with higher scores indicating more disability
e. Scores range from 0 to 100, with higher scores indicating better functioning

f. Scores range from 0 to 100, with higher scores indicating better social functioning
g. Scores range from 1 to 5, with higher scores indicating more symptoms
h. Scores range from 1 to 5, with higher scores indicating more attachment unsafety
i. Scores range from 1 to 7, with higher scores indicating higher frequency
j. Scores range from 1 to 7, with higher scores indicating better quality of social contact
k. Zero indicates no job; 1, having a volunteer or paid job.

Table 4. Care Satisfaction

	9-mo follow-up				18-mo follow-up			
Satsifaction measure	No of obser-vations [a]	Mean (SD) score	*t*-Test (df)	Cohen *d* (95%CI)	No of obser-vations [a]	Mean (SD) score	t-Test (df)	Cohen d (95% CI)
CSQ [b]								
FACT as usual	67	2.89 (.43)	-2.62	.45	58	2.80 (.44)	-2.22	.41
FACT plus RG	70	3.09 (.46)	(135)[c]	(.11 – 0.79)	63	3.01 (.57)	(116)[d]	(.05 - .77)
VSSS-EU [e]								
FACT as usual	67	3.15 (.89)	-3.96	.48	58	3.01 (.74)	-4.40	.59
FACT plus RG	70	3.73 (.81)	(132)[f]	(0.14 – 0.82)	63	3.70 (.98)	(115)[f]	(0.22-.95)

Abbrevations: CSQ: Client Satisfaction Questionnaire; FACT: flexible assertive community treatment; RG = resource groups; VSSS-EU: Verona Service Satisfaction Scale- European Version.

[a] Uses only available data without performing imputation

[b] Scores range from 1 to 4, with higher scores indicating more satisfaction

[c] P = .009

[d] P <.05

[e] Indicates relatives involvement. Scores range from 1 to 5, with higher scores indicating more satisfaction

[f] P <.001

Discussion

To our knowledge, this randomized clinical trial is the first to examine the effectiveness of RGs for people with SMI as a way to facilitate empowerment and enhance involvement of significant others. Our results show that empowerment improved significantly when RGs were integrated into FACT compared with FACT as usual. The medium effect size we found is large compared with effect sizes found in other social interventions for people with SMI (56–58). In addition, FACT plus RG improved quality of life, personal recovery, disability, quality of social contact and general and social functioning more than did FACT as usual. No differences between conditions were found regarding psychopathological symptoms, attachment, frequency of social contact, or employment. At both 9 and 18 months, treatment satisfaction was higher in the FACT plus RG condition than in the FACT as usual group. Our findings are consistent with those of previous uncontrolled studies of the RG method (25,28,52), supporting the use of RGs to improve community-based mental healthcare for people with SMI.

The strongest effects of the RGs were observed for empowerment, as we expected. The question then arises in what way the RG has driven the process of empowerment. A possible explanation for this is offered by the qualitative study on working mechanisms by Tjaden and colleagues (59), which showed that when patients were encouraged to be directors of their RG and to think about important aspects of their care – such as whom to involve and which recovery goals to discuss– their ownership concerning illness and recovery was vitalized. This reflects the content of the Netherlands Empowerment List, and indicates that working with the RG method made patients feel more confident about their capabilities, such as having meaningful relationships and facing the challenges of their disease.

In addition, within the RG method, significant others were structurally involved, constituting an important difference from the control condition. This may have further strengthened patients' belief in their own capabilities. Previous studies (20,60,61) have shown the importance of family and a social network to the process of empowerment because they facilitate self-esteem and a self-concept of being capable and valuable. The RG method thereby fits within a relational, contextual perspective that underscores the pivotal role of the social context in coping with illness and recovery. Previous studies (62,63) have recognized that people with SMI often see themselves as inferior and shamed in their relationships with professionals and people from their social networks. Recovering from such disbalance via the openness and joint decision making-processes inherent to the RG meetings may contribute to the empowering effects of the method (64).

Our findings are in line with studies showing that interventions directed towards involving family and the social network are amongst the most effective for people with SMI (2,6). Nevertheless, poor implementation rates for social network involvement are consistently reported (3–6). In this light, most participants with SMI allocated to the intervention condition being able to set up an RG for a longer period of time is noteworthy and suggests that the RG method is a feasible means of providing network-oriented mental health care. However, implementing the method was still challenging, as reflected by the 21 participants that did not have an RG meeting. These implementation difficulties are previously described (59,64) and show the importance of investigating barriers and facilitating factors. The method could also be useful for improving collaboration between services. Rather than referring patients to specialists such as employment or housing, continuity in the different phases of illness and recovery can be fostered by inviting these specialists to join the RG meetings.

Overall, our exploratory secondary analyses provide further evidence of the effectiveness of the RG method, although the effect sizes were smaller than those for empowerment. In addition, the mediation analyses showed that a portion of the improvement in several secondary outcomes seen between the 2 groups was accounted for by the change in empowerment. These findings support the notion that empowerment is not a traditional outcome but can be seen as a mediator that functions as an effective strategy for changing an individual's health behaviors, eventually leading to improved mental health outcomes (10,13,20). Empowerment and other clinical outcomes may thus have reciprocally reinforcing influences, and effects might stretch beyond our follow-up timepoints. However, we did not power on the mediation analyses, thus they should therefore be considered exploratory. Future studies with longer follow-up are needed to further unfold how the RG method, empowerment, and other outcomes are related.

We did not detect a significant difference in psychopathological symptoms between conditions. Clinical recovery may be addressed sufficiently within FACT. Medical and psychiatric care are indeed well implemented in FACT but there are difficulties with services oriented toward recovery and rehabilitation (65). Indeed, in FACT as usual, mean empowerment scores did not show change at 18 months. Hence, it seems that the main added value of working with RGs within FACT concerns the functional and personal components of recovery, that relate to reengagement in social interactions and a sense of personal agency.

Strengths and Limitations

A key strength of the study is our comparison of the RG method with an active control intervention with effectiveness that has repeatedly been demonstrated in uncontrolled studies (66–69). Furthermore, the trial was adequately powered and used blinded assessors and the multisite nature adds to the generalizability of findings.

Our results should also be interpreted in light of some limitations. First, professionals could have been biased during eligibility screening to approach patients who already had a well-functioning social network and/or ability to be an RG director. However, Dutch studies investigating the SMI population in community-based services report comparable Global Assessment of Functioning Scale scores (70) and similar demographic and employment characteristics (71). Although a comparison with social indicators was not available, this indicates that our study is based on a representative sample. A second limitation is that our model fidelity scale was not validated but designed parallel to the present study. In future research of the validity of the scale, a dose-response relation can be deduced to increase our understanding of the effective elements of the method. Third, the experimental condition was performed in the same teams as the control condition. Despite the significant differences between conditions, participants in the control condition may have been exposed to elements of the RG method (ie, spill-over). Last, we did not collect any data on potential harms, our power calculation was not based on the secondary outcomes and 10.9% of the assessors were not blinded during data-collection. In addition, participants were not blinded, which may have affected their response on the self-report measurements.

Conclusion

In this randomized clinical trial, integrating RGs within and into FACT improved empowerment and other mental health outcomes for people with SMI. Replication of the results in various local and international contexts and health economic data are recommended.

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Table 5. The Six Phases of the Resource Group Method

Phase	**Actions**
Preparation	Patient and case-manager draft sociogram; Patient and case-manager nominate members for the RG; Patient and case-manager draft the RG plan
Investment	Case-manager establishes contact with nominated significant others; Case-manager interviews nominated significant others, covering at minimum: • Their expectations, commitment and responsibility in the RG • Their relationship and previous experiences with the patient and other nominated members
Planning	Patient and case-manager set date of first meeting; Patient and case-manager set up and print agenda; Patient decides on: • The location • The chairman • The frequency
First meeting	All RG members introduce themselves or are introduced by the patient; The patient and/or case-manager give a short explanation on the RG method and confidentiality; The RG discusses the agenda: • The recovery goals (both long term and short term) • The crisis plan • The role of each member, concrete actions to achieve the goals
Follow-up meetings	During the follow-up meetings: • The RG evaluates goals, assignments and progress • The RG updates the goals and the recovery plan, and decides on new actions to achieve the goals • Skills trainings are available for RG members (e.g., problem solving and emotional communication) The composition of the RG can change if different persons are better suited to achieve the updated goals; Once a year the psychiatrist attends the meeting
Reorientation	Discussion on composition of the RG, depending on the phase of care (e.g. transition to general practitioner/social domain or to only informal RG members possible)

Abbreviation. RG = resource group

Table 6. Description and Criteria of Scores on the Resource Group Model Evaluation Tool

Item	**Description**	**Score** 1	 2	 3	 4	 5
1	The minimum number of RG meetings during the study is 4.	0 meetings	1 meeting	2 meetings	3 meetings	4 meetings
2	Integration is achieved, when: 1. The psychiatrist attends the RG at least yearly 2. The degree of perceived support from the FACT team is > 3 is on a scale of 5. 3. The RG-meeting is discussed with the FACT team. 4. The treatment plan is discussed and established annually in the RG.	None of the criteria have been met	1 criterion has been met	2 criteria have been met	3 criteria have been met	4 criteria have been met
3	Preparatory in-depth interviews have been held with informal RG members.	With 0% of the informal RG members	With 25% of the informal RG members	With 50% of the informal RG members	With 75% of the informal RG members	With 100% of the informal RG members
4	Agency is facilitated if patients have (co)decided on the following points: 1. Recovery goals 2. Agenda of the meeting 3. Composition of the RG 4. Chairman 5. Location 6. Frequency	2 points	3 points	4 points	5 points	6 points
5	A complete RG plan consist of the following points: 1. Short term goals 2. Long term goals 3. Agreements for the RG per goal 4. Crisisplan	0 points	1 point	2 points	3 points	4 points
6	A RG-meeting is complete, when the RG covered the following points: 1. Short term goals 2. Long term goals 3. Agreements for the RG per goal 4. Crisisplan 5. Skill training for the RG members	1 point	2 points	3 points	4 points	5 points
7.	The mean score of expressed emotions during the RG meeting is determined by scores on: 1. Hostility 2. Critics 3. Overinvolvement 4. Warmth (reversed) 5. Positive comments (reversed)	Mean score between: 8 - 10	Mean score between: 6- 8	Mean score between: 4 - 6	Mean score between: 2 - 4	Mean score between: 0 -2

Table 7. Frequency, Mean and SD of Scores on Items of the Resource Group Model Evaluation Tool [a]

Item [b]	Frequency					Mean (SD)
	1	2	3	4	5	
1	0	15	11	7	26	3.75 (1.27)
2	0	4	26	22	7	3.54 (0.80)
3	4	1	14	5	35	4.03 (1.31)
4	0	3	11	13	32	4.25 (0.94)
5	0	2	1	7	49	4.75 (0.66)
6	0	7	21	24	7	3.52 (0.86)
7	0	0	6	19	34	4.07 (0.83)

[a] Data was collected after each RG meeting; RGs without a RG meeting are therefore not included. Additionally, the amount of RG meetings and thereby data of the scores per RG could differ.

[b] Description of items and scores can be found in Table 6.

Table 8. Outcomes Linear Mixed Model Sensitivity Analyses of Primary and Secondary utcomes of Participants With ≥2 RG Meetings

Outcome and Effect	Slope (SD)	Cohen *d* effect size [95%CI][a]
PRIMARY OUTCOME		
Empowerment (NEL) [a]		0.61 [0.28 to 0.93]
Control Group	0.031 (0.004)	
Treatment Group	0.499 (0.005)	
SECONDARY OUTCOMES		
Quality of Life (MANSA) [b]		0.32 [0 to 0.64]
Control Group	0.187 (0.007)	
Treatment Group	0.541 (0.011)	
Personal recovery (I.ROC) [c]		0.47 [0.15 to 0.79]
Control Group	0.268 (0.007)	
Treatment Group	0.781 (0.011)	
Disability (WHODAS 32) [d]		-0.42 [-0.1 to -0.74]
Control Group	-2.599 (2.924)	
Treatment Group	-11.663 (4.365)	
General functioning (GAF) [e]		0.33 [0.01 to 0.65]
Control Group	3.435 (1.522)	
Treatment Group	8.541 (2.168)	
Social and occupational functioning (SOFAS) [f]		0.35 [0.03 to 0.66]
Control Group	2.012 (1.513)	
Treatment Group	7.328 (2.148)	
Symptoms (BSI) [g]		0.07 [-0.24 to 0.39]
Control Group	-0.216 (0.016)	
Treatment Group	-0.099 (0.023)	
Attachment unsafety (RAAS)[h]		0.14 [-0.17 to 0.45]
Control Group	-0.057 (0.004)	
Treatment Group	-0.178 (0.007)	

Outcome and Effect	Slope (SD)	Cohen *d* effect size [95%CI][a]
Frequency social contact[i]		0.07 [-0.24 to 0.39]
Control Group	-0.216 (0.016)	
Treatment Group	-0.099 (0.023)	
Quality social contact[j]		0.26 [-0.06 to 0.57]
Control Group	0.035 (0.005)	
Treatment Group	0.261 (0.007)	
Employment[k]		0.19 [-0.13 to 0.5]
Control Group	-0.028 (0.000)	
Treatment Group	0.877 (0.000)	

Abbreviations: NEL, Netherlands Empowerment List; MANSA, Manchester Short Assessment of Quality of Life; I.ROC, Individual Recovery Outcomes Counter; WHODAS, World Health Organization Disability Assessment Schedule 2.0; GAF, Global Assessment of Functioning Scale; SOFAS, Social and Occupational Functioning Scale; BSI, Brief Symptom Inventory; RAAS, Revised Adult Attachment Scale.

a. Scores range from 1 to 5, with higher scores indicating better empowerment
b. Scores range from 1 to 7, with higher scores indicating better quality of life
c. Scores range from 1 to 6, with higher scores indicating better recovery
d. Scores range from 1 to 5, with higher scores indicating more disability
e. Scores range from 0 to 100, with higher scores indicating better functioning
f. Scores range from 0 to 100, with higher scores indicating better social functioning
g. Scores range from 1 to 5, with higher scores indicating more symptoms
h. Scores range from 1 to 5, with higher scores indicating more attachment unsafety
i. Scores range from 1 to 7, with higher scores indicating higher frequency
j. Scores range from 1 to 7, with higher scores indicating better quality of social contact
k. Zero indicates no job; 1, having a volunteer or paid job.

Table 9. Outcomes Mediation Analyses

	Total Effect	AMCE[a]	ADE[b]	Proportion Mediated
Quality of Life (MANSA)				
Overall B	0.30	0.18	0.12	0.56
(95%CI)[c]	(-0.04 to 0.67)	(0.01 to 0.38)*	(-0.19 to 0.44)	(-2.04 to 3.53)
N	119	119	119	119
Personal Recovery (I.ROC)				
Overall B	0.57	0.19	0.38	0.32
(95%CI)[c]	(0.25 to 0.89) ***	(0.01 to 0.38)*	(0.10 to 0.67)**	(0.03 to 0.70)*
N	119	119	119	119
Disability (WHODAS -32)				
Overall B	-0.27	-0.07	-0.19	0.26
(95%CI)[c]	(-0.46 to -0.05)	(-0.16 to 0.00)	(-0.39 to 0.00)	(-0.02 to 0.88)
N	119	119	119	119
General Functioning (GAF)				
Overall B	10.05	1.39	8.67	0.13
(95%CI)[c]	(5.31 to 15.07)	(0.06 to 3.40)	(3.84 to 13.48)	(0.01 to 0.36)

	Total Effect	AMCE [a]	ADE [b]	Proportion Mediated
N	119	119	119	119
Social and Occupational Functioning (SOFAS)				
Overall B (95%CI) [c]	9.06 (3.63 to 13.22)	1.16 (-0.03 to 2.88)	6.90 (2.41 to 11.99)	0.13 (-0.01 to 0.41)
N	119	119	119	119
Symptoms (BSI)				
Overall B (95%CI) [c]	-0.08 (-0.36 to 0.18)	-0.14 (-0.29 to 0.00)	0.05 (-0.19 to 0.28)	0.80 (-6.87 to 15.02)
N	119	119	119	119
Attachment unsafety (RAAS)				
Overall B (95%CI) [c]	-0.09 (-0.31 to 0.13)	-0.07 (-0.16 to 0.00)	-0.02 (-0.23 to 0.18)	0.44 (-5.21 to 6.78)
N	119	119	119	119
Frequency social contact				
Overall B (95%CI) [c]	0.36 (-0.06 to 0.79)	0.10 (-0.00 to 0.25)	0.26 (-0.17 to 0.70)	0.24 (-1.23 to 1.80)
N	119	119	119	119
Quality social contact				
Overall B (95%CI) [c]	0.24 (-0.01 to 0.50)	0.10 (0.01 to 0.20)	0.15 (-0.08 to 0.39)	0.38 (-0.31 to 2.12)
N	119	119	119	119
Employment				
Overall B (95%CI) [c]	0.17 (-0.03 to 0.37)	0.01 (-0.03 to 0.06)	0.16 (-0.05 to 0.36)	0.04 (-0.56 to 0.84)
N	119	119	119	119

Note. [a] ACME = average causal mediation effects; [b] ADE = average direct effects; [c] B = standardized mean difference, CI = Confidence Interval

Abbreviations: NEL, Netherlands Empowerment List; MANSA, Manchester Short Assessment of Quality of Life; I.ROC, Individual Recovery Outcomes Counter; WHODAS, World Health Organization Disability Assessment Schedule 2.0; GAF, Global Assessment of Functioning Scale; SOFAS, Social and Occupational Functioning Scale; BSI, Brief Symptom Inventory; RAAS, Revised Adult Attachment Scale.

* p < .05

** p< .001

Chapter 7.

Economic Evaluation of Resource Groups for People with Severe Mental Illness

A Randomized Controlled Trial

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Abstract

Background

Severe mental illnesses (SMI) are associated with personal suffering and societal costs. Involvement of significant others supports processes of recovery and may reduce healthcare expenditures but is poorly implemented in community-based mental healthcare. Evidence was found for the effectiveness of resource groups (RG) in engaging the social network and promoting empowerment, but health-economic evaluations are lacking. This study evaluates the cost-effectiveness of RG integrated in Flexible Assertive Community Treatment (FACT) for people with SMI versus FACT as usual.

Methods

The health-economic evaluation was conducted alongside a multisite, assessor-blind randomized controlled trial including 158 patients, randomized either to RG + FACT (n=80) or FACT as usual (n=78). Data was collected at baseline and at the 9 and 18-months follow-up. Incremental cost-effectiveness ratios were calculated for treatment response and for quality-adjusted life years (QALYs).

Results

Compared to FACT as usual, the RG + FACT condition showed a cost reduction of €1082 after 18 months. In addition, RG + FACT yielded a 21% greater probability of treatment response, and an incremental QALY gain of 0.055. All in all, the RG method had a 59% probability of being the dominant (i.e., preferred) approach for treatment response; and a 53% probability of being dominant for gaining a QALY. Sensitivity analyses attested to the robustness of these findings.

Conclusions

This study demonstrates that integrating RG in FACT for people with SMI has a reasonable probability to be an economically viable approach because health gains are obtained at no additional cost or even less cost.

Introduction

Severe mental illnesses (SMI) refer to psychiatric disorders with a duration of at least two years, associated with impairments in multiple life domains thereby adversely affecting educational attainment, work productivity and life expectancy (1). With the growth of the international movement towards recovery-oriented mental health services for people with SMI, clinical practice moves beyond symptom reduction towards restoration of a meaningful life and social inclusion (2).

Although the potential benefits of involving significant others in mental healthcare for people with SMI are well documented (3,4), poor implementation rates are often reported (5–9). The resource group (RG) method, which builds on traditions of family intervention and integrated care, is a promising initiative to overcome this problem by providing a structure to ensure that family, friends and carers maintain full involvement in routine services, thereby becoming collaborative partners throughout the recovery process. Patients constitute an RG from their informal (i.e., friends, family) and formal network (i.e., nurse, psychiatrist, peer-worker). The group meets quarterly to discuss patients' recovery goals, and to jointly develop a plan for achieving them. By being part of an RG, significant others can acquire skills to contribute to the goals, and there is attention and support for their role, burden and needs.

Furthermore, as the RG method views patients as the directors of their RG, they are encouraged to take ownership in shaping the support that meets their needs and aspirations. The method hereby aims to foster patients' empowerment, defined as a process in which patients rediscover their identity and "take their lives in their own hands" (10). Empowerment is identified as a key aspect of recovery-oriented mental healthcare (11–14). Empowered mental health consumers have improved abilities to manage their disease, and adopt healthier behaviours (15–17), which may suggest that fostering empowerment may also contribute to a more cost-effective mental healthcare.

Previous studies investigated the effectiveness of RG in improving symptoms, functioning and well-being, (18–21). A recent randomized controlled trial (RCT) demonstrated that RG improved empowerment, personal recovery, and global- and personal functioning in persons with SMI (22). By linking informal and formal resources and promoting patients' empowerment, the RG method may also lead to a more efficient use of services and reduction of healthcare costs. However, to our knowledge there are no economic evaluations of RG. To inform policy makers and healthcare providers, evidence is needed on the health impacts and economic costs of RG.

The aim of this study is to conduct a trial-based cost-effectiveness analysis and cost-utility analysis alongside an RCT comparing RG integrated into care-as usual with care-as usual in patients suffering from a SMI. Care-as usual consisted of Flexible Assertive Community Treatment (FACT) (23–25), a community-based outpatient psychiatric treatment model.

Methods

Participants and design

The health-economic evaluation was embedded in a pragmatic, multisite, assessor-blind RCT with two parallel groups comparing the effectiveness of RG + FACT with FACT as usual for people with SMI (see (26)). Participants were recruited from 20 FACT teams in 9 mental health services throughout the Netherlands. There were six inclusion criteria: age ≥ 18 years; an SMI according to the Dutch consensus definition (27); FACT team's involvement was expected to last at least 12 months; willingness and capacity to provide written informed consent; and good command of the Dutch language.

We conducted a cost-effectiveness analysis (CEA) and cost-utility analysis (CUA) by comparing costs and effects at baseline (T0), after 9 months (T1) and after 18 months (T2) of the intervention condition (RG + FACT) with those of the control condition (FACT as usual). A societal perspective was adopted as recommended by the Dutch guideline for health economic evaluations (28). The trial was registered in the Netherlands Trial Register (NTR6737) and approved by the Medical Ethics committee of the VU University Medical Centre. Analyses were conducted in accordance with the Dutch guideline (28) and the CONSORT (29) and CHEERS (30) statements.

Procedure

Eligibility screening and enrolment was conducted by FACT professionals during intake-phase for new patients of the FACT team. After informed consent and baseline assessment, patients were randomized to either the intervention or the control condition in a 1:1 ratio by an interactive web-response system based on the random-allocation sequence and stratified for FACT teams generated by a statistician not otherwise involved in the trial. To conceal allocation sequence, random permuted blocks with sizes 2 and 4 were used. Participants and professionals were not blind to allocation status. Research staff conducting follow-up assessments at 9 and 18 months were independent of the trial and masked for the participants' allocation.

Interventions

Resource groups condition

Working with RGs within FACT involved six phases to establish an RG that would meet quarterly. The intervention protocol was adapted from the RACT program (18,31) and is described in detail elsewhere (see (22,26)). Briefly, patients drafted their RG plans, with the support of the professional that was trained in the RG method, which comprised short and long-term recovery goals and early warning signs. They then asked ("nominated") significant others and/or professionals that could contribute in working towards the goals, to join the RG. The composition was flexible, and could change according to patients' goals and phase of recovery.

Together with their mental health professional, patients prepared the first RG meeting by setting the agenda and by deciding on the location and chairperson. Before the first RG meeting, the professional invited the nominated RG members for an in-depth interview to discuss mutual relations and involvement. The RG met quarterly to discuss and evaluate patient's recovery goals and the plan for achieving them.

FACT as usual condition

FACT is a community-based treatment model that provides flexible multidisciplinary support. According to patients' needs, goals and preferences, this includes recovery-oriented case management, peer support, CBT for psychosis, and medication monitoring. Support and involvement of significant others can be part of treatment, but not in the structured way of the RG method. To date, the effectiveness of FACT has not been evaluated in the context of an RCT. Quasi-experimental and pre-post studies have shown an effective reduction in symptom severity and hospital admission rates (25,32–35). FACT belongs to the so-called community-based packages of care, which are effective in ameliorating many outcomes relevant to people with SMI, however data on costs are scant and no conclusions can be drawn about the cost-effectiveness of community-based mental healthcare (36).

Outcome measures

The outcome of interest in the CEA was self-reported empowerment, as measured with the Netherlands Empowerment List (NEL) (10). The 40 items were rated on a 5-point rating scale, with higher scores indicating greater empowerment. Internal consistency, validity, reproducibility and responsiveness were found to be good (10), sensitivity to change was demonstrated. The NEL was converted into a dichotomous treatment response variable using the Jacobsen and Truax algorithm for defining a reliable and clinically relevant change (37). Applied to the NEL, a reliable and clinically relevant change from baseline to follow-up corresponded with a minimum of 0.40 points change on the NEL. This threshold was used to dichotomize patients into treatment responders and non-responders in order to estimate incremental costs per responder.

For the CUA, the outcome was the quality-adjusted life year (QALY) gained over the period from baseline to 18-months follow-up. The QALY is a health measure that combines health-related quality of life with the amount of time spent in a health condition, such that one QALY is equal to one year lived in perfect health. The QALY was derived from the five-level version of the self-report EuroQol Five Dimensional Questionnaire (EQ-5D-5L) (38), measuring health-related quality of life in five dimensions. The five dimensions have five scoring levels (from no problems to major problems) so that 5^5=3125 distinct health states can be described. The preference for each health state is expressed in utilities, for which the Dutch tariffs were used (39). A utility represents a numerical value of an individual's health state in which a value of 1 represents perfect health and 0 would represent death. Changes in utilities over time were converted to QALYs with the area under the curve method (39,40).

Costs

Cost data were collected using the Trimbos/iMTA questionnaire for Costs associated with Psychiatric Illness (TiC-P) (41). The TiC-P is found to be a reliable and valid questionnaire for collecting data on healthcare consumption and productivity losses (42). We used a recall period of 1 month, except for hospital admissions and medication use for which we used a recall period of 3 months and 2 weeks, respectively. Unit cost-prices were based on the Dutch standard prices for the year 2014 (28) and were indexed to the year 2019. Full economic cost prices of used resources were computed when standard prices were not available. Indexed prices as used in the present study are available online (Supplementary Table 1).

With the TiC-P, four types of costs were derived:

1. *Healthcare costs* related to the utilization of healthcare services. To calculate these costs, healthcare units were multiplied by the standard cost prices (43). The costs of medication were calculated by multiplying the costs per Daily Defined Dose (http://www.medicijnkosten.nl) with the number of prescription days.
2. *Patient and family out of pocket costs* included participants' travel expenses to receive professional help and informal caregivers opportunity costs for the time spend assisting the participant (e.g., running errands for participants), valued at €14 per hour (43).
3. *Costs of productivity losses* included productivity losses stemming from absenteeism and presenteeism (i.e. being less productive while at work) in paid work and/or

volunteer jobs. These were estimated with the friction cost method (44,45) using standard hourly productivity costs (43). With regard to the prevailing Dutch labour market conditions, the friction period equals 85 calendar days, after which the person on sick leave is replaced by another employee and productivity losses cease to exist (28).

4. *Intervention costs* consisted of time spent by informal caregivers in the RG, plus the time of the mental health professionals for being in contact with the informal others, and costs related to professionals' supervision. To calculate these costs, we used implementation data as reported in the RCT (22). Taken together and indexed for the year 2019, the per-participant intervention costs summed to €704 (see Table 1) for the 18 months study period.

Table 1. Per-participant intervention costs in €

	Hours	Costs informal caregivers	Costs professionals	Total costs
Preparatory in-depth interview	1	14,86	69,42	92,36
Attendance RG meetings	2	29,72	138,84	168,56
Supervision	6.5	-	451,23	451,23
Total				704,07

Note: Costs are calculated per RG. Number of RG meetings and informal caregivers involved are estimated based on implementation data as reported in the trial (22). Costs of time for informal caregivers and professionals were valued at respectively €14 and €65 per hour (28), and are indexed to the reference year 2019.

Analysis

The study was powered based on the treatment outcome (empowerment). Assuming an effect size of Cohen's *d*=0.5 (19), a 2-sided $\alpha = .05$, and repeated measurement analysis; a minimum sample size of 133 was required to detect a significant difference between groups with a power (β) of 80%. Analyses adhered to the intention-to-treat (ITT) principle. Sample characteristics at baseline were assessed to see if, despite randomization, baseline imbalances across conditions had occurred in prognostically relevant variables (i.e., variables that are strongly correlated with the outcomes). Because we found a considerable imbalance in costs between conditions at baseline (see Table 3), baseline costs were included as a covariate in our main analysis.

Imputation

Analyses adhered to the intention-to-treat (ITT) principle. To account for missing follow-up data, we used single imputation with predictive mean matching nested in 2500 nonparametric bootstraps of incremental costs and incremental effects as recommended by Brand and colleagues (46). To enhance precision and to adjust for possibly selective dropout, baseline variables predictive of clinical and cost outcomes and of the missingness mechanism were incorporated in the imputation model (47,48). Relevant predictor variables were identified by means of regression analyses with outcomes and missingness at follow-up (9- and 18-months post baseline) as the dependent variable, and included treatment condition, quality of social contact, number of hospital admissions, employment status, baseline utility, baseline empowerment, and baseline values of the corresponding dependent outcome variable. In our main analysis, missing NEL empowerment scores at follow-up were not imputed because a missing observation was considered to be a treatment non-responder.

Economic evaluation.

Seemingly unrelated regression equation (SURE) models were used on the imputed dataset to simultaneously regress incremental costs and incremental effects on condition with baseline costs as a covariate. To account for nonnormality in the data and to examine uncertainty, the SURE models were bootstrapped 2500 times, resulting in 2500 different samples. Incremental cost-effectiveness ratios (ICERs) of RG + FACT relative to FACT as usual for both the CUA and the CEA were computed by dividing the between-group cost differences by the difference in effect. The ICER is interpreted as the costs for gaining one unit effect (i.e. cost per additional treatment responder in the CEA; cost per QALY gained in the CUA) (49). The scatter of 2500 bootstrapped ICERs was plotted on the ICER plane.

The origin of the x-axis and y-axis in the ICER plane represents the care as usual condition; the x-axis represents the differences in effect; and the y-axis represents the differences in cost. Each simulated ICER falls into one of the four quadrants of the ICER plane. When most simulated ICERs fall into the northeast (NE) quadrant, better health is obtained with the intervention but at additional costs. In the northwest (NW) quadrant, the intervention generates less health and more costs than care as usual. In the southwest (SW) quadrant, the intervention generates less health, but is also less costly. Finally, in the southeast (SE) quadrant, the intervention generates more health gains and does so for lower costs; the intervention “dominates” the control condition. The distribution of the simulated ICERs over the four quadrants was used to determine the probability that the RG + FACT intervention is cost-effective compared to FACT as usual.

Finally, cost-effectiveness acceptability curves (CEACs) were graphed. CEACs inform decision makers about the probability that the intervention is deemed cost-effective, given a range of willingness-to-pay (WTP) ceilings for gaining one treatment responder and one

QALY. According to Dutch guidelines, willingness to pay (WTP) reference values vary with the disability weight of a disorder between €20,000 to €80,000 per QALY (50). For the present study, we used a WTP ceiling value of €50.000 per QALY gained, which seems reasonable given the substantial disease burden associated with SMI (51).

Sensitivity analyses

To assess the robustness of the findings, we carried out the following sensitivity analyses. First, we adopted a healthcare perspective and included only medical costs. The healthcare perspective is preferred in some countries, for example in the United Kingdom (52). Second, we performed a sensitivity analysis by Winsorizing extreme cost by replacing the highest costs by costs corresponding with the 95th percentile (53). Third, as we considered participants with missing NEL empowerment values at follow-up as treatment non-responder in our main analyses, we performed a sensitivity analysis for the CEA while imputing missing treatment response data. For the imputation we used baseline variables that were predictive of treatment (non)response, identified by means of a logistic regression analysis with treatment (non)response at 18 months as the dependent variable.

Results

Sample

In total, 403 participants were asked to participate of whom 158 were randomized to either RG + FACT (n=80) or FACT as usual(n=78). Overall, 37 of the 158 participants were lost to follow up (23.4%), at a similar rate in the intervention (21.3%, n=17) as in the control condition (25.6%, n=20) (X^2 (1, *N* = 158) = 0.22, *p* = .64). Regression analyses confirmed that there were no baseline variables predicting dropout.

Personal and clinical characteristics of the participants at baseline by condition are presented in Table 2. In brief, median age of participants was 38 (MAD: 24.1) and median years of contact with mental health services was 6 (MAD: 5.93). The majority of the participants were male (58.9%, n=93), Dutch (58.9, n=93), had completed education at college level (76%, n=120) and did not have a partner (66.5%, n=105).

Incremental Costs

Table 3 shows the various costs by condition and over the measurement points. Means of the (sub)totals are based on the imputed sample. Total cumulative societal costs between baseline and 18 months follow up were €78.913 for RG + FACT, and €63.374 for FACT as usual. The (between-group) incremental costs were –€1082 per patient. In other words, the RG + FACT condition was associated with less costs, even when implementing RGs entailed an additional amount of €704 intervention costs.

Incremental Effects

In the RG + FACT condition, 46.4% (95% CI: 0.33 – 0.62) participants fulfilled the criteria for clinically significant change in empowerment over the 18 months after study entry; in the FACT as usual condition this was 26.0% (95% CI: 0.12 – 0.42). Hence, the difference between the conditions was 46.4% - 26.0% = 20.5% more treatment responders in the RG + FACT condition. In addition, the mean QALY gain over 18 months in the RG + FACT condition was 1.02 (95% CI: 0.95 – 1.09); in the FACT as usual condition this was 0.97 (95% CI: 0.87 – 1.06). The difference between the conditions was therefore 1.02 – 0.97 = 0.055, a small QALY gain favouring the RG + FACT condition. See Table 4.

Table 2. Baseline characteristics

Characteristic [a]	**Entire sample (n=158)**	**FACT as-usual (n=78)**	**RG + FACT (n=80)**
Gender			
Male	93 (58.9)	46 (59.0)	47 (58.9)
Female	65 (41.1)	32 (41.0)	33 (41.3)
Age, median (MAD)	38 (13.34)	41 (11.86)	37 (14.09)
Educational attainment			
No or only elementary school/GED	37 (23.4)	20 (25.6)	17 (21.3)
At least secondary education	119 (75.3)	57 (73.1)	62 (77.5)
Partnered			
Yes	53 (33.5)	24 (30.8)	29 (36.3)
No	105 (66.5)	54 (69.2)	51 (63.8)
Employment			
Employed	26 (16.5)	15 (19.2)	11 (13.8)
Voluntarily work	24 (15.2)	10 (12.8)	14 (17.5)
Unemployed	79 (50)	37 (47.4)	42 (52.5)
Other	29 (18.4)	16 (20.5)	13 (16.25)
Living situation			
Alone	61 (38.6)	36 (46.2)	25 (31.3)
With partner and/or children	46 (29.1)	20 (25.6)	26 (32.5)
With parents	13 (8.2)	9 (11.5)	4 (5.0)
Supported housing	30 (19.0)	11 (14.1)	19 (23.8)
Other	8 (5.1)	2 (2.6)	6 (7.5)
Ethnicity [b]			
Dutch	93 (58.9)	47 (60.3)	46 57.5)
Western	19 (12.0)	9 (11.5)	10 (12.5)
Non-Western	45 (28.5)	22 28.2)	23 (28.8)
Unknown	1 (0.6)	0 (0.0)	1 (1.3)

Characteristic [a]	Entire sample (n=158)	FACT as-usual (n=78)	RG + FACT (n=80)
Years lifetime contact mental health service, median (MAD)	6 (5.93)	7 (7.41)	5 (5.13)
Lifetime admissions to psychiatric hospital			
Never	41 (25.9)	21 (26.9)	19 (23.8)
1	38 (24.1)	17 (21.8)	21 (26.3)
2-4	73 (46.2)	36 (46.2)	37 (46.3)
>4	6 (3.8)	3 (3.8)	3 (3.8)
Main clinical classification			
Schizophrenia or schizoaffective disorder	36 (22.8)	18 (23.1)	18 (22.5)
Other psychosis	22 (13.9)	15 (19.2)	7 (8.8)
Bipolar affective disorder	12 (7.6)	3 (3.8)	9 (11.3)
Depressive disorder	18 (11.4)	11 (14.1)	7 (8.8)
Anxiety disorder	4 (2.5)	0 (0.0)	4 (5.0)
Post-traumatic stress disorder	5 (3.2)	1 (1.3)	4 (5.0)
Substance-related disorders	23 (14.6)	11 (14.1)	12 (15.0)
Personality disorder	13 (8.2)	7 (9.0)	6 (7.5)
Autism	8 (5.1)	4 (5.1)	4 (5.0)
Other	6 (3.8)	2 (2.6)	4 (5.0)
Unknown	11 (7.0)	6 (7.7)	5 (6.3)

[a] Data are presented as n (%) of participants unless otherwise indicated.

[b] Ethnicity was classified according to national guidelines of Central Bureau of Statistics. Non-western included participants from former Dutch colony Suriname.

Incremental Cost-Effectiveness

The incremental costs were –€1082 (negative costs, hence a cost-reduction favouring the RG + FACT condition), the incremental effect for empowerment was 0.205 (a larger fraction of transitions to clinically significant change in empowerment) and the QALY difference was 0.055. Therefore, the mean incremental cost-effectiveness ratio (ICER) for the CEA was estimated to be –€1082/0.205 = –€5293 (dominant) for an additional treatment response, see also Table 4. The mean ICER for the CUA was estimated to be –€1082/0.055 = –€19.665 for an additional QALY (dominant).

On the ICER plane, depicted in Figure 1, each point represents one simulated ICER. Most of these were located in the SE quadrant (59% for treatment response and 52% for QALYs), representing the likelihood of obtaining health gains for less costs by the RG + FACT intervention relative to FACT as usual. The NE quadrant contained 41% of the simulated ICERs for empowerment gains and 32% for QALYs, indicating that the probability that RG + FACT is deemed cost effective also depends on the WTP for one additional health gain.

When there is no WTP per additional treatment responder, RG + FACT has approximately a 60% probability of being more cost effective than FACT as usual. This probability increases when the WTP per additional responder increases, until 75% at a WTP ceiling of €10.000. With regard to QALYs, the analyses essentially conveyed the same message. When there is no WTP, the probability that RG + FACT is considered more cost-effective than FACT as usual, is 60%. The probability increases when society is willing to pay more for a QALY gained. Assuming a WTP ceiling value of €50.000 per QALY gained, RG + FACT has a probability of 75% of being cost-effective compared to FACT as usual.

Table 3. Mean costs in € of intervention and control condition at three different time points, indexed to the year 2019

	Baseline		T1 (9 months)		T2 (18 months)	
Cost type	**FACT as-usual**	**RG + FACT**	**FACT as-usual**	**RG + FACT**	**FACT as-usual**	**RG + FACT**
Intervention costs	0	0	0	704	0	0
Health care costs						
Mental health care						
Psychiatrist	918	1056	667	827	485	290
Social psychiatric nurse	1554	2366	1520	1518	1302	1220
Social work	877	968	774	625	594	863
Psychologist	870	954	879	670	785	635
Peer expert	260	226	112	304	203	243
Job coach	162	154	224	130	454	190
Psychiatric hospital	3712	12648	395	492	1517	902
Admissions						
Crisis care	799	239	180	71	268	48
Sheltered housing	4804	7614	3637	6909	6678	3868
Assisted living	1265	1013	932	958	353	1330
Peer group	69	33	310	47	112	138
Non-mental health care						
GP	533	592	445	321	450	358
Nurse practitioner	21	16	17	30	8	16
Social services	216	211	45	212	116	616
Dietician	24	16	5	31	24	40
Alternative health care	21	0	49	23	14	39
District nurse	764	248	352	0	88	315
Home care	588	693	1540	888	573	880
Family care	142	1164	33	31	37	246
Hospital care						
Consult medical specialist	359	197	157	136	277	291
Admission non-psychiatric hospital	272	152	68	64	1642	96
Emergency department	21	52	62	47	69	40

	Baseline		T1 (9 months)		T2 (18 months)	
Cost type	**FACT as-usual**	**RG + FACT**	**FACT as-usual**	**RG + FACT**	**FACT as-usual**	**RG + FACT**
Medication	1398	1833	1512	1981	1634	1941
Justicial contacts						
Prison	0	181	0	0	1143	24
House of detention	0	0	0	0	0	0
Total health care costs (95% CI)[1]	19775 (2477 – 70973)	32783 (3897 – 105096)	14116 (10699 – 18131)	16429 (12225 – 21256)	18991 (13120 – 26506)	15475 (10497 – 22086)
Patient and family costs						
Informal care [2]	2243	3109	1645	2637	1400	3677
Travel costs	7	8	4	4	6	6
Total patient and family costs (95% CI)[1]	2250 (0 – 11610)	3118 (2 – 11491)	1951 (1539 – 4341)	2690 (947 – 3735)	1682 (917 – 3003)	3453 (2212 – 4944)
Productivity losses						
Absenteeism (paid work)	1206	506	1206	567	923	706
Presenteeism (paid work)	519	518	411	228	719	314
Unpaid work	65	95	174	235	370	47
Education	96	354	314	49	0	47
Total productivity costs (95% CI)[1]	2130 (0 – 16069)	1531 (0 – 13024)	1671 (653 – 3231)	1465 (555 – 3097)	810 (43 – 3268)	1266 (192 – 3729)
Total costs (95% CI)[1]	24154 (3350 – 71261)	37432 (4949 – 120845)	17738 (13910 – 22251)	21287 (16851 – 26426)	21482 (15395 – 29297)	20194 (14761 – 27494)

[1] Based on single imputation nested in 2500 bootstrap replications (hence, mean costs of items do not necessarily add up to (sub)total costs).

[2] Informal care includes unpaid work (e.g. domestic work, taking care of children)

Sensitivity Analyses

Table 4 displays the main analysis and sensitivity analyses and Figures 2 and 3 show the ICER planes and CEACs of the sensitivity analyses of respectively the CEA and the CUA. The first sensitivity analysis, adopting a healthcare perspective, resulted in more costs savings for the RG + FACT condition (-€4310) than the main analyses and therefore more ICERs located in the SE quadrant for both the CEA (82%) and the CUA (71%), indicating an increased probability that RG + FACT is associated with better effects and reduced costs compared to FACT as usual.

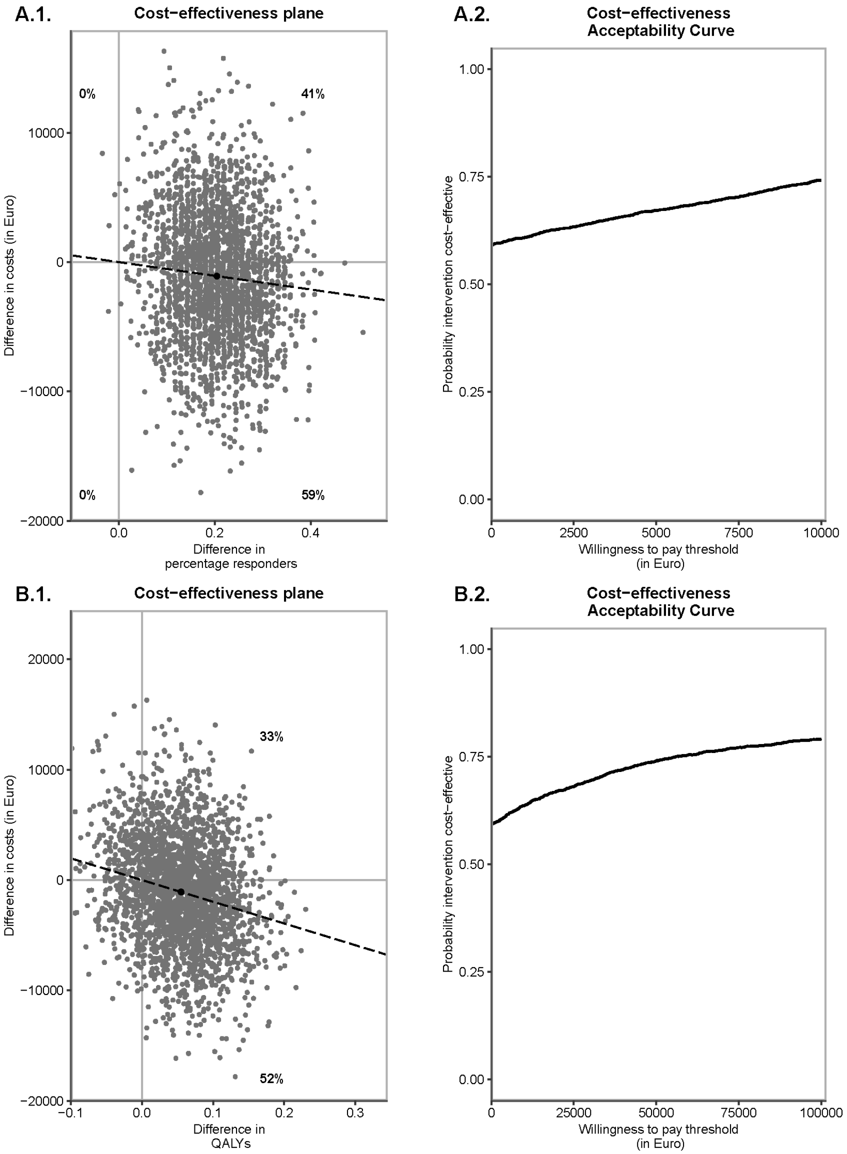

Figure 1. Cost-effectiveness plane and cost-effectiveness curve of the main analysis.
NB: A1 and A2 = CEA (NEL treatment response as the outcome); B1 and B2 = CUA (QALY as the outcome).

Winsorizing the data, as we did in the second sensitivity analysis, yielded conclusions that were comparable with those of the main analyses, although the probability of RG + FACT being cost-effective for both the CEA and CUA slightly decreased.

Results of the third sensitivity analysis, in which we imputed missing treatment response using baseline variables, were similar to the main CEA in which we treated missing NEL values as treatment non-response.

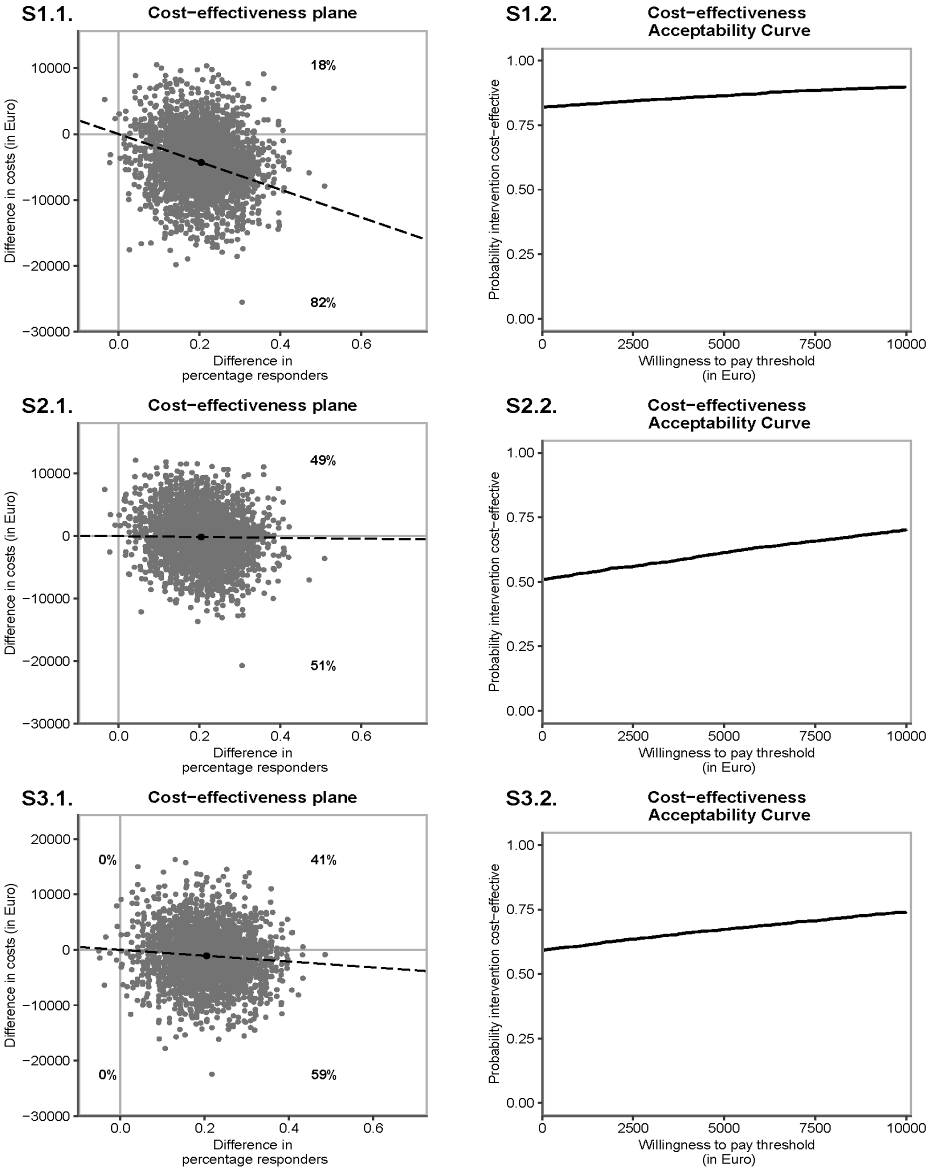

Figure 2. Cost-effectiveness planes and cost-effectiveness acceptability curves of the sensitivity analysis of the CEA. NB: S1.1 and S1.2 = healthcare perspective; S2.1 and S2.2 = winsorizing the data; S3.1 and S3.2 = imputing treatment response.

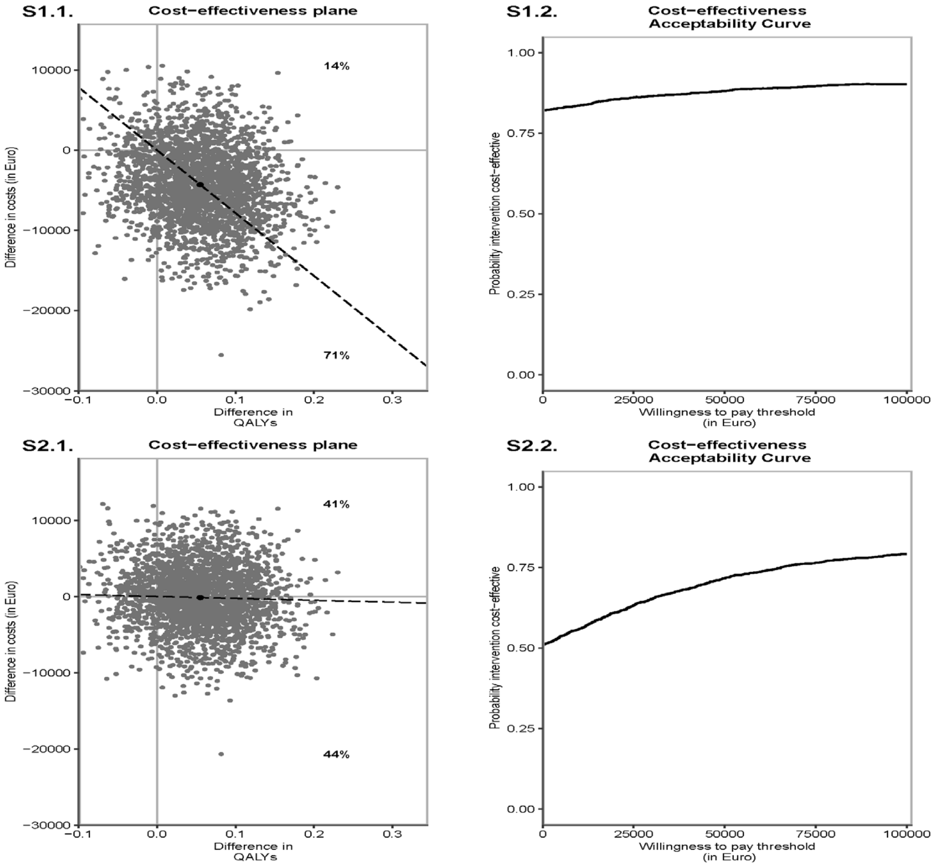

Figure 3. Cost-effectiveness planes and cost-effectiveness acceptability curves of the sensitivity analysis of the CUA.

NB: S1.1 and S1.2 = healthcare perspective; S2.1 and S2.2 = winsorizing the data

Table 4.Results of the main analysis (employing the societal perspective) and sensitivity analyses, based on 2500 bootstrap replications

				Distribution of cost-effectiveness plane, %			
	Incremental costs, €	Incremental effects	Mean bootstrapped ICER/ICUR	NE	NW (inferior)	SW	SE (dominant)
CEA, empowerment responder							
Main analysis	-1082.19	0.205	-5293.08 (dominant)	41	0	0	59
Healthcare perspective	-4310.39	0.205	-21082.49 (dominant)	18	0	0	82
Windsorizing	-137.25	0.205	-671.28 (dominant)	49	0	0	51
Imputation of responders	-1082.19	0.205	-5288.77 (dominant)	41	0	0	59
CUA, QALY							
Main analysis	-1082.19	0.055	-19665.28 (dominant)	32	8	7	52
Health care perspective	-4310.39	0.055	-78327.37 (dominant)	14	4	11	71
Windsorizing	-137.25	0.055	-2494.01 (dominant)	41	8	7	44

Discussion

Principal findings

This study evaluated the cost-effectiveness of RG integrated in FACT for people with SMI compared to FACT as usual. Costs and effects were measured at baseline and 9- and 18-months follow-up, alongside an RCT. Taking the societal perspective, the main analyses showed that RG + FACT is likely to reduce the per-participant costs by €1082 while increasing treatment response (defined as reliable and clinically meaningful increase in empowerment), and small QALY gains. When accepting a WTP ceiling of €50.000 per QALY gained, the probability of RG + FACT being cost-effective increased from 59% to 75%.

We performed three sensitivity analyses to replicate the main findings. Winsorizing outliers in the costs and redefining treatment responder using imputed NEL follow-ups yielded similar conclusions; adopting the healthcare perspective instead of the societal perspective showed larger per-participant cost-savings (€4310) and hence increased dominance of RG + FACT over routine FACT.

Results in context

Because no previous cost-effectiveness analyses have been reported for the RG method, the obtained results cannot be directly compared. However, aspects of the method, such as emphasizing autonomy and enabling persons to take on active roles in their own care, have been associated with enhanced engagement and the likelihood that patients with SMI will stay in care long enough to derive benefit from it (54,55). In addition, involvement of family and/or social network is thought to reduce costs incurred by the mental healthcare system (6,56). Our findings are in line with these studies.

In the main analysis we took the societal perspective, which includes intervention costs, healthcare costs, patient and family out-of-pocket costs, and costs stemming from productivity losses. In contrast, the healthcare perspective only includes intervention and healthcare costs. Interestingly, we found that under the healthcare perspective the per-participant cost-savings became €4310, which is more than the cost reduction of €1082 observed under the societal perspective. We have three possible explanations for this. First, within the RG + FACT intervention patients are encouraged to engage and activate resources external to formal support– which entails a shift in resource use away from the formal healthcare system. Second, the improved collaboration between professionals from in- and outside mental healthcare may have also reduced healthcare costs because this leads to more efficient and adjusted care structured around the patient. Third, by being more in charge of their own care (e.g., more empowered), patients are able to shape care that is better adapted to their needs and wishes, and hereby need less mental healthcare. Hence, for managers and decision makers it is important to keep in mind that although the implementation of the RG method is associated with extra initial intervention costs for the mental healthcare team to establish a well-functioning RG; the cost-savings were also mostly found in the healthcare domain. Furthermore, in the RG + FACT condition cost reductions that were found between baseline and 9 months were further reduced between 9 and 18 months, which was not the case in the FACT as usual condition. This indicates that the cost savings, resulting from the increased empowerment and better collaboration, might not have been fully captured in the study's follow-up period.

Limitations

Some limitations should be noted. First, costs and health outcomes that occur in the future are usually valued less than present costs and benefits. For this reason, NICE guidelines recommend that costs and benefits beyond one year should be discounted. The procedure of discounting refers to adjusting future costs and benefits to "present values" by predetermined discounting rates (57). Our follow-up exceeded the one-year limit, indicating that discounting is recommended. However, because of the 9- and 18-months period it is not clear what fraction of the costs must be discounted, which would render any attempt at discounting speculative and indecisive. We therefore refrained from discounting, but the undiscounted effects and costs may have been overestimated.

Second, we used a recall period of one month for participants' self-report regarding healthcare usage and a period of one months in changes in productivity. The fact that patients had to self-report retrospectively might have led to recall bias. However, previous research has shown that a three-month recall period is acceptable for a cost interview (58,59). In addition, since recall bias (if any) would have been present in both conditions and at all assessments, we think that it could have only impacted the findings minimally. Another limitation is that the economic evaluation relied on participants' self-report regarding healthcare usage and changes in productivity; however, a validation study found a satisfactory to nearly perfect agreement between patient-reported data and data provided by health services (42).

Fourth, since baseline costs have a strong prognostic value for costs at 18 months and we aimed to obtain an unbiased estimate of the effect of the intervention, it seemed methodologically sensible to adjust for the baseline imbalance of costs between conditions. However, the higher baseline costs in the experimental condition may have contributed to the greater decrease during follow-up. Nonetheless, the decline in costs continued between 9 and 18 months in the intervention condition, but not in the control condition. This persistent trend may therefore point towards a more structural change stemming from the structural integration of RG within FACT.

Finally, the generalizability of our results is limited due to differences in healthcare systems across settings and countries. Therefore, we recommend replication in different settings and countries.

Conclusions

To the best of our knowledge this is the first study investigating the cost-effectiveness of the RG method for people with SMI, a recovery-oriented approach directed at fostering the patients' autonomy, systematically involving significant others and improving collaboration among resources. RG integrated in FACT demonstrated in FACT improved participant's empowerment, coupled with a decrease in costs compared with FACT as usual. These results show that using RG in FACT has a reasonable probability of being cost-effective, perhaps even cost-saving. Various sensitivity analyses attested to the replicability of these findings.

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Chapter 8.

General Discussion

The main research question investigated in this thesis concerned the meaning and effectiveness of resource groups (RG) in community-based mental healthcare for people with severe mental illness (SMI). This chapter starts with a brief summary of the main findings, clustered around the four aims. Next, five themes for discussion are being explored with the purpose to integrate the qualitative and quantitative results and to reflect on the findings: (i) recovery as a relational process; (ii) therapeutic alliance; (iii) attachment; (iv) implementation; and (v) integrated care. The chapter ends with a discussion of the limitations of the thesis, recommendations for future research and clinical implications.

Summary of the main findings

Aim 1: To explore the concept of empowerment by investigating the association between empowerment and attachment patterns

In **Chapter 3**, the primary outcome measure (empowerment) was explored using attachment theory. In this cross-sectional study, baseline data was used to investigate whether attachment theory could provide a theoretical framework to better understand the role of social relationships and interpersonal interactions in the empowerment process. We found that the majority of the people with SMI have insecure attachment patterns, and find it therefore difficult to trust and rely on others and themselves. Furthermore, high levels of attachment anxiety and attachment avoidance were significant predictors of low levels of empowerment. Quality of social contact also significantly predicted empowerment, while frequency of social contact did not. Taken together, the results emphasize that within the empowerment process it is important to work with the image that someone has of the self and the other in relationships and social situations. This establishes the value of social, contextualized interventions as routes to improving empowerment for people with SMI.

Aim 2: To gain in-depth understanding of the meaning, experiences and interpersonal dynamics when working with RGs

To this end, we conducted a longitudinal, qualitative multiple case-study design based on grounded theory methodology. In **Chapter 4** we describe that a well-functioning RG sets the stage for five processes to unfold: (i) experience of support, (ii) acknowledgment of significant others, (iii) activation, (iv) openness, and (v) integration. These processes in turn were found to facilitate a patients' entrance into what can best be described as a "pre-phase" of recovery: they developed an arousing curiosity about the world beyond illness and, together with their significant others, cautiously explored forms of reciprocity and equality in their social relations. On the level of mental healthcare, we found that the method reinforced the uniqueness of each person and his or her recovery process and hereby provided a way to anchor recovery-oriented principles in the daily work of professionals. The analysis also revealed three factors that interfered with establishing an RG that would serve as a safe basis for the unfolding of the recovery-facilitating processes and effects as described above: (i) implementation issues; (ii) a predominant network; (iii) and unaddressed tensions inherent in the RG setting.

In **Chapter 5** the interpersonal dynamics that arise within an RG as well as the influence of these dynamics on the patients' recovery journey are further explored. Here, we performed a narrative analysis in which we reconstructed and analyzed the stories of four men setting up an RG. It was found that, after difficult years of illness and long histories of dependence and risk prevention, being the director of the RG cannot be imposed. Instead, the degree to which the RG method contributed to recovery was associated with the extent to which existing roles and dynamics altered. Breaking through old patterns of inequality and the joint search for a new balance in the relationship proved to be crucial to pave the way for individuals with SMI to find their own voices and pursue their recovery journeys. The four stories provide insight in the struggles, fears and tensions that are related to finding new ways of relating to each other. An honest and reflective atmosphere in which all participants are encouraged to participate and to be curious about themselves and each other were found to be essential to change interpersonal dynamics. The RG method should therefore not only be considered an intervention to organize informal support for the patient, but also as a platform to expose and adjust the functioning of the patient's social network as a whole.

Aim 3: To investigate whether using the structure of RGs within community care has favorable effects on empowerment and recovery-related outcomes, compared to community care as usual within the context of Flexible Assertive Community Treatment (FACT) for people with SMI.

To address this aim we conducted an assessor-blind, multisite, pragmatic randomized clinical trial (RCT). The trial, described in **Chapter 6,** showed that empowerment scores had improved significantly more in patients allocated to RG + FACT (n=80) when compared to patients in FACT as-usual (n=78) both at 9- and 18-months follow-up. In addition, RG + FACT led to significantly greater improvements at 18 months regarding quality of life, personal recovery, disability and general and social functioning than FACT as-usual. No significant differences between conditions were found regarding psychopathological symptoms, attachment, frequency of social contact or employment. At both 9- and 18- months follow-up, treatment satisfaction was higher in the RG + FACT condition than in FACT as-usual. The majority of the people with SMI allocated to the RG + FACT condition (74%) was able to set up an RG for a longer period of time and in 84% of the RG meetings someone from the informal network was attending. This suggests that the RG method provides a feasible manner to involve significant others. In the chapter it is therefore concluded that the structure of an RG constitutes network-oriented mental healthcare that empowers people with SMI within their own environment and improves community-based services.

Aim 4: to evaluate the cost-effectiveness of integrating RGs into current care
To meet this aim, we conducted a cost-utility analysis and a cost-effectiveness analysis from a societal perspective alongside the RCT (**Chapter 7**). Four types of costs were derived: (i) healthcare costs; (ii) patient- and family out of pocket costs; (iii) costs of productivity losses; and (iv) intervention costs. The difference in costs and the difference in effects between the two conditions were compared. Although working with RGs was associated with additional implementation costs, costs were (slightly) reduced after 18 months. In addition, working with RGs led to slightly better effects, expressed in quality-adjusted life years (QALY) gained and treatment response (reliable and clinically relevant change in empowerment). All in all, the RG method had a 59% probability of being the dominant (i.e., preferred) approach for treatment response; and a 53% probability of being dominant for gaining a QALY. Sensitivity analyses confirmed the robustness of the main findings. The results demonstrate that integrating RG in FACT for people with SMI has a reasonable probability to be an economically viable approach because health gains are obtained at no additional cost or even less cost.

Discussion and reflection

Recovery as a relational process

In much of the literature, recovery is perceived as a process that takes place within and by the individual and in which autonomy, responsibility and self-determination are essential elements. In what has become a classic definition, Anthony (1) described recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals and/or roles" (p. 4). In this thesis, however, the deeply *relational* aspects in understanding, analyzing and responding to mental health difficulties and recovery became clearly visible and form the common thread throughout the different chapters. One of the most decisive features of the RG method was that the meetings reflected patients' position in their social environment and everyday life and that they exposed interpersonal patterns. From here, becoming the director of the group and determining important aspects of its functioning– such as who to involve, which recovery goals to discuss– could take place in the context of relationships and daily life. This thesis thus shows that working with RGs offers an opportunity to anchor a relational perspective on recovery at the heart of mental health services, and hereby leads to improvements of community-based mental healthcare for people with SMI. Below, this notion is further illustrated by integrating findings from the separate chapters.

In **Chapter 4** and **Chapter 5**, we observed that many people with SMI were scarred by the many years of illness and their boundaries had often been chronically crossed. As a result, they tended to be sub-assertive, afraid to stand up for themselves, or –at the other hand- somewhat detached and persistent to do it oneself. Although these can be described as individual characteristics, they were situated within the relation towards other people. A movement in these existing interaction patterns and finding new ways to relate to the world was in many cases needed for patients' agency, ownership and responsibility to grow. Thus, hereby it is suggested that (re)connecting with the interpersonal world in a manner in which both the self and the other are considered reliable partners, is a fundamental part of recovery and empowerment.

However, this (re)connecting is not a one-sided process. For some patients, this meant distancing themselves from certain relationships, establishing firmer boundaries in others or growth in self-determination after years of risk prevention. This is a reciprocal process because significant others also have needs, fears and old pain. Hence, the interpersonal changes that were needed to (re)connect concerned not only the patient but also the social network in order to facilitate, acknowledge, and live with them. Indeed, in **Chapter 5** it is described that it is essential that all RG members are encouraged to explore and question their own roles and what they need to truly believe in the recovery goals. By means of the structure of the RG method, in which the patient is the director of his self-chosen group and in which significant others gather on a frequent basis, these dynamics surfaced and could therefore, in some cases, become subject to change.

Not only are the relational aspects of recovery described and visible in the qualitative papers, they can also be put forward when considering the comparison study with FACT. In **Chapter 6** it was described that the majority of patients allocated to the RG + FACT condition had set up an RG after 18 months, and in 84% someone from the informal network had attended the RG meeting. In addition, the treatment satisfaction regarding relative's involvement was found to be significantly higher in the RG + FACT condition. Furthermore, in **Chapter 7** having an RG was associated with slightly increased family costs and decreased mental health costs. These findings together indicate that the resources outside formal support were more engaged and activated by means of the RG compared to the FACT as usual condition. Hence, being one of the main differences between the conditions, the structural involvement of significant others partly explains the significant improvement in empowerment and recovery-related outcomes in the RG + FACT condition. Taking the chapters of the thesis together, it can be concluded that by means of the structure of the RG, patients' relational and interpersonal world became more part of the recovery processes in care and this led to significantly better outcomes. The RG meetings were found to serve as platforms for interpersonal patterns to be exposed, explored and, sometimes, readjusted. Recovering from disbalance in the relationship and a restructuring in roles, patterns and perceptions of all the RG members (including professionals) facilitated the evolvement of intrapersonal concepts such as autonomy, responsibility and self-determination. Changes in the interpersonal dynamics thus paved the way for individuals with SMI to find their own voices and pursue their unique recovery journeys and hereby contributed to the empowering effects of the method.

Therapeutic alliance

It has been increasingly recognized that with the focus on developing evidence-based methods of treatment there is a risk to overlook beneficial factors besides specific components of a method (2). This has led to research that explores the importance of so-called common factors – i.e. factors that are not specific to any particular method but that instead occur in all forms of psychotherapy (3,4). The common factor that has received most attention is the therapist–client relationship, particularly the alliance that is formed between them (5). The alliance has been argued to be composed of three components: the bond, the agreement about the goals of therapy, and the agreement about the tasks of therapy (4,6). Synthesized evidence from research and recovery narratives show that the therapeutic alliance is an important component of care (e.g. (4,7–12)).

Despite being considered a common factor, the method of intervention can influence the nature of the therapeutic alliance. We observed that working with the RG method committed professionals to develop a more holistic and personalized approach towards their patients. Below we put forward three possible hypotheses of how the RG method contributed to developing such attitude and we describe how the resulting change in alliance may partly explain the empowering effects of the method.

First, in **Chapter 4** we interpret that the involvement of relatives and friends emphasized the person's uniqueness because their presence formed a representation of the multiple facets of one's identity, life stories and competencies. Furthermore, the professionals became- in many cases- part of the social context of family, significant others and community. This was not only during the RG meeting itself, but also in seemingly insignificant moments in-between, for example when a professional arrived for the RG meeting and joined in when a patient and his best friend were having a cigarette outside and talked about music. They became hereby involved in the language, habits, interactions, jokes and vulnerabilities of their patients' immediate surroundings. Inversely, the nature of the various relationships that the professionals had with family members and other social contacts influenced how the patient engaged in the relationship with the professional. Thus, the structural involvement of significant others stimulated professionals' relational and contextual awareness which led to developing a dedicated and mutual therapeutic alliance.

Secondly, professionals described – during in-between conversations or supervision – that working with RGs placed an additional emphasis on the process of setting personal recovery goals: there was a format to be filled in by the patient, there were extra tools available to make sure it was really the patient who was in charge of defining the goals, and by preparing the meetings extra time was spent on discussing them. Professionals felt that the goals were hereby a true reflection of what was important to the patient and that they were therefore working on that what actually mattered to the patient. This made professionals, the RG members and the patient more deeply and intrinsically involved and enhanced mutual agreement about the goals and the plan for reaching them. The agenda of the RG meetings ensured that the goals were indeed the topic of conversation, despite the presence of other, seemingly more pressing, illness-related issues. Thus, the extra awareness for the process of setting meaningful goals made that professionals were inclined to truly get to understand and make room for the patients' values, dreams, plans and needs in life so that these formed the basis for the goals and plans in treatment and care.

This can be illustrated with the unexpected observation that in several RGs important external events took place, such as a break-up, a moving; but also smaller happenings such as getting a dog, or making a new friend at work. During supervision, professionals related that these events had determined the well-being of an individual and the functioning of the RG. Although such unpredictability's were obviously not part of the RG method, we argue that external events could alter into turning-points in recovery *because* the professional could better recognize them as such, as a result of the increased engagement and connection. They could therefore frame them with appropriate value when helping to interpret the experience.

Thirdly, during the trainings, supervision and qualitative interviews, professionals emphasized that the biggest transformation in their attitude comprised letting go one's own urge to solve and save and, instead, follow the lead of the patient. It was also the most difficult one as it conflicted with their automatic and unconscious pattern of helping. Professionals described that it was a lot about *not* doing things: *not* giving suggestions, *not* placing one's own perspective on a goal, and *not* owning a problem. This was confusing and unsettling, as their role, and therefore importance in the recovery journey, was seemingly minimized. The uncertainty and not being in control was also hard to endure as it conflicted with a sense of responsibility and nourished a fear that things will go wrong. In addition, professionals were dedicated and eager to provide care and did not always have the trust or patience to wait for the insight or judgement of the patient. By means of the RG method professionals became aware of these automatic reactions and the RG meetings stimulated them to reflect on themselves and to give back the responsibility of the process to the patient and his/her RG. Although a very active role, this activity did not concern determining or controlling the outcomes. Instead, it included helping to consider options, recognize vulnerabilities, incorporate different perspectives, encourage to try new ways and explore one's own thoughts, feelings, experiences and patterns.

The above-described observations are in line with how the role of a recovery-oriented practitioner in the literature is characterized. Extensive service user-led reviews define the basis for recovery-oriented practice [as] the ability to build up respectful relationships with service users, in which the worker has a genuine interest in the person (13). The relationship between professionals and patients moves away from being expert/patient to being partners on a journey of discovery (5,14,15). Efforts and interventions of the professional should serve to minimize the role of professionals in a person's life and maximize natural supports (16). Gradually, people are being encouraged to become self-determining in what they need and want in their care. In other words, professionals are there to be “on tap, not on top” (17–19).

In addition, the described role of the professional in the RG shows several similarities with the Open Dialogue (OD) approach. Within OD, the elements of tolerating uncertainty and dialogism are identified to be essential in the way that professionals relate to the patient and his/her network. Tolerating uncertainty refers to avoid premature decisions and treatment plans as a reflexive desire to remove the uncertainty. Instead, connection to the distress being experienced is key and thus not acting too rapidly to bring about change (20). This is in line with the described letting go of one's own urge to solve within the present study. Dialogism is defined as a focus on creating dialogue, where a new understanding is constructed in the area between the participants (21). Openness and authenticity were classified as important to the dialogical process (22,23). These notions overlap to a great extent with the above-described changed role and attitude of the professional in the RG. This confirms that such changes represent an important part when constituting relational, contextual mental healthcare.

To sum up, based on the qualitative study and observations during the course of the study, it seems that aspects of the RG method- the social context becoming part of care and placing emphasis on setting goals of the patient- stimulated professionals to develop a different attitude. It supported them to engage with who people are, what has happened to them and what they pursue in life. The RG method hereby committed professionals to develop a recovery-oriented attitude and changed *how* they do their work, which- in turn- might have mediated the empowering effect of the method.

Attachment

Given the high prevalence of insecure attachment in the population of people with SMI, as described in **Chapter 3** and also in the literature (24–26), we hypothesized that having an RG would nourish the secure attachment system. Attachment styles are assumed to be stable over time but recent research shows that they can change, according to context and new experiences (27–31). Re-experiencing a new pattern of interpersonal relationships, one that provide a sense of security of the self and the others, enables a person to re-explore the world from a different, healthy angle. This is called a corrective emotional experience (32) that counters previous experiences and is therefore presumed to lead to adaptations in the attachment safety system (33,34).

During the RG meetings, the patient would be validated, empathized with and listened to, and the involvement of significant others would offer opportunities to work towards trustful mutual relations. These processes could serve as a corrective emotional experience, hereby modifying internalized attachment representations of the social environment. In **Chapter 4** this is supported by qualitative findings. The experience of support was here identified as one of the five important processes unfolding in an RG. Seeing their own RG gathered in a room made patients realize they are being loved, acknowledged, valued and encouraged. This is in contradiction with the negative views and expectations in interpersonal relationships that characterize insecure attachment patterns (24). For the majority of the participants in the study, having an insecure attachment style, the experience of support could thus be a corrective emotional experience.

However, the findings of the RCT (**Chapter 6**) did not support this hypothesis as there was no significant difference in the course of attachment (un)safety between participants having an RG and those without. This is contrary to the found association between empowerment and attachment reported in **Chapter 3**. When taking a closer look at Table 4 in **Chapter 6**, we see a non-significant but consistent decrease in attachment unsafety over time in the group of participants having an RG while this was not apparent in the FACT as usual group. This indicates that having an RG is associated with a trend of decreased attachment unsafety, but this trend was not significant.

An explanation of this lack of significance is that changing an attachment style that has been developed throughout years is a time-consuming process and 18 months are therefore not sufficient for the effect to become big enough to be significant. This is supported by the notion that the decrease of attachment unsafety in the RG + FACT condition between baseline and 9 months became larger during the 9 months that followed, which was not observed in the FACT as usual condition. Possibly, the unfolding of the effect, thus a further decrease in attachment unsafety in the RG + FACT condition and not in the FACT as usual condition, may stretch beyond the 18-month follow-up. In addition, our study may have been underpowered to detect a small effect, as power calculations were directed towards our primary analysis, expecting a medium effect size.

On the background of the high prevalence of attachment insecurity in the population of people with SMI and given the several studies that found that attachment style can impede subjective recovery (35,36), the development of RGs and its working mechanisms can nevertheless profit from insights of the extensive attachment research in various ways.

First, it can increase understanding of why equality in relations, as described in **Chapter 4** and **5,** seemed such a vital element in empowerment and recovery. As long as social contacts are characterized by the one-sided nature of 'standing alongside' and offering support, the working models of the fragile, unlovable self and the strong, knowing other are confirmed and the tendency of depending on others for personal validation, acceptance and approval is verified. This - in turn - might stimulate feelings of being dependent on others which stands in the way of developing a sense of autonomy and agency, essential in empowerment (37,38).

Second, the attachment-related literature can also highlight certain aspects within the RG method. For example, attachment-based interventions emphasize the importance of working towards understanding the past from everyone's perspective (39–43). Placing this in the context of an RG, this establishes the importance of the preparatory in-depth interviews with significant others to investigate perspectives on past events. From here, a joint search within the RG for interpretations from different angles can be initiated. The systemic strategy 'reframing' can hereby be of use (44,45), referring to the therapeutic process whereby people come to think about and experience their situation differently.

Third, openness in communication is recognized as an essential part to create attachment security within a social system (42,43). This supports our findings in **Chapter 4,** and suggests that that all RG members should be encouraged to engage in the communication, to talk about frictions or differences in point of view and to be honest, reflective and curious about themselves and each other during RG meetings.

Lastly, the attachment framework and the high prevalence of attachment unsafety in our study in **Chapter 3** point to the importance of being alert to the presence of trauma-related difficulties for people with SMI. It is recognized that (childhood) trauma disrupts the person's ability to form secure relational bonds, leading to insecure attachment patterns (46). The consequences of trauma encompass a range of problems even beyond the criteria for posttraumatic stress disorder (PTSD), including problems with self-functioning, affect regulation and the capacity to form positive relationships (47,48). Such maladaptive patterns of relating as a consequence of the trauma may hinder the relational recovery processes within the RG. Treatment of PTSD has been found to be safe and free of negative side effects and should be available and offered (49). Next to diminished PTSD symptoms, dysfunctional meaning associations underlying the trauma-related fear are hereby altered or disconfirmed (50). Treatment of patients' trauma should therefore be considered to foster changes in interpersonal dynamics within the RG.

Implementation

Despite the support from evidence and policies and guidelines, network- and family-oriented approaches are poorly implemented in routine practice (51). In **Chapter 6** several implementation data of RGs in the present study are described. It is reported that 67 (84%) participants in the RG + FACT condition had initiated some form of RG-related activity, such as drawing up an RG plan or holding preparatory interviews with RG-members. Fifty-nine (74%) participants had had at least one RG meeting and 44 (55%) at least two. In 84% of the RG meetings someone of the informal support system was present. In 90% the mental health professional had invited the nominated significant other for the in-depth preparatory interview before the first RG meeting.

These implementation data indicate considerably good implementation of the RG method. Although not structurally investigated, experiences in the study suggest that the implementation has asked quite some effort that should not be overlooked when interpreting the findings. By integrating practical knowledge collected during the course of the study and scientific evidence we discuss four lessons learned below. Importantly, the scientific evidence that is incorporated is not obtained by a systemic search but is compiled to place the experiences of the present study in context.

Lesson 1: Embedding of implementation within teams and organizations

In **Chapter 4** it is described that mental health professionals experienced an increased workload when incorporating the RG method into their routine practice. Especially during the beginning phase, professionals needed extra time to prepare the RG meetings with the patient and to establish a good working relationship with significant others. This is supported by the cost-effectiveness study in **Chapter 7** that showed that although costs of the overall use of mental healthcare declined more in the RG + FACT than in the FACT as usual condition, implementing the RG method entailed initial costs. In the calculation of these costs, professionals' extra time encompassed an important component, see Table 1 in **Chapter 7**. This suggest that although implementing the RG method will most likely save costs at a later stage, mental health professionals need extra time to start up an RG. This is in line with much of the literature, in which staff reported that family work requires time, resources and funding (52–58).

For professionals to be able to invest this extra time, support from the management and organization is essential. Inherently to our research design was that only a few mental health professionals per participating FACT team were engaged with the RGs.

The amount of involvement of the rest of the team, and also the management and team leader, varied greatly between teams. The most important conclusion is that these differences corresponded to a great extent with the enthusiasm and devotion of individual professionals, and hereby also to the success of the RGs. As with other network-oriented interventions, we therefore argue that for successful and sustained implementation of the RG method it is necessary to include the management- and organizational level. This is in line with the literature in which it is frequently reported that involving families requires whole team commitment (51,58) and management prioritization (59–61). Specific needs reported for family work include flexible hours (52,62–64) and the accommodation of family requirements such as childcare facilities (63) or home visits (65,66). In addition, concerns such as privacy and power relations should be openly explored (51). Most importantly, evidence of the beneficence of RGs, needs to be believed by all participants involved (51,60).

Lesson 2: Implementation requires a format to exchange experiences

In the literature a commonly described barrier to implementation of family interventions is the lack of access to adequate supervision and training (56,67–70). This may link with reports of professionals feeling insecure and having doubts regarding their own competence in for example working with the existing interactional dynamics or problems, overcoming issues of privacy and fear of burdening the family (52,56,70–72).

To overcome such issues, the research staff set up telephonic intervision sessions in addition to the regular training days. Professionals from different teams gathered by telephone in small groups to share experiences and jointly think about arising difficulties according to an established intervision method. Initially these groups were meant to be self-organized (i.e., schedule the sessions, taking turns in keeping minutes of the session), but this led to a rapidly declining presence and the research staff took over the organization. A lot of effort was put into enabling and structuring the sessions, encouraging input from all professionals and stimulating group cohesion. Although this improved the structure and attendance, there were still professionals that could not be motivated to be involved and last-minute cancellations for reasons of crisis and high workload occurred regularly.

Nevertheless, we observed that the sessions were helpful in various ways: they served as an incentive to work with RGs; they contributed to the enthusiasm and eagerness of professionals; professionals experienced support in overcoming their diffidence in having contextual therapeutic conversations; they felt that sharing struggles stimulated them to face them instead of avoid them; they learned from each other's experiences; and differences in professional background, team and region of the Netherlands were helpful in obtaining multiple perspectives. Exchanging experiences and jointly thinking about arising difficulties – in the form of the telephonic intervision sessions- was hereby an important part of the implementation of the RG within the context of the study.

A dedicated person is essential as a driving force behind the organization and commitment of such sessions. Also, a sparring partner that could be approached in-between intervision sessions so that professionals were not discouraged in case of emerging difficulties was found to be important.

Lesson 3: the importance of the involvement of expert-by-experiences.

Within the RG method, it is encouraged that an expert-by-experience is involved with the setting up and unfolding of the RG. During the study however, there were only a few RGs in which this was implemented. Within these RGs the work of the experts-by-experience was found to be very valuable but the number of RGs was too limited to elaborate on this in the separate chapters.

The experts-by-experience invested a lot of time in defining, exploring and describing the recovery goals. Their lived experience gave the tools to thoroughly explore with patients what is really important to them, what is unique for their recovery, and how they can work on that. In other words, the unique expertise of the expert-by-experience ensured that the RG unfolded around the persons' narrative and patients' existential questions and needs. During the RG meetings the expert-by-experience could provide extra support for the patient by truly understanding how difficult it can be to open up and/or be vulnerable and by embodying hope and confidence in the future. Importantly, expert-by-experiences of the FACT team reported that the RGs served as a way to make their work more part of the treatment and care provided by the other professionals.

Despite these positive experiences, that are in line with studies reporting a range of benefits associated with employing peer workers (73–75), there were only a few RGs in which an expert-by-experience was involved. This shows that extra attention and commitment is needed to stabilize the role of the expert-by-experience within the RG so that the potential positive effects can be further investigated and expanded.

Lesson 4: skills training

According to the first edition of the handbook (76) and the Swedish RACT program (77,78), the RG method should include several skills training sessions next to the 3-monthly RG meetings. These trainings are aimed towards addressing maladaptive patterns and potential stressors in the patient's environment to create a healthy emotional climate around the patient. Based on the diathesis-stress theory, patients' underlying biological vulnerability is hereby protected.

Within the study only one RG had used these trainings. Professionals reported to feel a certain reluctance because it was not clear when there was a need for a training and who would decide on that. In addition, they did not feel skilled enough to do some trainings themselves and were hesitant to ask colleagues to take over. This shows that a clear strategy is needed, as the implementation of the training sessions don't naturally arise from working with RGs. The revised handbook (79) proposes a selection of essential trainings to clarify and structure the implementation. However, as we found beneficial and empowering effects despite the lack of the use of the trainings, the necessity for the effectiveness of the method remains unknown and future research should further investigate the use, implementation and effectiveness of these trainings.

Importantly, the four lessons learned above describe hindering and facilitating ingredients in the beginning-phase of the implementation of RGs. Sustainability has not been addressed as this stage has hardly been reached throughout the participating sites. At the time of writing, around 3,5 years after the start of the first RG and 2 years after the start of the last RG, quite some RGs do not longer exist. We lack structural information but reasons may include high staff turn-over, COVID-19, absence of the support of the research team and changed patients' recovery needs (less or more intensive care) with an RG that was not yet stable enough to be able to move along, with or without professionals. Next to solid support, commitment and training, a paradigm shift to considering the individual in the context of their social network is required if the implementation of RGs is to move beyond being an optional element towards mainstream practice.

Integrated care

Characteristic to suffering from an SMI, is experiencing difficulties and having aspirations in multiple domains of life. This requires support from different providers and services (80). By inviting involved professionals to join the RG meetings, the RG method intends to foster collaboration between these different services and to structure care around the RG plan (composing patients' recovery goals). With the patient being the director of the group, the RG method aims to shape transparent care that is tailored to the individuals' needs, preferences and context.

In **Chapter 4** it is described that by means of the RG a more unified support system around the patient emerged. This was observed to take place on a personal level in which patients felt that the RG was a more complete representation of their identity, including both their healthy and sick parts. On a professional level, the RG meetings served as a platform for better integration of the multiple disciplines involved. As an example:

> "… because the psychologist can also indicate where they are in their treatment process [..]. I think if [psychologist] wouldn't have been there, she [patient] would be higher on the medication than where she is now. That [patient] and also [psychiatrist] dare to lower her medication level. The encouragement and the confidence of [psychologist] have been decisive in that." *Case manager*

Implementation numbers of the trial only partly support these findings. Figure 1 presents the presence of RG members. Although there were professionals with multiple disciplines attending the RG meetings (e.g., housing, peer -support), in only 1% professionals from both mental healthcare as well as social services were present. Similarly, there was only one RG meeting in which a professional from the medical healthcare (e.g., general practitioner) was present. This suggests that for collaboration *within* mental healthcare the RG meetings seemed to have been useful but this was not achieved *across* different care domains. Unfortunately, we don't have the data to interpret the scarcity of professionals from other care domains in the RGs. That is, we don't know whether other care domains were not involved in the treatment and care (and if so: why not) and therefore not part of an RG; or that they were involved but patients did not nominate them to be part of an RG (and if so: for what reason).

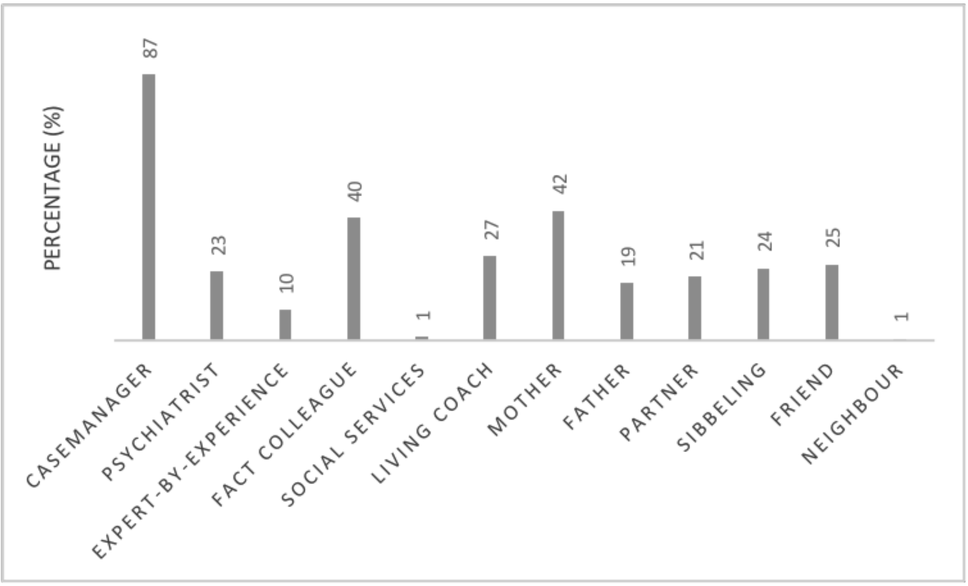

Figure 1.

Attendance RG members

Additionally, for the majority of the patients the RG meeting had not replaced the regular yearly treatment evaluation that is part of FACT. Anecdotal reports of professionals state that the RG plan was included as part of the treatment plan as adopted by the FACT team, or was uploaded as a separate pdf file in a patient's record. This indicates that the RG was considered to be an additional, separate element, instead of the primary platform from where important decisions were to be made.

This could have been a consequence of our research design. We only trained two or three professionals per team and did not involve different care domains in the training. As a result, working with the RGs may have been not established sufficiently to change the functioning of a FACT team and collaboration of different care domains in a broader sense. However, the lack of alignment between social care, medical care, addiction services and mental healthcare is internationally presumed to be the most persistent unresolved need for people with complex mental health difficulties (81,82), indicating that our findings reveal a more structural problem. The lack of alignment is often referred to as fragmentation of care, as each domain or professional focusses on one, fragmented piece of patients' difficulties and/or aspirations. The holistic view is hereby lost and interactions between individual, relationship, community and societal factors are omitted (83–85). Overcoming such fragmentation challenges conventional professional boundaries, payment systems and current norms of healthcare organizations (86). RGs not being able to improve collaboration across different care domains is hereby placed in a time-related perspective and thus seems to mirror the socio-cultural and organizational forces that are at play when aiming for integration of care. Implementing RGs should therefore be embedded within a broader plan of change in order to challenge such an interwoven, rigid and multilayered problem.

A new initiative called “network psychiatry” (87) aims to provide integrated care on the patient’ level and to enhance patients’ social capital. Several changes are proposed to organize care across different domains and throughout different phases of recovery.

Hereby, the range of possible solutions and forms of care for patients with complex problems is meant to be expanded. The movement “De Nieuwe GGZ” (88) advocates for a more personalized approach in mental health and tailored care. Here it is argued that traditional mental health organizations should have a radically different role. Instead of the main organizer of mental support, they should become part of the community around the individual person that is seeking help. Psychological suffering must be diversified and support should be aimed towards living a satisfying life. To develop the necessary skills, both care and social integration should take place within society, the place where people are and reside. When embedded within and strengthened by such models of change, the RG method could fulfill its potential to serve as a platform for improved collaboration across care domains. With its pragmatic character it might contribute in putting ambitions of integrated, tailored and transparent care into practice.

Limitations

This work was subject to various limitations, which are described below.

Influences on translating findings into practice

With its pragmatic character, this research has attempted to reflect effects in the “real-world”. However, two factors should be taken into account when translating the findings of this thesis into practice.

The first concerns possible performance bias. As with most psychosocial interventions, it was not possible to blind participants and personnel to allocation status. As a result, being randomized to FACT + RG, and thus being elected to be part of a new, innovative and promising development, may have had an empowering effect on patients on itself. Professionals were part of intervision sessions and received training. In addition, professionals were regularly contacted by research staff to discuss the progress of the RGs, arising interactional difficulties and possible implementation issues. Although the amount of hours professionals spent on a patient did not differ between conditions, this might have led to more enthusiasm and increased dedication of the professionals towards the few patients with an RG in their caseload, compared to the patients in the FACT as usual condition. In addition, although it was part of the research (i.e., enabling the comparison between conditions), the attempts of the research staff to motivate and support professionals may have served as an implementation strategy. The observation that quite some RGs do not longer exist after the ending of the study further supports the notion that a clear implementation strategy and efforts are essential in working with RGs. Taken together, the lack of blinding may have led to an overestimation of the found effects. The second factor concerns a possible spill-over effect because the FACT + RG condition was performed in the same teams as the FACT condition. This may have led to elements of the RG method being integrated into the regular FACT in the control group. Although no formal RGs were formed in the control condition, RGs taking shape in their team may have stimulated network-oriented thinking in professionals that were involved with treatment and care in the control condition. Inversely, professionals involved with the FACT + RG condition may have fall back to regular care because of the lack of support by their colleagues. The possibility of contamination may have led to an underestimation of the found effects.

Hence, based on observations during the trial, both an over-and an underestimation of the found effects could have taken place and our design does not allow to untangle these. Future studies (see below) should further clarify how and under what circumstances the RGs are effective. Above all, the implementation efforts of the research staff indicate that dedication, persistence and commitment are needed when working with RGs and should be taken into account when translating the findings into practice.

Operationalization of empowerment

The studies within this thesis were centered around the operationalization of empowerment as a process that is taking place within the interaction between the individual and his/her direct social environment. Although the NEL (89) includes the subdomain caring community, in the interpretation of the results and the qualitative chapters the importance of the wider socioenvironmental context, including important aspects such as stigma and discrimination may have been relatively underexposed. Van Regenmortel (90) emphasizes the inherent interweaving of the individual, collective and political-social level that is associated with the construct of empowerment. The individual level (referring to strength from within, including increasing self-confidence and exploring one's own qualities) and the collective level (referring to sources of strengths in one's direct environment, including support from family and friends, and sharing stories) are thoroughly addressed within the thesis. Influences at the political societal level are however not included, such as prejudices, laws, regulations, access to facilities and resources and acknowledgement of human rights for everyone, but are nevertheless considered to be determining aspects of an individuals' empowerment (90). When reading, analyzing and interpreting our findings it should therefore not be overlooked that there are many socio-economic forces at play when people with SMI are working towards "taking their lives in their own hands" (89).

COVID-19

The last 50 interviews (12.02%) of the 18-month follow-up included the influence of COVID-19 on both the data collection as well as on the interventions. Although the randomization design ensured that the confounding influence was in both conditions, it could be that having an RG or not interacted differently with the presence of COVID-19. Unfortunately, the time period was too short and there were not sufficient participants to reliably investigate whether, how and why COVID-19 influenced the effect of RGs.

A second consequence of the COVID-19 pandemic was that - although we have repeatedly discussed initial interpretations of the data with the participants during interviews- we have not been able to perform the intended formal member check of the qualitative findings.

Adherence/model fidelity

High model fidelity of community-based mental healthcare is often associated with improved patient outcomes (91–94), also in the Netherlands (95), although essential elements of a model are difficult to identify (van Vugt dissertatie, Assertie Community Treatment in the Netherlands, p. 18). In order to collect information and to be able to do some assessment of adherence, the Resourcegroup Model Evaluation Tool (R-MET) (see Table 1, **Chapter 6**) was created in parallel with the study. Although the R-MET provided insight in the unfolding of the different RGs, statistical investigations were troublesome. We calculated a model fidelity score for each RG based on the pre-determined criteria (see Table 1 and Table 3 in **Chapter 6**), but this score was for some RGs based on 6 RG meetings, while for others only on 1 or 2 meetings. In addition, many questions regarding adherence and critical elements in model fidelity of the RG method remain. For example, how many RG meetings are needed to call someone a completer? How many meetings should take place before there is any effect? Especially because each RG is different (e.g., in composition, frequency, extent of directorship of the patient, etc.), determining adherence or dose-response is complex. The R-MET fidelity scores should thus be interpreted with caution and future research is needed to investigate adherence, dose and essential components of the RG method.

Comparison involvement significant others between conditions

In the study protocol it is described that we would assess the consequences of patient's mental illness for significant others in both conditions by means of a questionnaire (the Involvement Evaluation Questionnaire) sent to significant others that were proposed by the patient. However, there were quite some patients that did not want to give personalia of their significant others; and there was also a high level of non-response. We could therefore not compare the consequences for significant others between conditions. Although we found that patients in the RG + FACT condition were more satisfied with how their significant others were involved compared to FACT as usual and we obtained insight in how significant others experienced the RG method by means of the qualitative studies, we lack the data to compare the experiences of significant others between conditions.

Recommendations future research

The findings in the thesis provide some answers but also raise many new questions. Below, several recommendations for future research are discussed.

Replication and extension of the found effects

As this is the first controlled study on the RG method for people with SMI, replication studies are needed. In addition, its effectiveness in other patient populations or different circumstances could be investigated. The structure is potentially useful and easy transferable to youth FACT and also to services for people with learning disabilities, in forensic settings, for traumatized patients or inpatient care. It would also be interesting to investigate its use in settings of coercive care to explore agency within a restricted or unvoluntary context. The method could also be effective in services related to early detection, as setting up an RG at an early stage might be of value in prevention.

Effective elements of the method

An important next step to be taken is to increase understanding of the effective elements of the method. A recent review of Freeman and colleagues on the effectiveness of Open Dialogue (OD) (96) highlighted the variety of ways in which the OD approach has been implemented and the lack of consistency in implementation strategies. As a result, no strong conclusions could be drawn about efficacy. This indicates the importance of defining and outlining clear guidance on the implementation (96). At the other hand, one of the main strengths of the RG method is that an RG can have a different function and meaning for each individual. This indicates that protocolizing the RG method would undermine its effectiveness. By collecting different perspectives (e.g., patients, RG members), future research should therefore seek for a balance in giving space for each RG to be unique and systemize essential structural (in-depth preparatory interviews, setting the agenda beforehand, setting recovery-goals, minimal frequency), relational (openness, reflection, dynamics, equality) and personal (ownership, directorship) components.

We propose that the R-MET could be structurally incorporated in the RG method as a joint yearly evaluation. Hereby, the goal is twofold. First, evaluation and reflection within the RGs is stimulated: by means of the questions an open and honest discussion among RG members is facilitated about how everyone experiences the RG meetings and whether there are any unaddressed needs. In **Chapter 5** it is described that this openness is important in adjusting existing roles and patterns and contributes to the empowering effects of the method. Second, collecting the data from these yearly evaluations in a research context provides valuable information about the scope and overlap of effective elements of the method. In addition, it might serve as a way to identify elements that predict stagnation or turning points of the RG.

Adjustment effects of the RG to the individual person and everyday real-world behavior

It is recognized that evidence-based effectiveness at the group level may not naturally result in patient-centered care (81). Although the qualitative study provided more insight in how the RG method unfolded differently for different persons, there remain many questions as to how the RG effects evolve over time and across situations that cannot be answered by the global, summary, and retrospective self-report scores that we used in the trial. For example: do people ask more for help? Or less? Does it change to whom? And do the subjects of topic change? Do people trust others better? In general (e.g., at the bus)? Or in specific persons (e.g., RG members)? Does the relationship with professional indeed change? In what way? And with significant others? Do the empowering effects culminate around the RG meetings? Or also in between? What is then the optimal frequency of the meetings for the individual person? Does this change over time and phase of recovery? Do patients talk with and/or involve their significant others about the goals in-between the meetings? Or do they save this for the meetings so that non-illness related subjects get more space in the relation? These kinds of questions are answered differently by different persons and may vary in importance for the individual and his/her recovery journey. Ecological Momentary Assessment (EMA) is better suited to provide insight in the unfolding of processes over time and in the interactions among these factors (97,98). This would further emphasize the uniqueness in the evolvement of each individual RG. Furthermore, data are collected in real-world environments, as subjects go about their lives which allows generalization to the subjects' real lives (i.e., ecological validity) (99).

Implementation

As a result of the limited follow-up of the present study and the efforts of the research team to foster implementation, it remains unknown what is needed from within the organization for long-term implementation of the RG method. The qualitative study focused on perspectives of those directly involved with the RG method (e.g., patients, significant others and practitioners), hereby omitting factors at other layers (e.g., management, policy) that may have been of influence for commitment and implementation. A solid implementation study is needed to determine the organizational steps required for sustained implementation of the RG method beyond the setting of a research study.

In addition, within the present study the extra trainings for RG members (such as: problem-solving skills, psycho-education, communication), were not used despite several attempts to implement these. Although we nevertheless found beneficial effects of the RG method, experiences in Sweden suggest that the skills training represent a crucial part of the method and that these are essential to form a sustainable RG that can also exist without the formal network. For better use of the skills training, hindering and facilitating factors for implementation and the added effectiveness should be investigated.

Ethnicity and culture

Ethnicity and culture are recognized to play a major role in mental health and illness as they affect how illnesses are expressed, experienced, and responded to (100); and how they vary with respect to course, outcome, care utilization and responses (101). Additionally, social network structures function differently among different ethnical background and cultures (102,103). This is specifically relevant to this study as it will influence how processes such as empowerment, autonomy, closeness and distance within an RG evolve. Furthermore, the relationship between patient, network and professional can be influenced by differences or communalities in cultural or religious backgrounds (104–106).

Because it was the first study on the effectiveness of RG, we have committed us to capture a broad effect in the study population of people with SMI in FACT and haven't included these factors when analyzing our trial data. In addition, being white researchers ourselves, we may have overlooked addressing such sensitive areas in the qualitative studies (107). Future research should further investigate such issues and also aim to include researchers with varying ethnic backgrounds to better grasp meaning of the variety of experiences.

Recovery journey of the significant other

The interviews with the significant others and the observations during the RG meetings provided insight in their experiences with the method and in the interpersonal dynamics but we did not zoom into their narrative, needs and well-being like we did with the patients. Consequently, the role of significant others not only in supporting the person with mental health problems, but also in undergoing their own recovery journey may have been underexposed in the study. A family's ability to cope, the incorporation of their caring role in their identity and the experienced psychological distress in the system is highly influential in both the recovery journey of the patient as well as that of the significant other (108–110). Future research should be focused on increasing understanding of these processes as this will be helpful in facilitating the functioning and resilience of the RG as a whole. In addition, future studies should include the perspective of significant others in the control condition to be able to compare between conditions from significant other's point of view.

Mediating role of therapeutic alliance

As described in the discussion above, aspects of the RG method- the relational context becoming part of care and placing emphasis on setting goals of the patient- seemed to have committed professionals to develop a recovery-oriented attitude and change *how* they do their work. Based on the findings in **Chapter 4** and **5** and observations during the study, it was argued that this change mediated the empowering effect of the method. To further support this, the therapeutic alliance should be taken into account in future research.

Stigma within the RGs

We found that overcoming interpersonal inequality and growing beyond the patient-role were important for the RG to contribute to the recovery path of the patient. That is, it is recognized that people with SMI often see themselves as subordinated, inferior, shamed and powerless in relation with both professionals as well as people from their social networks (111–113). In **Chapter 5** it is described that recovering such disbalance, by the openness and joint decision-making processes within the RG meetings, is thought to contribute to the empowering effects of the method. In the qualitative cases we studied in **Chapter 4** and **5**, we either observed the gradual evolvement of such interpersonal change or a stagnation within the first phases of an RG. However, within the intervision sessions it was mentioned that the RG could also contribute to stigma and thus confirm the subordinate and powerless sense of self. This is described as follows by one of the experts-by-experience we interviewed:

> *"If you involve your network, there is a risk that they become a kind of mental health professionals. They take on a coaching role. Like: 'I believe in you, you can do it! Keep up, don't give up! Let's go! Although probably meant nicely, it is worse than any illness, it really knocks you down."*

And later she says:

> *"I felt like a spectator of all the people that were so busy with doing stuff related to me. I just sat there and watched them."*

From these quotes we understand that involving the social network can also have stigmatizing effects by separating 'the rest of the group' from 'the patient', although it did not directly evolve from our qualitative analyses. Given the high association of stigma with empowerment (114,115) and recovery beliefs (116,117), future research with a longitudinal design should investigate the course of stigma and its influence on the group dynamics in the RG and recovery of the patient.

Clinical Implications

Should resource groups be added to the usual care for people with SMI?

Involvement of the social network and agency of the patient are already considered to be leading elements in FACT, and introducing RGs frequently led to resistance and "old-wine-in-new-bottles" critique. The quantitative as well as the qualitative investigations described in the separate chapters however show that working according to RGs entails a significant change. Importantly, this change leads to improvements in functional and personal components of recovery compared to regular community care. Taking into account the implementation efforts of the research staff, the majority of the patients were both motivated and able to set up a RG which is noteworthy given the poor implementation rates that are frequently reported in family-interventions. Adding RGs to FACT showed a reasonable probability of being cost-effective compared to FACT as usual.

Taken together, this thesis shows that the structure of a resource group establishes the engagement of significant others, the empowerment of the patient and the uniqueness of each recovery journey as cornerstones of care. The principles are not new in itself but the RG method provides a framework to anchor them as the fundamental points of departure in the daily work of professionals. It provides a promising, cost-effective way to facilitate patients' recovery processes and embed them within the social environment and everyday life. Although replication studies are needed, from our investigations it can therefore be concluded that working with RGs should be considered a substantial improvement of community-based mental healthcare throughout the Netherlands.

What could be the place of resource groups in Dutch mental health care?

We propose two ways in which the RGs could, given its proven effectiveness, be implemented in routine services for people with SMI.

First, the RG can be used during planning and unfolding of treatment and care. Within the study it was found that the main purpose of the RGs was different for each individual. For some, the emphasis on their own goals was deemed most helpful, for others it was the change in reflection and openness in the interpersonal dynamics or the feeling of support; whereas still others indicated that the regular, fixed evaluation moments were most beneficial, serving as a motivation. Hence, one of the most decisive features of the RG method was that treatment and care could better evolve around what would fit best and what was needed. Accordingly, a more complete representation of what has happened, what is wrong and what is to be done about could develop within less time. Because this enables an improved adjustment to the needs and wishes, the RG can serve as a way to personalize care and is very suitable to start treatment and care.

Second, as proposed by “Network Psychiatry” (87), the RG have the potential to serve as a continuous factor through different phases of illness and recovery. As the needs, goals and wishes of the patient change, the composition of the RG can change along but the RG itself remains a stable factor. This way the intensity and nature of the provided care (e.g. clinical care, community-based mental healthcare, social services, general practitioner) can constantly adjust to the personal recovery process of the patient. Moreover, during the RG meetings all involved professionals from different sectors or parts of the recovery plan (e.g., mental health, social affairs, participation in recovery college, wellness recovery action plan, housing and employment) can be invited. The RG meetings provide established evaluation and adjustment moments so that there remains one coordinated and supported plan.

Is the RG method suited for every patient with SMI?

From the observations and reports of progress of the different RGs we did not identify contra-indications for starting up an RG. In the qualitative study we did find that the setting of an RG could be stressful for patients and could evoke feelings of vulnerability, insecurity, and weakness. This was especially the case when psychiatric or psychological symptoms and associated problems, such as suspicion, anxiety, low concentration, side effects, and abrupt alterations in goals, wishes, and motivation were not sufficiently recognized and acted upon. As a result, patients were placed in a position they were not able to live up to, which compromised the patient's agency and evoked feelings of blame and disappointment in significant others. In the qualitative study we found that overcoming such unequal interpersonal dynamics or disbalance was an important mechanism of change in the RG but when such a pattern would be present in several RG meetings, the setting of the RG could also confirm the subordinate and powerless sense of self and could thus be dis-empowering for the patient. Although Figure 3 in **Chapter 6** shows that within-empowerment scores of the majority of the participants allocated to the RG + FACT condition improved, contrasted to only a small part of the participants in the FACT as usual condition, professionals should be alert on this pattern and act upon it. However, as this pattern is also likely to present itself in daily life we do not consider such dynamics as a contra-indication for working with RGs.

In addition, in case of coercive care professionals reported to find it difficult to balance between the restrictions and the concept of agency within the RG, and this was confusing and unsettling for the patient. There were little patients with coercive restrictions in the present study and future studies should investigate whether and how the RG method and its principles functions within settings of involuntary care.

In the study, 27% of the patients were allocated to the RG condition but did not have an RG meeting after 18 months. Reasons included lack of motivation of the patient, lack of motivation or time of the professional, crisis and reference to other care or team. These numbers might not be representative of the FACT population as there were also patients that declined to participate in the study at inclusion. Future studies should therefore further investigate the reasons for stagnation in the FACT population. Nevertheless, taken together, the present study did not reveal contra-indications for working with RGs for SMI patients in out-patient care. Nevertheless, as described above, one of the most decisive features of the RG method was that treatment and care could better evolve around what would fit best and what was needed and therefore we argue that it provides a way to find best care for each individual patient.

What if a patient cannot or does not want to involve his/her significant others?

People with SMI often experience difficulty in developing and maintaining social relationships (118,119). Over half of them report feeling lonely (120), they have fewer close relationships (121) and not all relationships and social interactions are experienced as positive or supportive (110,122,123). Also in the study, professionals reported that some patients were hesitant and sometimes unwilling to involve their significant others.

Reasons included reluctance to burden their family even more or hesitance to mix their social life with their mental health support, as they were afraid to ruin good relations. This might be associated with the earlier discussed theme of stigma within the RG. According to the method, it is always the patient who has the final say in the choice who to nominate in the RG. However, in the literature there is broad consensus about the effectiveness of network-or family-oriented interventions for people with SMI (51,124,125) and increased social support is associated with a broad range of improved outcomes (126,127). In **Chapter 4** and **5** it is also described that increasing social support and promoting openness in the dialogue in the patient's direct social environment were found to be important mechanisms when working towards recovery.

Hence, for professionals it is helpful to investigate the underlying assumptions and fears of the hesitation or unwillingness, to explore the justification, possibly from multiple perspectives, and to motivate patients to nominate those who are most important to them. Also, significant others do not necessarily need to provide their *support*, being there during the RG meetings and sharing their story is just as important. If the patient nevertheless decides not to involve his/her significant others or does not have anyone, a small RG consisting of only professionals (or even only the case-manager) should also be viewed as an RG. That is, being the director of the RG, thinking about the recovery goals and the repeated evaluations imply a change of dynamics that is also important without the presence of significant others. In the preparation of the RG meetings and the unfolding of the RG plan, the professional should be alert on how patients describe their daily life and their goals and explore whether there is someone who could be involved.

What should be the role of the professional?

As described earlier, the attitude and role of the mental health professional was subject to change when working according to the RG. We encourage professionals to consider the following four themes.

Being there during change. When analyzing the qualitative data we observed confusion in distinguishing the concepts of agency and independence, which was found to interfere with the progress within the RG. The data showed that some patients struggled to find their own voice within their social environment; others experienced ambiguity in their goals; or suffered from their illness-symptoms or medication and needed support to oversee their dreams and vulnerabilities. Some professionals interpreted this way of dependency as not being able to develop agency over their RG and considered the method as not suitable for that particular patient or that they had to take over the lead. However, being an active agent doesn't necessarily imply that one is doing everything independently and doesn't need help. Agency is a constantly moving process of investigating one's capacities and limits and patients need others- including professionals- in phases of this process to be able to grow in their challenges. The role of the professional is to facilitate the search for patients' agency, and - most importantly- to be there and to be a reliable, supportive partner in this process of change. This involves helping to reflect on decisions, translate certain feelings or behaviors, identify and acknowledge boundaries, recognize and take responsibility for one's vulnerabilities and incorporate different perspectives.

Exploring identity. By working with the RG method, professionals became part of the social context of family, significant others and community and hereby got better insight in the values, habits and vulnerabilities of the person on a regular basis. Expanding this knowledge and attitude to the 1-to-1 contacts stimulated patients' process of discovering – or rediscovering- their sense of identity, separate from illness and disability. An important change in professionals' attitude in this process entailed letting go one's urge to help and solve; and instead to give space to patients' own ways; to encourage them to listen to their own voice; and to tolerate to not have an answer to the suffering. This notion resembles with what has been described as the inner conversation of the professional (128,129). It is outlined that professionals can actively use their own worries, reflexes or thoughts within a family session as a way to stimulate dialogue, mutual exploration, and joint understanding (130,131). Applied to the RG, this would suggest it is essential for a professional to recognize when their worries or feeling of responsibility interweaves with their genuine interest to jointly discover a patients' sense of personal identity and to reflect on this with the patient, RG or colleagues.

Stimulating connectedness. The basic human need for connection is about the desire to be embedded in meaningful relationships. But relationships can be complicated, especially in case of a psychological vulnerability in which past (traumatic) experiences might make it difficult to perceive relational safety and security. Hostility, estrangement, and a sense of not belonging are complicating the process of establishing connections with others. Such experiences are often very distressing and also difficult to share which has a further isolating effect. The process of re-establishing relationships is one of the most important processes within an RG, but can thus also be uncertain, frightening and overwhelming. Hence, professionals should understand the ambiguity of the willingness to (re)connect and the loneliness that many people with SMI suffer from. From such understanding, a joint exploration can follow into what a person needs to let others become important, reliable and enjoyable partners.

Monitoring the RG meetings. The final important role of the mental health professional is to decenter their professional expertise (i.e., "having the answers") during the RG meetings and, instead, monitor the processes within and of the RG. Thus, the expertise of the professional is in the process, instead of in the content of the conversation within the RG (130,132). This entails inviting RG members to share their thoughts and feelings; stimulating openness about frictions or differences in point of view; investigating what significant others need to truly believe in the goals; and provoking curiosity of each RG member about themselves, the situation, and the group process. The goal of this monitoring is to stimulate members to reflect on their needs and behaviors so that space can evolve in which the RG members can understand each other, meet each other and connect with each other. If individuals feel that they are understood by someone, they will be inclined to learn from them (133). Hence, when professionals take a step back in being the responsible, assertive problem-solver, but instead, stimulate the interactional processes, the RG can serve as a "we": a collaborative learning community in which new knowledge and meaning arise from mutually influencing processes (134,135).

How is the resource group method related to family-oriented interventions?

> *"Everything that goes on in the life of the patient is reflected in such a resource group. [...] but we are not trained as a systems therapist. " (nurse specialist)*

In this thesis it is argued that working with the RGs broadens the view of the professional to recognize the individual located within a social system. One of the most decisive features of the RG method was that the meetings reflected patients' position in their social environment and everyday life and that they exposed interpersonal patterns. We saw that for many RGs the exposing in itself provided an impulse for changes in the interpersonal patterns. However, in some cases the complexities that came up were rigid and stood in the way of the functioning of a safe RG, as is illustrated by the quote of the nurse specialist. In **Chapter 4** it is described that too many tensions towards the patient (e.g., judgmental, anxious, protective) or between RG members (e.g. blame, disagreement, disappointment) interfered with a well-functioning RG. This is illustrated in **Chapter 5**, where secrets, family's frustrations and interpersonal frictions stood in the way of the functioning of one of the RGs. When such tensions in the family and/or system do not decrease and openness in communication does not evolve, this indicates that the expertise of a specialized family and/or systems therapist is needed.

The purpose of the RG training and implementation is therefore not to educate large numbers of staff to become family therapists. Rather, it is aimed towards integrating awareness of the importance of the interpersonal dynamics for recovery in routine services. We argue that the RG method should not be viewed as a specialized (family/

systems) intervention that is deployed in certain cases, based on the professionals' assessment whether it could fit well. Instead, it is the other way around. The RG provides a format in which decisions regarding steps in treatment and care can be better adjusted to and owned by the patient and his/her daily life environment. When rigid complexities in the family and/or system appear, this is most likely a representation of existing tensions that underly all daily interactions. This indicates that the specialized expertise is needed to constitute a resilient social support system around the patient in which interpersonal dynamics can reshape.

Is the resource group method ready for further implementation?

Starting on the micro-level (patients, significant others and professionals), implementation of the RG method is feasible as a handbook, a manual and a format for training and supervision are developed and available. There are also experiences throughout the Netherlands that can serve as learning examples. Patients and significant others appear to welcome the intervention with enthusiasm and the chapters in this thesis have shown that it leads to improved patients' outcomes, regarding empowerment, quality of life and equality in relations. In addition, working with the RGs firmly establishes a shift from specific diseases or conditions to the individual needs as not everyone that has to live with an illness, experiences that the same way. The chapters in this thesis may be particularly informative in the further development of the method on this level.

On the meso-level implementing the RG method requires effort and commitment from within the organization in order to make the alteration of truly working in a more social network inclusive way. For example, team managers should ensure that staff has manageable workloads, appropriate supervision and flexibility in hours. The amount of implementation support varied greatly among the 20 participating teams, indicating that this does not naturally arise and is therefore a point of attention for future plans. In addition, the RGs have the potential to improve collaboration across service domains but, again, this does not necessarily follow from working with the method. It requires engagement and awareness on both the meso-level, the exo-level and the macro level.

On the macro-level policy guidelines show a gradual increase in awareness that the organization of care should be simplified, should take place on a small-scale community level, and should shift to fulfilling basic human needs of connectedness, social and societal participation and regaining a sense of purpose in life. However, on the exo-level mental health systems are tightened in many rules and obligations, hereby leaving little space to be guided by the individual person and his/her uniqueness. As described earlier, the current organization of mental healthcare has been criticized of leading to fragmented care. It has evolved into a complex system that is (too) busy with the logistical, administrative aspects of care and in which financial incentives are clustered around diagnostic stratifications and illness related deficits.

This is not a barrier that is specific to the RG method, but it does stand in the way of fulfilling its potential to create local networks with direct interactions and flexibility in consultation as a model for organizing mental healthcare. It is therefore important to connect the implementation of the RGs to other movements that rethink the way we address complex health and social problems and that aim towards changes at the exo- and the macro level. If not, there is a risk that the RG is perceived as just another additional element, hereby discarding the opportunity to use it as a way to provide transparent care on the patients' level and overcome fragmentation. For example, “Network Psychiatry” or “De Nieuwe GGZ” that advocate for leaving the one-size-fits all approach and aim towards personalized care are well suited to embed the use of RGs and may profit from the practical, feasible structure of the RGs.

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Chapter 9.

Summary

Nederlandse Samenvatting

Curriculum Vitea

List of Publications

Dankwoord

Summary

Background

The main research question investigated in this thesis concerned the meaning and effectiveness of resource groups in community-based mental healthcare for people with severe mental illness (SMI). We speak of an SMI if people are suffering from a psychiatric disorder for more than two years and experience severe limitations in several domains of life, for example work, living, relationships and/or finances. The limitations are both cause and effect of the disorder and coordinated care and treatment is needed. It is estimated that 281,000 people in the Netherlands suffer from an SMI, which is about 1.7% of the population.

Traditionally, SMIs were considered chronic diseases with persisting, relapsing or deteriorating symptoms. Recovery was perceived as a medical outcome defined by remission of mental health symptoms. Driven by a strong consumer movement, this view shifted around the 1980s. The movement challenged the view of the chronicity of a mental illness and criticized the mental health system with its emphasis on pathology, deficits and dependency. Today, recovery is defined as "…living a satisfying, hopeful, and contributing life, even with limitations caused by illness". This concept of recovery changed the ideas about shaping good care. Moving beyond remission of symptoms, recovery-oriented mental healthcare is aimed towards gradually (re)building a sense of purpose, agency and meaning in life, despite the profound consequences of the illness. In order to achieve this, research has shown the benefits of shifting treatment and care to patients' daily environment and to involve the important people in that environment (family, friends, assistance, housing assistance).

Although the importance of recovery-oriented mental health care for people with SMI is widely acknowledged, essential elements of the movement such as personalization of care and structural involvement of significant others are not adequately implemented in clinical practice. In order to firmly establish a recovery-orientation in community mental healthcare, this thesis investigated the use of resource groups (RG). The RG method builds on the work of Ian Falloon on integrated care and family interventions and has been further developed in Sweden by Ulf Malm and colleagues into Resource Group Assertive Community Treatment.

Resource Groups

According to the handbook of the RG (Leeman, Tjaden, Bovenberg, Mulder & Koenhorst, 2021), an RG is defined as 'a group of people, chosen by the patient, that can provide support to achieve personal recovery goals'. These people can be family members or other relatives (informal network), but also (family) experts by experience and professionals from mental health care and the social domain (formal network). The patient and the case-manager always attend the RG meetings. At least once a year the psychiatrist of the FACT team also attends to evaluate the recovery plan. On average, an RG meets once every 3 months to discuss, evaluate and adjust the patient's self-formulated recovery goals.

The RG method comprises six different phases, which are based on three fundamental principles: (i) patient's empowerment and the position of the patient as the director of the group; (ii) structural involvement of significant others and (iii) fostering collaboration between different sources of support.

By combining a clinical-effectiveness study with health economic data and an in-depth qualitative multiple-case study, this thesis aims to thoroughly investigate the RG method and to examine whether it leads to improvements of treatment and care for people with SMI. This dissertation therefore has the following aims:

1. To explore the concept of empowerment by means of the association between empowerment and attachment patterns;
2. To gain in-depth understanding of the meaning, experiences and interpersonal dynamics when working with RGs;
3. To investigate whether using the structure of RGs within community care has favourable effects on empowerment and recovery-related outcomes;
4. To evaluate the cost-effectiveness of using RGs within community care.

Study design

In **Chapter 2** the details of the research are described in the study protocol. The study was conducted within the context of outreaching, community-based mental healthcare for people with SMI. Currently, Flexible Assertive Community Treatment (FACT) is the service delivery model of choice in the Netherlands. In a FACT team, multiple disciplines work together, such as a psychiatrist, psychologist, social psychiatric nurse, social worker, occupational expert and experience expert, to provide treatment and support in different domains of life.

The study was carried out in 20 different FACT teams in 9 mental healthcare centers (*multicenter*) in the Netherlands. Two or three professionals per participating FACT team were trained in the RG method. Eligibility screening and enrolment of the study was conducted by FACT professionals during intake phase for new patients of the FACT team. There were six inclusion criteria: age ≥ 18 years; an SMI according to the Dutch definition

(28); estimated FACT team's involvement at least 12 months; in FACT for not more than 2 years; capacity to provide written informed consent; and sufficient Dutch language skills. Consenting participants were randomly assigned to the RG condition (n = 80) (RG integrated in FACT) or to the control condition (n = 78) (FACT as-usual). All 158 participating patients were followed for 1.5 years. To this end, a researcher visited them three times and questionnaires and interviews were conducted: at the start of the treatment (baseline), after 9 months and after 18 months. The primary outcome was empowerment: processes in which someone rediscovers his own strengths, talents and possibilities and "takes his life in his own hands". Secondary outcomes included: quality of life, personal recovery, quality and frequency of social contact, social functioning, psychopathology, attachment, disability in various life domains and care satisfaction. Information was also collected about use of care services, medication, and the amount of volunteers/paid work loss (absenteeism and presenteeism). Researchers visiting the patients were masked to patients' allocation status, patients and professionals were not.

Findings

Aim 1: To explore the concept of empowerment by investigating the association between empowerment and attachment patterns

In **Chapter 3**, the primary outcome measure (empowerment) was explored using attachment theory. In this cross-sectional study, baseline data was used to investigate whether attachment theory could provide a theoretical framework to better understand the role of social relationships and interpersonal interactions in the empowerment process. Attachment theory distinguishes two dimensions: (i) attachment anxiety: also referred to as the model of self and associated with a negative self-perception and an excessive need to be approved by others, and (ii) attachment avoidance: also referred to as the model of the other, and reflecting the extent to which a person distrusts the goodwill of other people, and strives to maintain emotional distance. We found that the majority of the people with SMI have insecure attachment patterns, and find it therefore difficult to trust and rely on others and themselves. Furthermore, high levels of attachment anxiety and attachment avoidance were significant predictors of low levels of empowerment. Quality of social contact also significantly predicted empowerment, while frequency of social contact did not. Taken together, the results emphasize that within the empowerment process it is important to work with the image that someone has of the self and the other in relationships and social situations. This indicates the importance of social, contextualized interventions as routes to improving empowerment for people with SMI.

Aim 2: To gain in-depth understanding of the meaning, experiences and interpersonal dynamics when working with RGs

To this end, we conducted a longitudinal, qualitative multiple case-study design based on grounded theory methodology. During a period of two years, the developments and processes in eight resource groups were explored by conducting a total of 74 interviews (e.g., with patients, significant others, and mental health professionals) and 26 observations of RG meetings. In **Chapter 4** we describe that a well-functioning RG sets the stage for five processes to unfold: (i) experience of support, (ii) acknowledgment of significant others, (iii) activation, (iv) openness, and (v) integration. These processes in turn were found to facilitate a patients' entrance into what can best be described as a "pre-phase" of recovery: they developed an arousing curiosity about the world beyond illness and, together with their significant others, cautiously explored forms of reciprocity and equality in their social relations. On the level of mental healthcare, we found that the method reinforced the uniqueness of each person and recovery process and hereby provided a way to anchor recovery-oriented principles in professionals their daily work. The analysis also revealed three factors that interfered with establishing an RG that would serve as a safe basis for the unfolding of the recovery-facilitating processes and effects as described above: (i) implementation issues; (ii) a predominant network; (iii) and unaddressed tensions inherent in the RG setting.

In **Chapter 5** the interpersonal dynamics that arise within an RG as well as the influence of these dynamics on the patients' recovery journey are further explored. Here, we performed a narrative analysis in which we reconstructed and analyzed the stories of four men setting up a RG. It was found that, after difficult years of illness and long histories of dependence and risk prevention, being the director of the RG cannot be imposed. Instead, the degree to which the RG method contributed to recovery was associated with the extent to which existing roles and dynamics altered. Breaking through old patterns of inequality and the joint search for a new balance in the relationship proved to be crucial to pave the way for individuals with SMI to find their own voices and pursue their recovery journeys. The four stories are ought to provide insight in the struggles, fears and tensions that are related to finding new ways of relating to each other. An honest and reflective atmosphere in which all participants are encouraged to participate and to be curious about themselves and each other were found to be essential to change interpersonal dynamics. The RG method should therefore not only be considered an intervention to organize informal support for the patient, but also a platform to expose and adjust the functioning of the patient's social network as a whole.

Together these two chapters provide insight into how the RG method unfolds in clinical practice. They also show that working according to the RG method anchors the view of mental health and recovery as a contextual and relational phenomenon. It cultivates a shift of treatment and care towards the context of patients' social environment and everyday life. As a result, the person's recovery work takes place in relation to the other people in his or her surroundings.

Aim 3: To investigate whether using the structure of RGs within community care has favorable effects on empowerment and recovery-related outcomes, compared to community care as usual within the context of Flexible Assertive Community Treatment (FACT) for people with SMI.

To address this aim we conducted an assessor-blind, multisite, pragmatic randomized clinical trial (RCT). The trial, described in **Chapter 6,** showed that empowerment scores had improved significantly more in patients allocated to RG + FACT (n=80) when compared to patients in FACT as-usual (n=78) both at 9 and 18 months follow-up. In addition, randomization RG + FACT was associated with significantly greater improvements at 18 months regarding quality of life, personal recovery, disability and general and social functioning. No significant differences between conditions were found regarding psychopathological symptoms, attachment, frequency of social contact or employment. At both 9 and 18 months, treatment satisfaction was higher in the RG + FACT condition than in FACT as-usual. The majority of the people with SMI allocated to the RG + FACT condition (74%) was able to set up a RG for a longer period of time and in 84% of the RG meetings someone from the informal network was attending. This suggests that the RG method provides a feasible manner to involve significant others. In the chapter it is therefore concluded that the structure of an RG constitutes network-oriented mental healthcare that empowers people with SMI within their own environment and improves community-based services.

Aim 4: to evaluate the cost-effectiveness of integrating RGs into current care

To meet this aim, we conducted a cost-utility analysis and a cost-effectiveness analysis from a societal perspective alongside the RCT (**Chapter 7**). Four types of costs were derived: (i) healthcare costs; (ii) patient- and family out of pocket costs; (iii) costs of productivity losses; and (iv) intervention costs. The difference in costs and the difference in effects between the two conditions were compared. Although working with RGs was associated with additional implementation costs, costs were (slightly) reduced after 18 months. In addition, working with RG led to better effects, expressed in quality-adjusted life years (QALY) gained and treatment response (reliable and clinically relevant change in empowerment). All in all, the RG method had a 59% probability of being the dominant (i.e., preferred) approach for treatment response; and a 53% probability of being dominant for gaining a QALY. Sensitivity analyses confirmed the robustness of the main findings. The results demonstrate that using the structure of an RG in FACT has a reasonable probability to be an economically viable approach toward improving health in a cost-effective manner for people with SMI.

Discussion

In **Chapter 8** several themes for discussion are explored that come up when integrating the different chapters. The chapter ends with a discussion of the limitations of the thesis, recommendations for future research and clinical implications.

Throughout the different chapters of this thesis, the social aspects in understanding, analyzing and responding to mental health difficulties and recovery became clearly visible. One of the most decisive features of the RG method was that the meetings often reflected patients' position in their social environment and everyday life and exposed interpersonal patterns. From here, the recovery work could take place in the context of social and daily life. It is suggested that (re)connecting with the interpersonal world in a manner in which both the self and the other are considered to be equal and reliable partners is a fundamental part of recovery and empowerment. Importantly, such (re)connecting is a reciprocal process, because significant others also have needs, fears and old pain. Hence, the interpersonal changes concerned not only the patient but also the social network in order to facilitate, acknowledge, and live with them. Working with RGs offers an opportunity to anchor such a social perspective on recovery at the heart of mental health services, and hereby leads to substantial improvements of community-based mental healthcare for people with SMI. Furthermore, we observed that working with the RG method committed professionals to develop a more holistic and personalized approach. By becoming part of the social context of the family and friends, professionals became involved in the language, habits, interactions, jokes and vulnerabilities of their patients' surroundings. Hereby they were inclined to truly get to know and to better understand the patients' values, dreams, plans and needs in life. As a result, a more dedicated and mutual therapeutic alliance could emerge, which may partly explains the empowering effects of the method.

Several implementation issues are also discussed in the chapter, that should be taken into account when starting to work with the RG method. In addition, the potential of the RG to provide tailored and transparent care across domains and to overcome fragmentation of care is considered. As this is one of the main challenges within the current mental healthcare it is suggested that, to fulfill this potential, implementing RGs should be embedded within a broader plan of change.

Limitations of the thesis concern the active role of the research staff that may have served as an implementation strategy in the trial; the underemphasis of the importance of the wider socioenvironmental context in processes of empowerment; the lack of different perspectives in the model-fidelity score and the lack of a comparison between conditions regarding the involvement of significant others from their perspective.

For future research it is recommended to replicate the present findings and extend them to other patient populations, for example youth FACT, traumatized patients or people with learning disabilities. Secondly, future research should aim to increase understanding of the effective elements of the method and for which patients RG might be most appropriate. Hereby it is important to seek for a balance in outlining essential structural (in-depth preparatory interviews, setting the agenda beforehand, setting recovery-goals, minimal frequency), relational (openness, reflection, dynamics, equality) and personal (ownership, directorship) components; and at the same time giving space for each RG to be unique. Thirdly, to better adjust effects of the RG to the individual person and allow generalization to everyday real-world, studies with Ecological Momentary Assessment (EMA) are recommended. Lastly, a solid implementation study is recommended to identify the barriers that influence the shift of culture to working with RGs throughout the organization on the long term.

The findings of this thesis have direct implications as the separate chapters show that working with RGs leads to significant improvements compared to regular treatment and care for people with SMI. The role of the professional entails to jointly discover patients' conceptions of self and others to better understand how the individual frames and perceives the world. Although a very active role, it does not concern determining the outcome. Instead, it involves letting go one's own urge to solve, helping to reflect on decisions, recognize vulnerabilities and incorporate different perspectives.

The purpose of the RG training and implementation is to integrate awareness of the importance of the interpersonal dynamics for recovery in routine care. It is thus not aimed towards educating large numbers of staff to become family therapists. We argue therefore that the RG method should not be viewed as a specialized intervention that is deployed in certain cases, based on professionals' assessment whether it could fit well. Instead, it is the other way around. The RG provides a platform so that steps in treatment and care can be better adjusted to and owned by the patient and his/her daily environment. When difficulties in the family and/or system come up, this is most likely a representation of existing tensions that also underly daily interactions. For many RGs the surfacing of these tensions provided an impulse for change. In some cases the complexities that came up were rigid and stood in the way of a well-functioning, safe RG which indicates that the expertise of a specialized family and/or system therapist is needed.

Conclusion

Taking the different chapters of this thesis together, it can be concluded that the structure of the RG method emphasizes the engagement of significant others, the empowerment of the patient and the uniqueness of each recovery journey. The principles are not new in itself but the RG method provides a framework to anchor them as the fundamental points of departure in the daily work of professionals. Integrating RGs in regular services for people with SMI throughout the Netherlands should therefore be considered a substantial improvement.

Nederlandse Samenvatting

Achtergrond

Deze thesis heeft als doel om de zorg voor mensen met een ernstige psychische aandoening (EPA) te onderzoeken. We spreken bij mensen van een EPA als zij langer dan twee jaar lijden aan een psychische stoornis en daarnaast ernstige beperkingen ondervinden op meerdere levensgebieden, bijvoorbeeld werk, wonen, relaties en/of financiën. De beperkingen zijn vaak oorzaak én gevolg van de psychische stoornis en intensieve zorg en ondersteuning is noodzakelijk. Geschat wordt dat 281.000 mensen in Nederland lijden aan een EPA, dat is ongeveer 1,7 % van de bevolking.

Traditioneel werd een EPA beschouwd als een chronische ziekte met aanhoudende, recidiverende of verslechterende symptomen. Herstel werd gezien als een medische uitkomst gedefinieerd als de afwezigheid van ziektesymptomen. In de jaren tachtig is er een verschuiving geweest in deze visie op herstel van een EPA, met dank aan een sterke cliëntenbeweging. Tegenwoordig wordt herstel gedefinieerd als "…het ervaren van een bevredigend, hoopvol en betekenisvol leven, ondanks de beperkingen van de ziekte". Deze nieuwe visie op herstel veranderde de ideeën over het vormgeven van goede geestelijke gezondheidszorg (ggz). Herstelondersteunende zorg gaat verder dan de remissie van ziektesymptomen en is erop gericht om een cliënt te ondersteunen in het versterken van diens eigen kracht, autonomie en regie. Op deze manier kan een cliënt ondanks de ingrijpende gevolgen van de aandoening op zoek naar het inrichten van een zinvol leven en deelnemen aan de maatschappij. Om dit te kunnen bewerkstelligen heeft onderzoek laten zien dat het van groot belang is om de zorg en ondersteuning naar de leefwereld van de cliënt te verplaatsen en de belangrijke mensen in die leefwereld (familie, vrienden, hulpverlening, woonbegeleiding) te betrekken.

Hoewel het belang van herstelgerichte zorg breed wordt erkend, worden essentiële elementen van de beweging, zoals personalisatie van zorg en structurele betrokkenheid van de sociale leefwereld, onvoldoende geïmplementeerd in de praktijk. De resourcegroepen (RG) methodiek vormen een veelbelovende manier om de sociale leefwereld structureel te betrekken en daarmee het bevorderen van herstelprocessen in de dagelijkse leefomgeving centraal te stellen. De methodiek bouwt voort op het werk van Ian Falloon over geïntegreerde zorg en familie interventies en is in Zweden onder leiding van Ulf Malm verder uitgewerkt tot Resource Group Assertive Community Treatment.

Resourcegroepen

Een RG is een groep mensen, uitgekozen door de cliënt, die voor de cliënt belangrijk is en die hem/haar helpt persoonlijke, zelfgekozen hersteldoelen te bereiken. Dit kunnen familieleden of andere naasten zijn (informele netwerk) maar ook (familie)ervaringsdeskundigen en professionals van de ggz en het sociaaldomein (formele netwerk). Vanuit de ggz zijn de persoon die de coördinatie voert over de behandeling (de regieondersteuner) en ook de zorgverantwoordelijke in ieder geval deel van de RG. Een RG komt gemiddeld eens per 3 maanden samen om de hersteldoelen van de cliënt te bespreken.

De RG-methodiek beschrijft zes verschillende fases, die zijn gebaseerd op drie uitgangspunten: (i) de eigen regie en empowerment van de cliënt staat voorop, en hij of zij is de regisseur van de groep; (ii) belangrijke naasten worden structureel betrokken; en (iii) samenwerking en afstemming tussen verschillende hulpbronnen wordt gefaciliteerd.

Doelstellingen van het proefschrift

Met dit proefschrift wordt beoogd een beeld te schetsen van het werken met RG in de Nederlandse context van behandeling en zorg van mensen met een EPA. Daarnaast wordt onderzocht of het leidt tot verbeteringen ten opzichte van de huidige zorg. Dit proefschrift heeft de volgende doelstellingen:

1. Verkennen van het concept empowerment aan de hand van hechtingstheorie;
2. Inzicht verwerven aangaande de betekenis, ervaringen en interpersoonlijke dynamieken van het werken met resourcegroepen;
3. Evalueren of het werken met resourcegroepen binnen de huidige zorg leidt tot het verbeteren van empowerment en andere herstelgerichte uitkomstmaten;
4. Evalueren van de kosteneffectiviteit van het werken met resourcegroepen in de huidige zorg

Opzet van het onderzoek

In **Hoofdstuk** 2 wordt de opzet en structuur van de studie nader beschreven. Er zijn twee onderzoeken uitgevoerd. Het eerste onderzoek betreft een verdiepende, kwalitatieve evaluatie waarbij werd gericht op het beter begrijpen van de methodiek en het in kaart brengen van de ervaringen van alle betrokkenen (cliënten, diens belangrijke naasten en de betrokken hulpverleners). Het tweede onderzoek betreft een kwantitatieve evaluatie waarbij een pragmatische, multicenter Randomized Clinical Trial (RCT) is uitgevoerd om effecten en kosten van het werken met RG te onderzoeken en te vergelijken met de huidige zorg voor mensen met een EPA.

De huidige zorg voor mensen met een EPA in Nederland bestaat uit Flexible Assertive Community Treatment (FACT). In een FACT team werken verschillende disciplines samen, zoals een psychiater, psycholoog, sociaalpsychiatrisch verpleegkundige, maatschappelijk werker, arbeidsdeskundige en ervaringsdeskundige, om behandeling en begeleiding te bieden op verschillende levensdomeinen. De studie werd uitgevoerd in 20 verschillende FACT teams van 9 ggz-organisaties *(multicentre)* verspreid door Nederland. Van elk deelnemend FACT team werd een aantal hulpverleners getraind om de RG methodiek toe te kunnen passen.

Cliënten die konden meedoen aan het onderzoek waren tussen de 18 en 65 jaar oud, voldeden aan de criteria voor een EPA en waren niet langer dan twee jaar in behandeling bij het betreffende FACT team. Cliënten die aan deze criteria voldeden en die hadden aangegeven mee te willen doen werden op basis van toeval (randomisatie) toegewezen aan de RG conditie (n=80) (RG opzetten binnen de behandeling bij het FACT team) of aan de controleconditie (n=78) (FACT zoals gewoonlijk zonder de RG). Alle 158 deelnemende cliënten werden vervolgens 1,5 jaar gevolgd en de resultaten van deelnemers in beide condities werden met elkaar vergeleken. Deelnemers werden hiertoe in het totaal drie keer bezocht door een onderzoeker waarbij vragenlijsten en interviews werden afgenomen: aan het begin van de behandeling (baseline), na 9 maanden en na 18 maanden. De primaire uitkomst was empowerment: de mate waarin cliënten het gevoel hebben greep te krijgen op de eigen situatie, en hun eigen sterke kanten, talenten en mogelijkheden (her)ontdekken. Daarnaast werd de effectiviteit van de RG ook gemeten aan de hand van secundaire uitkomsten zoals: kwaliteit van leven, persoonlijk herstel, plezier en frequentie van sociaal contact, psychopathologie, functioneringsproblemen op verschillende levensdomeinen en tevredenheid over de geboden zorg. Ook werd informatie verzameld over het gebruik van de zorg, medicatie en eventueel verzuim van vrijwilligers/betaald werk. Onderzoekers wisten niet in welke groep een cliënt was ingedeeld, cliënten en behandelaren wisten dat wel. Uit deze groep van 158 deelnemers werden vervolgens 8 cliënten gevraagd om deel te nemen aan het kwalitatieve onderzoek.

Bevindingen

Doelstelling 1: Verkennen van het concept empowerment aan de hand van hechtingstheorie

In **Hoofdstuk** 3 werd de primaire uitkomstmaat (empowerment) verkend aan de hand van hechtingstheorie. In dit cross-sectionele deelonderzoek is baseline data gebruikt (data die voorafgaand aan de interventieperiode is verzameld) om te onderzoeken of hechtingstheorie een theoretisch kader zou kunnen bieden om de rol van sociale relaties en interpersoonlijke interacties in het proces van empowerment beter te begrijpen. Binnen de hechtingstheorie wordt een onderscheid gemaakt tussen: (i) hechtingsangst, de angst om verlaten en afgewezen te worden, ook wel gebruikt om het beeld dat iemand van zichzelf heeft te beschrijven, en (ii) hechtingsvermijding, het vermijden van intimiteit en nauw contact met anderen, ook wel gebruikt om het beeld dat iemand van de ander heeft te beschrijven. Er werd gevonden dat een meerderheid van de mensen met een EPA onveilige hechtingspatronen liet zien op de betreffende vragenlijst. Dit duidt erop dat deze mensen het daarom moeilijk vinden om anderen en zichzelf te vertrouwen. Daarnaast bleek zowel verhoogde hechtingsangst als verhoogde hechtingsvermijding lage empowerment scores te voorspellen. Ook bleek dat kwaliteit van sociaal contact de mate van empowerment voorspelt, frequentie van sociaal contact echter niet. Samengevat benadrukken de resultaten dat het binnen het empowermentproces belangrijk is om te werken met het beeld dat een cliënt heeft van zichzelf en de ander in relaties en sociale situaties. Dit geeft het belang aan van sociale, netwerkgerichte interventies als routes om de empowerment van mensen met een EPA te verbeteren.

Doelstelling 2: Inzicht verwerven aangaande de betekenis, ervaringen en interpersoonlijke dynamieken van het werken met resourcegroepen

In de **Hoofdstukken 4 en 5** worden de bevindingen van de verdiepende, kwalitatieve studie besproken. De uitgangsvraag in **Hoofdstuk 4** was wat voor processen er op gang komen in een RG en wat het effect daarvan is op het herstel van de cliënt. Daartoe hebben we een longitudinaal, multiple case design gehanteerd en op basis van grounded theory-methodologie de studie uitgevoerd. Gedurende een periode van 2 jaar werden de ontwikkelingen en processen in acht resourcegroepen onderzocht door in totaal 74 interviews te houden (met cliënten, belangrijke naasten en professionals) en 26 observaties van RG bijeenkomsten. In **Hoofdstuk** 5 is er vervolgens met behulp van een narratieve methodologie dieper ingegaan op de interpersoonlijke processen binnen een RG en de effecten daarvan op herstel. De bevindingen zijn in de hoofdstukken beschreven en geïllustreerd met citaten.

In **Hoofdstuk 4** wordt beschreven dat er zich in een RG vijf herstel-bevorderende processen ontvouwden die gezien kunnen worden als werkende mechanismen: (i) visualisatie van steun; (ii) erkenning van belangrijke naasten; (iii) activering, van zowel cliënt als van de naasten ; (iv) openheid in de onderlinge communicatie; en (v) verbeterde integratie en afstemming van de zorg. Deze vijf processen brachten op hun beurt drie effecten teweeg. Op het niveau van de cliënt ontwikkelden deelnemers een voorfase van herstel: beschreven als een voorzichtige interesse om de wereld buiten de zorg te onderzoeken en een behoedzame nieuwsgierigheid om hun plek daarin te (her)ontdekken. Op het niveau van de sociale interactie werden relaties die gekleurd waren door patronen van afhankelijkheid en “zorgen voor”, gelijkwaardiger en wederkeriger. Op het niveau van de zorg werd gevonden dat de RG methodiek de hulpverleners een raamwerk bood om principes van herstel ondersteunende zorg stevig te verankeren in hun werkwijze. Hoewel de principes zelf niet nieuw waren voor de hulpverleners, zorgde het werken met de RG ervoor dat het bevorderen van eigen regie en de samenwerking met belangrijke anderen steeds het uitgangspunt vormden in het dagelijkse werk. Er werden ook drie factoren gevonden die het werken met RG en/of het ontvouwen van de herstelbevorderende processen belemmerden: (i) implementeren en vormgeven van de RG vergde extra tijd voor de betrokken hulpverleners; (ii) een overheersend, complex of over-betrokken netwerk; en (iii) niet geadresseerde spanning en stress van cliënten inherent aan de RG bijeenkomsten.

In **Hoofdstuk 5** is vervolgens dieper ingegaan op de interpersoonlijke dynamieken die zich voltrokken binnen een RG en de effecten daarvan op herstel. In dit hoofdstuk zijn de verhalen van vier verschillende RG gereconstrueerd en geanalyseerd, deze studie maakte dus gebruik van een deel van de data van het grotere kwalitatieve onderzoek. Er werd gevonden dat de mate waarin de RG methodiek daadwerkelijk bijdraagt aan herstel samenhing met de mate waarin bestaande rollen en dynamieken een verandering ondergingen. Het doorbreken van oude patronen van ongelijkheid en het gezamenlijk zoeken naar een nieuwe balans in de relatie waren cruciale processen voor het tot stand brengen van een RG die empowerment bevorderde. Hiermee ontstond namelijk ruimte voor mensen met een EPA om hun eigen stem te vinden en hun unieke herstelreis vorm te geven. Dit betekent dat het belangrijk is dat een ouder of partner ook reflecteert op diens eigen rol in de ziekte en herstel van een cliënt. De vier verhalen geven een beeld van de worstelingen en angsten die deze interpersoonlijke beweging met zich meebrengt. Een eerlijke en reflectieve sfeer binnen de RG, waarin alle deelnemers worden aangemoedigd om deel te nemen en nieuwsgierig te zijn naar zichzelf en elkaar, bleek essentieel om dergelijke veranderingen te doen ontstaan. De RG methodiek is daarmee niet zozeer een interventie om informele ondersteuning voor de cliënt te organiseren, maar moet eerder gezien worden als een platform om het functioneren van het sociale netwerk van de cliënt als geheel bloot te leggen. Vanuit daar kan vervolgens ruimte ontstaan om dit aan te passen en daarmee het herstel van de cliënt te bevorderen.

Samengenomen geven deze twee hoofdstukken inzicht in hoe de RG-methode zich ontvouwt in de praktijk en in de betekenis die betrokkenen eraan geven. Ze laten ook zien dat het werken met RG de visie op herstel als zijnde een contextueel en relationeel fenomeen verankert. Het impliceert een verschuiving van de zorg en behandeling naar de context van de sociale omgeving en het dagelijks leven van de cliënt. Hierdoor vindt het herstelwerk van de cliënt plaats in relatie tot de andere mensen in zijn of haar omgeving.

Doelstelling 3: Evalueren of het werken met resourcegroepen binnen de huidige zorg leidt tot het verbeteren van empowerment en andere herstelgerichte uitkomstmaten
Hoofdstuk 6 toont de resultaten van de vergelijkingsstudie van het werken met RG ten opzichte van de huidige zorg (FACT). Er werd gevonden dat het werken volgens de structuur van een RG een effectieve manier is om empowerment te bevorderen bij mensen met een EPA. Het werken met RG leidde ertoe dat na 9 en 18 maanden empowerment scores meer waren toegenomen dan wanneer er werd gewerkt volgens de gebruikelijke zorg. Daarnaast waren er significant meer verbeteringen na 18 maanden op het gebied van kwaliteit van leven, persoonlijk herstel, sociaal contact, sociaal functioneren, beperkingen als gevolg van de ziekte op verschillende levensgebieden. Ook waren mensen na 9 en 18 maanden van werken met de resourcegroep tevredener over de zorg en ook over hoe hun naasten waren betrokken. Er werden geen verschillen gevonden in ervaren klinische symptomen, frequentie van contact, hechtingsproblemen en het wel/niet hebben van een betaalde baan of vrijwilligerswerk. Implementatiecijfers laten zien dat bij driekwart van de cliënten het gelukt is om een RG te vormen en dat in 84% van de bijeenkomsten iemand van het informele steunsysteem aanwezig was. Dat geeft aan dat de structuur van de RG een haalbare manier is om de samenwerking met het sociale netwerk te bevorderen. Samenvattend blijkt het werken met RG binnen FACT te leiden tot verbeteringen voor mensen met een EPA. Het maakt dat het sociaal netwerk beter wordt betrokken in de behandeling en dat het gevoel van eigenaarschap over ziekte, de geboden zorg en het dagelijks leven voor mensen met een EPA werd vergroot.

Doelstelling 4: Evalueren van de kosteneffectiviteit van het werken met resourcegroepen
In **Hoofdstuk 7** is de kosteneffectiviteit van het werken met de RG onderzocht. Vier verschillende kostenposten werden op basis van zelfrapportage en vanuit een maatschappelijk perspectief berekend voor beide interventiecondities: (i) zorggebruik, (ii) verzuim of verminderd functioneren bij betaald/vrijwilligerswerk, (iii) geboden hulp door naasten; en (iv) implementeren van de interventie. Het verschil in kosten en het verschil in effecten tussen de twee condities werd tegen elkaar afgezet (kosten-batenanalyse). Er werd gevonden dat het werken met RG na 18 maanden (licht) kostenbesparend was, ondanks de extra implementatiekosten bij de start. Daarnaast leidde het werken met RG tot betere effecten, uitgedrukt in gewonnen quality-adjusted life years (QALY) en behandelrespons (klinisch betekenisvolle toename in empowerment). Kosten werden met name in de zorg bespaard: cliënten met een RG kregen minder ondersteuning van de zorg, en wat meer van familieleden of anderen binnen hun informele netwerk. Al met al had het werken met RG in FACT een redelijke kans op betere effecten tegen lagere kosten (m.a.w.: kosten-effectiever) wanneer vergeleken met FACT zoals gewoonlijk. Gevoeligheidsanalyses bevestigden de robuustheid van deze bevindingen.

Discussie

In **hoofdstuk 8** worden verschillende thema's bediscussieert die naar voren komen bij het integreren van de verschillende hoofdstukken. Het hoofdstuk eindigt met een bespreking van de limitaties van het proefschrift, aanbevelingen voor toekomstig onderzoek en implicaties voor de praktijk.

Door de verschillende hoofdstukken van dit proefschrift heen werden de sociale aspecten bij het begrijpen, analyseren en reageren op mentale gezondheidsproblemen en herstel duidelijk zichtbaar. Een van de meest onderscheidende kenmerken van de RG-methode was dat de bijeenkomsten de positie van cliënten in hun sociale omgeving en het dagelijks leven weerspiegelden en dat de interpersoonlijke patronen werden blootgelegd. Van hieruit kon het herstelwerk van de cliënt plaatsvinden in de context van het sociale en dagelijkse leven. Er wordt gesuggereerd dat het (her)verbinden met de wereld om je heen op een manier waarop zowel de zelf als de ander als betrouwbare partners worden beschouwd, een fundamenteel onderdeel vormt van herstel en empowerment. Dit (her)verbinden is een wederkerig proces, omdat ook de belangrijke naaste behoeften, angsten en oude pijn hebben. De interpersoonlijke veranderingen die nodig zijn om te (her)verbinden hadden dus niet alleen betrekking op de cliënt, maar ook op het sociale netwerk. Het werken met de RG biedt een manier om zo een sociaal perspectief op herstel stevig te verankeren in de zorg en ondersteuning, en het leidt daarmee tot substantiële verbeteringen van de ambulante geestelijke gezondheidszorg voor mensen met een EPA.

Daarnaast wordt gesuggereerd dat het werken met RG hulpverleners ertoe aanzette om een meer holistische en gepersonaliseerde benadering te ontwikkelen. Door onderdeel te worden van de sociale context van familie en vrienden, raakten professionals betrokken bij de taal, gewoonten, interacties, grapjes en kwetsbaarheden van de directe omgeving van hun cliënten. Hierdoor waren ze geneigd om de waarden, dromen, plannen en behoeften van de cliënten in het leven echt te leren kennen en beter te begrijpen. Dit had tot resultaat dat er een meer toegewijde en wederzijdse relatie tussen cliënt en hulpverlener ontstond, wat mogelijk de empowerende effecten van de methodiek gedeeltelijk verklaart. In het hoofdstuk komen ook een aantal implementatie-issues aan de orde, waar bij het aan de slag gaan met de RG-methode mee rekening gehouden moet worden. Daarnaast wordt gekeken naar het potentieel van de RG om gepersonaliseerde en transparante zorg over domeinen heen te bieden en zo versnippering tegen te gaan. Aangezien dit een van de belangrijkste uitdagingen is binnen de huidige ggz, wordt gesuggereerd dat, om dit potentieel te realiseren, de implementatie van RG moet worden ingebed in een breder veranderingsplan.

Beperkingen van het onderzoek betreffen de actieve rol van het onderzoekersteam in de RCT dat mogelijk heeft gefungeerd als een implementatiestrategie; de beperkte nadruk op de bredere sociaal-maatschappelijke context in processen van empowerment; het ontbreken van verschillende perspectieven in de totstandkoming van de modelgetrouwheidsscore en het ontbreken van een vergelijking tussen condities van de betrokkenheid van belangrijke naasten vanuit hun perspectief.

Voor toekomstig onderzoek wordt aanbevolen om de huidige bevindingen te repliceren en ze uit te breiden naar andere cliëntenpopulaties, bijvoorbeeld naar jeugd-FACT, getraumatiseerde cliënten of mensen met een verstandelijke beperking. Ten tweede zou toekomstig onderzoek gericht moeten zijn op het vergroten van het begrip van de effectieve elementen van de methode. Hierbij moet dan gezocht worden naar een balans in het schetsen van essentiële structurele (verdiepingsgesprekken, vooraf de agenda bepalen, hersteldoelen opstellen, minimale frequentie), relationele (openheid, reflectie, gelijkwaardigheid) en persoonlijke (eigenaarschap, regie) componenten; en het ruimte geven aan elke RG om uniek te zijn. Ten derde worden studies met Ecological Momentary Assessment (EMA) aanbevolen om de effecten van de RG beter af te stemmen op de individuele persoon en een verbeterde generalisatie naar het dagelijks leven mogelijk te maken. Dat soort onderzoek is namelijk beter geschikt is om inzicht te geven in hoe de processen zich verschillend ontvouwen voor verschillende personen. Ten slotte wordt een gedegen implementatiestudie aanbevolen om de belemmeringen te identificeren die de verschuiving van een cultuur naar het werken met RG door de hele organisatie op de lange termijn beïnvloeden en om meer zich te krijgen voor welke cliënten RG meer dan wel minder werkzaam zijn.

De bevindingen van dit proefschrift hebben directe implicaties voor de zorg en ondersteuning voor mensen met een EPA, aangezien de afzonderlijke hoofdstukken laten zien dat werken volgens RG tot substantiële verbetering leidt met betrekking tot de reguliere zorg. De rol van de professional houdt in om vanuit gezamenlijkheid te ontdekken wat voor beeld een cliënt heeft van zichzelf en de ander, om te begrijpen hoe iemand de wereld waarneemt en vormgeeft. Hoewel dit een zeer actieve rol is, is het niet gericht op het bepalen of beheersen van de uitkomst. In plaats daarvan gaat het juist om het loslaten van de eigen drang om op te lossen en in plaats daarvan te helpen nadenken over beslissingen, kwetsbaarheden te herkennen en verschillende perspectieven te onderzoeken.

Het doel van de RG-training en -implementatie is om bewustzijn van het belang van interpersoonlijke dynamieken voor het herstel van een cliënt te integreren in reguliere zorg. Het is er dus niet zozeer op gericht om grote aantallen hulpverleners op te leiden tot systeemtherapeuten. Daarom stellen we dat de RG-methode niet moet worden gezien als een gespecialiseerde interventie die in bepaalde gevallen wordt ingezet, op basis van de beoordeling van de hulpverlening of deze goed zou kunnen passen. In plaats daarvan is het andersom. De RG biedt een platform waarin stappen in zorg en ondersteuning beter kunnen worden afgestemd op de cliënt en zijn/haar dagelijkse leefomgeving en waarin het herstelproces eigendom wordt van dit systeem. Wanneer er complexiteit in het systeem optreedt is dit een weerspiegeling van reeds bestaande spanningen die spelen binnen de dagelijkse interacties. Voor veel RG was het samenkomen en het aan de oppervlakte komen van deze spanningen op zichzelf een aanzet tot veranderingen in dergelijke interpersoonlijke patronen. In sommige gevallen waren de complexiteiten echter rigide en stonden ze het een goed functionerende en veilige RG in de weg, dit is een indicatie dat de expertise van een gespecialiseerde familie- of systeemtherapeut nodig is.

Conclusie

Als we de verschillende hoofdstukken samen nemen kan worden geconcludeerd dat de RG-methode leidt tot meer empowerment en verbeteringen op andere levensgebieden in vergelijking met alleen FACT. De RG methode benadrukt het belang van de betrokkenheid van belangrijke anderen, en het unieke karakter van elk hersteltraject. Hoewel de principes waarop de RG methode is gebaseerd op zichzelf niet nieuw zijn, biedt de RG een manier om deze als bouwstenen van de reguliere werkwijze van hulpverleners te verankeren. Het toepassen van de RG methode kan daarom beschouwd worden als een substantiële verbetering van de huidige zorg voor mensen met een EPA.

Curriculum Vitae

Cathelijn Diana Tjaden was born on July 3rd 1990 in Amstelveen, the Netherlands. In 2009 she graduated from pre-university education at the Vrije School in Zeist. After travelling through Mexico and Guatemala, she moved to Utrecht to study clinical psychology at the Utrecht University. Part of her bachelor she did in Barcelona, Spain, where she did several courses in systemic therapy. In 2017 she obtained a cum laude research master degree at the University of Amsterdam, which she combined with a clinical psychology degree. With her masterthesis about reconsolidation of fear, which she partly conducted in Stockholm (Sweden), she won the research master FMG thesis prize.

In March 2017 she started with her PhD project, Resourcegroups in FACT, at the Trimbos Institute in collaboration with the Department of Tranzo at the Tilburg University and the Erasmus Medical Center. From November 2019, she started working part-time as a psychologist at Compass Zorg. After finishing her PhD she will obtain her BIG certification as a healthcare psychologist at Abate, an expertise center for trauma and anxiety.

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